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Personal Agency in Hospice Patients

by

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Abstract

The concept of personal agency depicts the person as a proactive contributor, motivated to meet challenges and to plan and execute appropriate action to exert influence over their functioning and life circumstances. Thus, the person is perceived as a non-deterministic but biological being who, when their environment poses a new significant challenge, enacts the concepts of free-will, self-efficacy and self-development to survive. A hostile condition like the diagnosis of a life-limiting illness may challenge how the person experiences themselves as being able to work out ways to overcome their environmental constraints. Substantial evidence exists representing the person as having the capacity to face adversity and to effect appropriate action across different situations. Despite how common a diagnosis of a life-limiting illness is, a literature search did not reveal studies that have specifically focused either on the expression or measurement of personal agency in hospice patients. This lack of research and knowledge within literature highlights the need to investigate how and to what extent hospice patients experience personal agency. The purpose of this research was to carry out a systematic inquiry, involving three distinct studies, using a mixed methods design to investigate how and to what extent hospice patients experienced their personal agency. The principal objective of this research was to investigate a) how hospice patients express their sense of personal agency and b) whether that sense of personal agency can be measured. A secondary objective was to find out if Emotion-Focused Therapy (EFT; Elliott et al., 2004) can be used as an agency-enhancing treatment to help hospice patients to experience an increase in their personal agency.

Study 1 was a descriptive-interpretive, qualitative study, with a multiple case study design adopted as the strategy of data collection. The aim was to discover whether a previously described hierarchy of levels of personal agency would be supported with a new sample of four out-patients and four in-patients. Each patient received up to six sessions of Emotion-Focused Therapy, with therapy sessions audio-recorded and transcribed for qualitative analysis. The second study, a measure development study, used a quantitative approach to create and to evaluate a self-report questionnaire and an observation measure for assessing personal agency in hospice patients. The self-report questionnaire (based on Likert-type items) and the observation measure (based on a behaviourally anchored rating scale) were used in a pilot study with a sample of 10 out-patients. Data from an initial pilot study helped to a) reduce the number of items in the self-report measure and b) clarify descriptors on the observation measure with a new sample of 12 out-patients and 12 in-patients. Study 3, a mixed method, multiple systematic case study design that integrated both qualitative and quantitative approaches, built on the data from Studies 1 and 2. This study, a) implemented and evaluated the new self-report questionnaire and observation measure with a new sample of four out-patients and three in-patients and b) determined whether Emotion-Focused Therapy could be associated with a change in personal agency in hospice patients by tracking them over time.

Results of Study 1supported the hierarchy of levels and sub-levels of personal agency that emerged in the earlier MSc study. The sub-levels were expanded to reveal more subtle distinctions of personal agency in hospice patients. With categories of agency robust within and across patients, the hierarchy was developed in Study 2 into a self-report questionnaire and an observation measure for assessing personal agency in hospice patients. The original 53 item self-report questionnaire was reduced to a 16-item revised version, with a good level of internal consistency reliability for out-patients and a less than acceptable level for in-patients. Results indicated that the level of test-retest reliability was acceptable for in-patients but less than acceptable for out-patients. Results of Study 2 showed moderate to strong levels of inter-rater reliability for the observation measure, for out-patients and in-patients, respectively. However, the convergent validity between the self-report and the observation was not acceptable. Regarding face validity, the observation measure required no revision. Results of Study 3 indicated a very good level of internal consistency, an almost perfect inter-rater reliability and an excellent test-retest reliability. The convergent validity between the two measures was again not statistically significant. Overall, results of this three-part research study established that, with further research, the newly developed self-report questionnaire and the observation measure could be used for assessing personal agency in hospice patients and that change over time in hospice patients could be associated with Emotion-Focused Therapy.

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Chapter 1: Introduction

1.1 Rationale for this Research

The purpose of this research was to discover how and to what extent hospice patients diagnosed with a life-limiting illness, experience their sense of personal agency (Gallagher, 2012; Jeannerod, 2003). That is, the sense they have of themselves, as being able, or not, to influence their feelings, thoughts and actions in a way that is helpful for them as they face the challenge of living every day with an incurable illness. The principal objective of the research programme was to investigate a) how hospice patients express their sense of personal agency and b) whether that sense of personal agency can be measured. A secondary objective was to find out if Emotion-Focused Therapy (EFT; Elliott et al., 2004) can be used as an agency-enhancing treatment that will help hospice patients to experience an increase in their sense of personal agency. Participants for this research were patients of St. Andrew's Hospice, Airdrie, Scotland, and were identified based on their medical records and specific inclusion and exclusion criteria.

Despite the World Health Assembly acknowledging in 2014 that 40 million people required palliative care every year and pressing for the development and implementation of palliative care to be available universally, it has remained underdeveloped in many places, worldwide. According to Horton (2018), it is described as one of the most neglected dimensions of global health. In 2020, the World Health Organisation (WHO) reported that only 14% of people had access to palliative care and yet, it was estimated that 56.8 million individuals worldwide needed that specialised care. It is believed that this number will almost double over the next four decades (Sleeman et al., 2021). In addition, Sleeman et al. (2021) emphasized that it is important, ethically, and economically, that governments plan for and provide services, education, and medicines to alleviate suffering, and in conjunction with research to inform how these services are developed and achieved.

Even although the diagnosis of a life-limiting illness, a global experience, a literature search failed to uncover research studies that specifically focus either on the expression or measurement of personal agency in hospice patients. This lack of research and knowledge within literature provides the opportunity and the motivation to generate new understandings of a) how hospice patients see themselves as agentic and b) whether a sense of personal agency in hospice patients can be evaluated through the development of a self-report and observation measure, respectively.

In the first instance, this chapter sets out to present an overview of the central role of personal agency in human existence, highlighting the personal capacity of the human individual to intentionally influence their functioning and their life circumstances (Bandura, 2006, 2018). The chapter will then outline the ethos of a hospice, with focus on the expertise, values, beliefs, and history relating to the care provided to improve the lives of individuals who have the diagnosis of a life-limiting illness. This chapter will also provide an overview of Emotion-Focused Therapy (EFT; Elliott et al., 2004) as the practice of therapy informed by an understanding of the role of emotions in a therapeutic change (Greenberg, 2015, 2017). Emotions are consequential as they inform the individual what is important in a situation and acts as a guide towards appropriate action. EFT helps the individual to become more aware and make productive use of their emotions that are basic to the construction of the self and is central to self-organisation.

Also, this chapter presents an outline of my previous MSc study leading to this research project. A hierarchy of eight levels of personal agency emerged from that study, laying the foundation for this thesis. The value of this research for palliative care will be discussed in this chapter. This chapter also outlines the three distinct studies, with the introduction, method, and findings for each set out in Chapters 4-6, respectively. Finally, this chapter introduces the context for the review of literature that is given focus in Chapter 2. Existing literature, relating to personal agency, will be reviewed, based on its relevance to this thesis.

1.2 Central Role of Personal Agency in Human Existence

According to Bandura (2006, 2018), the human individual is a proactive contributor to their life activities. He states that, as an agent, or actor, in their life, the individual is not solely reactive but is motivated to meet challenges and to plan and execute appropriate action to achieve their goals in dealing with a range of situations. This requires that the individual has the capacity to assess their own capability, anticipate the potential outcomes of different courses of action, evaluate limitations and manage their behaviour correspondingly. Due to the evolutionary emergence of an ability to symbolise (Bandura, 2006, 2018), the human individual acquires a capacity for self-awareness that allows them to be more than spectators of their life circumstances. Hence, through their capacity for reflexive awareness, the individual can reflect upon themselves, enabling them to re-assess their circumstances and influence the demands of their environment. Thus, the individual contributes to their life circumstances and is more than just a product of them.

The concept of agency depicts the individual as a non-deterministic organism, enacting the concepts of free-will, self-efficacy and self-development (Bandura, 1977, 1997, 2006, 2018; Rogers, 1959; Ryan & Deci, 2017). However, from a biological perspective (Dreyfus, 1996; Merleau-Ponty, 1962) the question is whether a highly distressing, hostile condition, like the diagnosis of a life-limiting illness, can limit the individual's sense of agency. That is, whether a life-limiting illness, with its destructive process in the body, may affect how much a human individual is able to make decisions (Weissman, 2004) to have control over a physiological determinant such as disease (Bandura, 2004, 2012).

With the diagnosis of a life-limiting illness, hospice patients live with the tension between their awareness that their existence is threatened and their wish to continue to be. This brings them into contact with their deepest feelings, thoughts, and actions and may leave them feeling frightened and powerless, with their beliefs, until now held without question, violated by an unwanted diagnosis (Janoff-Bulman, 1992; Maher et al., 2020). As a result, patients may no longer see the world as amiable and certain and may experience themselves as ineffective and vulnerable. Thus, whilst representing an influence external to the individual, a life-limiting illness can give rise to the experience of physical and psychological distress that brings about change, physical, psychological, and behavioural, within the individual (Stolorow, 2015; Yalom, 1980).

Thus, with no ability to either avoid or resolve their circumstances (Jaspers, 1961; Peach, 2008) patients are confronted with the fear of death that "rumbles continuously under the surface" (Yalom, 1989, p.27). Consequently, patients, with a heightened awareness of their personal mortality, may sense themselves as having little or no control over their circumstances. Thus, the feeling the individual has of self as the source or influencer of their own actions may be limited by threatening situations (Bandura, 1977) like a life-limiting illness. Moreover, the individual's experience of their ability to act as an agent may be significant for the way in which the individual chooses to live and develop (Frith, 2014; Sartre, 2003).

In other words, with hospice patients directly encountering major existential issues (Stolorow, 2015; Yalom, 1980) the question is whether they can exercise control over their circumstances and experiences with a view to determine what will or will not happen to them (Joseph & Linley, 2005; Ryan & Deci, 2017). That is, whether hospice patients can construct themselves as agents, to some degree, so that they can take part in self-reflective exploration, promoting a re-evaluation of their new-found circumstances that would enable them to adapt or make changes in this most challenging of ontological confrontations (Stolorow, 2015).

Whilst Bandura (1977) agreed, in part, with the behaviourist theories of Skinner (1971), Bandura posited that both environmental and cognitive factors interact to influence learning and behaviour. For Skinner, it was the external environment that determined the behaviour of the individual. Rogers (1951, 1961) did not focus on dysfunction but, instead, put emphasis on the human innate drive to attain potential and maximise well-being. Based on that premise, the human individual has an ability to choose how they act (Ryan & Deci, 2017). However, the ability to make choices assumes that the individual is free to choose how to act from several options. From a humanistic perspective (Mruk, 2008; Rogers, 1967), personal agency may be perceived as the exercising of free will as expressed in choice of action, direction of path taken and, importantly, the consequences of these decisions. Yet the human individual, with the ability to freely make decisions, may relinquish their right to choose to act (Frith, 2014; Sartre, 1971; 1974; Yalom, 1980).

1.3 Ethos of a Hospice Environment

It is said that the concept of hospice goes back to fourth-century Rome when Fabiola, a member of the Roman patrician, opened her home for the poor, travellers, hungry and sick (Milicevic, 2002). At that time, the word *hospis* meant both host and guest, and the *hospitum* the place where hospitality was given. It is believed that the first places committed to caring for the ill and dying originated in Malta around 1065 (Milicevic, 2002). During the European Crusading movement in the 1090's, the incurably ill *en route* to and from the Holy Land were accommodated in designated places dedicated for treatment. However, it is accepted that the term *hospice* was first associated with the care of dying patients in France in the nineteenth century when, in 1843, Mme. Jeanne Garnier opened the first hospice in Lyon, France (Milicevic, 2002). According to the World Health Organisation (2020), the modern-day model of a hospice is an approach that improves the quality of life of patients (adults and children) and their families who are facing problems associated with life-threatening illness.

For hospice patients, quality of life is supported through the provision of palliative care, and that may be from the point of their diagnosis to the end of their life. Based on a multi-disciplinary approach, and delivered by professionals, palliative care is aimed at the prevention and relief of suffering through early identification, accurate assessment and treatment of pain and other problems, whether physical, psychosocial, social, or spiritual. That is, patient care within a hospice setting (NICE, 2012; WHO, 2020) sets out to offer a support system to help millions of dying patients worldwide, to live as actively as possible until death through understanding each patient as a unique, holistic individual.

1.4 Emotion-Focused Therapy as an Agency-Promoting Intervention

Emotion-Focused Therapy (EFT), with its focus on helping the patient to access useful information implicit in their emotions, is a process-experiential approach to change that supports the provision of a therapeutic relationship and the humanistic principles of experiencing, agency, self-determinism, authenticity, and a tendency to growth (Greenberg et al., 1993). Furthermore, EFT is an intervention that promotes patient personal agency through a step wise process. Firstly, EFT promotes a deep level of empathy by the therapist, establishing a trusting relationship with the patient, which in turn enables the patient to collaborate with the therapist in determining the kind of work, referred to as a 'therapeutic task', they will do together.

In therapy, through tracking and guiding, the therapist helps the patient to use their emotions to become aware of their assumptions, values, needs, and goals and their perceptions of themselves as agents in relation to their world. This gives the patient an opportunity to experience their emotions more deeply within a boundaried, safe space, facilitating a belief in self and self-efficacy and with that an increase in confidence and willingness to choose how to proceed. That is, these self-experiences may enable the patient to appraise their circumstances and prepare to take adaptive action that will, for example, enhance their personal agency to affirm self or change the way in how they live their remaining life. Thus, the patient experiences themselves as a reflexive agent, having the ability to change how they construct themselves by embracing different ways of being in the world (Bohart & Tallman, 1999; Greenberg et al., 1993).

A person-centred approach (Rogers, 1957) involves a way of being by entering the internal frame of reference of the client and by following and responding to their experience, empathically. However, EFT combines the person-centred approach with a more guiding, process directive Gestalt therapy (Perls et al., 1951) style of engagement with clients to help deepen their experiences intervention. The overall therapeutic style of EFT incorporates being with doing and following with leading. In this thesis, Emotion-Focused Therapy (Elliott et al., 2004) played two different roles. That is, naturalistic counselling, within the EFT approach, was selected to allow individuals to express how they experienced themselves as agents and, also as an agency-promoting.

In the first instance, the researcher set out to collect qualitative data to discover how individuals experienced personal agency, with the researcher showing an interest in their experiences and encouraging them to elaborate by providing more detail and clarification. EFT allowed the researcher to be actively involved in a ‘continuous analysis’ (Elliott & Timulak, 2021) through active listening, empathic responding and checking understandings and unclarities with patients. This allowed the researcher to hear not only what was said but what was also implied. However, as the focus of these sessions was therapeutic, and not only for data collection, but patients were also not constrained from discussing experiences not relevant to the aims of the research.

Hence, although the entirety of each therapy session was recorded and transcribed, only patient descriptions of experiences relevant to personal agency were selected. That is, in accordance with the notion of ‘judgement of relevance’ (Wertz, 1983), the data was collected and checked and retained on their relevance for the research. In addition, McLeod (2001) and Brinkman & Kvale (2015) support the emancipation of qualitative research, whereby the patient is given a ‘voice’ that affords them a sense of liberation through their communication of their experiences. Thus, during the collection of qualitative data, the ‘ownership’ was dependent on the patient as the expert on their knowledge of the research topic. EFT can be agency-promoting. That is, when client awareness gives rise to their own anxiety through, for example, imagining fears as going to be true in their future, they want to rid themselves of the associated discomfort through expression and thus, block their emotions and stand up for themselves (Elliott et al., 2004). Thus, through self-interruption, the client experiences a greater sense of personal agency and come to realise that whilst they can be the creators of emotional and physical discomfort within themselves, they can also change these feelings.

1.5 Previous Research Leading to the Present Study

A previous MSc study focused on the personal agency as perceived and communicated by individuals who were diagnosed with life-limiting illnesses. In that qualitative study, with its strategy of inquiry a multiple case study (Yin, 2009), four female hospice out-patients, diagnosed with life-limiting illnesses, received five or six sessions of humanistic counselling, with each session lasting 30 minutes. All sessions were audio-recorded and transcribed to provide a therapy text for each patient. While drawing on grounded theory and phenomenological approaches to qualitative research (Creswell & Poth, 2016), the analysis focused on how patients made meaning through their language; thus, an interpretive approach was adopted for analysing the therapy texts (Packer & Addison, 1989). Analysis of each of the four patients was carried out separately and the results cross-analysed for consistencies across cases. During that process, the categories, the sub-categories together with the overall structure of main categories and sub-categories were reviewed, renamed, and fine-tuned.

Results of that earlier study indicated the extent to which hospice patients were not just products of their life givens but actively assessed their limitations, made judgements about their capabilities, and brought about desired effects through their own initiation. Eight main categories emerged from the analysis, forming a hierarchy of levels of personal agency, representing a range of self-communications expressed in degrees of agency. The number of levels of personal agency experienced and communicated was determined by the data and categories as there appeared to be meaningful distinctions as expressed by patients. Categories, ranging from Level 0 to Level 7, represented individual levels of agency*: 0-Non-Agentic; 1-Limited; 2-Reflexive; 3-Collective; 4-Reacting; 5-Willing/Wanting; 6-Enriched; 7-Fully Agentic.* Also, sub-categories emerged in the main categories, Levels 0 to 6, contributing additional, useful information; they were ranked accordingly, as shown in Figure 1.1 and Table 1.1.

Figure 1.1

Agency Hierarchy

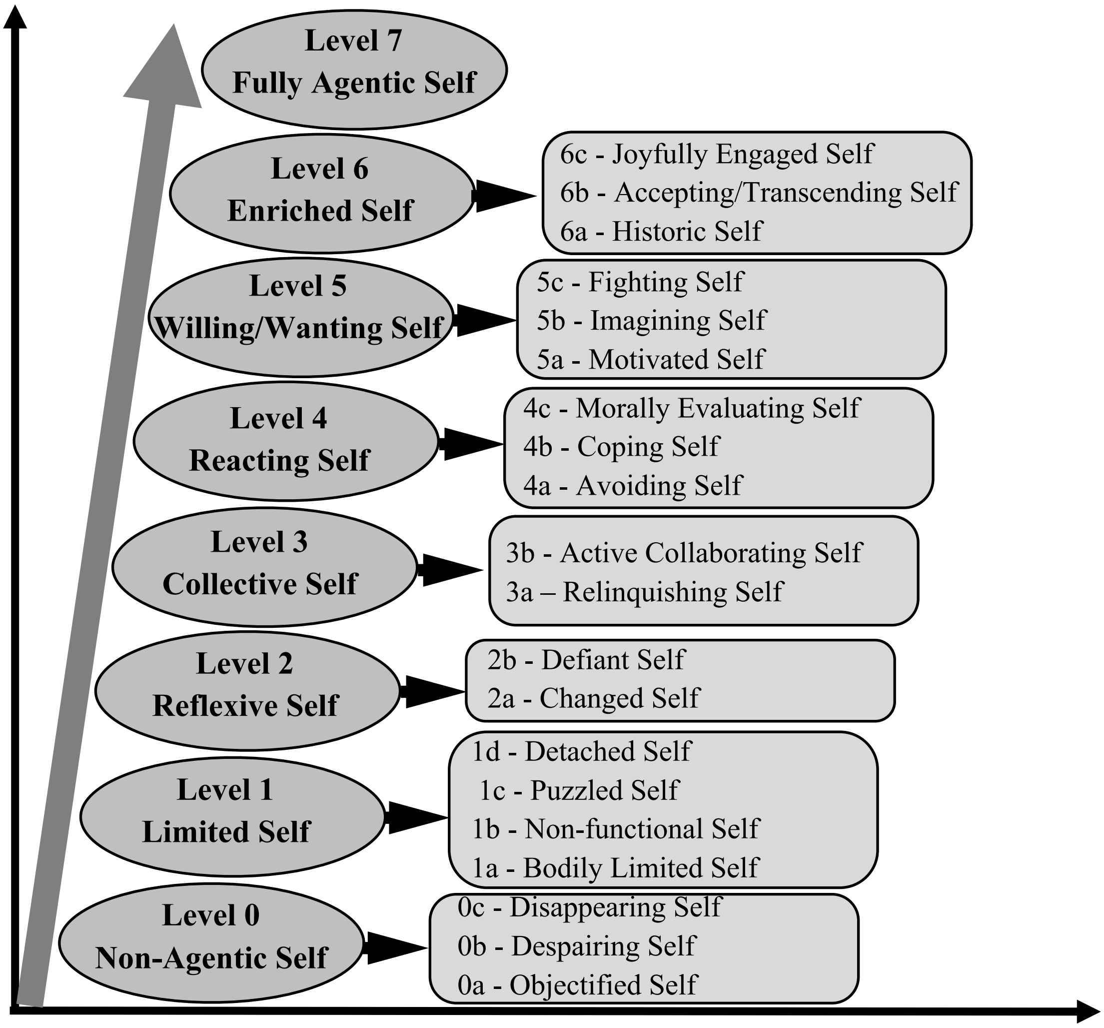


Table 1.1

Table of Levels of Personal Agency

Levels	Main Category	Sub-category	Definition
7	**Fully Agentic Self**		Experiencing self as optimistic, realistic, goal oriented, contented and autonomous
6c		Enriched	Enjoying purposeful engagement in life
6b		Accepting/ Transcending	Accepting self as finite, transcending finite self through belief in a form of afterlife
6a		Historic	Experiencing a want to restore to the historic, past self
6	**Enriched Self**		Experiencing enhanced value and meaning in the present life
5c		Fighting	Approaching circumstances as goal-oriented and with a strong sense of self-efficacy
5b		Imagining	Providing self with an ability of thinking of self in the future
5a		Motivated	Striving to strengthen own efficacy to achieve personal goals
5	**Willing/Wanting Self**		Experiencing the desire or need to initiate action
4c		Morally Evaluating	Monitoring and judging personal reactions to circumstances
4b		Coping	Taking stock of physical, psychological and social resources
4a		Avoiding	Self-protecting or emotionally escaping from illness
4	**Reacting Self**		Responding, internally, to circumstances and appraising illness
3b		Actively Collaborating	Engaging willingly with helpful others
3a		Relinquishing	Passing autonomy to appropriate others
3	**Collective Self**		Seeking to collaborate with others
2b		Defiant	Resisting to accept/comply with change brought about by illness
2a		Changed	Experiencing change in their usual self
2	**Reflexive Self**		Striving for self-preservation

1d		Detached	Disconnected from the reality of what is happening
1c		Strongly Puzzled	Having difficulty in making suitable decisions from personal facts and experiences
1b		Non-Functional	Unable to enact effectively
1a		Bodily-Limited	Vulnerable to illness and treatment
1	**Limited Self**		Susceptible to unwanted limitations that affect every-day life
0c		Disappearing	Unable to prevent the illness threatening continuance of life
0b		Despairing	Unable to make life personally manageable and worth living
0a		Objectified	Unable to be autonomous; reduced to status of object
0	**Non-Agentic Self**		Unable to initiate change through own actions

1.6 Overview of Thesis

This research aimed to carry out a process of systematic inquiry, involving three distinct studies, using a mixed methods design (Brannen, 2005; Creswell & Creswell, 2018) to allow the collection of data, the documentation of significant information, and the analysis of that data/information, to be in accordance with the research questions of each study. According to Brannen (2005), a mixed methods design should be selected primarily based on the needs of the study as opposed to being motivated principally by epistemological considerations. That is, whilst the choice of method is required to answer the research questions and take account of their philosophical position, the research strategy is also required to signify a pragmatic perspective, oriented to the production of results. Mixed methods research design enables the analysis of data to build from one study to another. That is, each study constitutes an individual study that, when completed, represents a necessary element, integral to the overall research programme.

The thesis is structured in seven chapters, with Chapter 1 setting out the context of the study and finally providing an overview of the thesis. Chapter 1 introduces the context for a review of existing literature relating to personal agency detailed in

Chapter 2. That is, Chapter 2 provides a broad evaluation of how the concept of personal agency has been perceived by many different theorists and, while the chronology of the development of these views has not been discounted, the review sets out to be primarily argument based. For example, Bandura (2001), defines agency as the capacity of the human individual that allows them to self-reflect and to initiate their own actions to influence their personal lives. Engels (1998) argued that human individuals live and relate to the world within an active, experiential relationship, expressing an ability to create, support, alter or even destroy their world rather than responding to it as a given (Cordova et al., 2001; Joseph & Linley, 2005; Ryan & Deci, 2017; Stern, 1985). However, a traumatic event like a life-limiting illness may render the person powerless, restricting or preventing them from taking action due to a limitation of options available to them. Thus, it is important, first, to determine (a) the nature and types of personal agency (Bandura, 2006) communicated by hospice patients and (b) whether personal agency is a measurable concept.

Chapter 3 lays out the general strategy for the research presented here, along with its elements. This chapter explores a) the qualitative and quantitative elements of the mixed methods design used in this study; b) the operationalisation of the hierarchy that emerged in the first study of this research programme c) the construction and testing of two quantitative instruments, namely, a self-report questionnaire, based on the Likert Scale (Likert, 1932), and an observation measure, based on Behaviourally Anchored Rating Scales (Schwab, Heneman & DeCotiis, 1975; Smith & Kendall, 1963) to be used to measure personal agency in hospice patients; d) and the evaluation of the effects of Emotion-Focused Therapy as an agency-promoting intervention.

Chapters 4, 5 and 6 present the actual studies. In Chapter 4 Study 1, entitled, "A Qualitative Study of the Experiences of Hospice Patients" is detailed. Qualitative in its approach, Study I aimed to map how hospice patients represent and communicate their sense of personal agency. Thus, Study1 aimed to find out whether the hierarchy of levels of personal agency that emerged in the MSc were supported with a new sample of hospice patients in Study 1. The main research question of Study 1 asked

“How do hospice patients experience the nature of their control over their thoughts, feelings and actions during their dying process?” That question aimed at understanding how hospice patients, diagnosed with a range of life-limiting illnesses, experienced themselves as having the ability to act in accordance with their desired wishes and goals as well as sensing that they could improve the quality of their remaining life. Chapter 4 also assesses whether the hierarchy of personal agency in Study 1 suggested that it could be constructed into valid and reliable self-report and observation measures for assessing personal agency in hospice patients.

In Chapter 5, Study 2, entitled, “Measuring Personal Agency in Hospice Patients”, it was determined whether, or how well, the hierarchy of eight levels of personal agency from Study 1 did provide the basis for constructing valid and reliable self-report and observation measures for assessing personal agency in hospice patients. Study 2, with its quantitative approach, posed the principal research question: “Can the hierarchy of personal agency be developed into a pair of valid and reliable measures (self-report and observation) for assessing hospice patients?”. Also, Study 2 generated more detailed research questions; a) “Is there adequate internal consistency among the items of the self-report; b) Is there sufficient inter-rater reliability between rater/researcher observations? c) Is there adequate test-retest reliability (self-report and observation measures)? and d) Is there sufficient convergent validity between self-report and observation measures?”

Chapter 6 presents Study 3, entitled “Multiple Systematic Case Study of the Development of Personal Agency in Hospice Patients”. This chapter evaluates how well the newly developed self-report and observation measures did in assessing and tracking the evolving personal agency of hospice patients. Study 3, the final study of the research programme, was designed to integrate both qualitative and quantitative approaches to the research and build on the data and information that emerged from Studies 1 and 2, respectively. As its main research question, Study 3 asked, “Can the new self-report and observation measures of personal agency be implemented for assessing personal agency with a new sample of hospice patients?” This chapter also assesses a secondary objective that aimed to discover “Is Emotion-Focused Therapy associated with the development of personal agency in hospice patients?’ That is, could Emotion-Focused Therapy be associated with being used as an agency-enhancing treatment to help patients develop their sense of personal agency, allowing them to make decisions that are important for them, giving rise to useful action and active engagement in their every-day living? In general, the question is to what extent Emotion-Focused Therapy may be perceived as promoting a sense of personal agency in hospice patients?

Chapter 7 discusses the findings from Studies 1, 2 and 3 from the perspective of obtaining new knowledge and better understanding of the levels and types of personal agency in hospice patients (Bandura, 2006, 2018). Also, the chapter deliberates over the findings with reference to a) the self-report and observation measures as valid and reliable measurements of agency and b) the effects of EFT as an agency-enhancing treatment. The importance of this research within a palliative care setting is also discussed; thus, a) the potential to add knowledge and generate better or new understandings of how patients receiving palliative care experience and communicate their everyday living with the diagnosis of a life-limiting illness and b) the development of self-report and observation measures to facilitate and inform in the planning of intervention and treatment; and c) the use of EFT as an intervention that helps hospice patients to experience an increase in their personal agency. All the previously mentioned may be helpful in alleviating the physical and emotional pain for millions of patients in palliative care worldwide. Also, this present study represents an initial attempt to promote and measure personal agency in patients receiving palliative care.

1.7 Importance of Proposed Research

The data produced in this study have potential practice implications. Within a palliative care setting, the self-report and observation measures may be used to track the degree of change in agency as reported by patients due to their experience of a life-limiting illness. This may promote patient self-management and improve patient health literacy (Nielsen-Bohlman, 2004), their capacity to seek, understand and act as best they can on health information that includes their diagnosis and prognosis. Research will identify both out-patients and in-patients so that findings may indicate whether the self-report questionnaire and observation measure may be implemented with both populations. That is, with respect to out-patients, in-patients may experience more severe effects of illness due to their illness having progressed further, and thus, may impact the patient responses to the self-report questionnaire and to the ratings observed.

I argue that, grounded in the illness experience, each measure has the potential to provide useful, easy to understand, easy to use methods for on-going assessment of change along a continuum of agency. Consequently, both measures have the potential to provide a common language for information exchanges among healthcare professionals, promoting the implementation of intervention plans more quickly for individuals diagnosed with a life-limiting illness. As well as providing reference measures for practitioners, this research has the potential to enhance the training of individuals involved in medical, psycho-social, and spiritual care therapies.

1.8 Chapter Summary

In this chapter, I attempted to set out the rationale for this research, including the principal objectives. I defined the concept of personal agency in relation to hospice patients and presented an overview of the thesis. In the next chapter, Chapter 2, “Literature Review: Personal Agency” I present an overview of the concept of *personal agency*, based on a review of the existing literature.

Chapter 2: Literature Review: Personal Agency

2.1 Overview

As outlined in the Introduction, personal agency in hospice patients is central to this research. In this chapter, I present an overview of the concept of *personal agency*, based on a review of the existing literature, with focus on investigating the features of personal agency that relate more specifically to the circumstances of a life-limiting illness. That is, I have chosen to review the existing literature based on the human individual as a non-deterministic but biological being who, when their environment poses a new significant challenge, is required to meet their needs to survive. Thus, I have chosen to structure this review on arguments that show whether the human individual a) is able to adapt and b) to what extent they can adapt to a new hostile environment, a life-limiting illness. Also, I have chosen to indicate how the non-deterministic but organic human individual has been shown to be or not, over time, as an agentic individual with influence over their environment. This is not a systematic literature review, rather, I am presenting a comprehensive background of the literature, relevant to the topic of the research. That is, this literature review aims to gather information from relevant, credible articles and studies; evaluate, critically review, and compare these research studies; and highlight gaps in knowledge. Lastly, this literature review aims to contribute to current knowledge and debate.

I am defining personal agency as an inherent capacity that affords the human individual the opportunity to play a part in their self-development and adaptation through their own motivation and self-efficacy (Bandura, 1977, 1989, 1994, 1997, 2008, 2011, 2012, 2018). That is, the individual, as a biological and yet a non-deterministic organism, has the potential to exercise their free-will, expressed in action, to rebuild to strive or to become. On that basis, the individual is represented as being able to face challenges, to plan, and to effect appropriate action across different situations. The question in this project is whether hospice patients are more than just onlookers but can interact with their environment, a hospice setting, to become agents of their experiences and to bring about their desired effects through their own influence. Given that, I present philosophical and theoretical evidence of personal agency, attempting to distinguish subtle differences between views, discover common ground, and assess and assimilate new and unfamiliar ideas and knowledge. Moreover, whilst existing literature does not provide studies that directly relate to this research project, I present personal agency in a manner that is more tangible and can relate specifically to real-life experiences of hospice patients diagnosed with a life-limiting illness.

2.1.1 Etymology of Agency

In both the Greek and Latin languages, the word stem *ag*- signifies a sense of 'doing' and 'moving'. That sense of doing is defined in the abstract noun, *agentia*, from the Medieval Latin *agentem* meaning effective and powerful, with a*gêns* the present participle of *agere* conveying 'acting, doing and driving forward'. According to the Oxford English Dictionary, the earliest use of 'agent' in English was documented in a discourse on alchemy in 1471, where it was used to represent a "force capable of acting on matter". The semantic development of 'agency' has been influenced by association with 'agent', defined as a 'one who exerts power', i.e., 'the doer of an action'.

2.2. Personal Agency and Sense of Agency

According to Bandura (2006, 2007, 2017, 2018) to be an *agent* is to act purposefully, through forming intentions that include both action plans and the means of bringing about these plans. That is, as an agent, the individual has a) the capacity to construct, assess and re-organise alternative courses of action to deal with environmental circumstances and b) the motivation to bring about their prized outcomes. Based on that premise, the human individual is represented as self-reflective, self-determining, and self-governing, a pro-active contributor in their own self-development and re-construction. Accordingly, *agency* refers to the capacity of the human individual that allows them to influence, intentionally, their own functioning and life circumstances (Littlejohn, 2021).

From a subjective perspective, a *personal sense of agency* (shortened to personal agency: Chambon et al., 2014, 2018; Gallagher, 2012; Haggard, 2017; Jeannerod, 2003; Moore, 2016; Wegner, 2002) can be described alternatively as a) the experience a person has of themselves as having control over their actions or b) the experience of how the person feels when they bring about their desired goals or have a desired effect on their world. That is, acting on the world is accompanied by a personal sense of agency and, according to Gallagher (2012), incorporates two elements, namely, the feeling of agency and the judgement of agency. Gallagher (2012) posited that the *feeling of agency* is initiated during the preparation of an action and so precedes the action while the *judgement of agency* is the result of comparing the predicted and actual outcome of that action. Hence, agency is a) dependent on the close match between the predicted and actual effect and b) is inferred after an action has been carried out and the consequence determined. According to Synofzik et al. (2008) the judgement of agency signifies that an outcome was or was not caused by the individual's action, while the feeling of agency refers to the experience, pre-reflective and sensorimotor, of being the creator of an action. Karsh & Eitam (2015) suggested that having a positive judgement of agency can influence action selection and so enables the individual to adjust their environment.

2.2.1 Personal Agency: An Abstract Concept

Personal agency is an abstract concept and thus lacks a concrete referent (Connell et al., 2018). Introducing abstract concepts in a concrete way can make them more tangible and relatable. For example, being alive requires action and for the reflexive individual this involves choice to adapt to and make sense of their environments. Moreover, awareness of a sense of personal agency promotes a sense of control over experience as well as a healthy detachment from certain experiences. Thus, when the hospice patient can say, "I feel I can do that" a sense of agency is created as they recognise themselves as the creator of their experience. Thus, action is possible, and change can occur. In addition, there are circumstances that can hinder or facilitate the exercise of agency (Berger, 1991). How and to what extent does the individual experience a sense of personal agency? By taking an abstract concept, like personal agency, and creating an example of real-life experiences can solidify the meaning of the concept. According to McNay (2004), experience is essential to an account of personal agency (McNay, 2004). However, discussions of agency do not adequately anchor the concept in lived experience and, indeed, the more removed a discussion about the human individual is from the actual human experience, the more unreliable the idea of agency becomes (Hitlin & Elder, 2007).

Thus, theory and research on personal agency may have largely occurred in isolation. Mapping types of agency and their relation to the reflexive self, can promote more empirical treatments about the concept, that is, to move forward from the debates over the nature and existence of the topic. Operationalisation of the abstract concept allows the systematic collection of data and evaluation of the phenomenon, personal agency, that are not directly observable. That is, operationalisation allows non-quantifiable or abstract concepts into quantifiable data. Thus, the abstract concept of personal agency is turned into a set of specific procedures (counselling sessions and audio-recordings that provide therapy transcripts; multiple case studies; self-report questionnaire and observation measure). Analysis of data of these provide data that help to represent a sense of personal agency in the context of hospice patients diagnosed with a life-limiting illness. This allows the theoretical concept to be investigated and, whilst there is the possibility of subjective or biased interpretations, the goal is to be aware of them and bracket them as well as we can.

2.2.2 Action: Non-voluntary and Voluntary

Given the understanding of action as something that is done or accomplished, what is the relationship between the individual, as agent, and the enacting of an action? Actions are classified according to whether they are defined as non-voluntary or voluntary, with non-voluntary actions such as reflex actions representing activity that occurs automatically without volition, with the individual having no direct control. For example, through the action of cardiac muscle cells, the human heart not only maintains its own intrinsic rhythm, but the rate can be increased or decreased in accordance with environmental circumstances. Thus, whilst the heart is functioning optimally, the individual is not consciously taking part in its regulation (Gordon et al., 2015). Similarly, homeostasis is maintained through the non-voluntary action of motor and sensory nerves (Goldstein, 2019). In essence, these reflexes keep the individual alive by way of mechanistic activity that is sensitive to the environment to which they respond, but generally out of conscious awareness. Indeed, the physical body appears well-informed through its instinctive tendency to preserve the well-being of the body's physiology and hence the individual themselves (Gordon et al., 2015).

On that basis, involuntary actions do not provide a sense of agency. Haggard (2008) proposed that a voluntary action is produced by choice or intention and is subject to cortical control. For Aristotle (Charles, 2009) and Karsh & Eitam (2015), voluntary signified that an action is selected, with the starting point the agent's desire or choice to do something. Indeed, both Aristotle (Charles, 2009) and Karsh & Eitam (2015) argued that the human individual has an inherent capacity to choose, voluntarily, and to act in particular ways in accordance with identified circumstances. Thus, voluntary action is not a response to a stimulus but, through rational deliberation, is self-generated and goal-oriented towards a future event. In addition, for Aristotle in his "Nichomachean Ethics, Book I" (around 340 BC), the choice of action is based on what is believed to be virtuous or useful. Davidson (2001) agreed with Aristotle, arguing that the person, as an agent, has a reason for doing something. That is, the action is of interest to the agent, with the consequence of the action representing something that the person wanted, held in high esteem, and considered beneficial. Thus, the person requires a primary reason, and the primary reason for the action is its cause.

Furthermore, and according to Elliott et al. (2004) and Greenberg and Paivio (2003), human action is achieved through the identification of goals and a preparedness to act, and not merely the result of responses to environmental stimuli. Moreover, Elliott et al. (2004) posited that the emotions of the human individual are the regulators of their mental functioning, facilitating both thought and action. That is, emotion informs the individual about what is important, with the knowledge made available crucial for helping the individual to appraise the situation, and to identify needs and desires. This results in a source of action that is goal-oriented towards the promotion of well-being. For the most adaptive outcome of action, cognition is also needed to make sense of the situation, and, by way of reasoning, the individual can decide which option to enact to best achieve their goal or resolve their circumstances (Elliott et al., 2004).

In his social cognitive theory, Bandura (1986), posited that human individuals deliberate over future courses of action that are appropriate for their constantly changing circumstances, appraise the prospect of their personal effectiveness, co-ordinate and implement their preferred options, estimate the sufficiency of outcomes, and make changes as they deem required. Thus, this theory sees the person not merely reactive, but as 'generative, creative, proactive, and reflective' (Bandura, 2006, p.167).

2.3 The Four Core Elements of Personal Agency

Bandura (1986, 2001, 2006, 2018) maintained that there are four core elements of personal agency that help facilitate the individual's engagement in and influence over their complex and sometimes challenging world. That is, these four properties enable the individual to contribute to their self-development, adaptation, and self-reconstruction. The first of these properties is *intentionality* (Brentano, 1874; Millikan, 2004) whereby people form intentions that not only represent future courses of action to be performed but also involve a self-initiated, change-oriented commitment to bringing them about. Thus, it is the way in which individuals experience their world that plays a part in their expectation and prediction of future actions, thus, giving meaning to these future courses of action.

Forethought, the second core property, is the ability of the individual to anticipate the consequences of their actions. Thus, the way in which the individual acts is influenced by their envisaging of the future which they bring into their present to act as a guide and stimulus for action. On that basis, the individual selects and constructs action plans that are liable to bring about their desired outcomes and disregard those that they view as unfavourable. Thus, the exercise of forethought, through forming beliefs about what they can do together with their consideration of likely outcomes, can enable the individual to re-assess what is significant to them and construct their life accordingly. This in turn helps to provide the person with direction and the ability to deal with everyday life stressors (such as a life-limiting illness); while also giving meaning and quality to one's life through purpose, significance, satisfaction, and fulfilment. Thus, when hospice patients accept their circumstances while striving to deal with what is important to them, they gain a sense of self-fulfilment by being able to improve the quality of their remaining lives.

As well as planning and anticipating the consequences of their actions, the third core feature, *self-reactiveness*, also portrays the individual as a self-regulator. Searle (2003) maintained that it is not enough to merely select an intention and an action plan. That is, whilst careful consideration is given to the making of choices and action plans, the individual is also required to construct relevant courses of action, and to influence and manage their implementation. Through self-evaluation, the individual does things that give self-satisfaction and a sense of pride and worth and avoids ways of behaving that promote self-dissatisfaction, self-devaluation, and self-condemnation.

The fourth core property of human agency, *self-reflectiveness*, describes the individual as a self-assessor of their own functioning. Through reflective self-consciousness, the individual steps back and appraises their self-efficacy, motivation, integrity of their thoughts, actions, and values, and the significance of what they hold dear in their living. In addition, the individual can adjust if necessary. Thus, through intentionality, forethought, self-regulation and self-assessment, the individual is a proactive contributor to their life circumstances and not solely the product of their givens.

According to Bandura (1986, 2006), the way in which the individual acts is the outcome of a triadic, interdependent interaction of intra-personal, environmental, and behavioural determinants, with the contribution of the individual towards the outcome dependent on the experience of themselves as agents, the nature of activity and the situational circumstances (Bandura,1986, 2006). Thus, if the circumstances vary in degree and kind, the skills called for need to be diverse and adaptive to suit the intended goal. Hence, to function effectively, this requires the individual to be generative in their construction and implementation of creative skills to deal with different or challenging, and often unpredictable, circumstances. Thus, this asks whether the contribution made by individuals is dependent on their level of personal agentic personal resources and on the environment they encounter.

According to Bandura (2007), the human individual acts on their environment; creating it, transforming it, not merely reacting to it. But what enables the individual to attain their potential and to maximise well-being? If agency is a human capacity does the individual come into the world with the ability to make things happen through their own actions? Can the experience of that human capacity, the personal sense of agency, be diminished by the destructive process of disease in the form of a life-limiting illness? In addition, is personal agency a variable human attribute that different individuals experience differentially, depending on their specific circumstances?

2.4 Relevance of Personal Agency in the Human Individual

2.4.1 Human Agency and Evolution

The evolutionary process not only shaped the body, but also the brain, including, the psychological mechanisms it accommodated and the behaviour it could produce. Yet, whilst evolution provides bodily structures and biological potentialities, it does not dictate behaviour. Thus, the individual was not merely a reactive consequence of natural selection (Buss, 2019; Darwin, 1998). On the contrary, these neuro-physiological systems, brought about by evolutionary demands, provided the individual with the capacity for mental action, including acquiring of knowledge and understanding through experience, thought and the senses. That is, these mechanisms were psychological adaptations that helped individuals, through their own agency, to formulate ways of adapting competently to different environments, including overcoming environmental restrictions, as well as constructing and re-constructing environments that are more acceptable to them and generate behaviour that helped achieve desired effects.

Key among these mechanisms was the evolutionary emergence of the capacity for advanced symbolisation. Unique to humans, this ability to symbolise, helps human individual to re-process their emotions and introduce new aspects of meaning that can give rise to a sense of control over their living (Bandura, 1986, 2006, 2018). That is, when an experience can be represented freely, that is, without misrepresentation, it can be made accessible to the individual’s awareness through symbolising. That symbolisation may not necessarily be represented in verbal symbols. However, by using metaphoric words, the individual can generate new perspectives on their emotions. In this way, the individual can experience greater understanding of how they feel and take ownership of their feelings as a more organised self- 'agent', by saying, '*I feel X.*"

Whilst symbolisation can enable the individual to initiate novel ideas, symbolisation can also promote personal distress if used to ruminate over troublesome pasts and stressful arousal that may inhibit action. Indeed, symbolisation of unwanted or distorted experiences may be prevented from being symbolised by the conscious self. This raises the question about the process of *subliminal perception* or *subception* (Rogers, 1959) that allows hospice patients to apply unconscious strategies to protect themselves from the experiences of their unwanted circumstances before these experiences enter their consciousness. Given that, subception is a strategy for keeping unconscious a subliminal, emotion-provoking stimulus that is either threatening or is incongruent with the self-concept. However, whilst subception allows the individual to distort their perceptions, it presents an inaccurate self-concept with the consequence that the individual may develop neurosis.

Consciousness, like symbolisation, is an emergent property of the physical activity of the neurons of the brain. That is, conscious states are caused by neurobiological processes in the brain, and they are realised in the structure of the brain. Consciousness may be defined as the symbolic representation of some part of the individual's experience and may present itself in varying degrees of awareness. However, the promotion of conscious control may be more difficult if the individual tries a) to meet needs that have not been made consciously accessible or b) to react to experiences that are not owned by the conscious self (Rogers, 1959). Moreover, this may also account for anxiety experienced by hospice patients as *subceptions* when symbolisation of their circumstances might be damaging to the self. The result is an individual who does not feel unified and so becomes unsure of their path. However, when symbolisation is accurate, and experiences are accessible to awareness, integration and sense of direction can be achieved, leading to increased conscious control. This in turn may help hospice patients to adapt better to their life circumstances because their actions are less influenced by misrepresented or dismissed experiences. Thus, functional consciousness involves purposeful accessing and processing of information required for the selection, construction, regulation, and evaluation of courses of action.

Moreover, evolution saw the emergence of an innate faculty for language acquisition, language use and grammar based in specific neuronal structures. The structures and functions of consciousness and language are pivotal in the exercise of human agency. Evolution has also provided the human individuals with an emotionally based, experiential information-processing system. The amygdala, cingulate gyrus and limbic cortex are parts of the limbic system in the human brain responsible for preparing the individual to become motivated and respond to stimuli in their environment. These areas in the limbic system serve to improve not only survival but growth and development. However, whilst emotions, perceived as adaptive, work as internal signals to support life, it is the integration of the two systems, emotional and cognitive, that facilitates adaptive functioning. Furthermore, the capacity to symbolise an emotionally traumatic experience, may allow the individual to make sense of what may have been too intense and distressing to be expressed consciously.

2.4.2 Human Agency and Biology

According to Bandura (2006), social cognitive theory does not "question the contribution of genetic endowment" (p. 173). On the contrary, this endowment provides the physiology that enables the human individual to intentionally influence their functioning and life circumstances. The lateral frontal pole prefrontal cortex appears to be the "inner" voice that guides the individual when they are inclined towards what is harmful and unhelpful (Edelman et al., 2011). Thus, the question is whether the human organism is more than molecules and their interactions, with mental life more than biological processes. Mental life (James, 1983) is not only a function of biological processes, with the causes of behaviour brought about in the nervous system. Indeed, from an ontological viewpoint, the notion of *physicality* does not point to the reduction of psychology to biology, and, on that basis, the individual is not reduced to molecules and their interactions. Yet, it is on the body that the existence of the individual depends, providing the opportunity for active exploration of environments.

Central to being a human individual is the idea of *embodiment* (Dreyfus, 1996, 1998; Merleau-Ponty, 1962). According to Merleau-Ponty (1962, p. 139) “the animated, living experiential, material body is our way of being in the world.” The human body is composed of many millions of building blocks called cells that differentiate to perform specific functions. Differentiation of human cells give rise to the sensory, motor, and cerebral systems that enable the individual to perform the tasks and goals that are important to them and their living (Harré & Gillet, 1994). Indeed, sense of agency is not just a philosophical concept but is also represented in the right inferior parietal cortex and temporoparietal junction of the human brain (Farrer et al., 2003). The sense of agency appears to be strongest when there is a strong motivation to act, a distinct plan and a specific cortical motor command that endorses the action (Bandura, 2001).

According to Haggard (2017), processes, like selecting an action from several alternatives, occur in the frontal cortex before action is initiated. Front and prefrontal areas select and initiate intentional action, taking information to parietal areas that monitor intentions, actions, and outcomes. Also, according to Schlaghecken et al. (2004), fluent action selection can increase the feeling of control over the action that is made. Moreover, the biological circuits operate, prospectively, in advance of actions, as well as retrospectively making it possible to so monitor whether an action has achieved the intended outcome (Chambon & Haggard, 2012). That is, these biological circuits enable the individual to behave in a goal-directed way and help to promote their control over their environment.

Thus, individual responsibility relies heavily on brain mechanism underlying sense of agency (Bandura, 2001). Evidence presented by Gilmore et al. (2018) has indicated that the basic structural and functional framework of the brain is in place by the second year in life. Imaging studies allow understanding of genetic and environmental influences affecting cognition, behaviour, and risk for neuropsychiatric disease. On that basis, the way the body functions, or fails to function, can change based on experience. Devitt & Ormrod (2007) stated that intelligence is a product of the interaction between inherited abilities and environmental factors. Furthermore, the ability and willingness to access emotions for the promotion of self-awareness, control of impulses and self-motivation, depends on effective emotional functioning.

Mayer & Salovey (1997) supported an *ability model*, that is, an inborn set of abilities that influence ways individuals manage their personal emotions and influence and understand emotions within others. This set of abilities, referred to as *emotional intelligence* (Mayer & Salovey, 1997) is used by individuals to identify, access, and generate emotions to facilitate thought, understanding, reflection and regulation in the promotion of growth. Thus, this model may have impact on how individuals experience themselves as agentic. That is, the ability to self-rule, self-construct, and generate a variety of options to expand freedom to act, may vary within and across individuals. Hence, with embodiment largely a given, the question is whether the capacity of the individual to exercise agency is dependent upon the integrity of their biology, that is, whether biological factors, physical, physiological, chemical, neurological, and genetic that can introduce inherent constraints and limitations.

2.4.3 Human Agency: An Inherent Capacity?

There have been many theories about the capability (or the lack of it) of the child to experience themselves as deliberately influencing how they function, through their own actions on their environment. For example, Plato (428-348 BCE), was the first in the Western tradition to deliberate about *innatism*, the philosophical and epistemological tenet that the mind is born with ideas and knowledge. In his “Meno” (Bluck, 2011), Plato set out to explain his belief that learning is due to recollection and so had no need to be created or validated by experience. On that basis, if children are born with a defined amount of knowledge, the emphasis is on internal forces and the role of nature. This suggested that the human infant is not creative or proactive but essentially reliant on the information given them. Thus, the infant exercised little influence over their world. In modern times, the role of nature and the concept of *innatism* continued to be upheld. For example, Chomsky (1995, 2000) theorised the existence of an innate “language acquisition device”, attributing language not merely to the evolution of culture but to an inborn and natural capacity. Thus, Chomsky (1995, 2000) appeared to ignore social interaction and instead argued for something we are born with and that is triggered during infancy.

Unlike Plato and Chomsky, Aristotle did not perceive the human child from the perspective of innatism. However, like Plato, Aristotle (384-322 BCE) disagreed with the predominating notion in Ancient Greece whereby children were regarded as miniature adults, with their minds able to function like those of adults. Aristotle contended that the human infant is an irrational individual (Charles, 2009) due to their undeveloped ability to guide their actions. He maintained that human children live as their desires urge them but, as their development is incomplete, their desires may give rise to destructive outcomes. Indeed, Aristotle saw children as not having the capacity to decide what is right for them and, held instead that it is better for them to rely on discerning adults (Rackham, 1934). Sharon and Ghossainy (2023) suggested that the ability of children to evaluate the extent and relevance of their knowledge is inadequate. That is, children often show ill-suited dependency on their own limited knowledge and experience and as a result, they often mistake non-reality for reality (Sharon & Woolley, 2004). Based on these arguments, the human child is not presented as a self-reflective, pro-active influencer in their self-development. Rather, the infant is shaped by external forces, with the focus on nurture.

The image of the human child as obedient, unassertive, and dependent on others can be found in the writings of Locke (1975; Rousseau (see Bloom, 1979) and others (Dawkins, 1995; Gilbert, 1991; Harris, 2012); and stemmed from the beliefs of Aristotle and Plato. For example, Locke (1975) proposed that, at birth, the human infant is a *blank slate*, written on by experience from the interaction with people and the environment. Harris (2012) claimed that children do not rely on subjective experience, but they attend to and take in what they hear from others, for example, from parents, school, church, and culture. Dawkins (1995) took an evolutionary perspective and argued that what we are told by adults is in part, adaptive, as children would learn less rapidly if they doubted adult teachings. Rousseau (Bloom, 1979) did not agree with emphasis on the importance of nurture, or external forces. However, he supported the idea that the child develops by way of an innate biological timetable that takes the form of stages of development. However, these stages are not merely determined by adult teachings or social reinforcement such as smiles, praise, or other signs of approval. Nevertheless, none of these accepted theories supported the human infant as an autonomous being. In effect, children were not seen as having the capacity to actively influence their environment to bring about their desired effect.

However, the *rationalism* or *nativism* of Plato (Hamilton, 1961) and Rousseau (Bloom, 1979) and the *tabula rasa empiricism* of Aristotle (Dawes, 2021), and Locke (1975) were rejected by the German philosopher, Immanuel Kant (Timmerman, 2007). Having said that, Kant did agree with the empiricists that experience was crucial for learning and so he proposed the merging or synthesis of the two conflicting perspectives. In effect, he put forward the view that the human child is born with definite mental structures that allow them to interpret input from their senses in distinct ways. That is, during interaction with the environment, these mental structures direct and organise experience. Whilst Kant promoted a concerted interaction between the child and their environment, he believed that they lacked real autonomy. Nevertheless, with an active role as organisers of experience, the human child could no longer be perceived as deferential and malleable, receiving sensory stimuli, as in empiricism, or complying with some biological agenda, as in rationalism.

Despite this, the belief in the human child as intentionally influencing their own functioning and life circumstances appeared to reach an impasse. The British Empiricist, Locke (1975), helped to provide the foundations for the doctrine of psychological behaviourism (Bandura, 1977; Parkay & Hass, 2000; Skinner, 1938, 1966; Watson, 1913, 1920). This doctrine saw traditional behaviourists support the *black box* notion, (Skinner, 1938) whereby its main concern was the effect of the environment, the input, on behaviour, the output. In essence, behaviourists explained both human and animal behaviour with reference to external physical stimuli, responses, learned histories and even reinforcements. On that basis, the origins of behaviour with respect to experience would be superseded by behaviour due to physical events in the environment. Furthermore, with respect to thoughts and ideas, these would be replaced by overt or observable behaviour. Thus, the human child was perceived as mechanistic, with the influence of feelings, motives and intentions disregarded.

Thus, behaviourists not only missed the cognitive, representational, interpretive, goal-oriented, purposeful interactions of the human individual, but appeared to negate the phenomenal qualities of experiences. If, as Watson and Skinner posited, environmental stimuli, and not feelings, are the cause of action, the individual is not able to experience themselves as an agent of their actions. According to Watson (1913, pp. 158-177), "It can be done in terms of stimulus, and response, in terms of habit formation, habit integrations and the like." Thus, whether Watson (1920) in his theory of *classical conditioning* or Skinner (1938, 1980) in his support for *operant conditioning*, both beliefs presented the human individual as having no sense of control or ownership of their actions.

Indeed, in his theory of *operant conditioning*, Skinner (1938, 1966), argued that the history of *reinforcements*, rewards, that whether concrete, such as sweets and money, or abstract like praise and approval, not only direct but shape behaviour. Moreover, for Skinner, whilst reinforcements are rewards for desirable behaviour, undesirable behaviours are quelled by the lack of reinforcements. On that basis, the human child is not perceived as the source or originator of their actions. But did behaviourism decline or is it still relevant? In his Social Learning Theory (SLT) (1977), Bandura proposed that people learn from others. This theory is like that of Skinner in respect of the presence of external stimuli and the influence of the environment. SLT sees reinforcement as promoting the individual's attention, retention, reproduction, and motivation (Bandura, 1977). However, Bandura (1977) also considered the individual as an information processor, thinking about the relationship between their behaviour and consequences.

Thus, whilst SLT could explain some behaviour, it was unable to adequately explain how the individual generates a range of behaviour, including thoughts and feelings. Indeed, Bandura modified his theory and renamed it as a Social Cognitive Theory (1986) to better describe how individuals learn from social interactions. According to Stanbridge (2002), children in the modern classroom are exposed to learning based on behaviourist philosophy, and with a positive outcome. Students learn through reinforcement in the form of a) regular, speedy, worthwhile feedback and b) websites that promote student engagement. Also, the observing of routine and repetition of tasks to improve test scores, whilst noticeably behaviourist, are considered effective. However, it must be noted that for learning to take place, the desired response must be rewarded.

Whilst behavioural theory suggests that stimuli repetition is the most effective way to achieve the wanted outcome, the child is shaped by their external environment. As such, the child is compliant and is not the source or generator of their experience. Consequently, the child has little or no control over their actions and effect on their world. Yet, the concept of agency does not represent the individual as compliant and easily influenced by the constraints of nature or nurture. The Swiss developmental psychologist, Piaget (1952), supported an active role of the human infant and postulated that the human baby is born with an ability to adapt and learn from their environment. That is, from birth, the human individual has a capacity to actively select and interpret information from the environment as opposed to absorbing and accumulating a stock of knowledge with an acceptance that shows no active response or resistance.

Thus, knowledge is constructed by the child playing an active role through gleaning information from the environment and using it to make alterations to existing basic processes to make sense of the information. On that basis, the human child has become widely recognised from an interactional or constructivist position that focuses on the interaction between biological and environmental components. This viewpoint recognises the child a) as actively involved in their own learning, with knowledge a dynamic, ever-changing vision of their world, and b) as having the ability to grow and discover.

However, the belief that the human infant is born with no sense of individuality or personal agency was proposed by Bandura in his “Toward a Psychology of Human Agency” (2006). He supported the idea that the self requires to be socially constructed through *transactional experiences* with the environment (Bandura, 2006, p.169). That is, the emphasis is placed on the two-way, interdependent effects of the child and its environment. On that basis, neither stimuli nor reinforcements control behaviour. Rogers (1959) stated the human individual was inherently motivational and had a “regulatory system” and “feedback” (pp. 222-223) with respect to the meeting of their motivational needs. According to Bandura (2006, 2018), the developing child begins to experience that their actions can make things happen. Thus, with the child recognising that they have an ability to be the influencer of an effect, they experience themselves as having a sense of personal agency.

That is, they become aware that they are the instigators of action through their own intentionality, planning and executing of their plans. This points to a shift from their dependence on environmental factors to determine effect, to some extent, to a perceptiveness of personal causality (Piaget,1932). Thus, the individual has the intention to bring about a particular effect, separate from the influence of external circumstances. This helps to give rise to the perception of an experiential self, intentional, purposive, generative, and spontaneous, providing the individual with a sense of playing a part in the creation of their own future. In other words, the child recognises self as the agent of their actions.

2.4.4 The Human Individual as a Non-deterministic Organism

As both non-deterministic and biological, the human individual experiences themselves as both agentic and subject to different determinants, internal and external. The question is whether the human individual can meet challenges, choose, and plan appropriate courses of action that will achieve their goals to overcome threatening situations? For example, hospice patients are faced with the diagnosis of a life-limiting illness that they know cannot be avoided. Yet do they perceive themselves as individuals who are sick with limited opportunities, or are they motivated to defend and preserve their threatened existence against nausea, pain, and destruction (Goldstein, 1947, Rogers, 1963, Ryan & Deci, Stolorow, 2015; Seligman 2011, 2018)? According to literature, human individuals and other living organisms are motivated to develop and broaden their own unique capacity towards growth and self-enhancement (Angyal, 1941; Aristotle as cited in Barnes, 1982; Driesch as cited in Rogers, 1963; Goldstein, 1939; Jeannerod, 2003; Joseph & Linley, 2008; Rogers, 1951; Ryan & Deci, 2000; 1959; Seligman, 2011; Tedeschi & Calhoun, 2004). That is, the individual experiences themselves as having a capacity, to some degree, to be the source of actions that are useful and meaningful to them.

Conversely, if the individual's behaviour was controlled by internal or external forces, human behaviour would be predictable. However, Bandura (2006, 2008, 2012, 2018) saw the human mind as creative, generative, and proactive. Moreover, the agent is goal-directed, with the ability to select and execute the most appropriate action to achieve the intended goal. Also, Rogers (1951, 1959, 1961) and Bandura (2006) maintained that, even within the unhealthy person, there is a striving to become, to develop and to grow. In circumstances like life-limiting illnesses, a key question becomes whether individuals can rebuild themselves as originators or initiators of action. Indeed, literature supports that, when the human individual experiences a mismatch between themselves and their environment, they, through their self-awareness, try to change their environment or alter the ways in which they choose to act (Bandura, 2006, 2008, 2012, 2018; Rogers, 1951, 1959, 1961).

Even, unicellular organisms like the *amoeba*, which comes from the Greek word 'to change', can change form, build shells, and farm its own food. Moreover, when environmental conditions are favourable, amoebae choose to reproduce through binary fission, that sees them duplicate their genetic material, deoxyribonucleic acid (DNA), and then divide into two parts, with each new organism receiving one copy of DNA, and an end-goal of preservation. By contrast, the human individual is recognised as self-determined, with behaviour varying from externally controlled to intrinsically motivated "to seek out novelty, challenges, to extend and exercise one's capacities, to explore, and to learn.... (Ryan & Deci, 2000, p.70). On that basis, through adaptive functioning, the individual can adjust to their environment befittingly and effectively. That is, through their capacity as an agent, the individual work out ways to overcome environmental constraints by altering their behaviour to respond to the demands of their environments. Moreover, the individual's process of adjustment sees them re-construct their environments to their personal liking, with the notion of maintaining equilibrium between needs and circumstances. This process may be impacted on by many factors, including a life-limiting illness, that may vary across both circumstances and individuals, including hospice patients.

It is when the needs of the individual are not met that they experience dissatisfaction and become motivated towards self-fulfilment. In effect, the individual is driven by a state of tension produced by a need. For example, the need for food drives the individual to search for and eat food. Thus, hunger is the motive that not only initiates the action but persists until the goal is attained. When this need is met, there is a reduction in tension and a return to homeostasis. The question is whether action is in accordance with the strongest motive and are the motives provided by hereditary or the environment or perhaps both? There are different types of motives, namely, a) biological motives also known as physiological motives such as temperature regulation and pain avoidance that are essential for the survival of the individual and with focus on hormones, neurotransmitters, and brain structures; b) social motives such as achievement, aggression, altruism, and power; and c) personal motives like goals, aspirations, and interests. Whilst the motive provides the individual with a reason, motivation is the force that initiates, guides, and maintains goal-oriented behaviour. However, according to Rogers (1967, pp. 185-186) the individual is not determined by a state of drive-reduction (Hull, 1943), or tension-reduction, or homeostasis. Rogers (1967) maintained that in all organic and human life there is a drive to expand, become autonomous and to develop, with enhancement of the organism or self. However, is there an over-emphasis on cognition and behaviour? It may be easier to centre on cognition rather than on implicit emotions a) as they are accessible to consciousness and b) it is easier to try to change behaviour than automatic emotional responses (Elliott & Greenberg, 2017).

What is the role of emotion in this? Emotion is a brain phenomenon greatly different from thought and has its own neuro-chemical and physiological basis (Greenberg, 2015). Moreover, emotions regulate mental functioning, organising both thought and action. Firstly, they establish goal priorities and organise the individual for specific actions (Frijda, 1986). Secondly, emotions set the goals toward which cognitions and action attempt to accomplish these goals. In essence, emotions inform the individual that an important need, goal, or value may be enhanced or damaged in a situation. Thus, as emotions act as a guide as to what the individual needs or wants, affect is a key influence in human conduct (Elliott et al., 2004; Pascual-Leone, 1992). As an affective state, tension can be associated with conflict, dissonance, instability, or uncertainty. When associated with negative emotions like fear or distress it may be accompanied by discomfort and uneasiness that may create a desire for more stable and consistent states and feelings of expectation (Lehne & Koelsch, 2015). This may see the individual seek relief through talk and action. However, tension can also be experienced as a positive state and act as a motivator to take part in certain activities (Lehne & Koelsch, 2015). Moreover, tension may also arise from lack of control caused by an inability to influence a course of events. This may see action tendencies turn out to be ineffective as it becomes evident that the course of events cannot be changed. For hospice patients this may lead to a feeling of helplessness and powerlessness since they are aware that their circumstances cannot be resolved. However, this does not mean that the experiences of tension are without action tendencies (Lehne & Koelsch, 2015). On the contrary, the experience of tension can act as a motivator to prepare the individual for action that may provide a better quality of remaining life.

According to Elliott et. al. (2004) and Greenberg & Paivio (1997), the emotional centres in the brain receive and process input earlier than do the planning and decision-making centres. That is, emotion is basically about motivation and action, setting goals and preparing the individual for action. Alternatively, cognition is about knowledge and action. On that basis, emotion tells the individual what is of concern to them and organises them for action. The individual then needs cognition to help them make sense of their experience and reason to help them work out the best way to accomplish or satisfy their need or want. Moreover, the individual in enhancing environments issue a challenge to themselves to maintain a sense of coherence and strive to become more complex. This helps the individual to respond more confidently and flexibly in their pursuit of life projects important to them. Thus, emotions have influence over cognition and behaviour (Greenberg, 2015). How does this fit with Emotion-Focused therapy (EFT)? What does EFT do? It helps the individual to build emotional awareness and intelligence (Elliott et. al., 2004; Greenberg & Paivio, 2003). EFT sees the emotional system as the main motivational system throughout life and necessary for survival and adapting to new information and experiences. Thus, EFT tries to change the focus by drawing attention to the significant role of the experience of adaptive and maladaptive emotion within therapeutic change. As an intervention, EFT provides a therapeutic relationship, with the therapist following and guiding the client's emotional processing in different ways at different times. When the client can experience an empathic, safe, and genuine connection with the therapist, centres in the brain that process emotions, are affected and new possibilities are made accessible for the client. In therapy, the client is encouraged by the therapist to attend to their moment-by-moment experiencing to promote the development of more adaptive functioning. This is achieved through the therapist helping the client to focus on their felt sense and emotions and, initially, change involves acceptance of, for example, emotional pain. Emotions are connected to the needs of the individual and working through them within a curative relationship helps the individual to change emotion with emotion (Elliott, 2016; Greenberg, 2015). On that basis, emotional change is crucial for lasting cognitive and behavioural change. Moreover, EFT proposes that first the individual feels and then they think, that is, "I feel, therefore I am'.

It is believed the human individual is motivated to act on either internal desire, intrinsic motivation, or by actions that are driven by external rewards, extrinsic motivation (Reiss, 2012). Intrinsic motivation provides the individual with satisfaction, competence, harmony, and autonomy, whilst extrinsic motivation provides rewards like financial gain and approval. Motivation requires the individual to have the capacity to reflect on themselves and to endorse or discount their values, relationships, and perception of themselves. With the incentive to execute a valued goal and the expectancy that they can be effective in attaining the goal, the individual experiences themselves as highly motivated. Moreover, the human individual is not only an agent capable of executing actions to satisfy needs, they also self-evaluate the performance of their own functioning. On that basis, the individual requires both "proactive control" and "reactive control" (Bandura, 1991, p. 260) and this is achieved through their self-influence. According to Bandura (1991), motivation depends on goal intention and is facilitated through a) affective self-evaluation; b) perceived self-efficacy; and c) on-going self-regulation. Whilst the human individual may be presented as non-deterministic, these three types of self-influence may also involve a variation in motivation. Yet, with the individual attentive to their goal outcomes, their goal setting may increase and along with that, perhaps, be more fully elaborated.

Moreover, is knowing how they are doing helpful to the individual with respect to whether they modify their subsequent behaviour? Gaining an understanding of their emotional states, level of motivation and performance provides the individual with guidance for self-regulatory control. Performance achievement may in the appropriate circumstances lead to the setting of further goals. Furthermore, performance evaluation, that is, what is considered beneficial or negative by the individual, will depend on the standards set by the individual. Literature has claimed that even the infant who experiences success in exerting influence over their environment becomes more heedful of their own ways of behaving and more adept in learning to respond in ways that will bring about the best outcomes for them than the infant for whom the same environment happenings occur without their regard. When the infant experiences success in exerting of control, their social and cognitive competency develops (Bandura, 1991, 2006, 2018). In addition, and according to Bandura (1991, 2006, 2018), attainment of personal standards provides the individual with self-satisfaction (happiness in EFT terms) whilst failing to meet those personal standards sees the individual feeling discontent and disapproving, or angry at self or ashamed. Progress can take the form of a) changing goals; b) perseverance toward their original goal; c) lowering of their goals or expectations; or d) deciding on a more challenging or relevant goal.

2.4.5 Determinism Versus Freewill

The exercise of human agency gives rise to the argument between the concepts of *determinism* and *free will.* Determinism maintains that behaviour is governed by both internal or external factors and as such has a set of causes and is predictable, with the individual devoid of control (Skinner, 1953). Furthermore, determinism requires that both the past and the future are fixed. Determinism assumes that the ways in which the individual acts is the result of biological structures, environmental conditions, or past experiences. Moreover, the relationships between these determinants and the resultant behaviours give rise to generalisations like the laws that describe regularities in nature. On that basis, is the human individual a compound of inherited capacities and reactions to environmental stimuli?

Bearing that in mind, a diagnosis of Parkinson's disease, a life-limiting, neurodegenerative condition, can be attributable to genetic factors giving rise to the loss of nerve cells in the substantia nigra part of the midbrain, that produces the neurotransmitter, dopamine. Given that dopamine is essential for motivation, movement, mood, sleep and behaviour regulation, a of lack of it may contribute to a reduced sense of responsibility and accountability, thus limiting the person's capacity to experience themselves as agents, that is, to make internal causal attributions (Kelley, 1973; Shapiro et al., 2010). Thus, the individual depends on a functioning brain, which is vulnerable to disease or injury.

Moreover, Parkinson's disease can result from head trauma (Crane et al., 2016) or through the impact of an environment of toxic chemicals like pesticides and herbicides on dopamine-producing cells (Caudle et al., 2012). Whilst human behaviour is largely influenced by experience, genetic factors play a part, to varying degrees, in every activity through which the individual responds to external and internal environments (Dunn et al., 2019). Thus, genetic factors not only have a bearing on the potentialities of behaviour but can influence how environments are experienced and constructed by the individual. On that basis, the genetic factors may dictate the susceptibility of the individual to environmental influences (Lunati et al., 2018). For instance, does an illness like Parkinson's Disease undermine the concept of free will? Thus, whilst what is conferred by inheritance may generate a range of potentialities, the manifestation of those potentialities may be shaped by environmental factors.

The problem with determinism is that it discounts the social notion of embracing responsibility and self-control, the basis of both moral and legal obligations. Hence, determinism sees the individual devoid of freedom, dignity and with the result of the devaluing of human behaviour. This serves to underestimate the uniqueness of the individual. The question is whether there can be free will in a world of determinism? Skinner (1971), a *hard determinist* and *behaviourist*, maintained that free will is no more than an illusion. Yet, for Maslow (1943) who explained motivation through the satisfaction of needs arranged in a hierarchal order and Rogers (1951), freedom is not only possible but is essential if the individual is to become fully functioning. From a humanistic perspective, personal agency may be perceived as the exercising of *free will*, as expressed in choice of action, direction of path taken and, importantly, the consequences of these decisions. Then free will may be perceived as the capacity of the individual for self-direction. In other words, the human individual is self-determined. Indeed, James supported the notion that free will was no illusion '(I) believe in my individual reality and power' (1920, pp.147-148).

For List (2014, 2019), free will is freedom in the sense that the individual, as agent, has the possibility of acting in other ways. That is, free will requires that more than one alternative course of action is available to the agent. Moreover, determinism alludes to the fact that only one course of action is possible. Indeed, List (2019) proposed that free will is dependent on intentional agency, alternative possibilities, and causal control. Hospice patients with the diagnosis of a life-limiting illness, detected changes in their environment and through their own capabilities, challenged their *limit situations* (Jaspers, 1954; Peach, 2008), constructing themselves as agents, to varying degrees (Campbell et al., 2014). On that basis, individuals who experience themselves as having control in their living may realise their desired futures to a greater extent, in contrast to those who lack a sense of personal agency (Bandura, 1986, 2006, 2017, 2018). Thus, whilst a free will approach involves the owning of autonomy even in the face of external influences, a deterministic approach sees the individual relinquishing autonomy for their actions. That is, as an autonomous being, the individual is self-determined and responsible for their personal choices and their living. Acting from choice may be seen as a psychological need that promotes the well-being of the individual.

2.4.6 Human Agency and Choice

Defined as an expression of free will, choice is the ability of the human individual to make decisions when they are presented with two or more options. Choice includes a) options from which to choose and b) the act of choosing. According to Martin et al. (2006) choice is defined as the presence of multiple stimuli, at least one of which is relatively effective and relatively likely to result in a desired outcome in comparison to the others in that situation. Thus, choice involves giving up something else. Catania and Sagvolden (1980, p.77) claimed that "An organism can choose among alternatives only to the extent that stimuli are correlated with their availability". Whilst it is through choice that individuals exercise control over their environment, the individual may perceive some situations as lacking in choice. Moreover, choices may include significant decisions that may occur once in a lifetime, or they may occur many times during the life of the individual. Thus, how can the concept of choice help hospice patients to make important decisions about how they deal with their unwanted circumstances?

As choice establishes a link between desired intention and values and beliefs, the individual selects behaviours that are helpful in achieving agreeable outcomes whilst avoiding those outcomes seen as undesirable. Moreover, the expectation would be that having the opportunity for choice is more desirable than having no choice. Indeed, according to Leotti et al. (2010), choice is more desirable even when there is no advancement or gain in the outcome. Leotti et al. (2010) also claimed that choice can enhance the feelings of confidence and success that may in turn promote belief in personal self-efficacy. Conversely, loss of control, through the removal or restriction of choice, has a negative effect on the individual. Even young children who become competent in an activity such as feeding themselves, experience a negative effect when an adult tries to influence the ability (Kochanska & Aksan, 2004). That is, for the infant, the reward may continue to be delivered but is not dependent on their own actions. That is, their choice has been restricted or removed.

How does the individual select an option? Moghimi et al. (2019) proposed that selection involves the person ruling out less favourable prospective options available to promote growth and success. Hence, selection promotes specialization, with the individual attending to a restricted array of functional domains (Millon, 2011). Moreover, the individual engages in a) elective selection that involves commitment to a subgroup of goals; b) optimisation, planning and implementation for goal achievement that may require perseverance in the pursuit of goals; and c) compensation, whereby the individual increases or identifies alternative means to maintain their functioning (Freund, 2008). However, if the demands, such as a life-limiting illness, require sustained commitment and effort, this may give rise to anxiety and unfavourable consequences that may impact the psychological well-being of the individual. This may see hospice patients engage in loss-based selection (Moghimi et al., 2019) that may involve them re-organise their hierarchy of goals and seek alternative goals that are achievable.

Has choice a biological basis? We can say that the experience of control, as expressed through choice, involves brain activity associated with affective and motivational processing. Neuroimaging studies have shown that choice is associated with the neural circuitry involved in reward and motivation processing (Bjork & Hommer, 2007). Leotti et al. (2010) suggested that the human desire for control is not acquired through learning but instead is innate and most likely to be guided by the physiology of the individual. However, whilst the desire for the opportunity to choose has its basis in biology, the executing of choice is dependent on the cognitive means available to the individual and how the individual sees the choice as worthwhile based on personal experience.

How does emotions play a role in executing choice? Emotions are connected to the individual's most essential needs (Frijda, 1986) and working through them can help the individual to change distressful emotional states (Elliott et al., 2004; Johnson & Greenberg, 1992). By quickly alerting the individual to circumstances that have significance for their well-being, emotions provide them with information that is helpful or harmful, based on whether their needs are being met. Moreover, they help to prepare and guide the individual toward taking action in these important circumstances. For example, sadness informs loss; anger involves the urge to attack or break free; depression may be associated with being trapped. However, the individual is required to choose whether, for example, they desire to be free of entrapment. Whilst emotion supports an essential foundation for processing in action (Greenberg, 2015), the individual cannot change emotions simply by talking about them or by understanding where they originated. Instead, the individual is required to choose to allow themselves to firstly accept and experience their emotions and then to transform them and reflect on them to create new meaning (Greenberg, 2015). “So bad feelings can be replaced by happy feelings.” (Greenberg, 2015, p.11).

A fundamental belief in EFT is that emotion is crucial in the construction of self and has significant influence in self-organisation. The EFT therapist sees the client as the expert on their personal experience since they have the closest access to their emotions. In addition, the client is seen as the agent who constructs the meanings through which they live their life. EFT therapists put emphasis on the significance of the client’s freedom to choose, both in therapy and outside of therapy. For example, choice is facilitated when the therapist offers the client alternatives about therapeutic tasks and goals (Elliott & Timulak, 2003) with the therapist and client collaborating on these. EFT offers the client help to become more aware and make productive use of their emotions to foster growth (Greenberg et al., 1993; Rogers, 1959). Thus, therapy promotes conscious choice and well thought out action, based on increased access to and awareness of inner experience and feeling. That is, when the client can say, “I feel happy”, they create meanings that, if they choose, can guide their way of living. Moreover, open dialogue among the different parts of the self, promotes adaptive choice. (Elliott et al., 2004).

It seems obvious that the experience of a life-limiting illness may limit the options available to hospice patients and, as a result, may restrict the extent to which they can influence their circumstances. However, the circumstances experienced by patients may not prevent them from self-governing, even although their freedom to choose may be, from the existential-phenomenological perspective, *situated* (Heidegger 1962; Sartre, 2003). That is, whilst the freedom of the individual may be said to be absolute, it always takes place within specific conditions. For example, biology, history, society, and culture may all have importance and consequence upon freedom to choose. Nonetheless, individuals can organise and reconstruct themselves constantly through current their pursuits and not just based on past experiences. What is more, the ability to imagine alternative future courses of action means that the individual must confront the issue of choice and make decisions when they are presented with two or more options. The individual has freedom of choice through the dialectical relationship between the individual and possibilities.

Moreover, all voluntary action involves choice and so not only expresses a preference but promotes a sense of control and self-efficacy, the ability of the individual to exercise control over their personal motivation, behaviour, and environment (Bandura, 1977, 1986, 1997, 2006, 2012, 2018). Furthermore, agency is thought to be promoted in an environment in which opportunity and choice are available. Also, the concept of autonomy presupposes that the individual is directed by deliberations, desires, and motivations that are independent of the manipulation by external forces and that the individual has the capacity to self-govern (Dworkin, 1988). In addition, the individual authentically chooses to act from several alternative possible options (Joseph, 2019; Newman, 2018), committing to one of them and taking responsibility by owning their actions. Choosing to feel, act and think is synonymous with self-creation and promotes curiosity, a sense of self, and identity. Thus, the individual plays a part in the creation of their own future.

Sartre (2003) maintained that the individual is designed to choose. However, whilst all individuals have the potential to control their lives, many are afraid to do so (Fromm, 1941) and thus refrain. Consequently, the individual gives up their freedom and allows circumstances, other people, or irrational feelings to govern their lives. For example, the individual may experience feelings of powerlessness, or a sense of woundedness, shame, or being unloved and unlovable. These emotions are *maladaptive* (Greenberg & Paivio, 1997) and are reactions to situations that stem from previous responses to often traumatic experiences. Thus, these emotions can no longer help the individual to cope constructively with the circumstances that evoke them. Indeed, maladaptive emotions hinder constructive functioning (Elliott et al., 2004). This may see the individual become stuck and see no other possibilities, with the consequence that the construction of alternatives is disrupted. Moreover, *secondary reactive emotions* (Elliott et al., 2004) see the primary adaptive emotion obscured by either a self or external reaction to the primary reaction. This leads to actions that are not relevant for the current circumstances. For example, the individual who meets rejection may experience feelings of helplessness and isolation and become stuck in a maladaptive state of uncontrollable helplessness.

The EFT therapist tries to help the client to change the experience of the maladaptive emotion to the primary emotion. That is, the goal of EFT is to help the individual to acknowledge and experience the primary adaptive emotion and needs that they previously avoided or did not symbolise (Greenberg & Watson, 2006). However, it is also important that the individual considers the accessing of these needs and the associated action tendencies. It is the need and action tendency associated with the primary emotion that leads to adaptive action. In therapy, the client is helped to contact the need and appropriate action tendency. This promotes motivation and direction for change and a new way of responding.

Nonetheless, the giving up of freedom still represents a choice. That is, individuals who wish not to take responsibility, continue to make conscious choice and are essentially responsible for what happens because of their inaction. However, to live authentically, the individual is required to take full responsibility for their choices and actions within the situation they find themselves. Indeed, if the individual cannot freely choose a course of action, they undermine the notion of what it is to be an autonomous being. On that basis, the experience of a life-limiting illness may see hospice patients choose not to live their lives with a sense of individual autonomy. Consequently, they may choose to show a receptiveness towards help to seek alternative was of altering their experience through initiating their participation in the exercise of collective agency with appropriate others. That is, with their capacity to bring about change in their circumstances constrained, together with a lack of personal, relevant knowledge, the individual becomes aware that help is only available through experts who will act for their beneficence.

2.5 Life-limiting Illness: A Determinant

2.5.1 Concept of Health

World Health Organisation (2017) defines *health* as “a state of complete physical, mental, and social well-being and not merely the absence of disease or infirmity.” In 1999 this definition was amended to include a spiritual dimension of health. For the individual, health is an expectation and yet a significant and, perhaps, an unnoticed phenomenon (Gadamer, 2018). However, as health cannot be objectively measured, but is rather determined in comparison to other states, it is an abstract concept. Thus, it may be seen as a biological belief of adaptation (Boorse, 1977), with adaptation a relation between the individual and their environment. Starfield (2001) defined health as the extent to which the individual can satisfy their needs or cope with biological, social, or interpersonal environments. Other writers have proposed health as experiential (Card, 2017); the ability to function and participate (Last, 2007; Leonardi, 2018); defined by its determinants (Shilton et. al, 2011) a unique and universal phenomenon (Starfield, 2001) and defined by the sense of personal agency the individual has over their lives (Scott-Samuel, 2011). Does the definition of health as proposed by Last (2007), “A structural, functional and emotional state that is compatible with effective life as an individual and as a member of society” fit with hospice patients? Health sees the individual being-in-the-World, active and engaged in everyday tasks (Gadamer, 2018; Heidegger, 1957).

2.5.2 Life-limiting Illness

Hospice patients are faced with the diagnosis of a *life-limiting illness*, that is, an incurable disease that they know cannot be put right. Indeed, they know that the progressive, destructive process of their illness will shorten their life. Thus, hospice patients are directly confronted with the reality of death, including the dying process and their absolute demise (Kissane, 2012; Yalom, 1980, 2008). Whether caused by an internal or external influence, a life-limiting illness gives rise to the experience of physical and psychological distress and brings about unwanted change, physical, psychological, and behavioural, within the individual. Thus, hospice patients, faced with uncertainty and the impermanence of their existence, must deal with how and when their body is going to change; the effect of the illness on their independence and relationships; and what time they have remaining (Murray et al., 2005). This in turn may give rise to shock, fear, anger, anxiety, denial, helplessness, sadness, and despair. Indeed, health then becomes a concern as the individual is a bodily being (Merleau-Ponty, 1962). Gendlin (1982) supported the idea that embodiment also produces a felt sense of emotional meaning to the individual. Thus, as an embodied and emotional being, the human individual is both proactive and receptive, that is, having a sense of personal agency, vulnerability, and receptivity.

2.6 Existentialism in Relation to a Life-limiting Illness

How do hospice patients diagnosed with a life-limiting illness experience their circumstances, including their prognosis? This leads to the form of philosophical inquiry that explores human existence, that is, *existentialism*, that dates to Kierkegaard in the 1800's. Kierkegaard, known as the "Father of Existentialism", argued that everyone finds their own way in life through making choices for themselves without relying on external standards and values. Thus, he placed emphasis on the significance of individuality and freedom of choice. Moreover, he proposed that anxiety and despair were necessary to human experience and that the individual was required to make choices based on free will despite their anxiety. In effect, existentialism tries to give insight into the mystery of human existence, with the occurrence of critical situations required to allow the human individual to be aware of their existence.

The theories of Frankl (2004), Heidegger, (1962), Jaspers (1961), Sartre (2003), and Yalom (1980, 2008), had their roots in the philosophical idea that the human individual has free choice and because of that free choice, the individual can create purpose and meaning in their lives. With that, the choices made by the individual are subjective (Kierkegaard, 1941). This proposes that the individual can choose who they want to be. Can hospice patients choose who they want to be? Heidegger (1962) argued that the concepts of death, meaninglessness, isolation, and freedom, are the "givens" of existence and as such are inescapable features of the human individual. Does the theory of existentialism with its ideas of death, authenticity, subjectivity, freedom, isolation, responsibility, and pursuit of meaning of life (Frankl, 2004; Heidegger, 1962; Jaspers, 1961; Kierkegaard, 1941; Sartre; 2003; Yalom, 1980, 2008) fit with hospice patients who are aware that that their illness is life threatening and cannot be avoided? For hospice patients, death is not a distant worry. On the contrary, they are aware that they are on the journey from this world. Literature supports that the experience of patients' new-found circumstances may limit the sense of themselves as having the ability to enter self-reflective exploration. This may interfere with their assessment of their predicament, preventing them from adapting to or meeting their needs. Hence, life becomes disorganised as the individual is faced with the real prospect of their death. Death, the ultimate separation is out with the control of the hospice patient and may lead the individual to reflect on their own finitude. Furthermore, the threat of death may give rise to the individual experiencing a sense of loss of existential hope, and in particular, the loss of a sense of the future (Ratcliff, 2008, 2015). Indeed, the world may become insignificant for the hospice patient, and they may feel disconnected from others as they feel that they live in a different reality.

Thus, individuals have a desire to avoid, make more tolerable, and ultimately accept the existential givens of life (Yalom, 1980). Cummings and Pargament (2014) viewed *religion* as a coping process regarding life challenges, suffering and death. Pargament (1997) defined religion as a search for significance in ways that relate to the scared, with sacred understood as concepts of God and higher powers. Thus, the individual is not solely reactive, but is goal-oriented, striving to attain something that has significance in their life (Pargament, 2011). A 14-item version of the Religious Coping Scale indicated the extent people engage in positive and negative forms of religion. However, Cummings and Pargament (2014) reported that various measures of religious coping were unrelated to quality of life in studies of patients with life-threatening illnesses. A Cochrane review published in 2012 indicated that the five included randomised controlled trials showed no conclusive evidence that interventions with spiritual or religious elements enhanced spiritual well-being. Kruizinga et al. (2016) evaluated the effect of spiritual interventions on the quality of life in cancer patient and found that narrative spiritual interventions can improve the quality of life in cancer patients in the short term. Also, several studies have indicated that people are more likely to engage in religious coping when religion is a larger part of their spiritual orienting system (Pargament, 1997).

A longitudinal study of patients with advanced cancer demonstrated that positive religious coping was related to active coping and acknowledgement of illness. However, some patients were a) more likely to choose intensive, life-prolonging end-of-life care, even in the last week of life and b) less likely to embrace advance care planning like healthcare proxy (Phelps, et al., 2009), preventing them from attending to their needs. Religious coping is associated with a) greater psychological well-being and b) better medication adherence in women diagnosed with breast cancer. However, multiple studies found no relationships between religious coping and active coping with patients who demonstrated their faith in God, seeing no need of medical care as God would suffice. They deferred their responsibility for protecting their personal health, indicating that religious coping may negatively impact the co-operation with medical care due to divine intervention. Thus, some patients may be viewed as *reacting* to their givens through acknowledgement or protestation; *detaching* themselves from their prognosis and mortality through denial; and *relinquishing* their autonomy to a higher being, God. This presents the individual as having little or no sense of personal agency. However, religious coping may be viewed as a resource for situational meaning making (Janoff-Bulman, 1992); patients may be able to identify beneficial consequences of their illness, including the striving for personal growth and the motivation to become.

Block (2005) provided a systematic, evidence-based review of the psychological issues faced by patients at end-of-life. She proposed that for patients at end-of-life, their psychological suffering is on a continuum and has its origins in grief through current and anticipated loss; threat to the future; unfinished business and worries about leaving loved ones behind. With that existing and new psychological disorders (depression, anxiety, lack of coping strategies, personal vulnerability associated with past experiences), family dynamics, financial worries may also contribute to the suffering. Moreover, Yalom stated that avoidance of death can result in psychopathological disorders (Yalom, 1980, 2008). This was supported by Sweeny and Dooley (2017) who proposed that death-anxiety can result in avoidance and inactive responding.

According to Hughes et al. (2023) persons at the end of their life may communicate a wish to die, even in the absence of a psychological disorder. This may be a reaction to physical and psychological suffering due to loss of self, and fear of the dying process. For Yalom (1980, 2008), death, the most important factor of human existence, can give rise to anxiety as the individual recognises that they cannot control the ending of their identity.

However, discussion of the individual's feelings, thoughts and actions may not cause distress but may be useful and helpful to and for the person (Campbell et al., 2014). Yalom (1980, 2008) and Solomon (2015) claimed that death-anxiety may give rise to adaptive action whereby the individual may reassess their projects and roles and so seek to review their choices and priorities (Campbell et al., 2014). That is from an EFT perspective, the individual's emotions will tell them what is important and knowing what is important tells them what they need to do and who they are. Thus, the intervention of EFT promotes the voice of growth in an environment that is hostile to the individual. This helps the individual to utilise adaptive emotions or transform maladaptive emotions so that they can change their experience by making decisions that are helpful for them. Indeed, Yalom (1980, 2008) reported that terminally ill patients may grapple with the notion of death by looking on the inevitability of death as a cause to experience positive changes. He proposed that patients are then able to communicate more openly with others; become less fearful; live more immediately and are less interested in the trivialities of life. However, to experience change involves choice.

2.6.1 Choice in Relation to a Life-limiting Illness

Sartre (2003) claimed that the individual can choose to be different from what they are and, even although the individual is a biological being, there are no general laws to hinder what the individual ought to be. However, for hospice patients the diagnosis of a life-limiting illness is not of their choosing, nor do they have the choice to avoid it or resolve it. Sartre (2003) also argued that being faced with choice can be a source of anguish as the individual is responsible for all their actions once they enter this world. For hospice patients, choice may be fraught with difficulty as they have, for example, to decide whether to a) deal with their unwanted circumstances; b) accept treatment; c) enter end-of-life discussions. Whilst the patient has the choice for their actions, the choice may not have the desired outcome. However, the patient cannot make excuses for the ways in which they act or blame another. Sartre (2003) takes this stance, as he proposed that our "essence" or blueprint is not pre-decided and, indeed, for him, the individual firstly exists and then has the freedom to choose. Kierkegaard (1941) and Sartre (2003) both believed that the values of the individual are subjective and as such the individual does not only play a part in creating who they want to be but must take responsibility by owning their actions. For Sartre (2003)) being responsible means being accountable for all that the individual experiences and does, including which they choose not to carry out. Some hospice patients may experience a sense of agency that enables them to make choices, implement and execute them and attain their goals (Campbell et al., 2014). That is, when the individual lives authentically, they recognise that they are not only free to act in many ways but are responsible for how they act. However, whilst other hospice patients may choose to relinquish their autonomy to helpful others, patients are still responsible for choosing to participate in collective agency. From a phenomenological standpoint, hospice patients are required to make choices under the circumstances of a life-limiting illness that is not of their own making and so their freedom is "situated". Nevertheless, according to Sartre (2003), hospice patients are the drivers in their own lives and so the motivators to act in ways that provide a sense of their identity and the choices they make in life.

2.6.2 Meaning in Relation to a Life-limiting Illness

However, from a spiritual perspective, the patient may struggle to find meaning and purpose in their remaining life and feel lonely and a numbing of emotional reactivity, "What's the point?" (Campbell et al., 2014). Moreover, hospice patients do not search for a vague meaning of life. On the contrary, they have a desire to improve their wellbeing and so their search for meaning of life is a concrete project that must be achieved within the constraints of uncertainty and finitude (Campbell et al. 2014). With that comes responsibility and the need to realise the potential meaning of their life (Frankl, 2004). According to Frankl (2004), the individual's search for meaning is the most important motivation in their living and as meaning is individual and it can only be achieved by them alone. Within hospice patients, the meaning of life may differ from hour to hour and so what is important is the meaning of their life at a given moment.

Moreover, throughout life, individuals develop and put trust in a set of beliefs and assumptions about the world (Clarke, 1989; Janoff-Bulman, 1992; Maher et al., 2020); this has helped them to influence their actions and provided them with a sense of meaning and purpose. However, with a significant life crisis, like a life-limiting illness, the individual may no longer perceive their world as a safe place with others there to protect them. Instead, their world becomes uncertain and unpredictable, and, as a result, they feel vulnerable and live with the unknown. Thus, for the individual, trauma is painful and frightening (Stolorow, 2015), challenging and shattering the individual's assumptive world (Janoff-Bulman, 1992, 2010; Tedeschi et al., 2018). When the previously held assumptions of self, others, and the world become shattered, the individual experiences a loss of meaning (Elliott et al., 2004). This sees the individual reconstruct themselves as victims in the face of their shattered cherished beliefs (Janoff-Bulman, 1992, 2010; Maher et al., 2020). Thus, they experience themselves as flawed, worthless, unable to integrate difficult feelings and their sense of agency challenged. One question is whether the individual, as a non-deterministic but biological organism, can choose and plan appropriate courses of action, guide, direct and carry out the plans to achieve their goals to deal with the experiences of their incurable illnesses? With a personal sense of agency compromised, the individual may be rendered powerless and helpless or even prevented from acting. These *cherished beliefs* (Clarke, 1989; Janoff-Bulman, 1992, 2010; Maher et al., 2020) are not irrational beliefs but include implicit beliefs that were taken for granted, allowing the person to believe that the world is responsible, that they are not vulnerable, and that others will protect them. These beliefs serve as a useful basis on which to live life. When these beliefs are shattered by, for example, the diagnosis of a life-limiting illness, the person needs to create meaning out of their challenging situation. Thus, the person reflects on both the challenging life event and the threatened cherished belief that may give rise to disappointment, disbelief, anger, and a feeling of being stuck.

The shattering of cherished beliefs sees the client enter a *meaning protest* (Elliott et al., 2004). This sees the client describe an experience that is inconsistent with their previously held beliefs. What can the intervention of EFT do to promote a sense of personal agency within the individual? The EFT therapist's task is to provide a caring, empathic relationship and to act as an additional processor of information through active listening and selecting client experiences of the cherished belief and challenging life event. The client and therapist collaborate through a) specification and clarification; b) facilitation of self-reflection to find origins of client beliefs; c) exploring and assessing the “then” versus “now” of the cherished belief; d) revision and emergence of a different form of the cherished belief; and e) plan of action based on revised belief (Elliott et al., 2004). One question is whether every individual who experiences trauma experience post-traumatic growth? Joseph and Linley (2005, 2008) claimed that distressing, traumatic experiences, such as life-limiting illnesses, promote growth within the individual. That is, in the face of adversity, the individual, through self-determination and self-direction, is guided towards greater wellbeing and fulfilment. Thus, the individual is intrinsically motivated towards growth (Rogers, 1951, 1959, 1961). For Rogers (1967), the individual has an innate capacity and tendency to move towards maturity. That is, when the person reaches a level of self-understanding with regards to their emotions, thoughts and actions and can choose how best to deal with situations that may cause pain and dissatisfaction. This tendency may be hidden by psychological defences or even denied. EFT supports that growth tendency has its basis on biologically adaptive internal processes that help them to assess what is important for their well-being (Elliott et al., 2004). Thus, the person needs to face their emotional pain and distress to identify the adaptive information they can provide and specifically these aspects that are growth oriented.

Research (Martela & Steger, 2016) has also shown that meaning presence (having goals, aims and life-direction) and significance (the inherent value of living a meaningful life) are positively related to post-traumatic growth following the experience of trauma (Updegraff et al., 2008). This may mean that having a life full of meaning may help to serve as an anxiety buffer against fear and promote wellbeing. Carver and Antoni (2004) stated that meaning-making strategies have focused on benefit-finding whereby the individual looks for positive features in challenging life circumstances such as a life-limiting illness. This may see the individual experience increased feelings of connectedness, acquiring a deeper sense of self, and prioritising life goals. Moreover, it has been claimed that benefit-finding in cancer patients can help to act against negativity stemming from the illness and help patients to create a meaningful reality, become competent, and sustain a sense of self-esteem (Carver & Antoni, 2004; Taylor, 1983). On that basis, existential worries, including a life-limiting illness, have the potential to promote meaning-making strategies (De Jong et al., 2020; Sawyer & Brewster, 2019), with authenticity and goal pursuits important to the individual as their death concerns become more significant (Rogers et al., 2019).

However, when the individual feels that they are no longer able to change their circumstances, they are required to change themselves (Frankl, 2004). Hence, it is for hospice patients to decide whether they give in to their circumstances or experience themselves as the defiant self. Thus, if hospice patients are self-determining, they will not just exist but will decide what they want to be even in the next moment. Indeed, death is a primary source of anxiety, but the diagnosis and prognosis of a life-limiting illness may see hospice patients veer away from trivial preoccupations. For Jaspers (2010), the fragility of life, heightened through the limit situation of death, can enable the individual to make changes in accordance with what is important in their life. That is, their newfound predicament may provide hospice patients with new ways of thinking to create alternative ways of constructing their experiences. This in turn may encourage the individual to make specific life changes, experience a greater intensity for life and enable them to live more authentically (Kastenbaum, 2000).

Moreover, Block (2005) found that many patients, even with significant vulnerability, achieve a degree of calmness and acceptance of their diagnosis and prognosis. Patients have also acknowledged their increased appreciation of life, their working towards personal growth and, in some cases, to transcendence through a connection to an afterlife (Campbell et al., 2014). However, research also supported that a prolonged search for meaning may give rise to an increase in negative outcomes and feelings of hopelessness (De Jong et al., 2020; Updegraff et al., 2008). Nevertheless, the individual has potentialities within them and on which to base their decisions, rather on their circumstances. Indeed, the individual, even under adverse conditions, can decide, through their inner freedom, what will become of them, mentally and spiritually. Given that, the individual may be more satisfied with their remaining life journey and less gripped by death anxiety (Campbell et al., 2014; Yalom, 1980, 2008). Thus, the hospice patient who is aware that treatment will no longer be appropriate, may accept their prognosis in a courageous and dignified way. Indeed, death may provide a sense of poignancy to life and an entirely different perspective that promotes determination and motivation within the individual to control the quality of their remaining life and inevitable separation from the world (Frankl, 2004; Heidegger, 1962; Yalom, 1980, 2008).

2.7 Can a Sense of Personal Agency Help Hospice Patients Diagnosed with Life-limiting Illnesses to Re-construct Themselves?

2.7.1 Post-traumatic Growth

The literature has maintained that distressing, traumatic experiences, such as life-limiting illnesses, can promote growth within the individual (Aristotle as cited in Barnes, 1982; Campbell et al., 2014; Cordova et al., 2001; Jannerod, 2002; Joseph & Linley, 2008; Rogers, 1951; Ryan & Deci, 2000; Seligman, 2011; Tedeschi & Calhoun, 2004, 2006, 2014). *Post-traumatic growth* (Tedeschi & Calhoun, 1995, 2004, 2018) is defined as the experience of positive psychological change that occurs because of the struggle brought about when the individual experiences highly challenging crisis, including the diagnosis of a life-limiting illness. From an EFT perspective, following traumatic events, the individual experiences extreme emotional arousal, leaving them overwhelmed by feelings of panic and fear and with vivid memories that linger in their memory. Post-traumatic stress comes from the intense reliving of these events (Greenberg & Paivio, 1997). From an EFT perspective, the individual has constructed powerful, accessible emotion schemes (Elliott et al., 2004; Greenberg & Paivio, 1997) that give rise to maladaptive emotional processes that are related to the trauma. Within EFT, emotion schemes are conceptualised as “emotion memory structures that synthesise affective, motivational, cognitive, and behavioural elements into internal organisations that are activated rapidly, out of awareness, by relevant cues” (Greenberg, 2022, p. 38). The individual may then experience fear, and anger. This may see the individual avoiding and interrupting the experiencing of the trauma (Elliott et al., 2004) as the feeling of uncontrollability in the traumatic experience, makes that experience emotionally overwhelming (Greenberg & Paivio, 1997). In therapy, the client is helped a) to develop trust that the therapist does understand and care; b) to reempower the self; c) to begin to trust their environments; and d) to reprocess the trauma (Elliott et al., 2004).

Individuals who can endure psychological struggle following an adversity can often see growth afterwards. Post-traumatic growth may be experienced as new-found understandings, a greater appreciation for life, the prospect of new possibilities, new beliefs, and an increase in a sense of personal strength (Campbell et al., 2014; Cordova et al., 2001; Jannerod, 2002; Joseph & Linley, 2008; Rogers, 1951; Ryan & Deci, 2000; Seligman, 2011; Tedeschi & Calhoun, 2004, 2006, 2014). Moreover, according to EFT, individuals in supportive environments respond more spontaneously in their pursuit of life projects because they challenge themselves to uphold their vision of their environments as manageable, understandable, and meaningful, allowing them to become more complex.

Tedeschi et al. (2018) proposed that there are different degrees of personal growth. Evidence indicates that it is the individual who validates their self in crisis and re-constructs their self as agentic, to varying degrees and who is more likely to experience growth in these circumstances (Campbell et al., 2014). Thus, if the individual can bring about their desired effects and obstruct those they view as undesirable through their own actions, they have an incentive to act or preserve when faced with adversity. Feelings and emotions can strengthen decision making by helping the individual to assess the importance to self of outcomes (Greenberg & Paivio, 1997). That is, they help the individual to reduce their options through preconsciously evaluating what they consider is good or bad for them. Thus, the individual may change how they may respond to circumstances by determining the choices made at significant points. When hospice patients can experience themselves as active agents, they can improve the quality of their remaining life by taking action (Campbell et al., 2014).

2.7.2 Self-efficacy

The belief of the individual in their ability to take an active role and produce the level of performance that can exert influence over events with attainment of a desired outcome is defined as *perceived self-efficacy*. Bandura conceptualised and published his theory of self-efficacy, “Self-Efficacy: Toward a Unifying Theory of Behavioural

Change" in 1977. Watts and Guessous (2006), proposed that self-efficacy and self-empowerment is central to a sense of agency, the belief that the individual can influence their environment through their own means. Self-efficacy beliefs will determine how the individual feels, thinks, and motivates themselves to carry out an action. This may lead to a more self-confident perspective of how the individual perceives their capacity to deal with life stressors, such as a life-limiting illness. Thus 'I' cognition indicates that the individual experiences a sense of control over their environment and confidence in their belief that they can make changes within their situation through their own agency. However, what makes some people able to deal with challenging situations, while others give up? According to Bandura (1977, 1986, 1997, 2008, 2012) belief in self-efficacy can influence whether the individual thinks optimistically or pessimistically. The mode of thinking will affect how the individual experiences themselves as motivated and able to persevere in unfavourable circumstances. The positive self-efficacy approach supports that the human individual can exercise control over their shortcomings and deteriorating physical conditions. Moreover, Schunk & Ertmer (2000) opposed the 'disease model' with its focus on what is wrong with the individual to put them right (Bandura, 2008; Seligman, 1998, 2011). Hospice patients are aware that they cannot be put right but try as best they can to experience some control over their circumstances for as long as they can (Campbell et al., 2014). From an EFT perspective, the individual needs to overcome trauma to re-connect with their ability to make meaningful choices and return to their life projects as they had become unable to function satisfactorily because of the sense of self as victim. The individual reaches re-empowerment of self through the therapist helping them to explore and express their emotions to promote self-protection and personal agency. This helps the client to face their environments and not be inhibited or overwhelmed by their feelings (Elliott et al., 2004).

It is the individual who judges whether they can influence their specific circumstances and whether they attempt to do so. From an EFT viewpoint, emotions are purposive and have a significant role in goal-directed behaviour as they give access to the action tendencies in emotion which, in turn, helps the individual towards their goals. How does that happen? EFT helps the individual to better identify, experience, accept, explore, make sense of, transform, and flexibly manage their emotions. This results in the individual becoming better skilled in accessing important information and meanings, provided by emotions, about themselves and their environment. Moreover, the individual becomes more skilful in their use of that information to live actively and with the ability to successfully deal with their environment. The individual who has great confidence in their capability addresses difficult tasks as challenges rather than problems to be shunned. Moreover, they do not only set themselves taxing goals but remain unwavering in their commitment to their goals. In addition, following problems and disappointment, they quickly recover their sense of self-efficacy. Perceived self-efficacy sees the individual intensify their endeavour and how long they persevere in the face of obstacles and unpleasant conditions. In contrast, the individual who doubts their capability to be self-efficacious, avoids what they see as difficult tasks as they experience a wandering of thought and a decline in performance. Thus, their efficacy expectation is low, and they dwell on their personal inadequacies and on difficulties they may encounter as well as on unfavourable outcomes (Bandura, 1989).

It is difficult for the individual to achieve when they have self-doubts about their personal efficacy, and this may see them they give up easily and experience themselves as slow to recover following unfortunate developments. Thus, the choices made by the individual may be influenced by their belief of themselves as self-efficacious. However, Schunk & Ertmer (2000), proposed that everyone can exercise agency and strengthen their self-efficacy so that they become more efficient, regardless of their past or current environment. According to Bandura (1989), the individual who sense that they can develop the ability to cope is more likely to withstand adversity and bounce back from difficult situations as opposed to the individual who views their ability as established and definite. Thus, the individual is required to make use of their knowledge to construct options, make predictions, assess performance, and recall which actions and attitudes provided the best outcome. Self-efficacy can be promoted through mastery experiences (Bandura, 2008). However, do these skills demand too much effort and perseverance for hospice patients who may be physically weak and emotionally vulnerable and fragile? It is through mastery that the individual's belief in their ability to succeed will grow as they acknowledge that their effort and perseverance afford them the satisfaction of achieving desired outcomes in the face of adversity. Also, facing difficulties in the quest for goals may be useful and helpful in promoting the resiliency of the individual. Then again, affective arousal may promote performance in the individual who has a positive perception of their self-efficacy, whilst for the individual who doubts their capacity for self-efficacy, affective arousal may have a hindering effect.

2.7.3 Hope

Shielding from unpleasant situations can see the individual unable to deal with prospective difficult circumstances. With loss of faith in their capabilities, the individual may become affected by stress and depression (Bandura, 2008; Dickson et al., 2011). However, the individual who believes they can face and direct control over threats do not evoke distressing, self-hindering thoughts. A key element in combatting depression is the concept of *hope* (Greenberg & Watson, 20022; Snyder, 1994, 2010). When people who are close to us are in distress, we lend them our abilities, calmness, and confidence. How is that carried out in EFT therapy? Perhaps, because of the therapist's experience of themselves or others, they can lend hope to the client through their emotional tone and earnestness. In therapy, the client is helped to experience concretely their unclear hopelessness and despair and share it with the therapist. This helps to promote the generation of hope and put in motion the client's longing for an end to isolation and re-connection with other humans. Hope promotes a desire to feel, to wish and to live. Patients receiving palliative care may hope for a cure or extension of life or to make the most of their remaining life; however, honesty about patient prognosis may help patients to engage constructively with their grief, replacing an unrealistic hope with a more resilient kind of life (Hill et al., 2023). According to Snyder (2010), individuals with higher levels of hope have more positive emotions; have a stronger sense of purpose; have lower levels of depression and are less lonely. Alternatively, the lack of hope among palliative care patients has the power to undermine the person's sense that life has an on-going intrinsic value (Chochinov, 2006). In therapy, the encouragement of hope helps to activate client-agency, motivating them to work towards their goals and ways in which to achieve them.

2.7.4 Resilience

Resilience is the process of adapting well in the face of adversity, trauma, tragedy, threats, or even significant sources of stress (APA, 2014). According to Southwick and Charney (2018) resilience involves biological, psychological, social, and cultural elements that interact with one another to determine how the individual responds to stressful experiences. Also, according to Southwick and Charney (2018), the genetic aspect of the individual has a significant influence on their response to trauma and stress. Whilst resilience is said to exist on a continuum (Pietrzak & Southwick, 2011), all individuals do not develop psychopathology following trauma and, indeed, some individuals who are traumatised may end up in a better place than before the trauma (Yehuda & Flory, 2007). Also, individuals who often experience positive emotions like happiness are more satisfied in their living and are better able to deal with challenges. Moreover, Seligman (2015) found that *personalisation, pervasiveness*, and *permanence* are three key emotional reactions to adversity. That is; by addressing these, the individual can build resilience and grow by developing their capability to adapt and to learn how to cope with problems and failures. Thus, *personalisation, pervasiveness*, and *permanence* help the individual to make sense of how their thoughts and beliefs affect their experiences. Resilience studies no longer conceptualise resilience as a trait but rather tend to recognise it as a process by which the individual's resources protect against the negative effect of the stressor to produce a positive result (Nath & Pradhan, 2012).

Close to an EFT perspective, Fredrickson (2001) claimed that positive (i.e., pleasant) emotions build resilience by undoing the effects of negative (i.e., distressing) emotions. Moreover, the ability to organise positive emotions in the face of stress is a critical factor of resilience. Unpleasant feelings see the individual attend to what is important to their well-being and promote adaptive action. However, if unpleasant feelings linger, overwhelm or are intense to evoke past loss or trauma, the individual may become at risk for mental health difficulties. As a result, resilience is lost as the individual experiences anxiety, powerlessness, and a sense of the self as inadequate or even bad. Davidson, (2000) defined resilience as the ability to maintain high levels of positive affect and well-being when faced with adversity. For Davidson, it is not that resilient individuals do not feel negative affect, but the negative effect does not endure. In transformation of emotions, that is, the construction of alternatives, the EFT therapist helps the individual to access the resilient self and new resilient responses that can challenge older, less adaptive responses. Thus, the individual is encouraged and helped to transform the maladaptive emotions and to challenge the destructive thoughts in their maladaptive emotional states, based on healthy primary emotions and needs (Greenberg & Watson, 2002).

2.7.5 Terror Management Theory

Terror Management Theory (TMT) was derived largely from the works of Becker (1971, 1973, 1975) who emphasised how death influenced the ways in which human individuals lived. Becker argued that, like other animals, the human individual had a biological drive to survive (Schimel & Arndt, 2010). However, unlike other animals, the human individual has a capability to be aware of self, the world around them and future possibilities. As the human individual evolved, their environmental demands saw them develop cognitive abilities that gave rise to adaptive benefits. However, these cognitive abilities also saw the individual becoming aware of their mortality and in many instances, it is claimed that biological and genetic predispositions may limit the extent to which the individual can cope with adversity (Timulak, 2015).

Despite how the individual may try, they cannot escape the inevitability of their death. Thus, the individual tries to manage the conflict between an innate desire for the preservation of their existence and the awareness that their life is not permanent. This may give rise to an existential dilemma that may promote anxiety or terror. On that basis, the individual may respond with avoidance by way of defence mechanisms that mostly stop the thoughts of death becoming conscious. These defences serve to remove these thoughts from focal attention when they do. In EFT terms, painful feelings are difficult to endure and thus, the individual tries to avoid them or interrupt their experience of them. With avoidance, adaptive information is neglected, leaving the individual disoriented. Moreover, avoidance sees the feelings and their effects remain, with feelings, thoughts, and actions in disharmony. This hinders the individual to cope or act on their emotions effectively, and with feeling blocked, the individual is stuck in a state of continued avoidance (Greenberg & Paivio, 1997). As a result, the individual may experience a discontinuity in their life narrative meaning-making processes (Elliott et al., 2004).

However, death anxiety is not experienced by most individuals daily, nor does the conscious thought of death prevail. Nevertheless, hospice patients must live every day with a threat to their existence. Inferences about the level of activation of death thoughts are referred to as *death-thought accessibility* (DTA), (Schimel et al., 2010). In their Theory of Terror Management, Greenberg et al. (1986), shed light on how efforts to handle worries about the inevitability of death may contribute to unpleasant human behaviour, including prejudice, greed, materialism, and support for war (Greenberg et al., 2008). Does this contribute to a view that the awareness of death promotes destructive outcomes? Greenberg et al. (2008) also supported that awareness and management of death concerns can help in the promotion of honourable, creative, and prosocial ways of acting, with terror management endeavours instrumental in effecting personal growth in fulfilling ways (Vail et al., 2012).

How does TMT support that death awareness can act as a crucial motivating factor in human behaviour? TMT supports a “dual component buffer system” (Vail et al., 2012, p. 304) whereby the individual can handle death awareness by maintaining their belief in a worldview and upholding the values it promotes (Vail et al., 2012). The first component of the buffer system is cultural worldviews that represents socially constructed and approved beliefs that can help the individual to supress death anxiety in several ways. For example, if the universe is perceived as orderly and stable, the individual may become calmer and believe, even implicitly, that death is no longer a concern. Moreover, the belief in a just world (Lerner, 1980) is acknowledged as a factor in the managing of anxiety. The belief in a just world allows the individual to assume that their personal security is likely. In EFT, there is one set of emotions that is pre-trauma, and this creates difficulty as the traumatic event, the diagnosis of a life-limiting illness, cannot be assimilated to this set of emotion schemes. However, another set of emotion schemes (terror and vulnerability) is activated during the trauma and represents the world of the traumatic event. Thus, the therapist tries to help the individual to re-experience a sense of personal agency; to no longer see the world as unsafe and unpredictable; to see others as caring and helpful.

In addition, this component may provide the individual with the concept of symbolic death transcendence through secular (being a parent or author of a book); and religious (Heaven) means (Vail et al., 2012). The second component, self-esteem, reviews the perceptions of how well the individual maintains the values set out by the worldview. If maintaining belief in cultural beliefs and self-esteem buffers death concerns, then *mortality salience*, the awareness that the individual must die (Rosenblatt et al., 1989) may motivate the individual to sustain and respect their worldviews and pursue self-esteem. According to Svet et al. (2023), the individual confronted with their own mortality, works hard to safeguard their self-esteem and close relationships (Fritsche et al., 2007) to give meaning to their life. However, there is a distinction between authentic and inauthentic ways of being in relation to death. Given that, an authentic way of existence is due to self-determined values and preparation for that inevitable event as opposed to hiding from it in agreeable cultural worldviews.

2.7.6 Locus of Control

Locus of control refers to the degree to which the individual believes that the outcome of an event is decided by their own actions or by those of external forces (Rotter, 1966). Also, Rotter (1975) posited that locus of control (LOC) exists along a continuum from a more internalised stance to a more externalised orientation, rather than a definite category of one or the other. The concept of LOC was created by Rotter in 1954 in his theory of social learning and describes the way in which the individual makes sense of the influences affecting their lives. LOC has two main influencing features, namely, internal control and external control. The internal control factor represents the individual's sense that their outcomes are determined by their own actions. Moreover, the external factor reflects the sense that outcomes are shaped by external influences such as chance, luck, fate, or powerful others. LOC, a non-cognitive skill, represents an attitude, belief, or expectancy with respect to the relationship between behaviour and outcomes (Lefcourt, 1976; Rotter, 1966).

Given the complexity of each individual, Rotter (1954, 1972) believed that in order to make predictions about behaviour, four variables were significant: *behaviour potential* (probability of a certain behaviour taking place with respect to a specific reinforcement), *expectancy*, (that reinforcement will accompany the selected behaviour), *reinforcement value* (desire for a particular reinforcement) and the *psychological situation* (attending to different dictates of the environment). Thus, the individual is likely to choose the behavioural option that they believe will provide the most favourable situation (Rotter & Hochreich, 1975). With respect to EFT, it is emotions as a) an adaptive form of information processing and b) action readiness that orient the individual to their environment and facilitate their well-being (Greenberg & Paivio, 1997). Also, Rotter believed that the expectancy of the reward and the perceived value of that reward were both necessary in determining whether the individual engaged in a particular behaviour. As a theory of learning, the behaviour in question is either reinforced or halted based on how the individual perceives LOC. From an EFT stance, it is emotions that tell the individual what is helpful, or not for them. Thus, emotions are involved in the setting of goals and are the result from the assessment of circumstances, based on the needs, desires and goals of the individual (Frijda, 1986). It is claimed that children as young as two months are capable of social learning and with a tendency to result in positive emotional reactions (Lefcourt, 1976). Instrumentality (Vroom, 1964) is the perceived probability that good performance will give way to desired outcomes. This means that to repeat a behaviour with purpose, the individual must be able to recall that their prior actions resulted in their desired outcome.

Rotter' s concept of LOC (1954, 1966, 1975) was extended by Wallston et al. (1978) to cover the multidimensional aspect of health-related behaviour and has had significant applications in education, health, and clinical psychology. Health LOC refers to the belief that health is within the control of the individual (internal) or not within them (external). Thus, does the individual who believes that they can control their own destinies act differently from those who expect that their outcomes are controlled by externals? When the individual believes that they are fully agentic, there is a difference between how the individual and less agentic others view the world and act upon it (Campbell et al., 2014). The individual's perception of control regarding life circumstances can affect the quality of their life and over-all mental well-being (Brown et al., 2015). Furthermore, high internal LOC has been associated with improved health habits, participation in screening tests, and improved mental well-being following the diagnosis of an illness (Brown et al., 2015). Alternatively, research has indicated that patients with high LOC chance, experienced decreased peace, meaning, faith, quality of life, and hope (Brown et al., 2015). Moreover, these patients experienced anxiety and depression at their end of life and had poor coping skills to deal with their circumstances (Hegelson, 1992). However, other research indicated that a high external LOC may allow patients to better adapt to their illness because they are able to separate themselves from their illness and see it as the responsibility of a powerful other (Broers et al., 2000).

LOC was originally described as a personality trait referring to the individual's beliefs of their self-efficacy (Rotter, 1966). Self-efficacy and LOC are two constructs that have been studied with respect to the relationship between stress and illness (Shelley & Pakenham, 2004). Moreover, the individual with high self-efficacy and an internal LOC may feel that they are in control of their own health and carry out the behaviours necessary to maintain health (Roddenberry et al., 2010). However, LOC has also been recognised as a coping resource to facilitate coping styles (Van den Brande et al., 2016). For example, laying the cause of an outcome on others (external LOC) has been related to avoidance coping, greater stress, and ill-health (Gore et al., 2016). Furthermore, with the experience of higher levels of stress and depression, the individual feels that they are at the mercy of outside forces. This may lead to anxiety and learned helplessness (Seligman, 1975). That is, the individual with depression may present a state of mind that reflects hopelessness. As a result, the individual does not believe that their actions will have any positive effect on the outcomes of their lives (Seligman, 1975). According to EFT, the individual begins to understand that they themselves may be contributing to their hopelessness and so their hopeless state is not merely the result of circumstances outside of them. The therapist helps the individual to explore their self as agent. For hospice patients, they may focus on the lack of belief in themselves to deal with their diagnosis and prognosis. When the individual can recognise that they are an agent contributing to their hopeless state, they can move from being overwhelmed and stuck to being able to self-explore. The therapist then helps the individual to work on accessing new feelings. The individual may then experience greater optimism and feel more confident, allowing them to move from feeling hopeless to feeling hopeful and empowered.

However, healthy adults rarely believe that everything is either entirely out of or entirely within their control. From an internal standpoint, the individual shows perseverance in the face of adversity (Schurer, 2014); emotional stability and conscientiousness; strategies to deal with pain, so reporting lower pain intensity; self-motivation and focus on achieving goals they have set for themselves. Alternatively, from an external stance, high external LOC associated with chance had a negative impact on the lives of cancer patients (Thomson & Young-Saleme, 2015) who experienced a sense of powerlessness and decreased quality of life. Furthermore, according to Rotter (1966) LOC is a continuum of perceived control as the individual does not see what happens to them in the future as wholly decreed by internal or external control. This may help to explain variances in psychological wellbeing (Garber & Seligman, 1980).

2.8 Modes of Agency

2.8.1 Collective Agency

In many situations, the individual may not experience themselves as having direct control over conditions that may affect them. For example, hospice patients may not experience their living in individual autonomy, that is, they may feel they are not in charge of their own lives or have the freedom to make their own choices. That is, hospice patients may not feel they have the information necessary to make decisions about their illness and treatment and may feel instead that the outcomes they want are only achievable through their reliance on others. Hence, the individual may choose to collaborate with others to secure what they are unable to achieve on their own (Bandura, 2020). That is, as the *collective self*, the individual may enter negotiation to surrender their autonomy to appropriate professionals whose collective expertise, experience and competence will respond positively to their needs through the realising of their goals. Bandura in his social cognitive theory (2020), broadened the notion of human agency to collective agency, whereby the perceived collective agency is more than the sum of the efficacy beliefs of the collaborating others. Thus, collaboration sees not only the sharing of knowledge and skills but harmonious synergy that sees the emergence of group-level properties (Smaldino, 2014) such as trust, transparency, and openness to diversity of ideas.

Furthermore, shared beliefs have influence over a) how individuals use their resources; b) how much effort is required to be a member of the collaboration; and c) the endurance required to overcome the setbacks when quick results are not achieved. Literature has indicated that the greater the co-operation, the more robust is the perceived efficacy of the collective collaborators (Stajkovic & Lee, 2001). However, if individuals choose to surrender their autonomy and construct themselves as *relinquishing selves*, they are not solely responsible for the creation of their future. That said, individuals may choose to experience themselves as *actively collaborating selves*. Thus, co-operating with helpful professionals allows them to be involved in decision-making, relevant to their circumstances. On that basis, as part of a collective self, the individual is both self-determining and inter-dependent (Kant, 1964). Moreover, Bandura (2006, p.168), maintained that human individuals are not 'just on-looking hosts of sub-personal networks autonomously creating and regulating their performances'. On that basis, the individual is pro-active, with on-going human action and goal achievement, including dealing with external stressors like life-limiting illness. Indeed, the motivational aspect of desiring to participate collectively, comes from the individual. Moreover, the individual has confidence in the co-ordination and integration of resources to respond prudently to their needs. However, a supportive environment, in the form of collective agency, may be required to enable the individual to experience personal power and move towards growth.

2.8.2 Moral Agency

Moral agency (Bandura, 1986, 1999, 2006, 2016) is the ability of the individual to make moral choices based on some notion of right and wrong and to be accountable for their actions. How is the individual, as a responsible agent, connected with their actions? Could the individual, as agent, have chosen to do otherwise? Social cognitive theory of moral agency (Bandura, 1999, 2006, 2016) proposed that this self-regulatory process is self-sanctioning giving rise to either a) a sense of guilt, remorse, and self-condemnation when the individual recognises themselves as not doing the right thing or b) self-approval as a sense of satisfaction and worth when doing right. The concept of *deontology* used by Broad (1930) is an ethical theory that says that actions are deemed good or bad according to an explicit set of principles, rather than on the consequences of the actions. Kant who supported the deontological perspective, argued that a) to act in the morally right way, the individual must act from duty and b) it was not the consequences of actions that saw them right or wrong but the motives of the person who carried them out. Kant in his *Categorical Imperative* upheld that a rule of conduct is unconditional for all goals, with the moral agent acting because of judgement of conscience to benefit society and disapprove of that which could cause harm. Indeed, individuals show respect for each other, promoting virtue and happiness.

Thus, being an agent, requires some sense of direction in life. That is, the individual, engages in a process of self- regulation that helps them to keep track of their behaviour, attitudes, and beliefs that they assess in relation to their personal moral standards and perceived current circumstances (Bandura, 1991b). Whilst this moral evaluation is an intra-personal process, *moral agents* translate their moral standards into moral conduct. Moreover, Bandura (2004b) proposed the idea that the practice of moral agency may be viewed from an inhibitive or proactive perspective. That is, the individual, as an autonomous agent, can choose to act to refrain from behaving inhumanely or conversely can act with beneficence. However, the individual may also indulge in moral disengagement through making unethical decisions when their usual self-regulatory processes that ordinarily hold back unethical behaviour are no longer effective (Bandura, 1999, 2006, 2016). Thus, from this perspective, as an agentic being, the human individual has the capacity to choose, assess, and incorporate information to make moral judgements.

2.9 This Research in Existing Literature

Based on this literature review of evidence, I anticipated that my own study, using data collection from hospice out-patients and in-patients, would help to fill gaps in the existing research by providing foundation a of knowledge on the topic of personal agency in relation to life-limiting illnesses, placing my own research within the context of existing literature on agency, making a case for further research. With respect to gaps in existing literature, Hitlin and Elder (2007) stated that whilst the human individual is an active being, the current treatments are too abstract to provide guidance for empirical research. Also, Hitlin and Elder (2007) maintained that many questions emerged from the effect of agency on health, but little research had been carried out to directly address the nature or measurement of personal agency. Park 2010), concluded that significant progress was required in understanding how meaning-making processes can undermine or enhance the experience of meaning in life.

Can existing measures sufficiently assess personal agency in hospice patients? For example, locus of control (LOC; Rotter, 1966) refers to the degree of perception that a reward follows from, or depends on their own behaviour or attribute, versus the extent they feel the reward is controlled by external forces. The Locus of Control Scale (Rotter, 1966) is a 29-item forced-choice questionnaire whereby participants select the item response that they agree with the most from two options. Regarding people's health, findings indicated a) LOC and self-control were distinct and b) pointed to the importance of both concepts for people's physical and psychological well-being (Botha & Dahmann, 2024). The Health Locus of Control Scale (HLC; Wallston et al.,1976), a measure of expectancies regarding LOC for prediction of health-related behaviour, is associated with different aspects of health, including the decision-making process regarding treatment. Wallston et al., (1976) acknowledged that the scale, like the Rotter 's Internal/ External Locus of Control Scale (1966), is a generalised measure of expectancy as opposed to beliefs about specific behaviours. A Multi-dimensional Health Locus of Control Scale (MHLC; Wallston et al., 1978) supported that health may be attributed to internal factors (healthy lifestyle), powerful others (doctors), or chance. Whilst MHLC was applicable to a variety of health-related behaviours and situations, evidence of the convergent validity of this scale is limited and mixed (Armitage et al., 2025).

The Perceived Self-Efficacy Scale (Schwarzer & Jerusalem, 1992) was based on the belief that people perform novel or different tasks to cope with adversities across domains. Perceived self-efficacy promotes goal setting, requires effort and persistence in the face of challenges like a life-limiting illness. This scale correlated with favourable emotions and dispositional optimism, but demonstrated negative coefficients with depression, anxiety, stress, and health concerns. Also, additional items are necessary to identify specific change regarding the specific content of the questionnaire.

Wallston & Smith (1994) supported that beliefs regarding the controllability of health may be detrimental when those beliefs are challenged, for example, by a life-limiting illness. Whilst Steptoe and Wardle (2001) found that LOC beliefs alone play only a modest part in explaining health behaviour, Smith (1989) argued that measures of LOC were weakly associated with self-efficacy. According to Bandura (2006), perceived self-efficacy is distinct from locus of control: perceived self-efficacy is a judgement of capability to carry out given kinds of performances while LOC is associated with belief about outcome contingencies. Sense of Agency Scale (SoA) was developed by Tapal et al. (2017), with correlations between LOC and SoA modest, indicating a conceptual difference between judgement of having, or not, control over desired outcomes. Moreover, Wallston et al. (1999) developed the God Locus of Health Control sub-scale. Also, a systematic review revealed that there is an increasing number of observational studies in palliative care, with many specific to level of consciousness measures (Krooupa et al., 2019). Only a few have been tested for their psychometric performance within palliative care, and none across all relevant measurement properties (Krooupa et al., 2019).

I believe that there is a need for the two proposed measures, self-report and observation. Existing scales would not be suitable as they would not capture the same understanding of personal agency in a population of hospice patients. In addition, a) all items and critical incidents used originated from verbatim statements of hospice patients and b) the hierarchy, a rational-empirical model of levels of personal agency discovered in the earlier MSc study and supported in Study 1, was the foundation of both proposed measures.

Block (2005) has stated that multiple methods of psychotherapeutic support for patients at end of life have been proposed. Whilst current research does not support the role of one approach over others (Block, 2005; Spira, 1997) patients did benefit from an approach that combines emotional support, flexibility, and a warm, genuine therapeutic relationship (Block, 2005). Moreover, Dezutter et al. (2013) supported that when patients with a chronic disease experience meaning in life, they are better able to adapt and experience an increase in their well-being. Routine monitoring of patient meaning-related concerns can identify patient decreases in meaning and increases in the search for meaning, indicating the need for a referral to therapy. Moreover, hospice patients receiving the intervention of EFT, did indicate an increase in their personal sense of agency as represented by the hierarchy of levels of personal agency, Figure1.1, Campbell et al., 2014) and Table 1.1 (Section 1.5). In the next chapter, I focus on the rationale for the methods used to aim to answer the research questions raised here.

2.10 Chapter Summary

In this chapter, I presented an overview of the concept of personal agency, based on a review of the existing literature, with focus on the traits of personal agency that specifically related to personal agency as experienced by hospice patients. That is, I chose to present a comprehensive background of the literature, relevant to the topic of the research by gathering information from relevant, credible articles and studies. Moreover, I evaluated, critically reviewed, and compared these research studies highlighting gaps in knowledge. Thus, I detailed how I reviewed the existing literature based on the human individual as a non-deterministic but biological being who, when their environment poses a new significant challenge, such as a life-limiting illness, is required to meet their needs to survive. Also, this literature review aims to contribute to current knowledge and debate. In the next chapter, Chapter 3, "Guiding Principles for this Research Topic", I present how the general strategy of how personal agency can be described, measured and promoted in hospice patients.

Chapter 3: Guiding Principles for this Research Topic

3.1 Overview

In this chapter, I present an overview of how I set out to learn whether and by what methods the abstract concept of *personal agency* (Bandura, 1977, 1989, 1994, 1997, 2008, 2011, 2012, 2018) can be described, measured, and promoted in hospice patients diagnosed with life-limiting illnesses. That is, in this chapter, my purpose is to lay out my general research strategy, rather than to describe the specific methods used, which will be covered in the appropriate chapter. I wanted to design valid and reliable measuring instruments that can assess the sense of control hospice patients have of themselves as having influence over their experiences and circumstances. Based on philosophical and theoretical arguments, I present here the rationale for selecting the research methodology, including assumptions about the nature of reality, knowledge, theory, and practice. Thus, I define and justify the broad strategy I used to carry out this research to ensure valid and reliable results that a) address its aims and objectives and b) answer the specific research questions. On that basis, I explain here my decision to adopt a series of three distinct studies, using distinct methods, within an overall mixed methods design, including both qualitative and quantitative approaches. In addition, I introduce the concept of *measurement* and describe *conceptualisation* and *operationalisation*, the first two steps in the measurement process.

3.2 Research Design and its Components

In this section I describe the overall research philosophy and strategy (Creswell & Creswell, 2015, 2018) that guided the many decisions from broad assumptions to precise methods (Creswell, 2009; Creswell & Creswell, 2018). It is informed by my chosen research paradigm, including its *ontology*, *epistemology*, and *methodology* (Creswell, 2009; Creswell & Creswell, 2018; Kuhn 1962; Terre Blanche & Durrheim, 1999) which guided my choice of relevant approaches to answer research questions through organised and systematic methods and procedures, known as methodology (Creswell, 2009; Creswell & Creswell, 2018). In the following section, I am going to talk about *paradigms* and their constituent components.

3.2.1 Overview of Research Paradigms

Kuhn (1962) defined a paradigm as a set of common beliefs and agreements shared between researchers in relation to how problems are understood and solved (Denscombe, 2008; Guba; 1990; Hemmings et al., 2013; Kuhn, 1962; Lincoln et al., 2011; Morgan, 2007; Schwandt, 2001). Other researchers were influenced by their *worldviews* that consisted of their beliefs and philosophical assumptions about the nature and understanding of the world (Creswell & Plano Clark, 2011). From a worldview perspective, a research paradigm reflects the researchers' assumptions about *ontology*, *epistemology*, and *methodology*, the formative components of the research inquiry (Makombe, 2017). *Ontology* (Patton, 2002) is concerned with what exists in the world, questioning whether reality is single, multiple, or even does not exist. It looks for classification and explanation about entities according to similarities and differences. *Epistemology,* the study of knowledge and how it can be obtained (Snape & Spencer, 2003), has the core concepts of knowledge, belief, truth, and justification (Zagzebski, 1996). Ontology and epistemology together comprise the research philosophy that ensures that research outcomes are meaningfully interpreted (Moon & Blackman, 2014). Different approaches have been developed (Creswell & Plano Clark, 2007) a) an a-paradigmatic perspective that disregards paradigmatic issues; b) a multiple paradigm approach; and c) a single paradigm approach, with qualitative or quantitative research carried out under a single paradigm. I chose a multiple paradigm approach and justified that decision based on the philosophical underpinnings of Studies 1 and 2.

With the philosophical underpinning for the Study 1 supporting multiple realities and subjective knowledge, this indicated an alignment to the *interpretative* paradigm (Bogdan & Biklen, 2003; Creswell, 2009; Creswell & Creswell, 2018; Chilisa & Kawulich, 2012). *Interpretivism* does not seek universal truths but to *interpret* and explain the actions and beliefs of human interaction, with meanings varying between and within the human individual depending on the context (Vygotsky, 1931; 1991) and with reality subjective, multiple, and socially constructed (Denzin & Lincoln, 2005; Greene, 2010; Mertens, 2009). Moreover, interpretivism is based on a humanistic philosophy, providing the grounds for qualitative research (Creswell, 2015, 2018; Denzin & Lincoln, 2005; Elliott et al., 1999; Elliott & Timulak, 2005, 2021; McLeod, 2003, 2010; Miles & Huberman, 1994; Silverman, 2006; Taylor & Bogdan, 1998), including grounded theory (Charmaz, 2006; Glaser & Strauss, 1967; Rennie et al.,1988), phenomenology (Creswell, 1998; 2008; Husserl, 1970**),** and empirical phenomenology (Giorgi, 1975; Wertz, 1983).

The underpinning for Study 2 is focused on what patients can achieve, expressed as personal agency, within the circumstances in which they must operate. Thus, the ontology and epistemology of Study 2 leaned towards *critical realism* (Bhaskar, 1975; Danermark, et al., 2019; Elliott & Timulak, 2021; Hastings, 2021) whereby it is possible to distinguish between the "real world" and the "observable world" by offering an alternative to positivist and interpretive paradigms (Zhang, 2022). Critical realism (Sayer, 2000) holds that a) there is reality to be known, even although imperfectly; b) ideas about reality can be enhanced by testing them against observations and data; and c) meaning is necessary for understanding human action; d) the nature of knowledge is context-dependent, incomplete, and fallible.

3.3 Methodology

In this section, I describe the *methodology* (Creswell, 2015; Creswell & Creswell, 2018). As noted earlier, research methodology consists of philosophical beliefs about the nature of reality, knowledge, values, and the theoretical framework that enlightens understanding and interpretation. Justification for the choice of methodologies and methods is dependent on the research objectives and questions, plus one's overall theory of method. Furthermore, it is important that the results can be evaluated by others and that the study could be replicated by other researchers. The research process consists of a series of actions necessary to effectively conduct the research, with sequencing of these actions crucial.

As Studies 1 and 2 (Chapters 4 and 5) indicate that as the data is experiential (self-report questionnaire) and observational (observation measure), respectively, the research requires both qualitative and quantitative approaches (Creswell, 2009; Creswell & Creswell, 2018). This research encompasses a series of three distinct studies, qualitative, quantitative and a third systematic mixed methods case study, comprising of both qualitative and quantitative approaches. That is, a pluralistic set of approaches following an overall mixed methods strategy (Creswell, 2009, 2015; Creswell & Creswell, 2018; Chilisa & Kawulich, 2012), involving both qualitative and quantitative data and group and single case designs, guided by different philosophical assumptions (Creswell, 2009, 2015; Creswell & Creswell, 2018; Chilisa & Kawulich, 2012). The following section provides an insight into the rationale for mixed methods research.

3.3.1 Overview of Mixed Methods Research

Mixed methods research (MMR) is increasingly used as a methodology in the health sciences (Plano Clark, 2010) and focuses on research questions that attempt to illuminate real-life contextual understandings. A research design that has philosophical assumptions and methods of inquiry (Creswell & Plano Clark, 2018; Maxwell, 2017), MMR uses both qualitative and quantitative data when neither are sufficient in themselves to capture the trends or details of circumstances. The underlying premise of mixing a) cancels the weaknesses and limitations in research that provides only one form of data; and b) uses the results from one method to help develop or inform the other method. Hanson et al. (2005) claimed that collecting both types of data provides a comprehensive understanding of the results, expands and strengthens the study's conclusions, adds knowledge to existing literature and ensures that validity is robust (Schoonenboom & Johnson, 2017).

3.3.2 Paradigms and Mixed Methods Research

In this section I present the need for paradigms in MMR. Whilst Hall (2013) stated that existing single paradigms do not provide an adequate rationale for MMR, Greene (2012) supported a *dialectical aim* where the interaction between different paradigms allows researchers to explore and hold different points of view. Similarly, Johnson (2017) advocated "*dialectical pluralism*" that, attending to each research question and purpose, allows more to be known about specific participants and the larger social context as researchers combine ideas from competing paradigms. *Dialectical pluralism* assumes that truths are provisional and multiple (Johnson, 2017; Tashakkori et al., 2021), and that paradigms can be mixed or combined, with the *incompatibility thesis* (Onwuegbuzie & Leech, 2005) not always applying to research practice. That is, according to the incompatibility thesis there is a paradigmatic incompatibility between qualitative and quantitative approaches as they have different philosophical worldviews, and this may have impact on the mixing of approaches in mixed methods research (Bryman, 2007).

My decision to mix the paradigms of interpretivism and critical realism was based on dialectical pluralism (Johnson, 2017). That is, firstly, the interpretivist researcher aims to generate, discover, or construct knowledge (Denzin & Lincoln, 2011; Yanow, 2014), with knowledge idiographic in its commitment to investigating the experience of individuals, prior to more general claims. Secondly, critical realism focuses on the nature of reality and insight to build knowledge about a real-world phenomenon, based on observing, experiencing, and acting on a complex, ever-changing world from a particular perspective and time (Ackroyd, 2010; Bhaskar, 1975; Danermark, et al., 2019; Elliott & Timulak, 2021; Hastings, 2021). Critical realism can be used for research methods to explain events in natural settings (Tikly, 2015).

3.3.3 Methodological Pluralism

The choice of the paradigms, interpretivism and critical realism, and mixed methods research was deemed appropriate for the three studies within the larger programme of study presented in this thesis. With the research topic of personal agency complex and contextually situated, a plurality of research methods is preferred to address this topic (Campbell et al., 2012). Methodological pluralism (Barker & Pistrang, 2005; Barker et al., 2015) involves finding value in various sources of information with the belief that no research method is generally superior to another but instead depends on the topic and aims of the study (Barker & Pistrang, 2012).

3.4 Methodological Pluralism with respect to Qualitative Approach

The following sections describe the qualitative approach used in Study 1 (Chapter 4) of this research, within the more general methodologically pluralist approach taken.

3.4.1 Strategy of Inquiry

To begin with, the Study1 qualitative study used a case study strategy (e.g., Freud, 1909; Kotter & Carlson, 2003; Yalom, 1989; Yin 1981a, 1981b, 2018), an empirical inquiry (Creswell, 2008; Denzin & Lincoln, 2005; McLeod, 2003, 2010; Miles & Huberman, 1994; Stake, 1995; Yin, 2009, 2018) that allows intensive investigation to provide in-depth, detailed data, with each case preserving the uniqueness of the individual and yet acknowledging possible commonalties. According to Harling (2012) and Yin (2009; 2018) a case study is a holistic investigation of a contemporary phenomenon in its natural setting.

Each case identified for research (Ragin & Becker, 1992) can be defined as a person, action, or event (Jett et al., 2016; Platt, 1992). For this research, each case was a hospice patient. Also, each case is *bounded* with respect to the time taken for the study; the individuals represented as cases; type of data collection and analysis; and what is relevant and workable (Harling, 2012). In addition, case studies can include single or multiple cases (Stake, 2006) and can provide a single set of "cross-case" results to generalise. Yalom (1989) stated that a multiple case design provides a basis for generalisation.

Case studies rely greatly on direct observation of the phenomenon being studied and on interviews of those involved with the phenomenon (Yin, 2009, 2018). An advantage of case study method is that data collection takes place within a real-world context and not within a laboratory environment. A strategy of inquiry is best suited to a particular purpose rather than dependent on a philosophical position (Brannen, 2005) and, when a body of studies is built on a phenomenon like personal agency, trust in the findings increases.

3.4.2 Sampling

Purposive or purposeful sampling (Denzin & Lincoln, 2005; Patton, 2002; Silverman, 2006) identifies participants based on their potential to contribute to the development and refinement of abstract concepts. Moreover, homogenous sampling, a purposeful sampling technique, is chosen to achieve a sample of cases that share similar circumstances.

3.5 “Grounded Theory and Variants”

According to Elliott and Timulak (2005, 2021), a variety of qualitative methods bearing different names are in fact variations on the basic principle of similar sets of strategies and procedures, referred to as *descriptive-interpretive (or interpretative)*. Elliott and Timulak (2021) support McLeod’s (2011) labelling of these as “Grounded Theory and Variants.” These include *grounded theory* (Charmaz, 2006; Glaser & Strauss, 1967; Rennie et al., 1988); *empirical phenomenology* (Giorgi, 1975; Wertz, 1983); *interpretive phenomenological analysis* (Smith et al., 2009) and others. The two important aspects of qualitative analysis are a) the understanding and the representation in words of each meaning unit relevant to personal agency and b) the categorisation of meaning units into groups according to similarities within groupings. To understand and translate meaning units for categorisation (Hill et al., 2005), the modes of *Meaning Unit Summary* and *Explicating Implicit Meaning* (Elliott & Timulak, 2021) were used. In the first mode, also known as *meaning condensation* in empirical phenomenology (Giorgi, 1985), the main point of the meaning unit is represented in a precise, concise way. Secondly, once the implicit meaning is conveyed, explicating the ideas of salient pieces of data allows the researcher to “read between the lines” as the speaker may presume to have shared their knowledge (Labott et al., 1992).

Moreover, meaning units are provisionally named and those showing similarities are clustered together to form categories that may be named and re-named. Naming of categories may be dependent on the subjectivity of the researcher, semantics, or an attempt to capture the reader’s interest. However, the naming of categories must reflect or illuminate the phenomenon (Timulak & Elliott, 2019) as they represent the findings in a hierarchical order. Categories are revised and re-named using open coding (Strauss & Corbin, 1998).

The following represents the reporting of the results using part of the *Disappearing Self* as an example:

Overview of Level 0c: Disappearing Self

Level	**Sub-categories: Disappearing due to**	**Number of Meaning Units**	**Number of Participants**

		For Category	Reporting
0c-1	**Effects of Illness**	**29**	**08**
0c-1.1	Physical Effects of Illness	22	
0c-1.2	Psychological Effects due to Illness	07	

Level 0c-1: The Sense of Disappearing due to Effects of Illness

With disruption of their body through disease, patients experienced interruption in their normal functioning that acted like advance notice of threat to their fragile lives.

Physical Effects of Illness

Patient reality that the physical symptoms of illness could not be stopped, they sensed a general response that they would disappear by no longer existing.

Out-patients

OP2-82: I'm not going to be here.

In-patients

IP1-99: Got told that the tumour has now travelled from the... ___up through... into my __

3.6 Methodological Pluralism with respect to Quantitative Approach

The following sections describe the quantitative approach used in Study 2 (Chapter 5) in this research, within the more general methodologically pluralist approach taken here.

3.6.1 Overview of Measurement

In this section I present an overview of measurement as the basis for developing measuring instruments. *Measurement* is the basis for determining what is enough (or not enough), what is fair (or not fair), with *measure* the controlling basis by which something is determined as acceptable or unacceptable. William Thomson, Lord Kelvin, (1889) maintained that measuring a particular topic and expressing it in numbers allowed knowledge about the topic. Moreover, when the topic could not be expressed in numbers, the knowledge could not be seen as robust. Campbell (1920) saw measurement as the assigning of numbers to represent qualities with quality a property that has specific ordering or classification (Stevens, 1951).

For many centuries, measurement was largely understood from an objectivist viewpoint (Rand, 1979) and so relevant only to physical quantities that were believed to exist independently of either human perception or thought. Objectivism sees measurement as the basis on which scientific developments are founded whenever dependable data are required (Margenau,1958). Closely linked to objectivism is positivism (Corry et. al., 2019; Durkheim, 1982) that stated that knowledge is determined from quantifiable observation of activity. Whilst the positivist viewpoint regards measurement as necessary to establish the truth or falsity of statements, the naïve realist perspective (Ross & Ward, 1996) upholds that each property of each object has a 'true value' and so the aim of measurement is to discover that value. In addition, measurement can be seen as a kind of transmission or communication process, through a mapping of one informational entity (the object under measurement) to another entity (a measuring instrument) and so in some way observable (Mari et al, 2023). Thus, a "true value" would be achieved through perfect measurement. However, according to Regtien (2004) a "true value" cannot be determined.

According to operationalists (e.g., Bridgman, 1927), there is a set of rules or operations that defines measurement as a specified operation, producing a number (Dingle, 1950). Moreover, the idea of numerical or symbolic assignment as the condition for defining measurement helped to shape the representational theories of measurement (RMT; Campbell, 1920; Cartwright & Chang, 2008). The central tenet of RMT is *representability* and characterises measurement as the mapping between two relational structures, an empirical one and numerical one (Luce et al., 1990). The mapping of relations between objects and mathematical entities constitutes a measurement scale, with numbers assigned to objects in accordance with different rules and scales for that purpose (Stevens, 1946). Thus, RMT gave rise to an abstract framework for scale construction and meaningfulness of representation (Narens, 2002) and to what Stevens called "nominal", "ordinal" and "interval" and "ratio" scales. In the next section I define *psychometrics* that involves the theory and method of psychological measurement.

3.6.2 Psychometrics

In psychology, measurement theory, is also known as psychometrics (Galton, 1879, 1887; Guilford, 1936). Rust and Golombok (2014) defined psychometrics as a scientific discipline concerned with how psychology research measures of designated phenomena can be used to arrive at meaningful conclusions (Jones & Thissen, 2007). Thus, psychometrics allows knowledge, abilities, and attitudes to be quantified. According to Borsboom (2006), measurement is concerned with the construction of assessment tools and measurement instruments that serve to connect observable phenomena (e.g., responses to items on self-report measure) to theoretical attributes (e.g., personal agency). Moreover, according to Sijtsma (2011), assessment may be carried out by one or more indicators (operational measures) that accurately represent the characteristic of interest. That requires making an abstract construct measurable to determine the extent of the construct.

3.6.3 Concept and Conceptualisation

In this section and the following section, I introduce the first steps in the process of measurement. In scientific research, concepts are cognitive abstractions that represent classes of things, events, or ideas (Seel, 2012). Moreover, they are viewed as semantic categories that allow things, qualities, and occurrences to be linked together, based on the similarity of characteristics. Thus, a concept may be defined as an accepted collection of meanings that is abstracted from experiences, with words used as labels to define them. According to Margolis and Laurence (2015), concepts are the building blocks of thoughts, and so are critical to categorisation, inferences, learning and meaning making. Abstract concepts, unlike concrete concepts, have no physical or spatial constraints and, as they have no direct representation in the physical world, are not available to the senses.

Consequently, it was important to reflect on personal agency in terms of its meaning and different understandings. For example, personal agency suggests certain images and, yet it can be difficult to define exactly these images. The first step in measurement is *conceptualisation* (Gruber, 1995) that aims to avoid misinterpretation by providing a precise definition of the unobservable. A conceptual definition is specific about what is to be measured, with the concept placed in the context of existing literature to review different definitions. This ensures that the researcher, participants, and other researchers outside the research have the same or similar understanding of the concept. Conceptualisation is vital in refining research questions, providing consistency, directing data collection and analysis, and in promoting accurate research.

Conceptual Definition of Personal Agency

For example, the conceptual definition of personal agency can be given as follows: Personal agency is the capacity of the individual to influence, intentionally, their own functioning and life circumstances; ability to cause or generate an action; ability to choose and make plans (Bandura, 2006; Gallagher, 2012). For example, a) to construct, assess and re-organise alternative courses of action to deal with environmental circumstances and b) the motivation to bring about desired outcomes.

3.6.4 Construct and Operationalisation

A construct is an abstract concept that is specifically chosen or "created" to be used as a tool to provide a framework for understanding abstract aspects of human behaviour and experience. Personal agency represents a domain of covarying behaviours, but as abstract, behaviours must be measured indirectly. Operationalisation (Campbell, 1920) turns abstract concepts into measurable observations, allowing the measurement of the construct to be more than a description of its presence or absence. As the second step in the measurement process, operationalisation, begins with an operational definition that consists of the following components a) the variable being measured and its attributes b) the kind of measurement to be used and c) the way of interpreting the data collected from that measure to draw conclusions about the variable (van Thiel, 2014).

Operational Definition of Personal Agency

Following the above considerations, here is the operational definition I developed for the construct of personal agency, as the construct was specified and deepened: according to the literature:

> Personal agency has attributes that include hope, imagination, motivation, resilience, self-efficacy, locus of control, intentionality, moral responsibility, ways

of coping, self-awareness, and self-determination; (See Chapter 2). Valid and reliable measuring instrument formats (Bandalos, 2018) were selected: a self-report questionnaire based on the Likert Scale (Likert, 1932) and an observation measure based on Behaviourally Anchored Rating Scale (Schwab et al., 1975; Smith & Kendall, 1963).

The developed measures, self-report, and observational were required to meet the criteria of internal consistency, test-retest reliability, inter-rater reliability, and convergent validity.

To elaborate this operational definition, Cronbach's alpha, α, is used to provide a measure of internal consistency reliability of a test or scale and is expressed as a number between -1 and 1. Internal consistency is the extent to which all items in a test, like a self-report questionnaire, measure the same construct, like personal agency, and thus it is associated with the inter-relatedness of the items within the measure (Streiner, 2003). Internal consistency should be determined before a measure is used. If items are correlated to each other it is expected to obtain a high degree of internal consistency. Alpha can be influenced by the number of items in a measure or by the specific sample of participants responding to items on the measure (Streiner, 2003). Moreover, alpha assumes that each item measures the same latent construct on the same measure (Streiner, 2003). Cronbach's alpha was elected to assess the internal consistency reliability of the self-report questionnaire in this study.

Pearson's r test is a parametric statistical test of correlation that allows the determination of significance. A correlation indicates whether two variables are related to each other and if so in what way. That is, they provide information about how strong the relationship between two variables (magnitude, = + 1 or – 1) and what kind of relationship the two variables have with each other (directionality). If the two variables have a positive correlation, they move with each other in the same direction, whereas with a negative correlation, they move against each other in different directions. Moreover, r is a pure number and is thus, unaffected by the units of measurement, ensuring compatibility across different scales. Pearson's r is used when there is the availability of quantitative measurements of different items of a series. The Pearson correlation coefficient, r, was elected to assess the test-retest reliability of the self-report questionnaire; the inter-rater reliability with respect to the observation measure; and the convergent validity between the self-report questionnaire and the observation measure in this study.

3.6.5 Self-Report Likert-type Questionnaire

Firstly, a self-report measure is a non-experimental method of collecting data where participants provide information about themselves like their thoughts, feelings, and actions. Thus, information provided does not rely on interpretations of what participants are thinking of or doing as in observation. Depending on the research question/s, self-report measures take either a quantitative or qualitative approach and can adopt the format of interview or questionnaire. Self-report questionnaires adopt Likert-style responses to items in terms of, for example, subjective experience, frequency, or intensity of specific constructs (Likert, 1932). Moreover, they can be used to obtain preferences of agree or disagree with the set of items. A Likert rating format, a type of psychometric scale was selected for this: ordered, graphic, and with a range of responses on a continuum, provides a way of looking at the nuances of how individuals experience a particular topic.

Advantages of a Likert-type questionnaire include a) data are easily obtained; b) cost is low; c) relatively easy to conduct; d) participants have inside knowledge of the content of items; e) easy to anonymise to provide confidentiality; and f) able to be tested for validity and reliability. Disadvantages might include the inability of participants to read; social desirability, participant bias on the reporting of items (Deveaux & Sassi, 2016); lack of introspective ability (Cleeremans et al., 2007); instrument considered as long and tedious. Moreover, Hopwood et al. (2018) suggested that a self-report questionnaire should complement another assessment tool such as an observation measure.

In constructing self-report questionnaires, the identification of an item pool is essential (Boateng et al., 2018; Miller-Carpenter, 2018). Care is taken to determine that items are concise, distinct, reflect the conceptual definition, and ensure variability of response whilst remaining unbiased (DeVellis, 2012). Methods for initial item generation (Boateng et al., 2018, Miller-Carpenter, 2018; Tay & Jebb, 2016) can be classified as *deductive* and *inductive.* The deductive approach involves item generation based on an extensive review of literature and pre-existing scales and importantly on existing theory (Boateng et al., 2018; Hinkin, 1995; Miller-Carpenter, 2018). In an inductive approach the focus of items is based on the qualitative information obtained from participant responses (Boateng et al., 2018; Hinkin, 1995; Miller-Carpenter, 2018) to different aspects of the construct. For example, for this research, verbatim statements of patients in the earlier MSc study were used to generate an item pool for this self-report questionnaire. Also, it was deemed appropriate that members of the direct care teams and other counsellors be invited to ensure that items were simple, straightforward, with no jargon, double negatives, ambiguous words, or double-barrelled items (DeVellis, 2012; Fowler, 1995).

However, it is also necessary to consider the most appropriate number of scale points that may range from two upwards. For example, a scale of two points (dichotomous) may restrict the ability of participants to communicate their experiences in varying degrees (de Leeuw et al., 2008). Moreover, a dichotomous scale might force participants to respond to something that was or was not present. Multiple choice scales allow participants to have a middle neutral. Furthermore, unipolar scales are commonly used with unipolar items reflecting relative degrees of a single item response. For this research, it was decided that the self-report questionnaire would be developed using a five-point scale, ranging from 0 to 4, in degrees of intensity, that is, “Not at all” to “Extremely”.

3.6.6 Observation Measure Based on Behaviourally Anchored Rating Scale

Observation is a systematic data collection approach that can be carried out using a quantitative observational protocol (Campbell, 2015). Observation can be clinical (e.g., set in a laboratory) or naturalistic (e.g., within hospice setting). Observation can be naturalistic, direct, and systematic. Thus, observation involves first-hand observation and takes place consistently over a period using a rating scale with items or incidents that are representative of the overall construct. If observation is covert, the observer is undercover, and patients are unaware that they are being observed.

For this research, observation will be overt with patients knowing a) the observers (the main researcher and members of the direct care teams of the out-patient and in-patient units, respectively); b) they are being observed; and c) the purpose of the research. As an observation measure is quantitative in nature it aims to a) be objective and unbiased to reduce the potential for subjective interpretation; b) establish relationships between variables; c) promote replicability; and d) be valid and reliable. Moreover, each perceived, specific reported aspect of the construct constitutes a count. To meet the needs of the development of the observational measure, the Behaviourally Anchored Rating Scale (BARS; Smith & Kendall, 1963) approach was deemed suitable for this research.

BARS is the generic term for scales that anchor a continuum with behavioural examples representing performance through at varying levels of the continuum (Kell et al., 2017). The critical incident technique (Flanagan, 1954) provides focused examples of behaviour, with examples analysed for similarities in content and grouped to represent performance dimensions. An incident is an observable human activity that is sufficiently complete to allow inferences to be made about the individual carrying out the act (Flanagan, 1954). Furthermore, to be critical, an incident must happen where the intent of the act is clear to the observer and where its outcome is adequate. For this research, critical incidents (verbatim out-patient hospice quotations from the earlier MSc study) as anchor statements, were placed alongside a quantified scale to represent levels of personal agency. Also, the critical incident technique is a flexible guide that may require modification based on circumstances (Flanagan, 1954).

3.7 Sampling

Sampling was as for the qualitative approach, Section 3.4.2.

3.7.1 Pilot Study

In psychological research, new measures must be tested in a pilot study to ensure that they are valid and reliable. A pilot study acts as a rehearsal of either the full-scale research programme or of a specific study and can provide accurate information for future studies (Lancaster et al., 2004). Pilot studies validate the feasibility by testing designs, procedures, and operational strategies, including deficiencies in newly developed research instruments. In pilot studies, researchers are required to repeat the procedure to be used for later data collection and analysis.

3.8 Methodological Pluralism with respect to Qualitative and Quantitative Mixed Approach

This section refers to Study 3 that aimed to implement the newly developed measures, self-report and observational, with a new sample of out-patients and in-patients. Also, it aimed to find out if EFT is associated with an increase in personal agency in hospice patients. Study 3 was designed with both a distinct qualitative and quantitative data collection formats. The methods and procedures are as described for qualitative Study 1 (Chapter 4) and quantitative Study 2 (Chapter 5).

3.9 Chapter Summary

In this chapter, I attempted to set out how I justified the philosophical assumptions and rationale for the methodology adopted for this research. That is, I defined how I carried out the research programme with the aim of addressing the research objectives and questions. Based on that, I explained my decision to choose a mixed methods research design that included both qualitative and quantitative approaches. My objectives were aimed a) to develop a new self-report questionnaire and an observation measure for assessing personal agency in hospice patients and b) to discover whether Emotion-Focused Therapy was an agency- enhancing treatment. In the next chapter, Chapter 4, I report Study 1, “A Qualitative Study of the Experiences of Hospice Patients.”

Chapter 4: A Qualitative Study of the Experiences of Hospice Patients

4.1 Introduction

In this Chapter, I present Study 1 of the overall research programme. The aim of Study 1 is to discover whether the hierarchy of levels of personal agency in an earlier study (Campbell et al., 2014) was a reliable indicator of the sense of personal agency experienced by hospice patients in their everyday living. Study 1 had its focus on the subjective accounts of hospice patients with respect to experiences, interactions (Creswell, 2009; McIntyre, 2005); situations and events, Bryman (1989); and the communications and actions of them within specific social and time-based contexts (Goodwin & Horowitz, 2002; Morrill & Fine, 1997). Out-patients and in-patients were included in this study to discover whether the main categories and sub-categories of personal agency in the hierarchy were the same or different as illnesses progressed. Emotion-Focused Therapy (EFT) was used in this study based on its principal premise. That is, emotion is significant to the construction of the self and central to the process of self-organising. Thus, emotion identifies what is significant for well-being, enabling the person to assess their circumstances and to decide the action that appropriately meets their needs. Therefore, by using EFT the study aimed to discover whether the expressions of the experiences of a sample of new hospice patients (out-patients and in-patients) supported the hierarchy of personal agency as a reliable indicator. The earlier study indicated that hospice patients actively assessed their limitations, made judgements about their circumstances, developed different understandings of themselves and brought about their desired wishes through their own action. Moreover, the study found that these experiences could be represented by a hierarchy of eight main categories and sub-categories of personal agency. I, present the research question for this study: "How do hospice patients experience the nature of their control over their thoughts, feelings, and actions during their dying process?"

4.2 Method

4.2.1 Summary of Design

In this next section, I set out the design for Study 1. This distinct study constitutes a qualitative study of the experiences of hospice patients within an overall mixed methods research design. As a qualitative study, Study 1 enabled differences and similarities of personal agency to be investigated and represented (Philip, 1998). Thus, an intensive design, with repeated measurement for each patient was deemed appropriate as the strategy of inquiry to allow a) categories to emerge within a naturalistic environment and b) findings that may suggest a logical chain of evidence (Yin, 2009). Also, it was believed appropriate to gather data from each individual patient, using audio-recorded EFT therapy sessions to provide a transcript for each therapy session. That is, collecting date from each participant would enable the uniqueness of each individual to be preserved and allow data from each to be analysed, indicating any similarities or differences. In addition, analysis of data was required to reflect how hospice patients made sense of their world (Saunders et al., 2007). Aspects of grounded theory and empirical phenomenology were seen as suitable to make clear the relation of actions to context and identify categories, with coding allowing the breaking of data into discrete parts. Across-case approach, bringing all transcripts together, was elected as the final phase of analysis.

4.2.2 Sampling

In this section I describe the kind of sampling used in this study. Purposeful sampling, and in particular, homogenous sampling, ensured that potential participants shared similar circumstances, namely, the diagnosis of a life-limiting illness. According to Yin (2011), the advantages of a multiple case design is limited if fewer than four or more than ten units of analysis are chosen. Giorgi (1997) recommended that the optimal number of cases is between four and six. Limited resources may be significant for the choice of sample size identified and, indeed, identification of hospice patients as participants was limited due to the severity of the physical symptoms relating to illness.

4.2.3 Participants

In this section, I define the participants who were identified to take part in Study 1. A sample of nine patients, five out-patients and four in-patients, including males and females with different life-limiting illnesses were initially identified to take part. All nine patients were identified as adult hospice patients of St. Andrew's Hospice living through the experience of a life-limiting illness. Identification of patients as potential participants was carried out by clinical staff of the direct care teams of the out-patient and in-patient units, respectively. Also, clinical staff were the first to contact patients for the purpose of research. However, one male out-patient decided not to take part in the study. The patient asked to engage in counselling with myself as counsellor; I met with the patient for counselling on the day he attended the hospice. No patient was excluded based on the inclusion and exclusion criteria.

Inclusion and Exclusion Criteria

Inclusion Criteria

- Were diagnosed with an illness that was life-limiting.
- Were attending the Out-patient Unit or were an in-patient in St. Andrew's Hospice
- Were over the age of 18 years.
- Were interested, willing and mentally and physically able to undergo a series of counselling sessions.
- Were able to give informed consent, voluntarily.

Exclusion Criteria

- Had physical inability due to progression of disease, pain, or chronic fatigue.
- Had diminished cognition due to illness or medication.
- Had inability to give informed consent, voluntarily.
- Were known to the researcher.
- Were presently engaged in other counselling or research.

All participants were Scottish: four females and four males. Whilst most patients were diagnosed with cancer, some were diagnosed with more than one life-limiting illness. Each patient provided therapy transcripts for analysis. Table 4.1 represents the demographics the of eight participants who participated.

Table 4.1

Participant sample

Research Identity	Gender	Ethnicity	Illness
OP1	Male	Scottish	Cancer, Heart Failure, COPD
OP2	Female	Scottish	Cancer
OP3	Female	Scottish	Heart Failure
OP5	Male	Scottish	Cancer
IP1	Female	Scottish	Cancer
IP2	Male	Scottish	Cancer
IP3	Female	Scottish	Cancer
IP4	Male	Scottish	Cancer

Note: OP1, OP2, etc: Participant Out-patients; IP1, IP2, etc: Participant In-patients
COPD: Chronic obstructive pulmonary disease

Ethical Approval

This and the following sections set out the ethical requirements necessary, prior to commencement of the research. Ethical approval was granted from South East Scotland Research Ethics Committee 01 (Appendix A); the University's Code of Practice on Investigations on Human Beings: University Ethics Committee, University of Strathclyde; and Risk Assessment, University of Strathclyde.

Safe-guarding Participants

Also, to safeguard the welfare and rights of patients, each potential participant received a Participant Information Sheet (PIS) (Appendices B and C) and a Letter of Invitation (Appendices D and E) before agreeing to take part in the research. The PIS was a written research protocol to outline the purpose, risks and benefits, nature of participation, length of participation, right of withdrawal, and participant access to data in easy-to-understand language. If the Letter of Invitation indicated that patients were interested in the research, the researcher had permission to meet with patients.

Participant Consent Forms (Appendices F and G) were short documents containing statements of what taking part in the research involved; what would become of the data collected; and had tick boxes that allowed participants to agree or disagree to consent to each of the statements.

4.2.4 Procedure

4.2.5 Data Collection

Out-patient participants were offered six sessions of EFT over six weeks, with each session lasting not more than 40 minutes and carried out within the out-patient unit. In-patients were offered eight sessions of EFT, with each session lasting 15 minutes over three weeks and within the ward area. The number and length of counselling sessions were determined following collaboration between me and clinical staff. Recommendations were based on physical (fatigue, level of concentration), and emotional symptoms of patients (breaking of bad news), medication and the attending of hospital appointments. I met with each participant, individually, within a respectful, empathic, and collaborative relationship for the purpose of engaging in naturalistic counselling within an Emotion-Focused approach to therapy (EFT; Elliott et al., 2004; Schmid, 2001c). Focus, pace and agenda of sessions were determined by patients. Each counselling session, for each patient, was audio recorded. By using EFT, the study aimed to discover whether the expressions of the experiences of a sample of out-patients and in-patients supported the hierarchy of personal agency (Campbell et al., 2014). At the end of each session there was time for debriefing when patients could reflect on their experience of the counselling. Whilst patients experienced some emotional distress and were given the opportunity to discontinue, each decided to continue. Only because of vomiting or fatigue did patients discontinue during a counselling session, and this only happened on a very few occasions.

4.2.6 Data Analysis

Before formal analysis, I prepared the data for analysis (Elliott & Timulak, 2021; Wertz, 1983). This involved the transcription of the collected data as accurately as possible, with the exact wording of what participants shared captured through verbatim therapy transcripts. To carry out the data analysis, I repeatedly read the transcripts choosing to understand and translate the data (Elliott & Timulak, 2021) through the grouping of meaning units to create categories, based on similarities expressed in the units (Wertz, 1983; 2005). Thus, through empathic immersion, I imagined myself within the patient's circumstances. Analysis was carried out line-by-line. Moreover, analysis was reliant on inductive reasoning, the iterative process that allowed the organisation of data into meaning units for the generation of categories (Cohen et al., 2011; Creswell, 2009). The subjective decision made about where one meaning ended and another began to create groups of meaning units or categories saw main categories and layers of sub-categories re-visited, reviewed and/or re-named for integration into higher or lower-order categories. I carried out this process using the key modes of understanding/translating modes of qualitative analysis (Elliott & Timulak, 2021) and, specifically, through *Meaning Unit Summary* and *Explicating Implicit Meaning* (Elliott & Timulak, 2021). Meaning unit summary, referred to as meaning condensation in empirical phenomenology (Giorgi, 1985), allowed me to look for the main point of what was being expressed and to reiterate the meaning in a shortened, accurate summary. Also, I used explicating implicit meaning that allowed me to provide missing contextual information. That is, patients did not always say explicitly what they meant and thus, left much to be read "between the lines". This mode of understanding and translating, referred to as expansion (Labov & Fanshel, 1997), was useful as patients did sometimes omit to verbalise what they found too distressing. As categories represented the findings (Elliott & Timulak, 2021), the naming of categories was, initially, tentative and provisional. New categories were added, and existing categories modified as appropriate. Thus, categories were neither pre-determined nor exhaustive (Elliott & Timulak, 2021). This "open coding" (Strauss & Corbin, 1998) and reviewing continued until all transcripts were deconstructed and organised into meaning units and categories. However, the named main categories and sub-categories discovered in the earlier study (Campbell et al., 2014) were not allowed to influence either the main or sub-categories that were expressed by participants in this study. There was no expectation that the findings would be the same as in the earlier study. Eight transcripts (one for each participant) were obtained from the audio recordings of the counselling sessions. Analysis of the eight transcripts was carried out separately, providing eight individual protocols.

Moreover, the groups of meaning units that were organised in clusters (Glaser & Strauss, 1967) led to the formation of main categories using participant's words, allowing the abstract concept of a category to be considered more concretely. For example, participant statements: "emotional wreck"; "it's getting worse and worse"; and "my life was over" indicated that participants did not perceive themselves as having a sense of control over their circumstances and therefore, were unable to experience a sense of personal agency. This cluster of participant statements led to the labelling of the main category, "Non-Agentic Self". Thus, participant statements allowed the concept of the category label to become more concrete through the metaphor "emotional wreck"; the empathy and embodied emotion associated with progression "it's getting worse and worse"; "my life was over". These statements gave rise to the sub-categories a) "objectified self" (exercising no autonomy); b) "despairing self" (loss of hope); and c) "disappearing self" (existence threatened). Through reification (Morrison, 2009), the conceptual definition of a category was perceived as more concrete. The final phase of analysis was a cross-case approach with eight individual protocols brought together to move-between-across-and-within cases in the search for similarities or differences (Appendix H).

4.2.7 Criteria for Assessing Quality of Research

Reliability. In this paragraph I describe the criteria used to assess the quality of Study 1. One of the research supervisors (Robert Elliott) listened to audio recordings of counselling sessions to gain an appreciation of the quality and quantity of the data generated. Continual examination of verbatim transcripts and analysis, such as checking the fit between examples, category labels, and category descriptions; checking for coherence within categories and across related categories; checking for clear distinctions between categories; and whether there were important distinctions within categories that had not yet been captured. This ensured that research presented an accurate account (Hammersley, 1992; Stiles, 1993) of how participants experienced themselves as agents. Also, results indicated a consistency across two different samples of hospice patients. Whilst it was not appropriate for all participants to check their transcripts, participants who were able to, indicated no inaccuracies. Twenty-five patents checked their transcripts: six from Study 1; five and 11 from the Pilot Study and Main Study, respectively, Study 2; and three from Study 3.

Validity. Validity is the extent to which an account accurately represents the experiential authenticity of the material. Key evidence of that was the degree to which the empirical evidence and theoretical rationales supported the adequacy and appropriateness of the hierarchy of levels of personal agency across two different samples of hospice patients.

4.3 Results

4.3.1 Overview of Results

In this section, I present an overview of the results of Study 1. It is important to note that these results were completely based on the analysis carried out on the eight therapy transcripts obtained in this present study. Results indicate that eight categories represented how each participant constructed themselves as specific selves: *Level 0*: *Non-agentic, Level 1: Limited, Level 2: Reflexive, Level 3: Collective, Level 4: Reacting, Level 5: Willing/Wanting, Level 6: Enriched and Level 7: The Fully Agentic Self* (Campbell et al., 2014). These categories were the same as was discovered in the earlier study (Campbell et al., 2014). Moreover, the results show that the same sub-categories, expressing subtle nuances of self, were identified within the main categories. In addition, sub-categories were expanded to provide a better understanding of how hospice patients perceived themselves as agents. However, this study was not the beginning of my investigating of personal agency in hospice patients as I was researcher and counsellor in the earlier study (Campbell et al., 2014). Thus, I did not start from scratch but looked intentionally for new data that did not fit the previous general framework of categories. Also, I used new data to challenge, revise and improve the sub-categories while mostly focusing on further differentiation of lower-level sub-categories. A cross-case analysis determined strong commonalties across all eight cases, indicating that the general experience of personal agency was experienced by a new sample of four out-patients and four in-patients. That is, with the progression of disease, the same main categories and sub-categories of personal agency were expressed by both out-patients and in-patients. However, the hierarchy of agency in Study 1did provide elaboration in the sense that the expansion of sub-level categories gave more detailed information regarding personal agency

Thus, this hierarchical configuration did represent the construction of self as agent, to varying degrees, that is, how participants were able to initiate control, with varying effect, on their personal circumstances. In terms of empirical phenomenology, this meant that all eight levels of agency identified were potential constituents of the phenomenon of facing a life-limiting illness. The emergence of the categories and sub-categories of agency is made explicit within their respective section below, along with examples of participants' narratives. Table 4.2 provides an overview of the levels of personal agency as expressed by hospice out-patients and in-patients. A complete account of the cross-case synthesis of all eight participants is available in Appendix H.

Not every patient provided data for all sub-categories and all distinctions of sub-categories. This was represented as (No data). As data allowed, I have provided one example from out-patients (designated by "OP" in the meaning unit code) and in-patients ('IP' code). Moreover, 'T' in examples represents 'therapist'.

Table 4.2

Overview of levels of personal agency

Levels	Main Category	Sub-Category	Definition
0	Non-Agentic Self		Unable to initiate change through own action
0a		Objectified	Unable to be autonomous, reduced to status of object
0b		Despairing	Unable to make life personally manageable and worth living
0c		Disappearing	Unable to prevent the illness threatening continuation of life
1	Limited Self		Susceptible to unwanted limitations that affect every-day life
1a		Bodily-limited	Vulnerable to illness and treatment
1b		Non-Functional	Unable to act effectively
1c		Strongly Puzzled	Having difficulty in making suitable decisions from personal facts and experience

1d		Detached	Disconnected from the reality of what is happening
2	Reflexive Self		Striving for self-preservation
2a		Changed	Experiencing change in their usual self
2b		Defiant	Resisting to accept/comply with change brought about by illness
3	Collective Self		Seeking to collaborate with others
3a		Relinquishing	Passing autonomy to appropriate others
3b		Active/Collaborating	Engaging willingly with helpful others
4	Reacting Self		Responding internally to circumstances and appraising illness
4a		Avoiding	Self-protecting or emotionally escaping from illness
4b		Coping	Taking stock of physical, psychological and social resources
4c		Morally Evaluating	Monitoring and judging personal reactions to circumstances
5	Willing/Wanting Self		Experiencing the desire or need to initiate action
5a		Motivated	Striving to strengthen own efficacy to achieve personal goals
5b		Imagining	Providing self with an ability of thinking of self in the future
5c		Fighting	Approaching circumstances as goal-oriented and with a strong sense of self-efficacy
6	Enriched Self		Experiencing enhanced value and meaning in the present life
6a		Historic	Experiencing a want to restore to the historic, past life
6b		Accepting/Transcending	Accepting self as finite; transcending finiteness through belief in a form of afterlife
6c		Joyfully Engaged	Experiencing purposeful engagement in life
7	Fully Agentic Self		Experiencing self as optimistic, realistic, goal-orientated, contented and autonomous

4.3.2 Level 0: Non-Agentic Self

As *Non-Agentic Selves*, patients experienced themselves as having no capacity to initiate change over their circumstances through their own actions. Devoid of a sense of personal agency, patients were unable to construct their experience in alternative ways that allowed them to self-organise, self-regulate, or self-reflect. Categories at this level were characterised by differences in intensity and immediacy, with 0a, the *Objectified Self*, being the most intense. Further analysis of the categories revealed additional knowledge about the experiences of patients as non-agentic.

4.3.2.1 Level 0a: Objectified Self

4.3.2.1.1 Overview of Level 0a: Objectified Self

Patients experienced themselves as reduced to the status of an object, with objectification destroying or stifling of their autonomy. This gave rise to an inertness experienced as a lack of sense of personal agency. Whilst that inertness might have been temporary, patients' judgement of their situation was not shaped by their own opinions and feelings, and thus, resulted in a lack of influence due to a denial of subjectivity. Within the sub-category of the *Objectified Self*, patients expressed their sense of lack of control due to 1) the effects of illness and 2) the challenge of treatment and 3) the involvement of others who they perceived as having influence with respect to their circumstances. This is presented in Table 4.3.

Table 4.3

Overview of level 0a: Objectified self

Level	Sub-categories: Objectified by …	Number of Meaning Units For Category	Number of Participants Reporting
0a-1	**Effects of Illness**	**35**	**07**
0a-1.1	Physical Effects of Illness	10	
0a-1.2	Psychological Effects of Illness	25	
0a-2	**Effects of Treatment**	**07**	**05**
0a-2.1	Physical Effects of Treatment	04	
0a-2.2	Psychological Effects of Treatment	03	
0a-3	**Involvement of Others**	**20**	**04**
0a-3.1	Feeling Disempowered	08	
0a-3.2	Feeling Ignored	05	
0a-3.3	Feeling Discarded	07	

Note: Number of Meaning Units for Category represents the number of reportings for each category, with the numbers in bold representing the total for the appropriate sub-category. For example: the total Effects of Illness for the Objectified Self equals the sum of the physical and psychological effects of illness, (10 + 25 = 35). Number of Participants Reporting represents the number of different participants who reported the meaning units, with numbers in bold representing the total for the relevant sub-category.

4.3.2.1.2 Level 0a-1: Objectified by Effects of Illness

Patients used metaphors to describe strong images that, although not literally true, helped them to provide a straightforward explanation and understanding of how illness deprived them of their ability to exercise any influence over their personal life circumstances. Patients indicated that the effects of illness impacted on both their physical and psychological well-being.

4.3.2.1.2.1 Physical Effects of Illness

Patients' typical communication of their illness was an intensely painful and powerful experience that they could neither predict nor forget.

> **Out-patients**
>
> OP2-18: ... Unforgettable and excruciating
>
> **In-patients**
>
> IP1-186: Then you get hit.

4.3.2.1.2.2 Psychological Effects of Illness

Patients revealed a general psychological impact of the illness through their choice of harsh-sounding words that presented an image of being brought down with no sense of control. Also, their use of the past participle supported the sense of lack of agency imposed on them.

> **Out-patients**
>
> OP5-8: Ah, boy... that floored me.
>
> **In-patients**
>
> IP1-49: … and I'm like... like a rabbit in the headlights.

4.3.2.1.3 Level 0a-2: Objectified by Effects of Treatment

Patients communicated that treatment was bothersome and distressing, rendering them devoid of feeling and unaware of what was going on around them. Also, patients indicated that the effects of treatment affected them both physically and psychologically.

4.3.2.1.3.1 Physical Effects of Treatment

Patients typically experienced treatment as cumbersome and requiring time to recover from the unpleasant after-effects was typical of participants.

Out-patients

OP1-12: It took the full day to put in... tubes everywhere... then out of it for the next 10 to 15 days.

In-patients: (No data)

4.3.2.1.3.2 Psychological Effects of Treatment

Patients' revelation was a variation of the extent of their lack of control and was heightened by their feeling of being used to test the effectiveness of treatment.

Out-patients

OP5-90: You just feel as though at times you're a guinea pig.

In-patients: (No data)

4.3.2.1.4 Level 0a-3: Objectified by the Involvement of Others

Whilst the involvement of others was intended to benefit, patients felt that, on occasions, they were not given the opportunity to influence their own circumstances. When they sensed that their feelings and experiences were not considered they felt *disempowered*, *ignored,* or *discarded*. Thus, patients experienced themselves as objectified and lacking in agency, subject to actions without responding or initiating an action in return.

4.3.2.1.4.1 Feeling Disempowered

Deprived of the power to make decisions, patients typically experienced themselves as made weak and having lost the ability to influence their circumstances.

Out-patients

OP3-136: I've just been passed from pillar to post.

In-patients

IP1-166: No, I didn't... I didn't feel treated as a person.

4.3.2.1.4.2 Feeling Ignored

Patients' revelation of sometimes feeling disregarded, and not acknowledged was typical of participants, suggesting at least half.

Out-patients

OP5-88: I got put into a room... small room with a bed... evening... sat in that room ...till the morning... nobody come near me...

In-patients: (No data)

4.3.2.1.4.3 Feeling Discarded

Patients described how they sometimes felt abandoned, forsaken, with interest in them relatively insignificant was a variant sub-category.

Out-patients

OP3-224: ... they've all brushed me off their hands... just left me to it... more or less left in the dark.

In-patients: (No data)

4.3.2.2 Level 0b: Despairing Self

4.3.2.2.1 Overview of Level 0b: Despairing Self

With the reality of their new, unwanted circumstances, patients experienced profound unhappiness and became discouraged about their world. Patients were unable to make their lives personally manageable, let alone worth-while, experiencing horror, awfulness, and loss of hope. Table 4.4 indicates that, as *Despairing Selves*, patients revealed that their experience of despair emanated from 1) the effects of illness 2) the harshness of treatment for the illness.

Table 4.4

Overview of level 0b: Despairing self

Level	Sub-Categories: Despairing due to …	Number of Meaning Units For Category	Number of Participants Reporting
0b-1	**Effects of Illness**	**71**	**08**
0b-1.1	Physical Effects of Illness	10	
0b-1.2	Psychological Effects of Illness	61	

0b-2	**Effects of Treatment**	**19**	**04**
0b-2.1	Physical Effects of Illness	02	
0b-2.2	Psychological Effects of Illness	17	

4.3.2.2.2 Level 0b-1: Despairing due to Effects of Illness

Patients experienced themselves as disheartened, deprived of hope and enthusiasm as they are confronted with the diagnosis of a life-limiting illness.

4.3.2.2.2.1 Physical Effects of Illness

Patients' awareness that they can neither remedy nor even improve their physical circumstances was a typical response.

Out-patients

OP1-93: ... and you're suffering... severe suffering.

In-patients

IP4-97: It really hurt.

4.3.2.2.2.2 Psychological Effects of Illness

Due to deep emotional suffering, patients generally experienced themselves as dispirited, stuck and with impending doom.

Out-patients

OP2-94: It's very scary... dark... very dark... a hole... no ladders to climb... no light.

In-patients

IP1-41: I kept thinking of my Mum... and Oh my God... this is coming to me now.

4.3.2.2.3 Level 0b-2: Despairing due to Effects of Treatment

Patients perceived themselves despondent and dejected due, not only to the cruel, difficult experience of the treatment, but to erosion of hope due to the discontinuance of treatment that was found to be ineffective.

4.3.2.2.3.1 Physical Effects of Treatment

Patients experience of treatment as intensely unpleasant and not necessarily successful in relieving their physical symptoms was a variant sub-category.

Out-patients

OP1-97: They (tablets) are not working... it's so severe.

In-patients

IP1-64: … didn't shrink the tumour …didn't do anything for the tumour.

4 3.2.2.3.2 Psychological Effects of Treatment

Patients' typical perception of themselves as despondent and dejected due to the cruel, difficult experience of the treatment, and erosion of hope due to the discontinuance of treatment that was found to be ineffective.

Out-patients

OP5-141: I've been to hell and back... oh, yeah... that's how it feels.

In-patients: (No data)

4.3.2.3 Level 0c: Disappearing Self

4.3.2.3.1 Overview of Level 0c: Disappearing Self

Patients communicated that their reality, the diagnosis of an incurable illness, was threatening their existence. Within this sub-category, patients described a) how the illness affected their physical existence and b) how that threat affected them from a psychological perspective.

Table 4.5

Overview of level 0c: Disappearing self

Level	Sub-categories: Disappearing due to	Number of Meaning Units For Category	Number of Participants Reporting
0c-1	**Effects of Illness**	**29**	**08**
0c-1.1	Physical Effects of Illness	22	
0c-1.2	Psychological Effects due to Illness	07	

4.3.2.3.2 Level 0c-1: The Sense of Disappearing due to Effects of Illness

With disruption of their body through disease, patients experienced interruption in their normal functioning that acted like advance notice of threat to their fragile lives.

4.3.2.3.2.1 Physical Effects of Illness

Patient realised that the physical symptoms of illness could not be stopped, they sensed a general response that they would disappear by no longer existing.

Out-patients

OP2-82: I'm not going to be here.

In-patients

IP1-99: Got told that the tumour has now travelled from the... ___up through... into my __

4.3.2.3.2.2 Psychological Effects of Illness

Patients exemplified the typical response of how with increasing awareness, patients experienced a sense of lack of personal control needed to change their circumstances and so could not prevent the shortening of their lives.

Out-patients

OP5-35: As far as I was concerned, I was on the road out.

In-patients

IP1-31: I knew my life was over... oh my God I'm going to die.

4.3.3 Level 1: Limited Self

Patients took stock of their personal sense of control and as they could not escape from their diagnosis of a life limiting illness, they became susceptible to unwanted limitations that interfered with and diminished their influence over the quality of their every-day living. Thus, patients discovered that they did not have the ability to adjust to or cope with their new circumstances. Within the main category, *Limited Self*, participants communicated their experience of limitations regarding their a) physical body, b) capacity to be effective, c) lack of ability to make sense about what was happening to them and d) emotional disconnect from their circumstances.

4.3.3.1 Level 1a: Bodily-Limited Self

4.3.3.1.1 Overview of Level 1a: Bodily-Limited Self

Patients were aware that their bodies provided the opportunity for active exploration of their environment. However, their bodies were susceptible to harm caused by illness, with the result that their physicality became vulnerable to disease and pain, giving rise to limitations. Patients tried to assess the limitations of their personal agency within their circumstances. This exemplified the typical response of how with increasing awareness, patients experienced a sense of lack of personal control needed to change their circumstances and so could not prevent the shortening of their lives.

Table 4.6
Overview of level 1a: Bodily-limited self

Level	**Sub-categories: Limited by ...**	**Number of Meaning Units for Category**	**Number of Participants Reporting**
1a-1	**Physical Effects of Illness**	**68**	**08**
1a-1.1	Physical Pain	34	
1a-1.2	Physical Tiredness	05	
1a-1.3	Mobility	14	
1a-1.4	Body Temperature	05	
1a-1.5	Other Physical Effects	10	
1a-2	**Physical Effects of Treatment**	**17**	**04**
1a-2.1	Sickness/Headaches/Diarrhoea	12	
1a-2.2	Loss: Hair, Toenails, Appetite	05	

4.3.3.1.2 1a-1 Physical Effects of Illness

With patients unable to escape from their illness, they experienced a general susceptibility to physical effects of pain, tiredness and mobility issues that interfered with their ability to move about freely and easily.

4.3.3.1.2.1 Physical Pain

Physical pain was a general response.

> **Out-patients**
>
> OP1-224: It's painful… when I do anything. Painful. Painful when I breathe even.
>
> **In-patients**
>
> IP1-15: Oh, it was sore… I was actually gripping… on to the side of things… gripping on to the radiators.

4.3.3.1.2.2 Physical Tiredness

This category was a variant response.

Out-patients

OP1-203: I’ve got more tired… oh yeah tired.

In-patients

IP3-169: I’m just so tired all the time.

4.3.3.1.2.3 Mobility

Response to mobility was general.

Out-patients

OP5-105: I’m weak in the legs… if I go out for a walk… I’ll have to take a stick with me.

In-patients

IP2-4: … to actually both… in my bottom limbs

4.3.3.1.2.4 Body Temperature

This category was exemplified as variant.

Out-patients

OP2-61: I took sweats and shivers, and I was frozen.

In-patients

IP4-31: People say as they’re coming in... this room’s warm... and I cannot... I don’t feel it warm... no.

4.3.3.1.2.5 Other Physical Effects

This category exemplified a typical response.

Out-patients

OP3 24: When I move … start getting this wheezing.

In-patients

IP4-75: There’s another wee (small) change there... slurring, slurring.

4.3.3.1.3 1a-2. Physical Effects of Treatment

Participants communicated that treatment could bring constant, unpleasant side-effects like sickness, headaches, and hair loss. Unwanted as these side-effects may be, patients could neither stop them occurring nor diminish them.

4.3.3.1.3.1 Sickness / Headaches / Diarrhoea

This was a typical response.

Out-patients

OP1-13: You feel violently sick... headaches... diarrhoea...

In-patients

IP4-43: It can make you feel sick and drowsy. Bla... bla... bla...

4.3.3.1.3.2 Loss of Hair / Toenails / Appetite

This was a variant response.

Out-patients

OP2-54: … lost the skin from my face... lost my fingernails... lost my toenails... had ulcers.

In-patients: (No data)

4.3.3.2 Level 1b: Non-Functional Self

4.3.3.2.1 Overview of level 1b: Non-Functional self

Patients, deprived of strength and power due to both their illness and their treatment, discovered that their personal resourcefulness was wanting and so perceived themselves as a) *helpless* b) *vulnerable* and c) *ineffective.* Thus, patients experienced that their body was reduced to a non-functioning entity. Patients described how feeling non-functional affected their physical and psychological well-being.

Table 4.7
Overview of level 1b: Non-functional self

Level	Sub-categories: Experiencing Self as …	Number of Meaning Units or Category	Number of Participants Reporting
1b-1	**Helpless**	**27**	**06**
1b-1.1	Helpless due to physical Effects of Illness	27	
1b-2	**Vulnerable**	**17**	**06**
1b-2.1	Vulnerable due Physical Effects of Illness	12	
1b-2.2	Vulnerable due to Psychological	05	

	Effects of Illness		
1b-3	**Ineffective**	**31**	**05**
1b-3.1	Ineffective due to Physical Effects of Illness	18	
1b-3.2	Ineffective due to Psychological Effects of Illness	13	

4.3.3.2.2 Patients Experiencing Themselves as Helpless

As patients did not sense being in control, they typically perceived themselves as feeble and, devoid of power and energy, were unable to help themselves.

4.3.3.2.2.1 Helpless due to Physical Effects of Illness

Patients generally expressed that loss of physical strength left them less able or incapable of providing self-support and so were unable to perform necessary, physical activities.

Out-patients

OP5-44: … still couldn't do things I was used to doing... stop playing golf... no energy to walk... I lived in a flat... couldn't climb the steps... when I went out it was an effort to get out and back in.

In-patients

IP3-66: Because of my back... can't bend to pick... things off the floor... and if I stand, I get ten minutes… I need to be back on the bed again.

4.3.3.2.3 Patients Experiencing Themselves as Vulnerable

Patients communicated that they experienced themselves as not feeling safe, either physically or emotionally.

4.3.3.2.3.1 Vulnerable by Physical Effects of Illness

Patients generally felt exposed to the possibility of being damaged or harmed as they were less likely to resist the hostile effects of illness.

Out-patients

OP1-237: I'll no go anywhere now. I couldn't cope on my own. I need someone with me.

In-patients

IP1-89: I don't go out anymore... panic attacks... don't even go shopping.

4.3.3.2.3.2 Vulnerable by Psychological Effects of Illness

Patients typically experienced apprehension and anxiety as they had an awareness that, with respect to their illness, they were open to attack and unable to not protect themselves.

Out-patients

OP3-73: ... it’s really frightening... because I’m on my own.

In-patients

IP1-102: So, I’ve had that (dying alone in the night) in my mind... most of the night.

4.3.3.2.4. Patients Experiencing Themselves as Ineffective

Patients experienced themselves as inefficacious, and inadequate.

4.3.3.2.4.1 Ineffective by Physical Effects of Illness

Patients typically expressed that, physically, they were no longer able to do what they wanted or desired.

Out-patients

OP3-104: I mean I can do absolutely nothing in the house now.

In-patients

IP3-112: But I’m not able to do that... anymore.

4.3.3.2.4.2 Ineffective by Psychological Effects of Illness

Patients typically communicated that they were unable to bring about any significant or desired change as they lacked the ability to have effect on their circumstances.

Out-patients

OP5-247: I couldn’t do... couldn’t for the life of me.

In-patients

IP1-18: I said, “I can’t do it.”

4.3.3.3 Level 1c: Strongly Puzzled Self

4.3.3.3.1 Overview of Level 1c: Strongly Puzzled Self

Patients expressed that they felt puzzled, troubled, and uncertain as they found difficulty in understanding what was happening to them or what was being done to them. Yet, they were aware that, since circumstances had changed, they were functioning differently. With personal resources lacking, they were unable to reason to form judgements, which could have allowed clarity about their situation.

Table 4.8

Overview of level 1c: Strongly puzzled self

Level	Sub-categories: Experiencing Self as …	Number of Meaning Units for Category	Number of Participants Reporting
1c-1	**Troubled**	**76**	**08**
1c-1.1	Troubled: Physical Effects of Illness	22	
1c-1.2	Troubled: Psychological Effects of Illness	35	
1c-1.3	Troubled: Lack of Effectiveness of Treatment on Physical Body	11	
1c-1.4	Lack of Effectiveness or inappropriateness of Treatment on Psychological Well-being	08	
1c-2	**Puzzled and Confused: By Current Status of Illness and Treatment**	**73**	**08**
1c-2.1	Puzzled and Confused: By Current Status of Illness from Physical Perspective	28	
1c-2.2	Puzzled and Confused: By Status of Illness from Psychological Perspective	31	
1c-2.3	Puzzled and Confused: By Physical Effects of Treatment on Current Status of Illness	07	
1c-2.4	Puzzled and Confused; By Psychological Effects of Treatment on Current Status of Illness	07	
1c-3	**Faced with the Unexpected**	**29**	**08**
1c-3.1	Unexpected Physical Effects of Illness	15	
1c-3.2	Unexpected Psychological Effects of Illness	11	
1c-3.3	Unexpected Psychological Effects of Treatment	03	
1c-4	**Uncertainty**	**31**	**08**
1c-4.1	Uncertainty: By Physical Effects of Illness	09	
1c-4.2	Uncertainty: By Psychological Effects of Illness	13	
1c-4.3	Uncertainty: By Psychological Effects of Treatment	09	

4.3.3.3.2 Patients Experiencing Themselves as Troubled

Patients revealed that they experienced themselves as deeply concerned about the actual and potential impact of illness on both their physical and psychological well-being.

4.3.3.3.2.1 Troubled by Physical Effects of Illness

Patients generally experienced new, visible signs and/or unpleasant physical sensations, and expressed that they could not control the occurrence of these signs or symptoms.

Out-patients

OP2-36: You got hotspots... hotspots... How many hotspots in my body?... What's a hotspot?... Is that something else... is that cancer?

In-patients

IP3-6: I got up and went to the toilet... came back and lay on my bed... and I don't know.

4.3.3.3.2.2 Troubled by Psychological Effects of Illness

Whilst patients generally revealed that their new circumstances disrupted their normal functioning, they were unable to understand their dilemma and so experienced themselves as perturbed, unsettled, and a loss of mental calmness.

Out-patients

OP2-50: I'm sitting with a ticking time bomb in me ... contain it?

In-patients

IP4-4: I've been told that because they've got nothing to fight it.

4.3.3.3.2.3 Troubled by Lack of Effectiveness of Treatment on Physical Body

Whilst patients were typically aware that treatment was intended to relieve symptoms, treatment did not always provide the outcome they expected.

Out-patients

OP3-227: I feel as if no matter how many different tablets and things I'm on... don't seem to be doing any good.

In-patients

IP1-209: ... medication... that's not worked... what else is there?... is there something else…?

4.3.3.3.2.4 Troubled by Lack of Effectiveness/Inappropriateness of Treatment on Psychological Well-being

Patients were typically apprehensive as they faced the probability that treatment might be ineffective or inappropriate for their circumstances.

Out-patients

OP5-99: ... scared to go to sleep... stuck between the rock and the hard place.

In-patients: (No data)

4.3.3.3.3 Patients Experiencing Themselves as Puzzled and Confused by their Current Status of Illness and Treatment

Due to the challenging change in their lives, patients were adrift in an absence of self-support and perceived themselves as muddled and lacking clarity.

4.3.3.3.3.1 Puzzled and Confused by the Current Status of Illness, from a Physical Perspective

As patients were generally unable to make sense of the information given to them about their illness, they wanted an appropriate professional to explain what was happening to their bodies.

Out-patients

OP2-48: What do you mean? There's nothing we can do. What do I do with this?

In-patients

IP2-54: ... but you don't know whether... they find it... it spreads or how you've got it.

4.3.3.3.3.2 Puzzled and Confused by the Current Status of Illness, from a Psychological Perspective

Patients revealed that they generally had difficulty with the assimilation of information about their illness, experiencing themselves as baffled and unable to give reasoned judgements that were logical and well-thought.

Out-patients

OP2-191: Because I'd had so many good results... when does the bad result hit me... shocked at getting that (secondary cancer) ... I did believe it... there must be something coming I don't like.

In-patients

IP3-2: I still wasn't sure what was real... what wasn't real... and what was actually happening.

4.3.3.3.3.3 Puzzled and Confused by the Physical Effects of Treatment on the Current Status of Illness

Patients typically expressed that either treatment made their physical condition either more difficult or was ineffective in relieving symptoms.

Out-patients

OP3-223: I know I had problems with my heart... but nobody has said... just kept giving me different tablets and ... things.

In-patients: (No data)

4.3.3.3.3.4 Puzzled and Confused by the Psychological Effects of Treatment on the Current Status of Illness

As patients were typically unable to understand and interpret their condition, they were unable to assess whether treatment was successful.

Out-patients

OP1-95: Half of the time you don't know where you are.

In-patients

IP4-78: ... medication does a lot of things to you... physically and emotionally.

4.3.3.3.4 Patients Experiencing the Effects of the Unexpected

Patients found difficulty in absorbing what had become their reality, the unforeseen, unplanned diagnosis of a life limiting illness.

4.3.3.3.4.1 Unexpected due by Physical Effects of Illness

With no knowledge or indication prior to its occurrence, patients generally expressed that they were faced with an incurable illness, with its impact manifesting itself in ways that they could not forecast.

Out-patients

OP2-178: If somebody had told me last year that I would be sitting... I would have told you. "No." ... If someone had said to me... "You'll be here next year. You'll be doing all this." ... I don't think so.

In-patients

IP2-51: ... had a little bit of treatment... the operation was good... recovered from that five years... and low and behold... this node pops up.

4.3.3.3.4.2 Unexpected due to Psychological Effects of Illness

Patients communicated that generally they did not have the ability to understand why their circumstances, that came from nowhere, left them not being ready to deal with their situation.

Out-patients

OP5-10: I wasn't expecting that. That was the last thing in my mind.

In-patients

IP2-50: (Doctor) ... I've got to give you the bad news... he told me it was cancer. [T. "Could you believe it?"] IP2. "No... because... all this started... I told you in January... all started prior to that... seven years prior to that... When I had ___ cancer at 43... yeah...

4.3.3.3.4.3 Unexpected due to Psychological Effects of Treatment

Patients typically expressed that they were surprised as they became aware that they were not responding to treatment as they had expected.

Out-patients

OP1-171: I thought they were doing good but... hanging (fragile) a bit.

In-patients: (No data)

4.3.3.3.5 Patients Experiencing the Effects of Uncertainty

As patients had no definite knowledge about their illness or treatment, they were unable to interpret available information to make it into something useful. Hence, with nothing immediately identifiable, patients were unable to predict what might happen and so were unsure of their future situation.

4.3.3.3.5.1 Uncertainty due to Physical Effects of Illness

Patients typically revealed that they engaged in internal dialogues to arrive at a conclusion regarding their physical situation from evidence either partially known or assumed.

Out-patients

OP2-11: I did say, "Could this be cancer?" I did ask.

In-patients

IP4-98: And I'm saying to myself... is this the kind of thing that's going to be happening to you... get these infections at any time.

4.3.3.3.5.2 Uncertainty due to Psychological Effects of Illness

As patients generally experienced their world as less stable, they were no longer confident about how to relate to it. With no sense of direction, they experienced a lack of surety, and no clear ideas of what they wanted to do or achieve.

Out-patients

OP3-171: Knowing that I'm on my own... What's going to happen?

In-patients

IP4-68: They maybe won't but they could get better... and there is a difference between getting better and could get better.

4.3.3.3.5.3 Uncertainty due to Psychological Effects of Treatment

As patients typically waited to discover whether they were eligible for treatment, they questioned whether treatment would protect or guarantee their future.

Out-patients

OP2-71: Waiting on treatment... what if? ... what's happening? ... no getting treatment...

In-patients

IP1-50: And I'm saying … and I'm thinking … am I getting (treatment)?

4.3.3.4 Level 1d: Detached Self

4.3.3.4.1 Overview of Level 1d: Detached Self

Whilst patients received information and had some degree of awareness about what was happening to them, they experienced themselves as emotionally disconnected from their unwanted state of affairs.

Table 4.9

Overview of level 1d: Detached self

Level	Sub-categories: Disconnected from the Reality of What is Happening	Number of Meaning Units for Category	Number of Participants Reporting
1d-1	Detached due to Psychological Effects of Illness	07	03

4.3.3.4.2 Detached due to Psychological Effects of Illness

Patients were typically able to hear what they were told about their diagnosis but, at the same time, information appeared to be independent of them and so not part of their lived experience.

Out-patients

OP1-109: It was unbelievable at the time... it didn't ...sink into me.

In-patients: (No data)

4.3.4 Level 2: Reflexive Self

Since their diagnosis of a life-limiting illness, patients were aware of a change in their identity that had introduced feelings of loss and lack of personal control, giving way to a state of dissatisfaction. However, despite the influence of illness, patients experienced an internal sense of agency that saw them strive for self-preservation.

4.3.4.1 Level 2a: Changed Self

4.3.4.1.1 Overview of Level 2a: Changed Self

As *Changed Selves,* patients experienced a change in their identity, bringing the feeling that patients would not remain the same persons as they were before diagnosis.

Table 4.10

Overview of level 2a: Changed self

Level	Sub-categories: Experiencing Self as …	Number of Meaning Units for Category	Number of Participants Reporting

2a-1	Changed: Becoming Different	16	07
2a-2	Changed: Becoming Replaced	13	07

4.3.4.1.2 Patients Experience Themselves as Becoming Different

Patients were generally aware that they no longer resembled the identity that once defined them as persons; instead, they felt that they were recast in a new identity that did not represent their self-image, or individuality.

Out-patients

OP2-151: It changed me... it has changed me.

In-patients

IP3-13: ... and I'd never felt like that before.

4.3.4.1.3 Patients Experience Themselves as Replaced with Another Self

Patients generally felt that their familiar identity had been removed and replaced by another, unknown to them.

Out-patients

OP2-217: … think it's not me... I don't think it's me... the old me died... a new one was developing.

In-patients

IP1-204: I just feel... I don't feel me.

4.3.4.2 Level 2b: Defiant Self

4.3.4.2.1 Overview of Level 2b: Defiant Self

As *Defiant Selves,* patients did not experience themselves as dominated by illness. They did not perceive themselves as a victim or bystander, resigned to Fate and Destiny, resisting the widely held, fixed image of a person with a life-limiting illness.

Table 4.11

Overview of level 2b: Defiant self

Level	Sub-categories: Resisting …	Number of Meaning Units for Category	Number of Participants Reporting
2b-1	To Accept/Comply with Illness	19	06
2b-2	To Accept/Comply with Self-defeating Attitudes	18	05

4.3.4.2.2 Patients Resist to Accept/Comply with Their Illness

Patients were generally non-defeatist, experiencing themselves with increased self-determination, aiming to maintain independence and continuity by standing up to illness and death.

Out-patients

OP2 273: I'm not ready to hang up my clogs yet.

In-patients

1P1-122: I'm not ready to go... I don't feel it's my time.

4.3.4.2.3 Patients Resist to Accept/Comply with Self-defeating Attitudes

As patients generally experienced a greater sense of control, albeit an internal sense of control, they avoided emotional disengagement due to lack of self-regulation. Patients purposefully confronted their distressing feelings and thoughts.

Out-patients

OP-95: Something in me fires me... You've had enough of me... you are not going to win.

In-patients

IP2-55: So, you just have to face it.

4.3.5 Level 3: Collective Self

As patients experienced that illness limited or prevented them from making their own decisions about their circumstances, they purposefully tried to generate other ways of constructing their experience through collective agency, choosing how they would participate in that collective agency.

4.3.5.1 Level 3a: Relinquishing Self

4.3.5.1.1 Overview of Level 3a: Relinquishing Self

As *Relinquishing Selves,* patients did not actively engage in decision-making but willingly handed over their autonomy, choosing to be guided by those perceived as experts. Patients felt confident that they could rely on professional healthcare experts with expertise and experience to co-ordinate knowledge, and to organise these resources to respond prudently to their needs.

Table 4.12

Overview of level 3a: Relinquishing self

Level	Sub-categories: Handing over Autonomy Regarding …	Number of Meaning Units for Category	Number of Participants Reporting
3a-1	Illness	15	06
3a-2	Treatment	23	07

4.3.5.1.2 Handing Over Autonomy with Respect to Illness

Patients were generally confident that relevant experts acted for their beneficence by drawing on knowledge and skill to make wise, well-judged decisions about the physical symptoms presented by patients.

Out-patients

OP5-195: No, I've never have asked questions... I just take... I'm a bit in awe of these people... they've got knowledge of these things, and I don't... I think these people are a step above me.

In-patients

IP4-88: When you start getting … bone marrow …taken out of you they're talking along the lines there... and they start talking about _____ and all that.

4.3.5.1.3 Handing Over Autonomy with Respect to Treatment

Patients generally had confidence in surrendering their autonomy to experts who, they believed, would choose the treatment that best meet their needs.

Out-patients

OP1-46: They told me the results... they decided to go ahead with this treatment.

In-Patients

IP2-24: So, they agreed they were going to keep us kind of going with that for a little bit longer... at this higher rate... was their advice.

4.3.5.2 Level 3b: Active Collaborating Self

4.3.5.2.1 Overview of Level 3b: Active Collaborating Self

As the experience of illness prevented patients from living their lives in individual autonomy, they willingly transformed from passive recipients of information to engage in valuable collaboration with another or others who recognised and respected their needs.

Table 4.13

Overview of level 3b: Active collaborating self

Level	Sub-categories: Collaborating with Helpful Others	Number of Meaning Units for Category	Number of Participants Reporting
3b-1.1	**Healthcare Professionals**	**47**	**08**
3b-1.2	**Therapist**	**51**	**08**
3b-1.2.1	Therapist: Mild Appreciation	29	
3b-1.2.2	Therapist: More Hear-felt Appreciation	22	
3b-3	**Family Members**	**22**	**08**
3b-4	**God / Friends**	**11**	**05**

4.3.5.2.2 Collective Agency /Efficacy with Helpful Others

Patients willingly chose a constructive approach to make joint decisions about their illness, collaborating with others perceived as helpful.

4.3.5.2.2.1 Healthcare Professionals

Patients generally engaged, actively, in collective decision-making with healthcare professionals, revealing a sense of motivation, indicating increased personal agency.

Out-patients

OP5-36: I... asked my doctor, “Do I need to go and book a bed in the hospice?” She asked me if I wanted a ____ nurse... I said, “I’ll take all the help I can get.”

In-patients

IP2-104: ... specialists will also be coming... doctors... the care team... the__ nurse... they’ll all come to the house... all got access... key-safe at the door.

4.3.5.2.2.2 Therapist

Patients engaged with the therapist in two different ways; a polite consideration for the therapist as well as communicating a deeper gratitude.

4.3.5.2.2.2.1 Therapist: Mild Appreciation

Patients typically used socially appropriate expressions to communicate mild and polite appreciation.

Out-patients

OP3-148: [T. "… it's very important... when you feel you've had enough... you tell me to stop...."] P3. "Well... I think that's probably enough for today."

In-patients

IP3-176: [T. "So, I'll not tire you out... I'll say cheerio for now... see you on Monday if that's OK with you?'] IP3. "That would be lovely." [T. "Lovely... I look forward to it."] IP3. "Thank you very much."

4.3.5.2.2.2.2 Therapist: More Heart-felt Appreciation

Patients generally expressed sincere, stronger, more heart-felt appreciation.

Out-patients

OP2-251: It helps me... talking about all the stuff I've been through... I'm actually, kind of seeing myself in a different light. It's probably taken me to do this... see who I have become... a chance to sit down and talk... it has helped... I know it has helped.

In-patients

IP1-259: It helps... speaking to you... So, it does. It helps us with feelings as well... helps us with our feelings... what we bring.

4.3.5.2.2.3 Family Members

Patients generally worked jointly with particular family members to make decisions about their illness and its impact on their living.

Out-patients

OP5-14: My sister said to me, "Come… stay with me... You're coming to stay with me." ... I went… stayed with my sister.

In-patients

IP3-48: We have made plans for afterwards and arranged what's going to happen with them ... they're going to stay with Dad.

4.3.5.2.2.4 Friends/Religious Professionals/God

Patients typically revealed that they perceived God and friends as helpful others.

Out-patients

OP3-211: I say to her (friend)... "Just you walk on… I'll take my time." I go and sit in a café... she comes... we get a taxi.

In-patients

IP1-172: He [Reverend] is coming... he'll help me out with details of the funeral.

4.3.6 Level 4: Reacting Self

As *Reacting Selves,* patients were survival-oriented, looking to preserve their physical body. Thus, they reacted to their circumstances by trying to keep distressing feelings and thoughts out of their awareness. Through a gradual increase in awareness, patients respond, internally, to their individual circumstances, and cautiously assessed their illness.

4.3.6.1 Level 4a: Avoiding Self

4.3.6.1.1 Overview of Avoiding Self

Patients tried to mentally distance themselves from the reality of their circumstances by adopting defence mechanisms. These protective mechanisms helped to buffer the effects of the perceived negative experience by reducing anxiety arising from painful thoughts and feelings.

Table 4.14
Overview of level 4a: Avoiding self

Level	Sub-categories: Avoiding by …	Number of Meaning Units for Category	Number of Participants Reporting
4a-1	Escaping from their Stressor	13	06
4a-2	Playing down their Stressor	19	06

4.3.6.1.2 Patients Escaping from Their Stressor

As patients generally did not have the capacity to deal effectively with their threatening circumstances, they tried to break free from the anxiety arising from their challenging situation.

Out-patients

OP1-71: I try and put it away from my mind.

In-patients

IP4-86: I don't want to know about it …get on with it… that's the end of it.

4.3.6.1.3 Patients Playing Down Their Stressor

Patients typically played down the psychological damage of their new-found circumstances through minimising, dismissing, rationalising, and distracting. Thus, they underestimated the significance of their circumstances; justified their feelings in a seemingly logical way to shun the true explanation, with feelings becoming consciously tolerable and unworthy of consideration.

Out-patients

OP-12: I found a lump …I thought OK …keep an eye on it …fortnight passed.

In-patients

IP3-97: …Keeping it simple… keeping things running… don't go deep.

4.3.6.2 Level 4b: Coping Self

4.3.6.2.1 Overview of Level 4b: Coping Self

As patients experienced feelings of loss, control, and psychological disturbance, they appraised their physical, psychological, and social resources. Their coping was an intra-personal, emotion-focused process, with patients developing a critical consciousness as their sense of awareness increased. Purposively and selectively, they affirmed those aspects of their circumstances they perceived as positive, whilst they complained and protested about those they identified as negative.

Table 4.15

Overview of level 4b: Coping self

Level	Sub-categories: Coping by …	Number of Meaning Units For Category	Number of Participants Reporting
4b-1	**Complaining/Protesting**	**183**	**08**
4b-1.1	Complaining Protesting about Negative Aspects of Illness	38	
4b-1.2	Complaining Protesting about Negative Impact of Illness on Psychological Well-being	114	
4b-1.3	Complaining Protesting about Negative Aspects of Treatment	21	
4b-1.4	Complaining Protesting about Negative Aspects of Treatment On Psychological Well-being	10	
4b-2	**Acknowledging /Accepting**	**130**	**08**
4b-2.1	Acknowledging Accepting Positive Aspects of Illness	23	
4b-2.2	Acknowledging Accepting Psychological Impact of Positive Aspects of Illness	84	
4b-2.3	Acknowledging Accepting Positive Aspects of Treatment/Surgery	14	
4b-2.4	Acknowledging Accepting Positive Aspects of Treatment/Surgery on Psychological Well-being	09	

4.3.6.2.2 Patients Complaining/Protesting

With the onset of their new-found situation, patients experienced a drastic change in their every-day living and felt aggrieved, expressing angry irritation through complaining and protesting. Their appraisal focused on the unfavourable and pessimistic aspects of illness and treatment.

4.3.6.2.2.1 Complaining/Protesting About Physical Aspects of Illness Perceived as Negative

Patients generally complained and protested about how illness was weakening and damaging their physicality, limiting their ability to be active.

Out-patients

OP-138: Biggest effect on my life … before I took the cancer … was a good golfer … played in the club team … I could still play … would have to sit in the buggy.

In-patients

IPI-120: … don't want to lie in pain.

4.3.6.2.2.2 Complaining/Protesting About Impact of Negative Aspects of Illness on Psychological Well-being

Patients were generally dissatisfied, perceiving themselves through selectively chosen negative constructs, portraying them as wronged and disapproving.

Out-patients

OP3-31: Somebody find me the next morning… lying in my bed … frightening … everything goes through your mind.

In-patients

IP2-80: Some things I don't need help with …they're treating me, a 61-year -old man, as if I'm somebody that's 80 or 90.

4.3.6.2.2.3 Complaining/Protesting About Impact of Aspects of Treatment Perceived as Negative

Patients typically expressed annoyance with the aspects of treatment perceived as harsh and causing much discomfort.

Out-patients

OP1-90: Treatment… affected me badly… 6 to 8 months it lasted… alright once you get it… ten days later you were away (incapacitated).

In-patients

IP4-46: … heart medication to take over and above all the rest of the medication that I've got to take… it's an everyday thing.

4.3.6.2.2.4 Complaining/Protesting About Impact of Negative Aspects of Treatment on Psychological Well-being

Patients were typically annoyed that the effectiveness of treatment was not predictable, with an unfavourable result bringing disappointment. As there might have been no alternative treatment, patients felt inclined to accept the offer of treatment.

Out-patients

OP5-101: I just feel if I was to say to the doctor, “I want to stop these. I don’t want to take any more.” He would just say, “Well there’s nothing more I can do for you. Away you go.” [T. “Are you afraid of hearing that?”] Yeah... I just feel I can’t because... he’s all I’ve got... I don’t have another option.

In-patients

IP2-34: The oncologist… is an interventionist... in terms of prolonging your quality of life... the action would have been ____ and ___ would have been bad... even worse losing your hair...

4.3.6.2.3 Patients as Acknowledging/Accepting

Patients were not trying to change how they felt but, expressed a willingness to experience their thoughts, feelings, and memories without avoidance. Hence, patients allowed themselves to recognise and validate the existence and significance of their situation.

4.3.6.2.3.1 Acknowledging/Accepting Physical Aspects of Illness Perceived as Positive

As patients generally acknowledged their life-limiting illness, they actively affirmed those perceptions that activated constructive, helpful experiences of themselves in the context of their illness.

Out-patients

OP1-137: I have deteriorated... bit slower... more aches and pains... could be the illness.

In-patients

IP4-64: Not at the moment anyway... I’ve never been violently ill or anything that would constitute to say... that you’re ready to go.

4.3.6.2.3.2 Acknowledging/Accepting Psychological Impact on Physical Being

Patients generally recognised the impact of their illness on their psychological well-being, and communicated its distinctive features, including the extent of its presence, and its ability, real or potential, to exert influence over them. However, patients used a more positive appraisal, focusing on altering the perception of their circumstances.

Out-patients

OP2-135: … like another person inside... an unwelcome visitor or guest... I've got to learn to live with this guest and I've got to let it live to the extent but not too much...

In-patients

IP3-140: Where's the point of being afraid... what's going to happen is going to happen... regardless.

4.3.6.2.3.3 Acknowledging /Accepting Aspects of Treatment/ Surgery Perceived as Positive

Patients generally communicated their belief in the effectiveness of treatment and surgery and acknowledged how either or both were significant in keeping them alive.

Out-patients

OP5-123: "Will I ever come off these." ... she (nurse) said, "No. You're on these until.... same with the injection... for life." ... rest of my life.

In-patients

IP2-15: So, what solved it was... made a difference... the use of steroids and morphine.

4.3.6.2.3.4 Acknowledging/Accepting Psychological Impact of Positive Aspects of Treatment

With favourable outcomes of treatment, patients typically communicated that they experienced less negative emotions and internal conflict.

Out-patients

OP1-43: We will just need to put up with it.

In-patients

IP4-80: That’s what you’re used to taking... it’s not there because they want to give you it... it’s there because it’s to help you.

4.3.6.3 Level 4c: Morally Evaluating Self

4.3.6.3.1 Overview of Level 4c: Morally Evaluating Self

As human beings, patients held standards of right and wrong that acted as their guiding principles. Hence, they consciously engaged in the process of self-regulation, monitoring and assessing how they reacted to their circumstances to keep track of what they felt, thought, and believed was appropriate within their circumstances. Moreover, they revealed how they would have conducted themselves by translating their moral thoughts into moral conduct, aided by wisdom and by upholding what they perceived as right.

Table 4.16
Overview of level 4c: Morally evaluating self

Level	Sub-categories: Showing …	Number of Meaning Units For Category	Number of Participants Reporting
4c-1	Consideration for Others	54	08
4c-2	Gratitude/Appreciation/Respect	40	08
4c-3	Regret	23	04

4.3.6.3.2 Patients Showing Consideration for Others

With open awareness, patients were typically not only attentive to their own thoughts and feelings but identified with to those of others. Moreover, with a growing self-awareness, patients had the self-regulation required to observe and review, with patients kindly expressing that the thoughts and needs of others were a matter of interest to them.

Out-patients

OP2-97: I don’t like disturbing people if they’re busy. They’ve a lot of people apart from me.

In-patients

IP1-199: [T. “Thank you for sharing.”] You’re very welcome. Sometimes, I break down when I talk to you... must be hard for you to listen.

4.3.6.3.3 Patients Showing Gratitude/Appreciation/Respect

Whilst patients were self-interested, they expressed a readiness to be thankful, and with full understanding of their circumstances, appreciated and admired the qualities and worth of those who had helped them. Patients were also grateful for favourable results of their care and treatment, communicating enhanced, personal well-being, as a variant sub-category within the Morally Evaluating Self.

Out-patients

OP3-213: Quite often... people will stop me and say, “Are you alright?” … nice of them... nice that they do that.

In-Patients

IP3-69: Here... somebody actually comes and gives me my food and deals with feeding me... help me get washed and dressed... it’s been lovely and they’re all so nice... they really are... they’re so nice.

4.3.6.3.4 Patients Showing Regret

As *Reacting Selves,* patients were self-reflexive, responding to their own reactions to their circumstances. They experienced feelings of sincere sadness, remorse, and disappointment due to guilt as they were “sorry about” their disagreeable conduct and lack of responsibility in relation to their life-style choices. This was a variant sub-category within the Morally Evaluating Self.

Out-patients

OP1-16: My son... was looking after me... he got the worst of it... I couldn’t help it... I couldn’t tolerate people.

In-patients

IP1-247: But it’s my own fault... (Pause)... It’s out of my hands now... My life has been taken right out of my hands.

4.3.7 Level 5: Willing/Wanting Self

As *Willing/Wanting Selves,* patients were not just responding to their circumstances but, rather, were pro-active and purposeful, knowing and wanting what was right for them. Patients experienced themselves as goal-oriented but whilst they did not implement action outwardly, they nevertheless experienced their agency in the form of action tendencies that organised them toward internal action, moving them toward their goals.

4.3.7.1 Level 5a: Motivated Self

4.3.7.1.1 Overview of Level 5a: Motivated Self

With patients wanting to continue their sense of self and a reduced feeling of uncertainty about themselves, they communicated their drive to strengthen their personal efficacy through the expression of their own personal needs and wishes. Whilst the active processes of willing and wanting provided channels for intrinsic motivation and a greater sense of well-being and full-filament, patients indicated that *Need/Reason; Willingness* and *Enthusiasm* were key components in the drive to achieve their goals.

Table 4.17

Overview of level 5a: Motivated self

Level	Sub-categories: Motivated by…	Number of Meaning Units for Category	Number of Participants Reporting
5a-1	Need / Reason	35	08
5a-2	Willingness	28	08
5a-3	Enthusiasm	29	07

4.3.7.1.2 Need/Reason

Patients engaged in self-evaluation, providing them with a better self-understanding of themselves, informing them of specific goals that they wanted to achieve. Their explanations and justifications for their goals, provided the impetus to reinforce their personal effectiveness to resist changes in their perceived self-concept, reported as a variant sub-category.

Out-patients

OP3-158: I need to watch what I'm doing.

In-patients

IP1-86: I'm trying to find memory boxes... funeral to organise... when you have children you should start doing it.

4.3.7.1.3 Willingness

Patients showed a readiness to persevere to re-construct their lives and tried to remain resilient and maintain a course of internal action despite their illness and effort required. To achieve what was important to them, patients recognised willingness as a resource, crucial in meeting their desires and needs through their own resolve, reported as a variant sub-category.

Out-patients

OP3-210: If I can manage to get out... even for a couple of hours... I'll do that.

In-patients

IP3-159: ... small party this afternoon for residents... have to be fit to do that.

4.3.7.1.4 Enthusiasm

Patients were goal-oriented, eagerly wanting to embrace life, and with an expectancy that something especially good would happen because of their own efficacy, reported as a variant sub-category.

Out- patients

OP2-119: I'll get up in the morning... where are we going? ... what are we doing?

In-patients

IP2-100: First goal is to get home... my own home... get settled... take it from there...

4.3.7.2 Level 5b: Imagining Self

4.3.7.2.1 Overview of Level 5b: Imagining Self

Patients communicated specific future goals and expressed these through the creation of ideas and images in their minds, reflecting on these images and their associated feelings. Through wishing, hoping, wanting, and constructing mental pictures, patients not only explored their options but were provided with a vision of themselves in a future that they cared deeply about.

Table 4.18

Overview of level 5b: Imagining self

Level	Sub-categories: Imagining by …	Number of Meaning Units for Categories	Number of Participants Reporting
5b-1	Wishing	18	08
5b-2	Hoping	48	08
5b-3	Wanting	42	08
5b-4	Fully Imagining	42	07

4.3.7.2.2 Wishing

Patients communicated their desires through vivid imagery, with an intensity of emotion but without much reasoned thinking. Whilst fantasy and imagery allowed patients to muse on what could be, their wishing conveyed a sense that their desires were unable to attain or achieve. However, patients revealed that wishing stimulated their creativity, and provided them with a degree of excitement, even if temporary. Thus, it was seen as a variant sub-category.

Out-patients

OP1-175: I'm too young to die yet (smiling). I hope... 20 years in me yet.

In-patients

IP3-145: [T. "What do you wish for... for yourself?"] Me?... That it goes quickly..." (Pause) (Tearful) Quickly and easily.

4.3.7.2.3 Hoping

By hoping, patients were able to consider, with reasonable confidence, what could have happened, what could have been. The drive to continue their sense of selves was increased as they worked toward a future in the face of adversity, even if it was hard to do so. This purposeful, goal-oriented process was internal, with patients expressing their agency through action tendencies, exemplifying a variant sub-category.

Out-patients

OP5-232: I can accept old age... I can accept that... but please let me stay the way I am for a... bit longer.

In-patients

IP1-97: Hopefully there's a plan... I hope so... I just hope so.

4.3.7.2.4 Wanting

With patients finding themselves in unwanted circumstances and dissatisfied with what they have become, they chose to initiate change, with imagining helping them to provide different ways of constructing their experience. As their capacity as agents increased, patients began to develop a sense of empowerment and self-direction. Whilst their agency was internal, it was through action tendencies that patients allowed wanting to take them out of their present and re-orientate them in the future, exemplifying a variant sub-category.

Out-patients

OP2-223: I want to be seen... I'm here to be counted.

In-patients

IP3-52: I want to be taken on a nice wee (short) walk to a nice beach... scattered on a nice beach.

4.3.7.2.5 Fully Imagining

Patients' personal constructions of mental imagery were more than exploring options. Along with the investment of time and effort, these quasi-perceptual experiences saw patients shift from the abstract to the more concrete, allowing them to anticipate possible, desired, future experiences, exemplifying a variant sub-category.

Out-patients

OP5-222: I could go on holiday... get a... change of scenery for a week.

In-patients

IP2-92: ... picking the kids up from school...

4.3.7.3 Level 5c: Fighting Self

4.3.7.3.1 Overview of Level 5c: Fighting Self

Whilst vulnerable to their circumstances, patients communicated a belief in their self-efficacy, with an orientation toward maintaining and enhancing themselves. They approached their situation with the expectation that they were able to exercise their influence by setting goals and trying to maintain commitment to them. Patients expressed that their fighting self was more evident during this particularly significant phase in their lives, impacting on their level of motivation, sense of worth and personal achievement.

Table 4.19
Overview of level 5c: Fighting self

Level	Sub-categories: Fighting Self …	Number of Meaning Units for Category	Number of Participants Reporting
5c-1	Believing in Self-Ability to Succeed	61	07
5c-2	Dealing with Circumstances	52	07
5c-3	Accomplishing a Challenge	40	08

4.3.7.3.2 Believing in Self-Ability to Influence/Succeed

Patients typically experienced a sense of optimistic confidence in their ability to alter the challenging demands of their circumstances. That is, patients believed that they could achieve their desired goals, anticipating favourable and promising outcomes.

Out-patients

OP2-130: The illness is not winning... I’m not ready to let you have another bit of me... so, sit there.

In-patients

IP4-66: I’ve got this belief in myself.

4.3.7.3.3 Dealing with Circumstances

Patients communicated a self-confident view of themselves as they experienced a strengthening belief in their personal self-efficacy. Hence, they engaged with their testing circumstances through attending and decision-making, with the expectations that they were able to produce their desired effects. This expectation provided the incentive for patients to persevere, be motivational, and enhanced their personal well-being. This was reported as a variant sub-category.

Out-patients

OP5-51: I had to learn to walk again... the 'Zimmer' first... and the sticks... learn to put on my clothes... two weeks you know.

In-Patients

IP3-93: I've been dealing with pain from day 1. It's not another thing to deal with. It's something I deal with in a regular basis.

4.3.7.3.4 Accomplishing a Challenge

Patients communicated a sense of personal achievement as they successfully completed a challenge, requiring physical, or mental strength and effort. With a greater belief in their self-efficacy, patients were less beset with self-doubts, allowing them to, not only set goals, but to plan courses of action designed to attain their aims and aspirations. As *Accomplishing Selves,* patients made more use of the first-person pronoun, reinforcing a greater reliance on their own capacity to initiate and influence.

Out-patients

OP1-60: I went back to the [hospital] and I got 18 treatments for this.

In-patients

IP1-144: Managed to get into the bath without the hoist... into the bath with my feet... my own legs.

4.3.8 Level 6: Enriched Self

Through an internal dialectical process, patients communicated that there was a gap between the partial restoration of their normal or historic, past self, and the accepting/transcending future self. However, patients indicated that this internal conflict saw them experience themselves as enriched and joyful, with enhanced value and significance in their present life.

4.3.8.1 Level 6a: Historic Self

4.3.8.1.1 Overview of Level 6a: Historic Self

As patients experienced an incongruence between their past self and their present self-concept, they wanted to re-establish the self before their diagnosis. Thus, with patients experiencing change in their every-day living, they acquired different understandings of themselves and so reconnected with their past selves by remembering past events, influenced by personal schemas. By way of their autobiographical memory, patients summarised, constructed, and interpreted specific times and occasions form their personal past.

Table 4.20

Overview of level 6a: Historic self

Level	Sub-categories: Experiencing One's Historic Self as …	Number of Meaning Units for Category	Number of Participants Reporting
6a-1	Incongruent Between Past and Present Selves	06	02
6a-2	Rosy Retrospection	04	01
6a-3	Being Restored to a Past State	03	02

4.3.8.1.2 Incongruence Between Patients' Past and Present Selves

Patients made comparisons between their past and present selves, with the self in the present experienced as less self- efficacious. Patients expressed frustration and so reminisced to return to their former selves. Their need to reduce incongruence and restore equilibrium between the past and transformed self-concepts, provided the motivation towards change. This exemplified a variant category.

Out-patients

OP3-241: I was called Mrs N__ ... was always out and about… always somewhere... theatre... cinema... always doing something.

In-patients: (No data)

4.3.8.1.3 Rosy Retrospection

Patients remembered their past selves as more positive than they judged their present, with nostalgia serving as a catalyst for the promotion of happiness, increased self-confidence, and closeness with people around them. This was reported as a variant sub-category.

Out-patients

OP3-123: I was out and about... couple of times a week... I was up at... down to... you name it I used to go... I loved it.

In-patients: (No data)

4.3.8.1.4 Being Restored to a Past Self

Dissatisfied with who they had become, patients wanted to return to their normal past selves who they perceived as more positive. Hence, through trying to break the connection with their present selves, patients tried to normalise their situation, experiencing themselves as more positive, exemplifying a unique sub-category.

Out-patients

OP2-117: The (me) I lost last year is coming back... slowly...

In-patients

IP1-126: I'm sitting talking to you... and I'm like... I feel normal.

4.3.8.2 Level 6b: Accepting/Transcending Self

4.3.8.2.1 Overview of Level 6b: Accepting/Transcending Self

As *Accepting/Transcending Selves,* patients no longer erected defences against full awareness of the inevitability of death but, rather, accepted their eventual non-being. Whilst some patients chose to believe in some form of after-life, others saw death as freeing them from physical limitations and emotional distress

Table 4.21

Overview of level 6b: Accepting/transcending self

Level	Sub-categories: Accepting/Transcending …	Number of Meaning Units for Category	Number of Participants Reporting
6b-1	Life as Finite	03	02

6b-2	Believing in Power of Higher Being/After Life	07	03

4.3.8.2.2 Accepting Life as Finite

Patients recognised that they did not have the ability to avoid death and so accepted that their existence was limited, not only from the perspective of the ending of their physical life but from the possibility of non-being. However, patients also perceived death as an escape from their illness and pain, physical and emotional. This was reported as a variant sub-category.

Out-patients

OP1-83: It (dying) means getting away... no more pain... no more worries.

In-patients

IP2-62: [T. "... is there something... When you are no longer here... is that the End?"] Yeah... my mother's dead... sister's dead... that's it... job done.

4.3.8.2.3 Believing in the Power of a Higher Being/After-Life

Patients revealed that they believed in something, undefined and beyond this earthly world, that had greater power than themselves. Also, they believed in an unspecified after-death existence, with the possibility of a reunion with people who were, presently, separated by death. This was reported as a variant sub-category.

Out-patients

OP1-79: He [God] will make the decision whether I go... this week or next... maybe in another 20 years' time.

In-patients

IP1-180: This is a journey. It's just a matter of finding each other... when you've crossed that path.

4.3.8.3 Level 6c: Joyfully Engaged Self

4.3.8.3.1 Overview of Level 6c: Joyfully Engaged Self

With patients fully acknowledging that they were finite beings, they chose to engage in their every-day living with an increased vigour, experiencing themselves as joyful and with a greater sense of personal agency. That is, patients chose to participate in activities that were important to them, experiencing increased satisfaction and a greater sense of self-fulfilment.

Table 4.22

Overview of level 6c: Joyfully engaged self

Level	Sub-categories: Experiencing …	Number of Meaning Units for Category	Number of Participants Reporting
6c-1	Joy	13	07
6c-2	Enjoyment	16	06
6c-3	Excitement for Life	19	08

4.3.8.3.2 Patients Experiencing Joy

As patients communicated a sense of being one with the world, countering the feeling of being desolate and embracing a desire to share their time and feelings with others, they experienced an increase in energy, self-confidence, and self-esteem. This was reported as a variant sub-category.

Out-patients

OP2-68: It's a good day... a good day... because it's another day I'm here... another day to celebrate... so, it's a good day.

In-patients

IP1-105: Oh... there was... I got to see them... father deer... mother... baby deer.

4.3.8.3.3 Patients Experiencing Enjoyment

Patients experienced pleasure and happiness resulting from the achievement and success through their participation in particular activities that required physical and /or mental effort. With patients' goals more realistic, they were more achievable, enhancing patients' sense of self, promoting their feeling of enjoyment, exemplifying a variant sub-category.

Out-patients

OP2-225: Live... each day... enjoy it... looking... plants for the garden... trees... take more time to see things... now I enjoy doing things...

In-patients

IP1-142: Got up this morning... had a lovely fried breakfast… So, I did… lovely.

4.3.8.3.4 Patients Experiencing Excitement for Life

Patients indicated an increase in their sense of personal agency, experiencing themselves as pro-active, with action tendency translated into action. As active initiators, showing a directional tendency towards growth and fulfilment of their potential for as long as possible, patients expressed a feeling of excitement, marked by enthusiasm, eagerness, and anticipation. This was reported as a variant sub-category.

Out-patients

OP2-150: I'm living... loving life... I get up and I think... I'm here... and I'm living it and loving it.

In-patients

IP1-169: I go out for a walk... going to rain... don't care ... sometimes you appreciate... the rain on your face... wind on your face.

4.3.9 Level 7: Fully Agentic Self

Whilst patients continued to acknowledge and accept that they had the diagnosis of a life-limiting illness, they did not allow themselves to be the victims of their diagnosis. Hence, whilst aware of their *givens*, that had brought, physical limitations, vulnerability, and a greater sense of themselves as finite beings, patients optimistically but realistically, chose to play a part in creating who they could become. Thus, patients moved towards a sense of freedom and responsibility as they came to fully acknowledge their inevitable experiences. Although their freedom was *situated,* patients reflected and chose between alternatives, committing themselves to act on their specific choices. As *"Fully Agentic Selves",* patients chose to live authentically, constructing themselves as contented, goal-oriented, responsible, autonomous, accountable human beings, promoting an enhanced quality to their remaining life.

Table 4.23

Overview of level 7: Fully agentic self

Level	Definition	Number of Meaning Units for Category	Number of Participants Reporting
7	Experiencing Self as Optimistic, Realistic, Goal-oriented, Contented, and Autonomous	23	05

Out-patients

OP2-181: Half of the stuff I dreamed of doing... I'm doing now... taking me to places that I didn't think I could do... realising I can do... I'll go with the flow... push boundaries... see if I can... believe more in myself and I believe more that I can win... more I do... more I win.

In-Patients

IP3-99: There's nothing nobody can do about it... nothing can change it... to be angry all the time... silly... takes up so much energy... for me it's best to accept what's going on... try and muddle... through it...

4.4 Discussion

Results indicated that eight main categories emerged in accordance with the earlier study (Campbell et al., 2014). That is, the same eight categories represented how each participant constructed themselves as the specific selves: Level 0: *Non-Agentic; Level 1: Limited; Level 2: Reflexive; Level 3: Collective; Level 4: Reacting; Level 5: Willing/Wanting; Level 6: Enriched; Level 7: Fully Agentic.* Moreover, the results showed the same sub-categories expressing the same subtle nuances within the main categories. Also, sub-categories were further expanded to provide a more extensive understanding of how hospice patients experienced themselves as agentic. Thus, results indicated the extent to which hospice patients are not just products of their life givens but actively assess their constraints, make judgements about their capabilities, and bring about desired effects through their own initiation. Moreover, the graded set of categories and sub-categories obtained from hospice out-patients and in-patients facing the ultimate threat to their ability to act as agents provides an argument that personal agency is prevalent in human existence.

It was each hospice patient who provided the categories through their knowing what 'it's like'; knowing what they could control and the extent of their control. As they lived through a life-limiting illness, they were faced with uncertainty, and had to deal with changes in their physicality, independence, and relationships and to ponder on their actual dying (Murray et al., 2005). Their world had stopped being a safe place, with disbelief, fear, anxiety, helplessness, sadness, and despair emanating from their diagnosis and prognosis. Their changed circumstances brought a sense of having a lack of control, and a feeling of being restricted that could have provoked an unavoidable crisis. As patients tried to control their conscious thoughts, they were unable to prevent the evoking of many feelings. They had to learn to accept these feelings and to learn from them to act. With their sense of agency compromised due to their life-limiting illnesses, hospice patients experienced themselves as powerless and helpless and were prevented from taking action. However, each hospice patient had to decide whether to succumb to their givens or to experience themselves as resisting to comply with their unwanted circumstances, that is the reflexive self. Each hospice patient had to choose who they wanted to become. With the load of the illness and effects of treatment weighing down on them, patients were exhausted and troubled, but it was important for them that they constructed new experiences. They were required to give a voice to whatever they were feeling.

All patients engaged in sessions of EFT, with no pre-prepared interview schedules, either in the form of a list of pre-arranged questions that were not in a structured form. Thus, the sessions of therapy were unstructured, and their main role was therapeutic (Denzin & Lincoln, 2005; Kvale, 1996). Emotion-focused theory holds that emotions tell the individual what is important in a situation and acts as a guide to what is needed or wanted (Elliott et al., 2004). That is, emotions help the person to work out what actions are appropriate for their circumstances. Moreover, a principal premise of emotion-focused therapy (EFT) is that emotion is essential in the construction of self and is a basic determinant of self-organisation. On that basis, EFT was used as the intervention to help patients to become more aware of and make productive use of their emotions through the setting of goals based on their needs and desires (Frijda, 1986). When patients were able to achieve this, they were able to promote self-growth (Greenberg et al., 1993; Rogers, 1959). However, choice and well thought out action are also required to facilitate self-creation, and a sense of self. Thus, it was important that I provided a supportive relationship, in which I acknowledged, understood and validated patients. This relationship helped patients to evoke negative experience so that the feeling of being discarded: ... *"they've all brushed me off their hands... just left me to it... more or less left in the dark" or in despair, "It's very scary... dark... very dark... a hole... no ladders to climb... no light."* became lived experience within the counselling session (Greenberg & Paivio, 2003). Once evoked, patients were able to differentiate and to explore the problems associated with their circumstances. This saw patients face their reality and access maladaptive emotion that included uncertainty, *"... is this the kind of thing that's going to be happening to you..."* and the adaptive emotion of sadness at loss, *"I'm not going to be here."*

Moreover, through empathic exploration and validation, patients accessed their needs and goals associated with what they felt. In my role as counsellor, I emphasised the emergence of adaptive needs to promote safety and encourage the facilitation of a shift in organisation, for example, a move from hopelessness to a desire through empathic reflection, empathic conjecture, and empathic affirmation. That is, I, as an EFT counsellor, helped patients to transform maladaptive emotions so that they could change their experience by making decisions that were helpful for them. Thus, their newfound predicament provided hospice patients with new ways of thinking to create alternative ways of constructing their experiences. This encouraged them to make specific life changes and experience a greater intensity for life, which enabled them to live more authentically (Kastenbaum, 2000). However, patients worked at their own pace, with the pace influenced by what patients perceived as progress (Greenberg & Paivio, 2003). At all times, I was aware that my role as counsellor was not to instruct but to facilitate exploration and to empathise with and validate new patient experience to help patients to create new and better understanding of their circumstances.

4.5 Research Limitations

This study, Study 1, is subject to some limitations. The first limitation concerned the availability of patients as potential participants due to severity and progression of illness. Physical and psychological effects of illness and treatment/ surgery, fatigue, and hospital appointments affected the availability of patients and thus, led to a delay in time and with difficulties collecting data. Results generated were based on the lived experiences of four females and four males, with all participants of the same ethnicity and the majority diagnosed with the same life-limiting illness, namely, cancer. A second unforeseen limitation was due to the major refurbishment of the research site. As this required the re-scheduling of time to travel to an alternative site, fitting with patient personal and medical care was not always feasible. Thus, engaging with patients did often require additional re-scheduling of time. This meant that Study 1 took a longer time to complete. These limitations had negative impact on my research and on myself as a person, giving rise to personal anxiety.

4.6 Conclusions

The research question for Study 1 was: "How do hospice patients experience the nature of their control over their thoughts, feelings, and actions during their dying process?" The findings of this study demonstrate that hospice patients construct themselves as specific selves: *Level 0*: *Non-agentic, Level 1: Limited, Level 2: Reflexive, Level 3: Collective, Level 4: Reacting, Level 5: Willing/Wanting, Level 6: Enriched and Level 7: Fully Agentic.* Moreover, using emotion-focused therapy as the approach to counselling with a sample of four out-patients and four in-patients, these findings supported the hierarchy of eight main categories and sub-categories of personal agency discovered in an earlier study, using a smaller sample (Campbell et al., 2014). Also, these finding support that hospice patients actively assess their limitations, make judgements about their circumstances, develop different understandings of themselves and bring about their desired wishes through their own action. Furthermore, results suggest that the hierarchy of levels of personal agency may have the potential to be developed to provide two measures, a self-report questionnaire and an observation measure, for assessing personal agency in hospice patients.

4.7 Chapter Summary

In this chapter I aimed to set out how well Study1, with a new sample of hospice patients would support the eight main categories and sub-categories of personal agency discovered in an earlier study (Campbell et al., 2014). I outlined the research questions; the design and procedures used to generate and analyse data; and provided an overview of the results. In the next chapter, Chapter 5, I detail Study 2, “Measuring Personal Agency in Hospice Patients” the study that aims to develop a Self-Report Questionnaire and an Observation Measure.

Chapter 5: Measuring Personal Agency in Hospice Patients

5.1 Introduction

This chapter details the findings from study 2. This quantitative study was built on the results of Study 1, a qualitative study that showed that hospice out-patients and in-patients experienced themselves, to varying degrees, as the source of actions that were useful and meaningful to them, even to the point of death. The aim of Study 2 was to use the hierarchy confirmed in Study 1 to create two measures, a self-report questionnaire and an observation measure, for assessing personal agency in hospice patients. Assessing the person's agentic behaviours and processes provided insight into how they negotiate their life contexts, navigate difficulties, and use resources, personal, relational, and community-based (Cavazzoni et al., 2022; Sutterluty & Tisdall, 2019). As the need for palliative care increases worldwide (Sleeman et al., 2021), a self-reporting and observational measure may a) provide new knowledge or complement existing knowledge; b) help to plan interventions and treatments; and c) promote research on personal agency within palliative care. With validity and reliability pre-requisites to ensuring the integrity and quality of measuring instruments (Kimberlin & Winterstein, 2008), such measures must measure what they claim to measure and be consistent. Moreover, as noted in Chapter 4, to enhance generalisability, both out-patients and in-patients were sampled, making it possible to indicate the quality of the measures for these two different populations that vary in severity and progression of illnesses. (In addition, as argued in Chapter 3, it was judged to be useful to develop both self-report and observational measures of personal agency). The overall research question for this study was: "Can the hierarchy of personal agency be developed into a set of valid and reliable measures (self-report and observation) for assessing hospice patients?" More detailed second level research questions were:

a) Is there adequate internal consistency among the items of the self-report measure?
b) Is there sufficient test-retest reliability (self-report and observation measures)?
c) Is the inter-rater reliability between ward staff and researcher observations adequate?
d) Is there sufficient convergent validity between observational and self-report measures?

5.2 Method

5.2.1 Summary of Design

Study 2 is a distinct, quantitative study within an overall mixed methods research (MMR) design. This study was quantitative, allowing variables to be measured using instruments like questionnaires, and providing numerical data that can be analysed using statistical analysis (Creswell & Creswell, 2018; Maxwell, 2016). The measurement approaches chosen for this study were a) a self-report questionnaire (Appendix M) consisting initially of 53 participant statements using a Likert Scale (Likert, 1932) with an ascending scale of five responses, ranging from “Not at all” (“0”) to “Extremely” (“4”); and b) an observation measure (Appendix N), based on the BARS (behaviourally-anchored rating scale) method (Smith & Kendall, 1963) with language from critical incidents representing eight main categories and sub-categories of personal agency along with descriptors and the provision for individual counts recorded at each level of agency during the observing. Also, the following procedures were used: a) transcripts from the previous MSc study provided “critical incidents” to generate items and descriptors for these measures; b) pilot testing was used for evaluating face-validity by clinical staff of St. Andrews’ Hospice and other counsellors; c) a pilot study with a sample of 10 hospice out-patients was carried out. Next, d) these pilot data were used to revise the measures; and e) finally, the revised measures were tested with a new sample that included 12 in-patients and 12 out-patients.

5.2.2 Sampling

In this section, I describe the type of sampling used in this study. Purposeful sampling (Denzin & Lincoln, 2005; Patton, 2002; Silverman, 2006) was used to make sure that potential participants shared similar key circumstances, namely, the diagnosis of a life-limiting illness. Sample size was limited due to availability of potential participants. However, whilst the sample sizes used here may be considered small (Kraemer & Blasey, 2016), repeated measurements from patient participants were used to increase sample size**. (**Under conditions like these, validity and reliability need not be jeopardised (Eckermann et al., 2010; Maxwell & Kelley,

2011) although standard statistical significance testing will be compromised by nonindependence of observations).

5.2.3 Participants

Pilot Study. In this section, I detail the participants identified to take part in the pilot study. As detailed in Study 1 (Section: 4.2.3) participants were adults who either attended the out-patient unit or were in-patients of St. Andrew's Hospice. Potential participants (n = 10) were identified by the senior members of the direct care teams of the out-patient and in-patient units, respectively. Also, these senior members were the first to contact patients for the purpose of research. In this study, the inclusion criteria were that participants had to be adult in-patients and out-patients of St Andrew's Hospice and be willing and able to take part in the study. All patients who were identified took part in the study. No participants were excluded. Table 5.1 represents the demographics of the 10 patients who took part.

Table 5.1

Participant sample for pilot study

Patient Identity	Gender	Ethnicity	Illness
OP1	Male	Scottish	Cancer
OP2	Female	Scottish	Parkinson's disease
OP3	Male	Scottish	Cancer
OP4	Male	Scottish	Heart failure
OP5	Female	Mexican	Multiple Sclerosis
OP6	Male	English	Cancer & Heart failure
OP7	Female	Scottish	MND
OP8	Male	Scottish	Cancer
OP9	Female	Scottish	Cancer
OP10	Male	Scottish	Cancer

Note: OP1, OP2, etc: Participant Out-patients.

Main Study. For this study, a different sample of patients, that included out-patients and in-patients was identified. Originally, 40 patients, 20 each from the out-patient and in-patient units were to be identified but due to restrictions of COVID-19, that number was not realisable**.** In the end**,** 24 patients, 12 each from the out-patient and in-patient units, including males and females participated in the research, using the revised versions of the self-report and observation measures. Table 5.2 represents the demographics of the 24 participants who took part.

Table 5.2

Participant sample for main study

Patient Identity	Gender	Ethnicity	Illness
OP1	Female	Scottish	Multiple Sclerosis
OP2	Female	Scottish	Parkinson's disease
OP3	Male	Scottish	Cancer
OP4	Male	Scottish	Cancer
OP5	Male	Scottish	Cancer
OP6	Male	Scottish	Cancer
OP7	Male	Scottish	Cancer
OP8	Male	Scottish	MND
OP9	Female	Scottish	Parkinson's disease
OP10	Female	Scottish	Cancer
OP11	Female	Scottish	Multiple Sclerosis
OP12	Male	Scottish	Cancer
IP1	Male	Scottish	Cancer
1P2	Female	Scottish	Cancer
IP3	Female	Scottish	Cancer
IP4	Male	Scottish	Cancer
IP5	Male	Scottish	Cancer
IP6	Female	Scottish	Cancer
IP7	Female	Scottish	Cancer
IP8	Female	Scottish	Cancer
IP9	Female	Scottish	Cancer
IP10	Male	Scottish	Cancer

IP11	Female	Scottish	Cancer
IP12	Female	Scottish	Cancer

Note: OP1, OP2, etc.: Participant Out-patients IP1, IP2, etc.: Participant In-patients

Ethical Approval and Safeguarding of Participants

Ethical approval and risk assessment was as for Study 1 (Section 4.2.3).

Pilot Study. For the safe-guarding of the welfare and rights of patients, each identified out-patient received a Participant Information Sheet (PIS) (Appendix J) and a Letter of Invitation (Appendix K). Like the pilot study, all participants gave informed consent prior to taking part in the study (Appendix L; Section 4.2.3). Due to COVID-19, research was suspended in March 2020 and re-started in April 2021. The re-start of research required protocols to be amended (Appendices O, P and Q) to meet the requirements of South East Scotland Research Ethics Committee 01; Research and Development, NHS Lanarkshire; St. Andrew's Hospice; and the University of Strathclyde.

Main Study. Wearing personal protective equipment, I was able to meet face-to-face with patients for the purpose of research. Each participant received a Participant Information Sheet (PIS) (Appendix R) and a Letter of Invitation (Appendices S and T). As for the pilot study, all participants also received a Participant Consent Form (Appendix U) that was signed prior to commencement of Study 2.

5.2.4 Procedure

5.2.5 Data Collection

In this section, I describe how data were collected and prepared for data analysis.

Pilot Study. The pilot study was carried out for the purpose of reducing the 53-item self-report questionnaire (the rationale for which was described in Chapter 3) and for revision if required, of the observation measure (rationale also described in Chapter 3). Prior to Covid-19, research was conducted in the out-patient unit and on the day the patient attended. Due to COVID-19, NHS Lanarkshire suspended research, including this study. Research was re-instated later, with restrictions that included carrying out this study via *Near Me*, a video platform that is approved as confidential and secure by the Scottish Government and NHS Scotland. Face-to-face engagement with patients was re-instated as restrictions were lessened. Patients completed the measures either using paper or by telling me their responses. They responded to 53 items (Section 3.6.5) in the self-report questionnaire by choosing one of five options to record their experience of each item. Completing the questionnaire lasted between 10 and 15 minutes. Also, patients were overtly observed for 15 minutes by the researcher or another rater, either on the same day or as was feasible, using the observation measure. Five staff raters took part in the observation in this pilot study. This length of observation time, 15 minutes, was deemed appropriate for the observing of a patient taking part, or not, in an activity such as craft work, engagement with other patients or members of staff. Both measures were offered six times as was appropriate due to illness and COVID-19. Eight out-patients completed the self-report questionnaire and were observed six times; one out-patient completed one questionnaire and was observed four times; one out-patient completed the questionnaire on two occasions and was observed once. All questionnaire item responses and observation counts, including the global observations, were entered in Excel spread sheets.

Before and after participation in the pilot study, patients and observers were asked to indicate, verbally, whether they deemed the observation measure to be relevant and appropriate for what it was assessing. That is, patients were asked to provide feedback that subjectively assessed the face validity of the observation measure to establish whether the clarity and comprehensibility of critical incidents and descriptors were acceptable indicators (Section 3.6.6) of their experiences of personal agency. Observers were asked to indicate whether critical incidents and descriptors were representative of patient behaviour during their observation. The data collected from the self-report questionnaires in the pilot study were used to reduce the number of items in the questionnaire.

Main Study. The new revised questionnaire and the observation measure were administered to a new, larger sample of hospice patients: 12 out-patients and 12 in-patients, each with a personal identifier. All patients completed the revised self-report measure, either by themselves or with assistance from the researcher. On the same day, patients were observed by the researcher and another observer. Twelve observers, four from the out-patient unit and eight from the in-patient unit took part in this study. As appropriate, out-patients and in-patients completed the self-reports and were observed as presented in Table 5.3.

Table 5.3

Number of EFT sessions, administrations of SR and observations completed, main sample

Patient ID	Rater ID	Number of Administerings of SR	Number of Observations
OP1	1, 2, 3, 4	6	6
OP2	1, 3, 4, 5	6	6
OP3	1, 4, 5	2	2
OP4	1, 3, 4, 5	6	6
OP5	1, 3, 4	6	6
OP6	1, 4, 5	6	6
OP7	1, 4	6	6
OP8	1, 4	6	6
OP9	1, 4	6	6
OP10	1, 4, 5	5	5
OP11	1, 4	3	3
OP12	1, 4	3	1
IP1	1, 10	6	6
IP2	1, 11, 12, 13	6	6
IP3	1, 10	6	5
IP4	1, 14	6	6
IP5	1, 14	1	1
IP6	1, 14	3	3
IP7	1, 14	6	6
IP8	1, 14	5	5
IP9	1, 12, 14, 15	6	6

IP10	1, 16	1	1
IP11	1, 14	1	1
IP12	1, 11, 14, 17	6	6

Note: In the Rater ID column, number 1 represents the main researcher, with all other numbers representing staff raters.

This main study was planned to be conducted as for the pilot study, as appropriate for each patient. That is, this study was designed to have the same a) process of identification of participants; b) number of times measures were offered; c) time taken to fill out the self-report questionnaire and be observed; and d) time assigned for the study. In preparation for data analysis, the data from this main study a)16-item revised self-report questionnaire responses and b) categories and global observations from the observation measure were entered in separate Excel spread sheets and identified as out-patients and in-patients, respectively.

5.2.6 Data Analysis

Pilot Study. In this section I present an overview of the data analysis. Cronbach's alpha (1951) is often used with a questionnaire that consists of multiple Likert statements to assess the *reliability* or internal consistency of the questionnaire. Analysis was carried out using SPSS, version 28. Cronbach's alpha was used to assess the extent to which the 53 items in the original self-report questionnaire, that were supposed to measure personal agency, were related to each other (Cortina, 1993; Kline, 1999). Cronbach's alpha gives an overall reliability coefficient, that is, it gives an indication of inter-relatedness between items on the self-report.

Principal Component Analysis (PCA; Fabringer et al., 1999; Hair et al., 2010) within an Exploratory Factor Analysis (EFA; Spearman, 1904) framework, was used to a) provide an initial exploration of the data and b) reduce the number of items in the self-report questionnaire. PCA was used to reduce data to pass as much information, in the form of estimates of commonalty, from the original 53 item questionnaire to a reduced version (Norris & Lecavalier, 2010). Thus, PCA, was used to decrease the dimensionality of the data to find the principal components, a set of underlying variables that would best describe the variance in the data. Firstly, the eigenvalue of 1 was used to give an estimate of the number of factors (Carroll, 1978; Fabrigar & Wegener, 2012). Factor extraction was carried out using principal components analysis (Kaiser, 1958; Merenda, 1997). Then the varimax procedure was applied to rotate the data (Cattell, 1978; Thurstone, 1947) to discover the factor loadings, the strength and direction of the relationship between each item and the extracted factors. Factors based on the theoretical understanding of personal agency were named using the names of the categories of personal agency in the hierarchy of levels of personal agency. Also, the scree plot (Cattell, 1966) was used to determine the number of factors retained (Fabrigar & Wegener, 2012; Norman & Streiner, 2014) by identifying the point of inflection (Cattell, 1966). However, I wanted to develop a revised self-report questionnaire consisting of 16 items, with two items representing each of the eight levels of personal agency. Thus, I carried out an extraction of a "fixed number of two factors" to obtain a lower number of factors than suggested by the eigenvalue and that represented the eight levels of agency (Pett et al., 2003; Velicer et al., 2000). Cronbach's alpha (1951) was used to determine the reliability of the 16-item revised questionnaire (Appendix V) before commencement with the main study.

Main Study. On completion of the main study, the Cronbach's alpha (1951) was again used to analyse the data obtained from the newly developed 16-item self-report questionnaires completed by out-patients and in-patients. Following the analysis of the main study, it was deemed appropriate to remove two items, one at a time, from the self-report questionnaire to try to improve the value of Cronbach's alpha. Thus, it was necessary to repeat the reliability analysis. Pearson's coefficient correlation, r, was used to measure the inter-rater reliability, that is, the level of consistency between the research rater and staff raters, after they had independently implemented the observation measure. The counts provided by the main researcher and the staff raters during observing were compared for out-patients and in-patients, using both the weighted means and the global ratings.

The weighted mean (Kalton & Flores-Cervantes, 2003) is different from the arithmetic mean and, for this study, is the average computed by giving different weights to individual scores on the observation measure. If all the weights are equal, then the weighted mean would be the same as the arithmetic mean. Also, data demonstrating a high weight (representing a larger number of observations) contribute more to the weighted mean. Moreover, the global ratings involve how raters, in a naturalistic context, give an overall rating to the entire period of observing. For this study, the global rating scores reflected the overall opinion of each rater (four for out-patients and eight for in-patients) once they had completed the item score sheet (Kelly et al., 2020) following their observation of out-patients and in-patients, respectively, within a hospice environment. That is, for this study, the global observation was the subjective perspective of each rater, with respect to an overall representation of personal agency as demonstrated by each patient during the observation time.

Also, Pearson's bivariate correlation (1896) was used to evaluate the degree to which the 16-item self-report questionnaire administered to the same individuals, over time, produced similar results, that is, the test-retest reliability. The analysis for test-retest reliability was carried out between the self-report questionnaire item means at a given session (e.g. session 1) and the self-report questionnaire item means for the next session with that patient (e.g. session 2). In addition, analysis was carried out for convergent validity, the degree of consistency between different measures that are supposed to measure the same construct. Pearson's bivariate correlation was used to assess the association between the self-report questionnaire and the observation measure. That is, both the weighted means and the global means for out-patients and in-patients were compared with the self-report questionnaire item means.

5.3 Results

5.3.1 Pilot Study

Tables 5.4 and 5.5 provide the means and standard deviations for the 53-item version of the self-report questionnaire and the observation measure. Descriptive statistics focus on describing and analysing a dataset's main features and characteristics without making any generalisations of inferences to a larger population. Descriptive statistics include the means and standard deviations that inform about each variable, that is, its general level (= mean) and how tightly or broadly it is distributed (= standard deviation). This allows differences in general level and distribution to be identified. However, they provide only limited insights beyond basic summaries and may have the potential to simplify data. These tables provide an indication of the means and standard deviations of variables before the process of reducing the items on the self-report questionnaire or revising the observation measure.

Table 5.4 includes the minimum and maximum values. These values refer to the responses reported by patients for each item. For example, SR27 (*Talking to people is too much for me*) representing level 4 (reacting self) in the hierarchy of levels of personal agency, was on average rated at the lowest level while SR23 (*I feel happy to enjoy the birds and trees*) and SR37 (*I feel happy to be in the land of the living*) both representing level 6 (engaged self) in the hierarchy were rated at the highest level.

Table 5.4

Descriptive statistics: Means and standard deviations for 53-item self-report questionnaire

Item	N	Minimum	Maximum	Mean	Std. Deviation
SR01	55	1	4	3.45	0.765
SR02	55	0	4	2.64	1.223
SR03	55	0	4	1.80	0.970
SR04	54	3	4	3.89	0.317
SR05	55	0	4	2.15	1.380
SR06	55	2	4	3.64	0.557
SR07	55	2	4	3.73	0.489
SR08	55	0	4	3.62	0.850
SR09	55	2	4	3.64	0.557
SR10	55	0	4	2.00	1.291
SR11	55	0	4	2.42	1.134
SR12	55	3	4	3.73	0.449
SR13	55	0	4	1.45	1.274
SR14	55	0	4	2.76	1.232
SR15	55	0	4	2.00	1.171

SR16	55	0	4	2.02	1.672
SR17	55	2	4	3.78	0.534
SR18	55	1	4	3.05	0.970
SR19	55	0	4	1.00	1.122
SR20	55	0	4	1.65	1.468
SR21	55	0	4	1.11	1.257
SR22	55	2	4	3.78	0.459
SR23	55	3	4	3.91	0.290
SR24	55	0	4	3.33	1.263
SR25	55	1	4	3.44	0.764
SR26	55	0	4	1.49	1.200
SR27	55	0	4	0.85	1.113
SR28	55	0	4	3.27	0.849
SR29	55	0	4	1.00	1.171
SR30	55	0	4	1.15	1.283
SR31	55	0	4	1.65	1.092
SR32	55	0	4	3.55	0.835
SR33	55	0	4	3.25	1.004
SR34	55	1	4	3.51	0.960
SR35	55	1	4	3.13	0.640
SR36	55	0	4	1.89	1.652
SR37	55	3	4	3.91	0.290
SR38	55	0	4	3.27	1.079
SR39	55	0	4	3.38	1.225
SR40	55	0	4	3.07	1.303
SR41	55	0	4	2.29	1.524
SR42	55	2	4	3.24	0.793
SR43	55	0	4	3.47	1.016
SR44	55	2	4	3.76	0.576
SR45	55	1	4	2.73	0.891
SR46	55	1	4	3.35	0.865
SR47	55	0	4	3.60	0.915
SR48	55	0	4	2.36	1.352
SR49	55	0	4	1.51	1.230
SR50	55	2	4	3.82	0.434

SR51	55	2	4	3.82	0.434
SR52	55	3	4	3.80	0.404
SR53	55	2	4	3.87	0.433

Note: SR represents self-report questionnaire (Appendix XX); N = 54 administrations

Observation Measure. Table 5.5 includes the minimum and maximum values as well as means and standard deviations of numbers of observations for the different categories of the observation measure. These values refer to the number of ratings assigned to each category by the observers, main researcher and staff raters. For example, Cat 0, representing level 0 (non-agentic self) in the hierarchy of levels of personal agency, was rated the least number of times and Cat 6, representing level 6 (enriched self) in the hierarchy was rated the maximum number of times.

Table 5.5

Descriptive statistics: Means and standard deviations for the observation measure

Level	N	Minimum	Maximum	Mean	Std. Deviation
Cat 0	47	0	1	0.02	0.146
Cat 1	47	0	7	0.62	1.36
Cat 2	47	0	4	0.49	1.04
Cat 3	47	1	16	3.89	3.515
Cat 4	47	0	6	2.11	1.605
Cat 5	47	0	8	2.36	1.858
Cat 6	47	0	17	4.34	3.422
Cat 7	47	0	6	2.00	1.268

Note: Cat represents the category or level of personal agency in the observation measure as indicated by the critical incidents (Appendix); N = 47 assessments

Verbal feedback from patients and observers communicated that the observation measure required neither revision nor clarification**.**

Self-report Questionnaire. Results indicated that the value of Cronbach's alpha (α) was .856 for the original 53-item self-report questionnaire, that is, the self-report questionnaire used in the pilot study with a sample of 10 out-patients, providing a total of 54 administrations. This indicated a good level of reliability (Kline, 1999), suggesting that the items did measure the same phenomenon, personal agency. According to Kline (1999), an instrument is reliable if $\alpha > .7$.

By conceptualising testing as a measurement activity, reliability is the consistency of repeated measurements of the same or like participants, namely, the focus of measurement or the test participant. Unless an identifiable factor gives rise to dramatic changes, comparable results would be expected across repeated test administrations, namely 54 administrations from the same out-patients in a sample of 10 different out-patients over time. Reliability means that a) the instrument constantly reflects the construct that it's measuring across multiple administrations and b) the reliability of a test reveals the effect of measurement of a cohort rather than of an individual (Cronbach, 1951).

Alpha was not used inferentially to discover statistical significance but rather consistency over time. Inferential statistics help to make comparisons and predictions based on sample data. Study 2 did not draw conclusions or make predictions about other samples, including larger samples to make generalisations about a population or inference for the unrestricted population (Le & Schmidt, 2006). The pilot study did not estimate statistical significance but rather refined the study procedures. As a) the value of alpha is sample dependent (Caruso, 2000) and b) Study 2 was informed by Study 1, it was deemed appropriate that out-patients were more physically able to fill out a 53-item self-report questionnaire, and with a less likelihood of missing data

Exploratory factor analysis using PCA indicated that there were more than four factors with eigenvalues greater than one that could have formed suitable factors**.** The scree plot (Figure 5.1) suggested that the point of inflection indicated that there were four factors.

Figure 5.1

Scree plot showing an extraction of four named factors

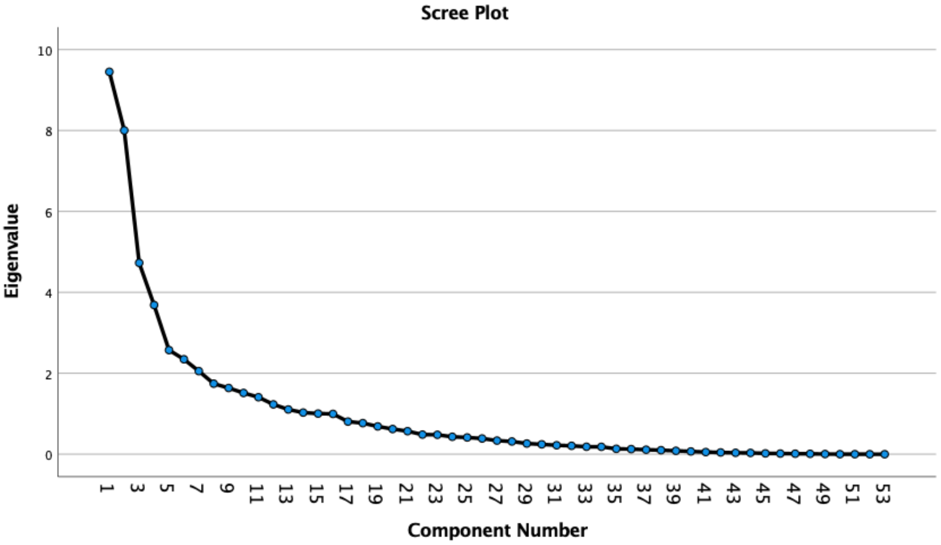


Table 5.6 indicates the items identified during the PCA using varimax rotation method.

Four factors were identified from the Scree Plot and were named accordingly. Factor 1 was named the Objectified/Limited Self as it represented the lower levels of personal agency in the hierarchy of levels of personal agency. Factor 2 was named as the Reflexive Self as, while it represented a low level of personal agency, it indicated a higher level of agency than did factor 1 and thus, it was deemed appropriate to be identified with level 2 in the hierarchy. The third factor, in accordance with the Scree Plot, was named the Collective Self and represented a medium level of personal agency in the hierarchy. Factor 4 represented a high level of agency, corresponding to the Willing/Enriched Selves that identified with levels 5 and 6, respectively, in the hierarchy of levels of personal agency. Table 5.6 indicates the items before they were renumbered for the revised 16-item self-report questionnaire using the pilot sample.

Table 5.6

Items form original 53- item self-report questionnaire identified as a result of using factor analysis in the pilot sample

Item	**Factor**	**Level and**	**Item**	**Factor**	**Level and**

	Analysis	Level Name		Analysis	Level Name
SR49	.846	0 – Non-Agentic Self	SR34	.861	6 - Enriched Self
SR29	.840	1 - Limited Self	SR43	.802	5 - Willing/Wanting Self
SR19	.794	0 – Non-Agentic Self	SR 24	.779	6 - Enriched Self
SR20	.767	1 - Limited Self	SR46	.757	6 - Enriched Self
SR05	.724	1 - Limited Self	SR40	.739	4 - Coping Self
SR11	.700	3 - Collective Self	SR52	.718	5 - Willing/Wanting Self
SR30	.680	4 - Coping Self			
SR26	.669	1 - Limited Self			
SR21	.664	2 - Reflexive Self			
SR27	.661	4 - Coping Self			

Note: SR represents the self-report questionnaire

The items in the sub-scales represented different levels of personal agency. However, a) all levels were not represented and b) those represented leaned towards particular levels. Table 5.7 indicates the items elected and renumbered for the revised 16-item self-report questionnaire using the pilot sample.

Table 5.7

Items elected and renumbered for the revised self-report questionnaire

Item	Factor Analysis	Level and Level Name	Item	Factor Analysis	Level and Level Name
SR14	.856	0 – Non-Agentic Self	SR08	.779	6 - Enriched Self
SR06	.838	0 – Non-Agentic Self	SR16	.767	5 - Willing/Wanting Self
SR02	.806	1 - Limited Self	SR11	.759	4 - Coping Self
SR07	.729	2 - Reflexive Self	SR05	.736	5 - Willing/Wanting Self
SR04	.693	3 - Collective Self	SR09	.719	3 - Collective Self
SR13	.614	2 - Reflexive Self	SR01	.631	6 - Enriched Self
SR12	.614	1 - Limited Self	SR03	.590	7 - Fully Agentic Self
SR10	.531	4 - Coping Self	SR15	.095	7 - Fully Agentic Self

Note: SR represents the self-report questionnaire

The revised 16-item self-report questionnaire constituted eight levels of personal agency, with each level represented by two items. This revised version gave a Cronbach value of .853, which is considered a good level of reliability (Kline, 1999).

5.3.2 Main Study

Tables 5.8, 5.9 and 5.10 provide the means and standard deviations for the revised version of the 16-item self-report questionnaire (after the reduction from 53 items) and the observation measure.

Table 5.8

Descriptive statistics: Means and standard deviations for 16-item self-report questionnaire used with main study of 12 out-patients

Out-Patients

Item Description	**N**	**Min**	**Max**	**Mean**	**Std Deviation**
SR01: Person, I used to be	61	0	4	2.36	1.141
SR02: Anxious about end	61	0	4	2.07	1.153
SR03: Each day at a time	61	0	4	3.13	0.885
SR04: Let doctors decide	61	0	4	2.20	1.263
SR05: Could walk again	61	1	4	3.36	0.817
SR06: Totally devastated	61	0	4	1.56	1.103
SR07: Lost sense of self	61	0	3	1.62	0.934
SR08: Be normal again	61	2	4	3.51	0.722
SR09: Ask questions	61	0	4	3.11	0.915
SR10: Angry about illness	61	0	4	2.20	1.123
SR11: Taking things for granted	61	0	4	2.72	1.067
SR12: Feeling restricted	61	1	4	2.98	0.866
SR13: Become another person	61	0	4	2.02	1.057
SR14: Feel afraid	61	0	4	1.80	1.327
SR15: Focus on being alive	61	0	4	3.11	0.968
SR16: Right for treatment	61	2	4	3.57	0.670

Note: SR represents the self-report questionnaire; N = 61 administrations.

Also, Table 5.8 includes the minimum and maximum values. These values refer to the range of responses reported by patients for each item. In addition, the means tell us the average level of endorsement across administrations, for example, SR06 (*Totally devastated)* representing level 0 (non-agentic self) in the hierarchy of levels of personal agency, was rated at the lowest level of intensity (m = 1.56), while SR16

(*Right for treatment*) level 5 (willing/wanting self) in the hierarchy was rated the maximum level of intensity (m = 3.57).

Table 5.9

Descriptive statistics: Means and standard deviations for the observation measure used with main study of 12 out-patients

Out-Patients

Level	N	Minimum	Maximum	Mean	Std Deviation
0 Non-Agentic	121	0	2	0.12	0.378
1 Limited	121	0	3	0.12	0.546
2 Reflexive	121	0	3	0.31	0.606
3 Collective	121	0	5	1.52	1.050
4 Reacting	121	0	3	0.98	0.935
5 Willing/Wanting	121	0	6	2.38	1.331
6 Enriched	121	0	6	2.25	1.075
7 Fully Agentic	121	0	4	1.31	0.949
Main Res. Wt. Means	121	3.25	5.71	4.80	0.69
Main Res. Global Ratings	121	3.00	6.00	5.17	0.60
Staff Rater Wt. Means	121	2.00	6.00	4.86	0.71
Staff Rater Global Ratings	121	3.50	6.50	5.19	0.57

N = 121 assessments

Also, Table 5.9 includes the minimum and maximum values. These values refer to the range of ratings assigned to each level by the observers, main researcher and staff raters during the observation. Moreover, the means indicate the average level of endorsement across ratings. For example, Level 0 and Level 1, representing the non-agentic and limited self in the hierarchy of levels of personal agency, were rated the lowest number of times and Level 5, representing the willing/wanting self in the hierarchy, was rated the highest number of times. In addition, Table 5.9 also provides the minimum and maximum values for the main researcher and staff raters. These values refer to the range of ratings assigned to each level on the observation

measure by the main researcher and staff raters. Furthermore, the values of the weighted means and global ratings indicate that the average endorsement across rating were almost the same for the main researcher and staff raters.
Table 5.10 presents the descriptive statistics for 16-item self-report questionnaire used with main study of 12 in-patients.

Table 5.10

Descriptive statistics: Means and standard deviations for 16-item self-report questionnaire used with main study of 12 in-patients.

In-Patients

Item Description	N	Min	Max	Mean	Std Deviation
SR01: Person, I used to be	53	0	4	2.60	1.149
SR02: Anxious about end	53	0	4	1.32	1.425
SR03: Each day at a time	53	1	4	3.13	0.810
SR04: Let doctors decide	53	0	4	2.75	1.343
SR05: Could walk again	53	0	4	2.83	1.205
SR06: Totally devastated	53	0	4	1.08	1.207
SR07: Lost sense of self	53	0	3	0.98	1.434
SR08: Be normal again	53	0	4	3.19	1.178
SR09: Ask questions	53	1	4	3.57	0.721
SR10: Angry about illness	53	0	4	1.19	1.316
SR11: Taking things for granted	53	0	4	1.70	1.310
SR12: Feeling restricted	53	0	4	3.00	0.981
SR13: Become another person	53	0	4	1.28	1.446
SR14: Feel afraid	53	0	4	0.98	1.232
SR15: Focus on being alive	53	1	4	3.28	0.769
SR16: Right for treatment	53	0	4	2.49	1.368

Note: SR represents self-report questionnaire; N = 53 administrations

Also, Table 5.10 includes the minimum and maximum values. These values refer to the range of responses reported by patients for each item. Also, the means tell us the average level of endorsement across administrations, for example, SR07 (*Lost sense of self)* and SR14 (*Feel afraid)* representing level 0 (non-agentic self) in the hierarchy of levels of personal agency, were rated at the lowest level of intensity (m

= 0.98) while SR09 (*Ask questions about treatment*) level 3 (collective self) in the hierarchy was rated the maximum level of intensity (m = 3.57).

Table 5.11 shows the descriptive statistics for the observation measure used with main study of 12 in-patients.

Table 5.11

Descriptive statistics: Means and standard deviations for the observation measure used with main study of 12 in-patients

In-Patients

Level	**N**	**Minimum**	**Maximum**	**Mean**	**Std Deviation**
0 Non-Agentic	105	0	3	0.60	0.754
1 Limited	105	0	2	0.61	0.766
2 Reflexive	105	0	3	0.56	0.820
3 Collective	105	0	3	1.28	0.612
4 Reacting	105	0	9	1.75	1.385
5 Willing/Wanting	105	0	4	1.70	1.028
6 Enriched	105	0	4	1.71	0.805
7 Fully Agentic	105	0	4	1.29	0.756
Main Res. Wt. Means	105	2.50	5.63	4.23	0.80
Main Res. Global Ratings	105	3.00	6.00	4.87	0.61
Staff Rater Wt. Means	105	2.50	5.56	4.32	0.79
Staff Rater Global Ratings	105	3.50	6.00	4.83	0.59

N = 105 assessments

Also, Table 5.11 includes the minimum and maximum values that represents the range of ratings assigned to each level by the observers, main researcher and staff raters. Moreover, the means indicate the average level of endorsement across ratings. For example, Level 2, representing the reflexive self and Level 0, representing the non-agentic self in the hierarchy of levels of personal agency were rated the lowest number of times and Level 4, reacting self, and Level 6, enriched self were rated the highest number of times. In addition, Table 5.11 also provides the minimum and maximum values for the main researcher and staff raters. These values refer to the range of ratings assigned to each level on the observation measure by the main researcher and staff raters. Furthermore, the values of the weighted means and global ratings indicate that the average endorsement across rating were almost the same for the main researcher and staff raters.

Internal reliability. Results of the data on the self-report measure analysed from the out-patients in the main study gave a Cronbach alpha value of .851, suggesting a level of good internal consistency (Kline, 1999). Also, an alpha value of .645, suggesting an acceptable reliability (Kline, 1999) was obtained from the data of 12 in-patients. In an attempt to increase the value of Cronbach's alpha, two items, SR05 ("I wish I could walk again") and SR09 ("I am able to ask questions about my treatment"), were removed one at a time, from the 16-item self-report questionnaire. With respect to the self-report questionnaire, alpha values of .861 and .857 were obtained for out-patients; alpha values of .710 and .637 obtained for in-patients. The values of alpha after removing both items gave an internal consistency reliability of .868 for out-patients, with an alpha value of .702 for in-patients. However, these alpha values represented the internal consistency of a 14-item self-report questionnaire that, whilst it did constitute eight categories of personal agency, did not represent each category with two statements for each level of personal agency. Thus, it was deemed justified to retain the 16 items because the 16 items were each associated with two levels of personal agency.

Inter-rater and Scoring Reliability. The findings for inter-rater reliability and scoring reliability are presented in Table 5.12. indicated that Pearson's correlation coefficient, for the inter-rater reliability with respect to *out-patients* were a) $r = .75$, $p < .01$ for the weighted means of the main researcher and four different staff raters; and b) $r = .81$, $p < .01$ for correlation between the global ratings for the main researcher and the same four staff raters. Also, for out-patients, the correlations between the weighted means and the global means for the main researcher and staff raters were carried out separately, to provide the values of a scoring reliability, with $r = .81$, $p < .01$ and $r = .76$, $p < .01$.

Moreover, results indicated that for *in-patients*, the inter-rater reliability between the weighted means for the main researcher and eight different staff raters was, r = .86, p <.01; inter-rater reliability for the global ratings between the main researcher and the same eight staff raters were, r = .80, p < .01. In addition, results showed that the scoring reliability (weighted means with global ratings) for the main researcher were, r = .65, p < .01, identical to the value for the eight staff raters.

Table 5.12

Value of inter-rater reliability using Pearson's correlation, r

	Inter-rater Reliability	**Value of r**
Out-patients	Weighted Means: Main Researcher with 4 Staff Raters	.75**
	Global Ratings: Main Researcher with 4 Staff Raters	.81**
	Scoring Reliability: Main Researcher Weighted Means with Global Means	.81**
	Scoring Reliability: 4 Staff Raters Weighted Means with Global Ratings	.76**
In-patients	Weighted Means: Main Researcher with 8 Staff Raters	.86**
	Global Ratings: Main Researcher with 8 Staff Raters	.80**
	Scoring Reliability: Main Researcher Weighted Means with Global Means	.65**
	Scoring Reliability: 4 Staff Raters Weighted Means with Global Means	.65**

**p < .01 Note: Out-patients, n = 58 assessments (12 out-patients); In-patients, n =53 assessments (12 in-patients). Asterisks indicate the values for which the null hypothesis is rejected; *p ≤ 0.05, **p ≤ 0.01

Test-retest reliability. Results indicated that the value of Pearson's correlation for the test re-test reliability between the self-report questionnaire item means and the self-report questionnaire item means for the next session were r = .84, p < .01 for *out-patients* and r = .39 for *in-patients*. Tables 5.13 and 5.14 set out the length of therapy, in days, between the start and end dates. The findings for test-retest reliability are set out in Table 5.15.

Table 5.13

Out-patients: Length of therapy in days with respect to test-retest reliability for 12 out-patients

Patient ID	Number of Sessions	Start Date	End Date	Length of Therapy in Days	Mean Interval Between Sessions
OP1	6	22/02/2022	29/03/2022	35	7
OP2	6	22/03/2022	24/05/2022	63	12.6
OP3	2	23/03/2022	30/03/2022	07	7
OP4	6	30/03/2022	18/05/2022	49	9.8
OP5	6	03/03/2022	25/05/2022	56	11.2
OP6	6	01/11/2022	06/12/2022	35	7.0
OP7	6	02/11/2022	21/12/2022	49	9.8
OP8	6	09/11/2022	14/12/2022	35	7.0
OP9	6	09/11/2022	21/12/2022	42	8.4
OP10	5	23/11/2022	18/01/2023	56	14
OP11	3	30/11/2022	21/12/2022	21	10.5
OP12	3	06/12/2022	20/12/2022	14	7

Note: Mean number of days for 12 out-patients = 9.28

Table 5.14

In-patients: Length of therapy in days with respect to test-retest reliability for 12 in-patients

Patient ID	Number of Sessions	Start Date	End Date	Length of Therapy in Days	Mean Interval Between Sessions
IP1	6	21/04/2022	18/05/2022	27	5.4
IP2	6	21/04/2022	12/05/2022	21	4.2
IP3	6	25/05/2022	19/05/2022	24	4.8

IP4	6	02/09/2022	11/09/2022	9	1.8
IP5	1	02/09/2022	02/09/2022	1	1
IP6	3	02/09/2022	06/09/2022	4	2
IP7	6	04/10/2022	19/10/2022	15	3
IP8	5	19/10/2022	27/10/2022	8	2
IP9	6	16/11/2022	29/12/2022	13	2.6
IP10	1	30/11/2022	30/11/2022	1	1
IP11	1	15/12/2022	15/12/2022	1	1
IP12	6	11/01/2023	20/01/2023	9	1.8

Note: Mean number of days for 9 in-patients = 3.07
Three in-patients, IP5, IP10 and IP11, were excluded from the calculation of the mean number of days as they only engaged in one session.

Table 5.15

Value of test-retest reliability using Pearson's correlation, r, for 12 out-patients and 12 in-patients

Test-Retest Reliability		Value of r
Out-patients	Self Report Item Means with Self Report Item Means next session	.84**
In-patients	Self Report Item Means with Self Report Item Means next session	.39

**$p < .01$ Note: Out-patients, n = 49 pairs of assessments; In-patients, n = 44 pairs of assessments.

Convergent validity. In addition, Pearson's correlation was used to assess the association between the self-report questionnaire and the observation measure for both out-patients and in-patients. Results for convergent validity are presented in Table 5.16.

Table 5.16

Value of convergent validity using Pearson's correlation, r, for 12 out-patients and 12 in-patients

Out-patients	Value of r

Main Researcher Weighted Means with Self-report Item Means	-0.07
Main Researcher Global Ratings with Self-report Item Means	0.12
Staff Rater Weighted Means with Self-report Item Means	0.14
Staff Rater Global Ratings with Self-report Item Means	0.11
In-patients	Value of r
Main Researcher Weighted Means with Self-report Item Means	- 0.51
Main Researcher Global Ratings with Self-report Item Means	- 0.31
Staff Rater Weighted Means with Self-report Item Means	- 0.50
Staff Rater Global Ratings with Self-report Item Means	- 0.08

Negative correlations indicate that as the value of one variable decreases, the value of the other variable increases. The results of this study provided an indication of the strength of the relationship between the self-report questionnaire and the observation measure. The closer the results are to zero, the more likely that there is no correlation between variables. Some convergence is preferred to none and, whilst small, these r values were moving in the same direction. However, these results indicated that there was a substantial departure from a convergent validity, $r = 1$. Moreover, results indicated that the values of r were considerably lower (and even negative) for in-patients than that for the out-patients.

Thus, it was deemed appropriate to examine the data for all 12 in-patients in the main study for inconsistent or invalid data. That is, patient responses to items on the self-report questionnaire and the ratings provided by raters for the observation measure were examined for each in-patient for indicators of inconsistent or invalid responding. It became evident that the anomalous result was due to in-patient IP3.

Whilst the item responses on the self-report questionnaire were often reported as high (represented as “extremely” on the self-report) by in-patient IP3, I believe that her responses were appropriate for her experience of her circumstances. This patient’s data might be regarded as constituting an “outlier”, highlighting that the process of IP3 was different from that of the other in-patients in the sample. Also, it was unlikely to be a problem with the observer measure, since the main researcher and the staff raters agreed with each other in their ratings of the observation measure. This gave rise to the question whether it was justified to exclude her data from the analyses. It was seen as fitting to re-run the various analyses of the data for the remaining 11 in-patients, that is, without the data from in-patient IP3. However, the results for the re-run of the analyses for 11 patients indicated that it was not helpful from a measurement point of view as IP3 was a major contributor to internal consistency reliability. Results for internal consistency, analysed using Cronbach's alpha, provided a value of $\alpha = .386$, using a sample of 11 in-patients. This value indicated a low internal consistency and suggested that one or more items were not consistent with each other. Results indicate that for inter-rater reliability for the sample of 11 in-patients, the values of r were, r = .76 for weighted means and r = .74 for global ratings. Also, for scoring reliability, the value for the main researcher was r = .68 and for the eight staff raters, r = .73. Table 5.17 represents the inter-rater reliability for the sample of 11 in-patients, that is, with removing the data of IP3.

Table 5.17

Value of inter-rater reliability using Pearson's correlation, r, for 11 in-patients

	Inter-rater Reliability	**Value of r**
In-patients	Weighted Means: Main Researcher with 8 Staff Raters	.76**
	Global Ratings: Main Researcher with 8 Staff Raters	.74**
	Scoring Reliability: Main Researcher Weighted Means with Global Means	.68**
	Scoring Reliability: 8 Staff Raters Weighted Means with Global Ratings	.73**

Note: In-patients, N = 47

Results indicated that the value of Pearson's correlation for the test-retest reliability between the self-report questionnaire item means and the self-report questionnaire item means for the next session was r = -. 23 for 11 in-patients. Table 5.18 presents the length of therapy in days with respect to test-retest reliability for 11 in-patients. The findings for test-retest reliability are set out in Table 5.19.

Table 5.18

In-patients: Length of therapy in days with respect to test-retest reliability, minus the data of IP3

Patient ID	Number of Sessions	Start Date	End Date	Length of Therapy in Days
IP1	6	21/04/2022	18/05/2022	27
IP2	6	21/04/2022	12/05/2022	21
IP4	6	02/09/2022	11/09/2022	9
IP5	1	02/09/2022	02/09/2022	1
IP6	3	02/09/2022	06/09/2022	4
IP7	6	04/10/2022	19/10/2022	15
IP8	5	19/10/2022	27/10/2022	8
IP9	6	16/11/2022	29/12/2022	13
IP10	1	30/11/2022	30/11/2022	1
IP11	1	15/12/2022	15/12/2022	1
IP12	6	11/01/2023	20/01/2023	9

Table 5.19

Value of test-retest reliability using Pearson's correlation, r, for 11 in-patients

	Test-Retest Reliability	Value of r
In-patients	Self Report Item Means with Self Report Item Means next session	-.23

N = 47 Sessions

Pearson's correlation was used to assess the correlation between the self-report questionnaire and the observation measure for 11 in-patients. Results indicated that the values of r were almost zero, with values of r = 0.03, 0.00, 0.05 and 0.09. That is, with the exclusion of the data provide by in-patient, IP3, results demonstrated that there was no convergent validity between the self-report questionnaire and the observation measure. Thus, that suggested that there was no correlation between the items in the self-report questionnaire and the descriptors of the observation measure even if that were supposed to measure the same latent construct, personal agency. The results for convergent validity for 11 in-patients are presented in Table 5.20.

Table 5.20

Value of convergent validity using Pearson's correlation, r, for 11 in-patients

In-patients	Value of r
Main Researcher Weighted Means with Self-report Item Means	.03
Main Researcher Global Ratings with Self-report Item Means	.00
Staff Rater Weighted Means with Self-report Item Means	-.05
Staff Rater Global Ratings with Self-report Item Means	.09

5.4 Discussion

In this section, I discuss the findings in relation to the existing literature. Findings indicated that the original 53-item self-report questionnaire, with items selected from the transcripts of hospice out-patients, demonstrated a good level of internal consistency. As the aim was to assess the extent to which patient responses were consistent between items (Connelly, 2011), Cronbach's alpha was used as the measure of internal consistency. Findings suggested that there was a good degree of interrelationship, or correlation, among the items in the self-report questionnaire. This suggested that the questionnaire measured the same construct, personal agency and, specifically, in hospice patients as alpha assumes that each test item measures the same latent construct on the same scale (Graham, 2006**).** That is, findings suggested that the questionnaire measured one construct and therefore, supported the one-dimensionality of the scale. Also, the self-report questionnaire could be said to be reliable as Cronbach's alpha demonstrated that there was a covariance (measure of the relationship) among the items relative to the variance (how far each item is from the mean and thus, from every other item.

However, the number of items in the self-report questionnaire was deemed too large for this present research and for its potential use as a measuring instrument in a palliative care setting. That is, a reduced version of the 53-item self-report questionnaire was seen as more fitting for the target population, hospice patients. Factor analysis facilitated the reduction of data and the conducting of an initial exploration**.** Exploratory factor analysis was applied to the data set from 10 out-patients responding to 53 items, with the aim to search for relationships between variables to reduce to a smaller number of items. PCA allowed the reduction of data and tried to preserve as much information from the original data set as possible. The self-report questionnaire was reduced to 16 items and the briefer version showed a good level of reliability. Moreover, the revised self-report questionnaire included items representing the eight levels categories of personal agency, with each category represented by two items.

Following the administering of this revised 16-item self-report questionnaire to a new sample of 12 out-patients and 12 in-patients, the value of alpha remained the same with respect to out-patients but was lower but acceptable with respect to the in-patients. However, the level of reliability can be increased or reduced with the addition or decrease in the number of items (Carmines & Zeller, 1979). Thus, the 16-item version of the self-report questionnaire was reduced to 15 and 14 items, for both out-patients and in-patients, respectively, before carrying out the main study. Cronbach's alpha was higher for the sample of 12 out-patients. For the sample of 12 in-patients, a similar removal of under-performing items provided a slight increase of reliability. However, with respect to the self- report questionnaire, it was apparent that the data of in-patient, IP3, were inconsistent with that of the other in-patients in the sample.

By examining all in-patient data in that specific sample, it became evident that in-patient, IP3, had responded with the intensity of "extremely" on the self-report on more occasions than did the other in-patients. It did appear that IP3 had an attachment to rating "extremely" as the patient felt that she had been discarded and that her lack of offer of treatment allowed her illness to overcome her physicality with speed and unrelenting pain and discomfort. The data appeared to constitute an "outlier", highlighting that her process was inconsistent with that of the other in-patients in the sample. Also, as the global ratings for the main researcher and the staff raters were almost the same, it was therefore unlikely that there was problem with the observation measure. Moreover, a re-run of the various analyses of the data for the remaining 11 in-patients, did not justify the exclusion of the data from IP3 from the main analysis

Whilst, with respect to the sample of out-patients, results indicated that the self-report questionnaire could be regarded as reliable, how levels of internal consistency reliability are interpreted is dependent on different authors. For example, Peterson in his “A Meta-Analysis of Cronbach’s Coefficient Alpha” (1994) stated that for a measure to be valid and possess practical utility, it must be reliable. Moreover, Peterson indicated that the required degree of reliability is a function of the research purpose, for example, whether research is exploratory or applied. Nunnally (1978) argued that a cut-off of 0.70 was appropriate in the early stages of exploratory research such as scale development. However, in his earlier works, Nunnally (1967) stated that values as low as 0.50 were acceptable for exploratory research. Contrary to other researchers, Lance et al., (2006), argued for more stringent cut-offs, with basic research 0.80 or higher. According to Kline (1999), values of Cronbach lower than .7 may be expected with some psychological constructs. In addition, Cho and Kim (2015) and Cortina (1993) advocated for caution against applying any arbitrary or automatic cut-off criteria. Instead, they claimed that the value should be based on the purpose of the research and on the stage of research, exploratory, basic, or applied.

In keeping with Cho and Kim (2015) and Cortina (1993), it was deemed relevant for this research, to balance the desire for a high value of Cronbach’s alpha with meaningful, relevant items that represented the construct, personal agency (Pett et al., 2003; Velicer et al., 2000. Thus, as in this research, if the relevance and significance of items selected is based on a well-founded reason like the inclusion of a specific number of levels of agency, the interpretation of Cronbach’s alpha may not be as clear-cut as high or low, good, or bad as this research is the first step in the development of two new measures. Also, whilst Hulin et al. (2001) stated that a high value of alpha does not necessarily indicate a higher the level of reliability, Graham (2006) supported that reliability might be underestimated if the number of test items is too small. Underestimation may be decreased by the removal of items or an increase in sample size to increase the value of alpha. Moreover, with a larger sample of in-patients, it might not have been necessary to remove the data in-patient, IP3. Table 5.21 presents selected recommended reliability levels, Peterson (1994).

Table 5.21

Selected recommended reliability levels

Author	**Situation**	**Recommended Level**
Davis (1964, p.24	Prediction for individual	Above .75
	Prediction for group of 25-50	.5
	Prediction for group Over 50	Below .5
Kaplan and Saccuzzo (1982, p. 106)	Basic research	.7-.8
	Applied research	.95
Murphy and Davidshofer (1988, p. 89)	Unacceptable level	Below .6
	Low level	.7
	Moderate to high level	.8-.9
	High level	.9
Nunnally (1967, p. 226)	Preliminary research	.5-.6
	Basic research	.8
	Applied research	.9-.95
Nunnally (1978, pp. 245-246)	Preliminary research	.7
	Basic research	.8
	Applied research	.9-.95

Reliability matters because it is important to be able to trust the information provided by measuring instruments and research (Aaronson et al., 2002). The newly developed self-report questionnaire allowed data to be collected with respect to how hospice out-patients and in-patients felt, thought, and acted. Thus, it was important that, as a measuring tools, the questionnaire and observation measures, were consistent, accurate and meaningful for hospice patients. As such, it was necessary to know the levels of the inter-rater reliability, test -retest reliability and the convergent validity**.** Pearson’s coefficient correlation, r, was elected as the statistical method to assess the levels of the inter-rater reliability, test-retest reliability and convergent validity. Also, it is important to note that the weighted means and the global ratings of the main researcher and staff raters were used for calculating the levels of inter-rater and scoring reliability.

Inter-rater reliability is a measure of the consistency between two or more raters or observers in their assessments, judgements, or ratings of a particular phenomenon. In this research raters independently observed hospice patients and recorded data that they judged were accurate representations of levels of personal agency as expressed by the hospice patients. Thus, inter-rater reliability addressed the implementation of the observation measure. The results of this study indicate that, the values of r for the main researcher and staff raters were high and consistent for the data sets of 12 out-patients and 12 in-patients. Thus, there is a definite relationship between the raters and the null hypothesis can be rejected. In addition, as the results indicated that the levels of the inter-rater reliability are high, the judgement process of the raters, main and staff, could be said to be stable, and the resulting scores reliable.

Ensuring high inter-rater reliability was essential as this study involved subjective judgement during observations and thus, confidence in being able to replicate findings without influence of individual rater subjectivity or biases was important. Thus, two raters may not be necessary for carrying out the scoring of the observation measure. Moreover, r showed a slight increase in the scoring reliability for the main researcher and eight staff raters. A scoring reliability for the main researcher and staff raters helped to reinforce the information obtained from the inter-rater reliability. Scorer reliability refers to the consistency between different ways of scoring the same test agree and may be seen as an additional value in the test for reliability for psychological measures. Results suggest that scoring methods (weighted means vs global rating) are interchangeable. The characteristics of the samples used to collect information did share similarities in terms of their life-limiting illnesses. Thus, if hospice patients of the sample are sufficiently similar, then the reported reliability estimates would also hold true for the population. Raters were provided with a training manual, a protocol that acted as a guide for recording observations, monitoring of data and there was an opportunity for feedback.

Test-retest reliability, the measure of consistency between the self-report questionnaire item means and the self-report item means for the following session or observation, was measured using Pearson's correlation, r, to obtain the correlation of the scores of out-patients and in-patients' responses between current and subsequent administering of the self-report questionnaire. Results indicated that for out-patients, r was substantial, providing a large effect size, with p statistically significant. For in-patients, the value of r was smaller. According to Revelle and Condon (2017), test-retest reliability assumes that the relative position of a person's score in the distribution of the population should be the same over the time period. In effect, test-retest is the systematic examination of consistency among two different assessments of the same individual, using the same measure, under the conditions whereby the individual is stable. However, these assumptions may be difficult to attain within the real-life environment of a hospice as due to the nature of life-limiting illnesses, conditions may change unpredictably and from moment to moment.

Test-retest reliability carried out in this research, did not assume that the administrations of the self-report would be identical and independent, nor that the performance of the patients would be consistent across points in time (Geisinger, 2013). Richardson and Jones (2009) stated if patients experience change on their construct at different rates between test occasions, the correlation between the occasions can be low even if the measurement instrument is precise. Thus, with respect to hospice patients, progression of illness may result in a change in how they construct themselves as having a sense of personal agency. That is, the stability of the construct has the potential to not remain stable due to the fluid nature of life-limiting illnesses. Also, this may be heightened with respect to in-patients due to the progression of their illness (Richardson & Jones, 2009).

For this study, all patients had the diagnosis of a life-limiting illness and were all receiving palliative care. Moreover, due to their illnesses, patients experienced change, the nature and rate of which was unpredictable and often gave rise to physical, psychosocial, and existential difficulties (Campbell et al., 2014). This had the potential to influence the measure of reproducibility of the self-report questionnaire, that is, the ability to provide consistent scores over time in a stable population (Aaronson et al., 2002). Also, this had the potential to indicate that patients did not experience themselves as agentic. Moreover, results demonstrated that the self-report questionnaire, with respect to out-patients and in-patients, could be regarded as reliable for out-patients, and less affected by random fluctuations (Kottner et al., 2011). Test-retest reliability was conducted to gain an understanding of the dependability of the self-report questionnaire within clinical environments, namely, the out-patient and in-patient units within a hospice. When assessing efficacy of treatment and intervention, it was important to know whether observed changes in outcome were attributed to real changes within the patient or due to instability of the measure.

Also, test-retest reliability can be influenced by the time interval between tests (Haynes et al., 2018). According to literature, the optimal time-interval will vary depending on the construct being measured, the stability of the construct over time, and on the target population (Evans, 1996). Also, according to literature, the number of days between tests impacts reliability coefficients. Chmielewski and Watson (2009) looked at how retesting using a 2-week interval versus a 2-month interval; they found reliability estimates were similar. Also, whilst Backhaus et al. (2002) found test-retest reliability was higher with a shorter time interval, Liao and QU (2010) found that reliability increased with an increase in time interval. For this study, it is important to note that the length of therapy in days ranged from seven to 62 days for out-patients and from one to 27 days for in-patients. Test-retest coefficient values of test-retest reliability are subject to varying standards from different researchers. According to Fleiss (2011) less than 0. 41 indicates low reliability; 0.41 to 0.74 is moderate reliability; 0 .75 to 0.9 is considered substantial reliability. In addition, the smaller the sample size the greater the likelihood of obtaining a spuriously small or large correlation coefficients. It is therefore uncertain if the lower correlations in the in-patient sample reflect a genuine poorer test-retest reliability or are extreme estimates due to their small sample size (Mundfrom et al., 2005**).** According to Richardson and Jones (2009) test-retest reliability can also be influenced by the effects of learning, memory, fatigue, and motivation. However, for this study, patients were always willing to take part and did not report that taking part caused them to be fatigued. Also, while completing the self-report questionnaire, patients did not appear to have memorised the items.

Convergent validity indicates whether a test that is designed to measure a particular construct correlates with other tests that assess the same or similar construct. Convergent validity is important when the researcher is using two different methods of data collection such as a questionnaire and an observation measure. In this research, the self-report questionnaire and the observation measure, the two formats operationalised to represent personal agency, were analysed for convergent validity using Pearson's coefficient correlation. Moreover, Pearson's correlations were carried out using four different forms of observer measurement. That is, the main researcher's weighted means and global ratings were compared, separately, with the self-report questionnaire item means for both out-patients and in-patients. Also, this was carried out for the staff raters. A high correlation between the two test scores would suggest that they are theoretically related to each other (Krabbe, 2017). For this study, results indicated that the levels of convergent validity did not support that the two measures were related to each other and thus, the null hypothesis was not rejected.

Currently, it appears that no other scales for measuring personal agency in hospice patients exists and thus, there was no opportunity to compare the newly developed measures with existing measures. Instead, two newly developed measures were required to be compared for discovering whether they were related to each other. Nonetheless, it was important to examine whether the correlation was able to demonstrate if the measures did capture meaningful information about hospice patients experiences of personal agency. Convergent validity verifies whether the scores of an instrument under study "make sense" in relation to the scores of other related measures. It focuses on similarities and is a matter of degree of two variables changing together at a constant rate. Factors affecting convergent validity are small sample sizes, restriction of range, random or systematic errors of measurement, amount of variability in the data, characteristics of the sample, gender, and attrition. However, in Study 2, the estimated values for convergent validity for out-patients, while mostly positive, but tended towards zero; all were negatively correlated for in-patients. Moreover, convergent validity is generally considered adequate if a correlation with an instrument, measuring the same construct is > 0.5. Cut off points may be arbitrary, but they provide guidance when assessing whether validity is adequate. A review of data from studies reported 144 estimates of convergent validity, ranging from r = .02 to r = .82 (Campbell and Fiske (1959).

The test-retest reliability for the self-report (SR) was robust for out-patients in Study 2 but not statistically significant for in-patients. Inter-rater reliability was robust for the observation measure (OR) for out-patients and in-patients. Thus, it was unclear whether the weak correlation was due to the SR or OR. Inter-rater reliability may be construed as evidence of validity as inter-rater reliability is interested in the convergence of rater inferences based on different cues. Inter-rater reliability is not only a form of reliability but a validity criterion that might be reduced by unreliability. If test-retest is high then the measures are relatively free of measurement error like change in participant mood that may cause a difference between SR and OR (Last, 2007). When using the same test-retest intervals and the same observers, statistics can provide a basis for comparing the validities of scales. If measures have good test-retest reliability and internal consistency, researchers may be more confident that the scores represent what they are supposed to.

Validity is normally assessed in terms of a nomological network of associations that is often difficult to compare quantitatively to the nomological networks of other scales (Haig, 2023). SR and OR may have different underlying theories about how to measure personal agency in hospice patients. SR sees patients a) construct themselves as specific selves regarding their sense of agency; b) assess their limitations; c) appraise their circumstances; d) develop different understandings of themselves; and e) select the item response they believe is appropriate for them. During observation, patients are actively engaged (mostly joyfully) in activities, on their own, with another or in group interactions. This may support that for OR, patient agency is more likely to be associated with the higher levels of agency. The collection of additional data would provide a greater number of administrations/observations, perhaps, giving rise to an increase in convergent validity between SR/OR. Given the values of Cronbach's alpha, replication of the research by other researchers would be advantageous and may allow the research to be included in a meta-analysis. Also, it is important to note that a smaller sample size of observations across patients affects the statistical validity, leading to a type II error. According to Kline (2016), a sample size of 10 to 20 participants per item is deemed to be sufficient sample size.

Also important is my choice of paradigms. For Study 2, critical realism, was the conceptual lens through which I examined the methodological aspects of this research. A tenet of critical realism (CR) is that the world exists independently of what we think about it, leading to the acceptance of the fallibility of our knowledge and the possibility of getting things wrong (Bhaskar, 1975). CR combines a realist ontology (there is something to find out about) with a relativistic epistemology (different people will come to know different things in different ways). Also, CR views social phenomena, like personal agency, as context-dependent, requiring interpretive understanding and allowing for the 'legitimate' combination of qualitative/quantitative methods. Legitimacy of quantitative methods with CR studies, relies on the interpretation of statistics as the use of statistical significance can suggest relationships. Agency can be activated or suppressed by contextual factors; CR helps to discover not just what is happening but 'why' and 'how' it is happening.

Whilst I had neither assumptions nor expectations about what results would indicate, analysis revealed counter-intuitive data insights. Counter-intuitive data refers to data that presents unexpected results that may clash with common sense or what has been previously published and accepted by the medical community (Doty et al., 2019). Whilst I was confident that the data for this study did not clash with what had been previously published and accepted, I had to decide whether I viewed the insights into data as valuable and impactful or challenging to communicate effectively**.** According to Doty et al. (2019), clinicians have dealt with counter-intuitive results piece-by-piece through investigating the state of the patient, the repeating of a test or tracking on-going monitor data. These clinician responses helped to identify whether the previous result could be seen as a non-repeatable error or as authentic anomaly (Doty et al., 2019**)**. Researcher bias was not a concern and the sampling process, including the inclusion- exclusion criteria was robust. However, I was aware that correlation did not equal causation, and that further research was needed to determine the underlying reason for the results of the analysis. For example, there was the potential of over-reporting and under-reporting by patients, giving rise to reporting bias (Doty et al., 2019).

5.5 Research Limitations

This research is subject to some limitations. An important limitation concerned how the confounding variables of the severity and progression of illness, levels of anxiety coming from physical and psychological effects of illness and treatment/ surgery, fatigue, and hospital appointments affected the availability of patients and consequently the gathering of data. The availability of patients, out-patients and in-patients, as potential participants to be identified to take part in the research was limited because of their life-limiting illnesses. Having given consent to take part, meeting with patients within an arranged schedule was not always feasible and sometimes resulted in the agreed number of six sessions having to be shortened and or reduced. This sometimes resulted in obtaining data from only one, two or three sessions with some of the patients, leading to the reduced access of data and the need for the identification of other patients as was appropriate. Also due to the fluid nature of their illness, patient responses were not always consistent and had an implication for the results obtained from statistical testing. However, it is important to note that this preliminary investigation provided valuable data from ground-breaking research and did allow statistical testing. With limited data, the ability to track the change in patients' experiences became

Due to the nature of life-limiting illnesses, the availability of patients was restricted, with the constraint of a small amount of data that may undermine the internal and external validity of a study. A small sample size (participants) can contribute to limited exploration of heterogeneity, attrition, the risk of random variability, and to limited generalisability. With a small sample, Pearson's correlation, r, even when statistically significant, may provide spurious results, with the true difference or effect not identified. This may lead to the research questions not adequately answered as well as the chance of seeing the study as falsely negative, leading to a type II error. Type II errors are more likely to occur when sample sizes are small. For Studies 1 and 3, the recommended optimal number of cases in a multiple case design is between four and six (Giorgi; 1997); Yin (2011) suggested a sample of between four and 10. Some statisticians agree that a sample size of 100 is the minimum needed to carry out factor analysis and to obtain meaningful results (Mundfrom et al., 2005). From an ethical standpoint, a study should not be performed with more patients than is necessary. Whilst this research was a preliminary investigation, it provided a) meaningful data, contributing to new knowledge and understanding of how hospice patients experience their diagnosis of a life-limiting illness and b) the development of self-report and observation measures for facilitating intervention and treatment in palliative care; c) psychometric testing that evidenced that personal agency can be measured in hospice patients; and d) evidence that personal agency exists until the time of death.

5.6 Conclusions

The overall research question for Study 2 was: "Can the hierarchy of personal agency be developed into a set of valid and reliable measures (self-report and observation) for assessing hospice patients?" More detailed second level research questions were:

a) Is there adequate internal consistency among the items of the self-report measure?
b) Is there sufficient test-retest reliability (self-report and observation measures)?
c) Is the inter-rater reliability between ward staff and researcher observations adequate?
d) Is there sufficient convergent validity between observational and self-report measures?

This study was composed of a pilot study that saw a sample of 10 out-patients respond to a 53-item self-report questionnaire and be observed by the main researcher and other staff raters, using an observation measure. Findings of that pilot study show that the internal consistency for the self-report questionnaire is good, with Cronbach's alpha = .856. That is, findings support that there is a correlation between the items in the self-report questionnaire and suggests that this measure is reliable. Also, face validity indicates that the observation measure did not need to be modified. Findings of the main study, carried out with a revised 16-item version of the self-report questionnaire and a new sample of 12 out-patients and 12 in-patients, indicate that the internal consistency is good for the sample of out-patients. Whilst the value of alpha is lower for the in-patient sample, it is, according to literature, acceptable. However, following a re-run of the analysis with 11 in-patients, findings indicate a decrease in the value of alpha. Findings suggests that there is substantially less internal consistency with respect to the self-report questionnaire and this sample of in-patients.

Findings demonstrate that for inter-rater reliability, the values of Pearson's r range from substantial to almost perfect agreement for 12 out-patients and for 12 in-patients. This suggests that the level of consistency among raters scoring the same measure that assessed the same latent construct with the same two sample of hospice patients is high. Moreover, the value of Pearson's r for test-retest indicates that there is good test-retest reliability for out-patients. This suggests that the stability of current and subsequent administration of the self-report questionnaire from each out-patient are good, suggesting that test-retest reliability can be assumed. However, for the sample of 12 in-patients, findings indicate that the test-retest reliability was substantially lower than that for out-patients. Findings suggest that, with respect to in-patients, test results are not consistent over time. The Pearson's correlation, r, used to calculate the convergent validity indicate that there is no correlation between the self-report questionnaire and the observation measure. However, as these results relate to specific samples of hospice patients, it is deemed appropriate to implement both the newly developed self-report questionnaire and the observation measure with a new sample of out-patients and in-patients to answer the overall question in this study, Study 2. This may provide information that may indicate whether different measures are required for out-patients and in-patients.

5.7 Chapter Summary

In this chapter, I aimed to present how the hierarchy of levels of personal agency from Study 1 could be developed to provide a self-report questionnaire and an observation measure for assessing personal agency in hospice patients. I outlined the research questions; the design and procedures used to generate and analyse data and provided an overview of the results. In the next chapter, Chapter 6, I detail Study 3, “Multiple Systematic Case Study of Development of Personal Agency in Hospice

Patients" that aims to implement both the self-report questionnaire and the observation measure with a new sample of out-patients and in-patients. Also, in Chapter 6, I ask "Is Emotion-Focused Therapy associated with the development of personal agency in hospice patients in this sample?"

Chapter 6: Multiple Systematic Case Study of the Development of Personal Agency in Hospice Patients

6.1 Introduction

In this chapter I present Study 3. This is the final of three distinct studies and builds on the qualitative Study 1 that supported the hierarchy of levels of personal agency (Campbell et al., 2014) and Study 2 that facilitated the development of the hierarchy to provide a self-report questionnaire and an observation measure for assessing personal agency in hospice patients. The aim of Study 3 was to assess the feasibility of the self-report questionnaire, and the observation measures developed in Study 2. That is, this final study aimed to determine whether a) the recently developed measures met the criteria of internal consistency, test-retest reliability, inter-rater reliability and convergent validity and so useful as reliable, valid measures for assessing personal agency in hospice patients; and b) emotion-focused therapy can help hospice patients to experience themselves as having a greater sense of control, giving rise to action that can enable them to live as best they can and for as long as they can with a life-limiting illness. Thus, Study 3 aimed to implement the revised 16-item self-report questionnaire and use the observation measure with a new sample of out-patients and in-patients. Study 2 indicated that the observation measure did not require revision. Moreover, the results of Study 2 indicated that the self-report questionnaire had good internal consistency for the sample of out-patients. Also, for out-patients, results showed a substantial to almost perfect inter-rater reliability and a good value for Pearson's r for test-retest reliability. For in-patients, the inter-rater reliability was substantial.

However, results indicated that there was no correlation between the self-report questionnaire and the observation measure. Taking into consideration that the development of the two measures constituted preliminary exploratory research, the results of Study 2 suggested that it was appropriate to attempt to implement the newly developed self-report questionnaire and observation measure with a new sample of hospice patients, out-patients and in-patients. I set out the specific research questions for Study 3.

The specific research questions for Study 3 were as follows: The principal research question was "Can the two recently developed self-report and observation measures be implemented for assessing personal agency with a new sample of hospice patients?" A more detailed second level research objective was "Can Emotion-Focused Therapy be associated with the development of personal agency in hospice patients?"

6.2 Method

6.2.1 Summary of Design

Study 3 was a longitudinal, mixed methods, multiple systematic case study design in which four out-patients and three in-patients were tracked over the course of their treatment. It was deemed appropriate to offer each of the seven patients up to six sessions of emotion-focused therapy and to audio-record each session to obtain a therapy text for each patient. The measurement methods elected for this study were a) a self-report questionnaire that consisted of 16 participant statements using a Likert-type Scale (Likert, 1932) with an ascending scale of five responses, ranging from "Not at all" ("0") to "Extremely" ("4"); and b) an observation measure, based on the BARS (behaviourally-anchored rating scale) method (Smith & Kendall, 1963) representing eight main categories and sub-categories of personal agency along with descriptors and the provision for individual counts recorded at each level of agency during the observing. This design was adopted to find out whether, by engaging in sessions of emotion-focused therapy (EFT), patients sensed an increase in their ability to become the source of initiating influence over their experiences of their circumstances, that is, to become more agentic. As a multiple case study design, each of the four out-patients and three in-patients had the opportunity to express whether they experienced an increase in their personal agency during their time as participants in this study. This had the potential to give rise to a build-up of knowledge that could contribute to conditional generalisation.

6.2.2 Sampling

In this section, I describe the kind of sampling used in this study. Purposeful sampling (Denzin & Lincoln, 2005; Patton, 2002; Silverman, 2006) was elected to ensure that patients as potential participants experienced shared similar key circumstances. However, as out-patients and in-patients were extremely ill on their arrival to the hospice, identification of patients as potential participants was greatly limited (Kraemer & Blasey, 2016). Thus, sample size was limited due to availability of patients as potential participants. Moreover, many patients who were willing to be identified to take part, were either physically unable to take part in or to complete the research.

6.2.3 Participants

In this section, I define the participants who were identified to take part in Study 3. As in Studies 1 and 2, potential participants were identified by the senior members of the direct care teams of the out-patient and in-patient units, respectively. Moreover, these senior members were the first to contact patients for the purpose of research. Also, as in Studies 1 and 2, the inclusion criteria required participants to be adult in-patients and out-patients of St Andrew's Hospice and who were willing and able to take part in research. Participants were excluded if their ability, physical or psychological, was diminished due to illness or medication and were not able to give informed consent, voluntarily. This is detailed in Study1 (Section: 4.2.3).

A new sample of seven patients, four out-patients and three in-patients, took part in the research. All participants were diagnosed with cancer and four had the presence of co-existing life-limiting illnesses. Table 6. 1. represents the patients who participated in Study 3. The four out-patients included three Scottish females and one Scottish male; the three in-patients, included one Scottish female and two males, one Scottish and one English.

Table 6.1

Participant sample for the implementation of the self-report questionnaire and the observation measure

Research Identity	**Gender**	**Ethnicity**	**Illness**
OP1	Female	Scottish	Cancer, Lung disease
OP2	Male	Scottish	Cancer, Heart disease
OP3	Female	Scottish	Cancer
OP4	Female	Scottish	Cancer, Lung disease
IP1	Female	Scottish	Cancer
IP2	Male	Scottish	Cancer, Lung disease
IP3	Male	English	Cancer

Note: OP1, OP2, etc: Participant Out-patients; IP1, IP2, etc: Participant In-patients

Originally, two patients each from the out-patient and in-patient units were to have been identified to take part in the research over six sessions. However, this was not feasible as no patients, either out-patients or in-patients were able, at that point in time, to be identified to take part in the research. This was due to the reduction in operational beds available and the uncertain nature of life-limiting illnesses, including the unpredictable attendance of out-patients, and the rapid progression of illness experienced by in-patients. During the data collection in this study, members of the direct care team attempted to identify additional patients who were potentially able to engage in a) six sessions of emotion-focused therapy; b) complete six self-report questionnaires; and c) be observed six times. Moreover, when there were patients available to be identified, the physical symptoms of illness and those associated with treatment, restricted the number of times patients were able to take part in the research**.** Thus, to gather adequate data, a total of seven patients, four out-patients and three in-patients, were eventually identified to take part. However, due to their illness, the seven patients only participated as was appropriate for each of them: one out-patient and one in-patient were able to receive therapy and have the two measures administered over four times; three out-patients were able to receive therapy and have the two measures administered three times; and two in-patients were able to receive therapy and have the two measures administered on two occasions.

Ethical Approval and Safeguarding of Participants

Ethical approval and risk assessment was carried out as for Study 1 (Appendix W; Section 4.2.3).

Each identified out-patient and in-patient received a Participant Information Sheet (PIS) (Appendix X) and a Letter of Invitation (Appendices Y and Z). All participants received a Participant Consent Form (Appendix AA) prior to commencement of Study 3, (Section 4.2.3).

6.2.4 Procedure

6.2.5 Data Collection

In this section, I give a summary of the data collection. For the qualitative component of Study 3, four out-patients and three in-patients engaged in sessions of emotion-focused therapy. Each session was audio-recorded, and the recordings were transcribed to provide therapy texts for each patient for data analysis. With respect to the quantitative element of Study 3, data collection was through the implementing of the revised version of the self-report questionnaire and observation measure. Qualitative and quantitative data were collected using the sample of four out-patients and three in-patients. Qualitative data collection was as for Study 1 (Section 4.2.5), with quantitative data collected as for Study 2 (Section 5.2.5.).

6.2.6 Data Analysis

In this section, I present an overview of the data analysis for Study 3. Qualitative data were analysed by way of understanding, translating, and categorising (*Meaning Unit Summary* and *Explicating Implicit Meaning;* Elliott & Timulak, 2021; Hill et al., 2005) meaning units using elements of grounded theory and empirical phenomenology (Charmaz, 2006; Giorgi, 1975; Glaser & Strauss, 1967; Rennie et al., 1988; Wertz, 1983; Section 4.2.6 of this document). The final phase of the qualitative analysis was a cross-case approach with seven individual protocols brought together to move-between-across-and-within cases in the search for similarities or differences (Appendix BB). As the data collected in the quantitative component in Study 3 were limited, it was deemed appropriate to combine the data sets obtained from the out-patients with that of the in-patients. Thus, one combined data set for seven hospice patients was used in the analysis. Quantitative data were analysed using the Cronbach's alpha measure to test for internal reliability and the statistical measure, Pearson's correlation coefficient (r) to obtain the values for inter-rater reliability, test-retest reliability and convergent validity (Section 5.2.6**)**.

Also, as Study 3 aimed to indicate whether emotion-focused therapy could be regarded as an agency-enhancing treatment with respect to this sample of hospice patients, it was deemed appropriate to elect the concept of reliable change (Jacobson & Truax, 1984) as an indicator of change. Following Jacobsen and Truax, the Reliable Change Index (RCI) specifies the amount of change a client must show on a specific psychometric instrument between measurements for that change to be reliable. That is, change must be larger than that expected due to measurement error to be regarded as reliable. However, the patient sample for Study 3 was small, and thus the number of observations was small. The reliable change index was calculated using a) the values of the standard deviation and test-retest reliability for the self-report item means, weighted means and global ratings for the main researcher and staff raters to produce the critical values and b) the critical values provided the cut-off values for establishing change between the baseline (session 1) and session two and between the baseline and sessions three or four as appropriate. Also, a near-zero probability level of $p < .05$ and a more flexible level of certainty of $p < .2$ were used to determine whether change was reliable.

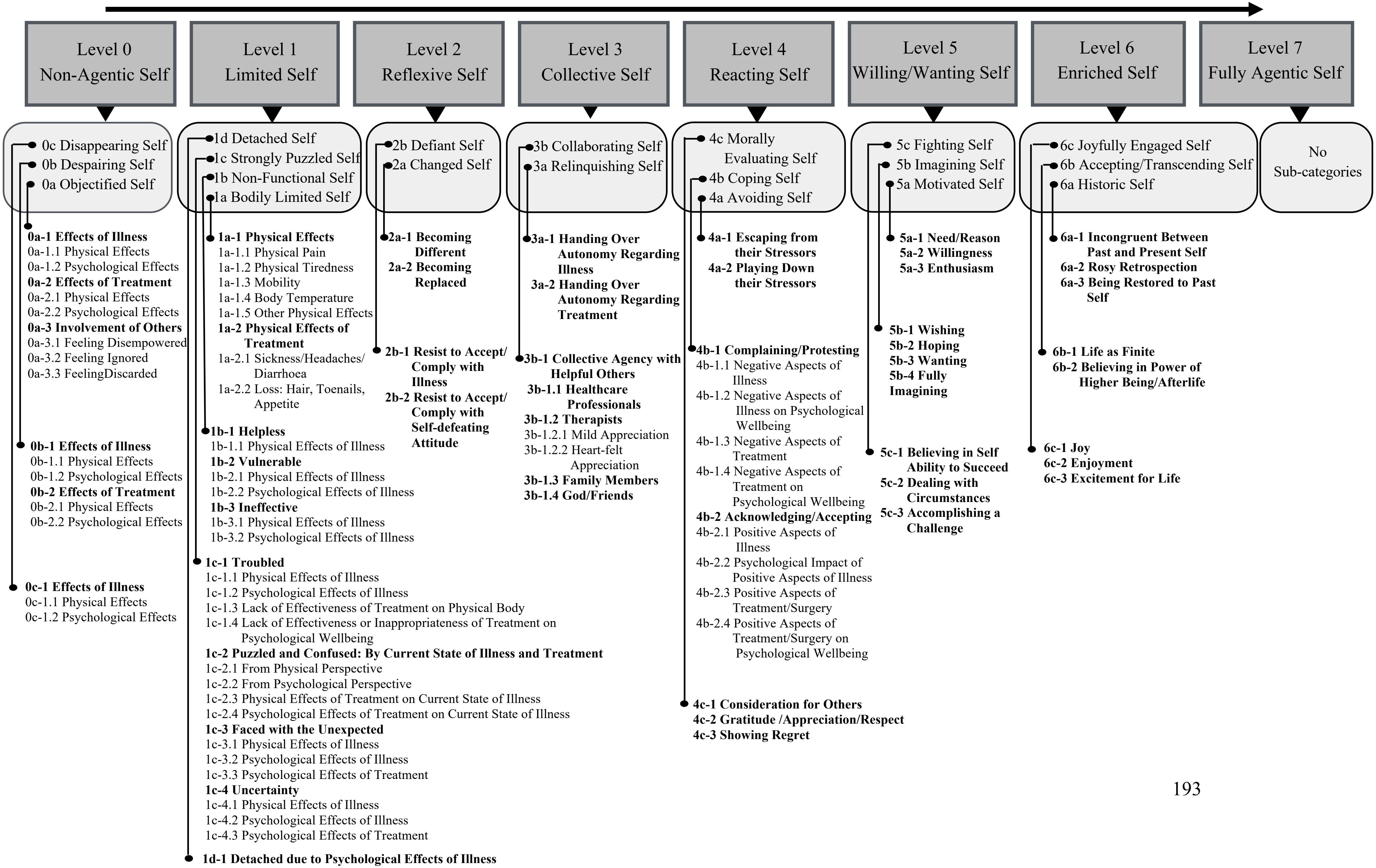
Seven individual figures, using the format of line graphs, were used to demonstrate the tracking of patient personal agency over time. For each figure, the x-axis represented the number of sessions for each specific patient. Similarly, the y-axis (SR and OR means) represented the self-report means, and the weighted means and global for the main researcher and the eight staff raters. In addition, a narrative was provided for out-patients, OP1 and OP2 and for in-patients, IP1 and 1P3. Also, segments of the transcripts of sessions three and four were provided for out-patient OP3.

6.3 Results

6.3.1 Overview of Results of the Qualitative Component is Presented in Figure 6.1

Figure 6.1

Overview of levels of personal agency showing main and sub-categories and expansions of sub-categories



- Level 0 Non-Agentic Self
  - 0c Disappearing Self
  - 0b Despairing Self
  - 0a Objectified Self
    - **0a-1 Effects of Illness**
      - 0a-1.1 Physical Effects
      - 0a-1.2 Psychological Effects
    - **0a-2 Effects of Treatment**
      - 0a-2.1 Physical Effects
      - 0a-2.2 Psychological Effects
    - **0a-3 Involvement of Others**
      - 0a-3.1 Feeling Disempowered
      - 0a-3.2 Feeling Ignored
      - 0a-3.3 FeelingDiscarded
    - **0b-1 Effects of Illness**
      - 0b-1.1 Physical Effects
      - 0b-1.2 Psychological Effects
    - **0b-2 Effects of Treatment**
      - 0b-2.1 Physical Effects
      - 0b-2.2 Psychological Effects
    - **0c-1 Effects of Illness**
      - 0c-1.1 Physical Effects
      - 0c-1.2 Psychological Effects
- Level 1 Limited Self
  - 1d Detached Self
  - 1c Strongly Puzzled Self
  - 1b Non-Functional Self
  - 1a Bodily Limited Self
    - **1a-1 Physical Effects**
      - 1a-1.1 Physical Pain
      - 1a-1.2 Physical Tiredness
      - 1a-1.3 Mobility
      - 1a-1.4 Body Temperature
      - 1a-1.5 Other Physical Effects
    - **1a-2 Physical Effects of Treatment**
      - 1a-2.1 Sickness/Headaches/ Diarrhoea
      - 1a-2.2 Loss: Hair, Toenails, Appetite
    - **1b-1 Helpless**
      - 1b-1.1 Physical Effects of Illness
    - **1b-2 Vulnerable**
      - 1b-2.1 Physical Effects of Illness
      - 1b-2.2 Psychological Effects of Illness
    - **1b-3 Ineffective**
      - 1b-3.1 Physical Effects of Illness
      - 1b-3.2 Psychological Effects of Illness
    - **1c-1 Troubled**
      - 1c-1.1 Physical Effects of Illness
      - 1c-1.2 Psychological Effects of Illness
      - 1c-1.3 Lack of Effectiveness of Treatment on Physical Body
      - 1c-1.4 Lack of Effectiveness or Inappropriateness of Treatment on Psychological Wellbeing
    - **1c-2 Puzzled and Confused: By Current State of Illness and Treatment**
      - 1c-2.1 From Physical Perspective
      - 1c-2.2 From Psychological Perspective
      - 1c-2.3 Physical Effects of Treatment on Current State of Illness
      - 1c-2.4 Psychological Effects of Treatment on Current State of Illness
    - **1c-3 Faced with the Unexpected**
      - 1c-3.1 Physical Effects of Illness
      - 1c-3.2 Psychological Effects of Illness
      - 1c-3.3 Psychological Effects of Treatment
    - **1c-4 Uncertainty**
      - 1c-4.1 Physical Effects of Illness
      - 1c-4.2 Psychological Effects of Illness
      - 1c-4.3 Psychological Effects of Treatment
    - **1d-1 Detached due to Psychological Effects of Illness**
- Level 2 Reflexive Self
  - 2b Defiant Self
  - 2a Changed Self
    - **2a-1 Becoming Different**
    - **2a-2 Becoming Replaced**
    - **2b-1 Resist to Accept/ Comply with Illness**
    - **2b-2 Resist to Accept/ Comply with Self-defeating Attitude**
- Level 3 Collective Self
  - 3b Collaborating Self
  - 3a Relinquishing Self
    - **3a-1 Handing Over Autonomy Regarding Illness**
    - **3a-2 Handing Over Autonomy Regarding Treatment**
    - **3b-1 Collective Agency with Helpful Others**
      - **3b-1.1 Healthcare Professionals**
      - **3b-1.2 Therapists**
        - 3b-1.2.1 Mild Appreciation
        - 3b-1.2.2 Heart-felt Appreciation
      - **3b-1.3 Family Members**
      - **3b-1.4 God/Friends**
- Level 4 Reacting Self
  - 4c Morally Evaluating Self
  - 4b Coping Self
  - 4a Avoiding Self
    - **4a-1 Escaping from their Stressors**
    - **4a-2 Playing Down their Stressors**
    - **4b-1 Complaining/Protesting**
      - 4b-1.1 Negative Aspects of Illness
      - 4b-1.2 Negative Aspects of Illness on Psychological Wellbeing
      - 4b-1.3 Negative Aspects of Treatment
      - 4b-1.4 Negative Aspects of Treatment on Psychological Wellbeing
    - **4b-2 Acknowledging/Accepting**
      - 4b-2.1 Positive Aspects of Illness
      - 4b-2.2 Psychological Impact of Positive Aspects of Illness
      - 4b-2.3 Positive Aspects of Treatment/Surgery
      - 4b-2.4 Positive Aspects of Treatment/Surgery on Psychological Wellbeing
    - **4c-1 Consideration for Others**
    - **4c-2 Gratitude /Appreciation/Respect**
    - **4c-3 Showing Regret**
- Level 5 Willing/Wanting Self
  - 5c Fighting Self
  - 5b Imagining Self
  - 5a Motivated Self
    - **5a-1 Need/Reason**
    - **5a-2 Willingness**
    - **5a-3 Enthusiasm**
    - **5b-1 Wishing**
    - **5b-2 Hoping**
    - **5b-3 Wanting**
    - **5b-4 Fully Imagining**
    - **5c-1 Believing in Self Ability to Succeed**
    - **5c-2 Dealing with Circumstances**
    - **5c-3 Accomplishing a Challenge**
- Level 6 Enriched Self
  - 6c Joyfully Engaged Self
  - 6b Accepting/Transcending Self
  - 6a Historic Self
    - **6a-1 Incongruent Between Past and Present Self**
    - **6a-2 Rosy Retrospection**
    - **6a-3 Being Restored to Past Self**
    - **6b-1 Life as Finite**
    - **6b-2 Believing in Power of Higher Being/Afterlife**
    - **6c-1 Joy**
    - **6c-2 Enjoyment**
    - **6c-3 Excitement for Life**
- Level 7 Fully Agentic Self
  - No Sub-categories

Results were based on the analysis conducted on the seven transcripts obtained in Study 3. Results indicate that the same eight main categories of personal agency found in this study were the same as for Study 1. That is, this sample of hospice patients constructed themselves as the same specific selves as in Study 1: *Level 0*: *Non-agentic, Level 1: Limited, Level 2: Reflexive, Level 3: Collective, Level 4: Reacting, Level 5: Willing/Wanting, Level 6: Enriched and Level 7: Fully Agentic Self.* Also, results indicated that the same sub-categories, and their expanded distinctions of sub-categories, expressed the same subtle nuances of self. However, it is important to note, as I did in Chapter 4, that Studies 1 and 3 were not my initial investigations of personal agency in hospice patients as I was researcher and counsellor in the earlier study (Campbell et al., 2014). Thus, I did not start from the very beginning but checked to see if data gathered in Study 3 fitted with the earlier general framework of categories. That is, I used the new data to challenge the sub-categories and lower-level sub-categories. The results indicated that the same main categories and sub-categories of personal agency were expressed by most out-patients and in-patients. However, because of the small sample of sessions, not all the expanded distinctions within sub-categories were fully represented**.** Nonetheless, results showed that 86.9% of all categories, including the finely tuned distinctions, were represented by the four out-patients and three in-patients, even although patients were unable to complete all six sessions that had been offered to them in taking part in the study. Results indicated that for this sample of four out-patients and three in-patients the hierarchy represented how patients constructed themselves as experiencing personal agency to varying degrees.

In terms of changes in personal agency, three out-patients and two in-patients were able to construct themselves as fully agentic. In contrast, results indicated that out-patient OP4 experienced a decrease in personal agency. Over-regulation of emotions meant that for this patient, whilst she did remain mindful of her experience of a life-limiting illness, she did not fully experience her circumstances (Greenberg & Watson, 2006). A cross-case analysis was able to support that there were commonalties across patients, and this was an indication that the general experience of personal agency was expressed and communicated by this sample of patients, with different levels more strongly represented across cases. A complete account of the cross-case analysis of all seven patients is presented in Appendix BB.

6.3.2 Overview of Results of the Quantitative Component

Descriptive data for the measures. This section indicates whether a) the 16-item self-report questionnaire and the observation measure could be implemented by this sample of seven hospice patients and b) the seven individual patients were able to show patient change, expressed as personal agency, using the quantitative data from the implementation of the two measures. Tables 6.2 and 6.3 provide the means and standard deviations for the 16-item self-report and observation measures, respectively.

Table 6.2

Descriptive statistics: Means and standard deviations for the revised version of 16-item self-report questionnaire with new sample of four out-patients and three in-patients

Item	Min	Max	Mean	Std Deviation
SR01: Person, I used to be	0	4	1.95	1.627
SR02: Anxious about end	0	4	1.95	1.532
SR03: Each day at a time	2	4	3.14	.793
SR04: Let doctors decide	0	4	3.05	1.359
SR05: Could walk again	1	4	3.19	.981
SR06: Totally devastated	0	4	1.71	1.454
SR07: Lost sense of self	0	3	0.95	1.024
SR08: Be normal again	0	4	2.81	1.436
SR09: Ask questions	2	4	3.38	.740
SR10: Angry about illness	0	4	1.57	1.207
SR11: Taking things for granted	0	4	2.24	1.375
SR12: Feeling restricted	0	4	2.24	1.480
SR13: Become another person	0	4	1.71	1.347
SR14: Feel afraid	0	4	1.57	1.399
SR15: Focus on being alive	2	4	3.67	.685

SR16: Right for treatment	3	4	3.86	.359
Overall Mean SR			2.44	1.17

Note: N = 21 sessions (7 patients). Abbreviated versions of items listed here.

In this data set the overall mean is the summary of the data set across sessions and participants and is represented by the value 2.44. That is, the overall mean represents the most representative value in the data set and acts as a yard stick for all the items. Further, SR07 (*Lost sense of self*) was represented by the lowest mean (0.95) indicating that patients endorsed this item at the lowest level but that the item was not representative of the sample of patients. While the mean of SR14 (*Feel afraid*) was less than the overall mean, it was more representative of the sample even although representing a low level of agency. With respect to SR15 (*Focus on being alive)*, the mean was higher than the overall mean, suggesting that it was representative of the sample and did indicate a high level of personal agency. In addition, SR16 (*Right for treatment*) was also representative of the sample of patients and demonstrated a high personal agency.

Table 6.3

Descriptive statistics: Means and standard deviations for the observation measure with new sample of four out-patients and three in-patients

Level	N	Minimum	Maximum	Mean	Std Deviation
0 Non-Agentic	42	0	2	.10	.431
1 Limited	42	0	1	.05	.216
2 Reflexive	42	0	1	.14	.354
3 Collective	42	0	1	.67	.477
4 Reacting	42	0	2	.33	.526
5 Wiling/Wanting	42	0	3	1.74	.857
6 Enriched	42	0	3	1.69	.563
7 Fully Agentic	42	0	2	1.07	.407
Main Res Wt. Means	42	2.33	5.80	5.10	.688

Main Res Global Ratings	42	4.50	6.00	5.60	.407
Staff Rater Wt. Means	42	2.33	5.80	5.29	.773
Staff Rater Global Ratings	42	4.50	6.50	5.60	.464

Note: N = 42 assessments (2 Observers x 21 observation days)

With respect to the observation measure, global ratings, the main researcher and the staff raters were in agreement with their scoring of the limited self, a low level of personal agency that was not representative of the patients being observed.

Internal Consistency Reliability. Results indicated that the value of Cronbach's alpha was .875 for the 16-item self-report questionnaire, with a sample of hospice patients that consisted of four out-patients and three in-patients. This value suggested a very good level of reliability (Kline, 1999) and that the items in self-report questionnaire did measure the same latent construct, assumed to be, personal agency.

Inter-rater Reliability. Findings indicated that the values for Pearson's correlation coefficient, r, used to measure the inter-rater reliability, with a combined sample of seven hospice patients, were, r = .954, p < .01 for the weighted means for the main researcher and eight staff raters and r = .876, p < .01 for the global ratings for the main researcher and eight staff raters. Moreover, the values of Pearson's r for the scoring reliability (weighted means with global ratings) were, r = .773, p < .01 for the main researcher and r = .678, p < .01 for eight staff raters, respectively. Thus, results indicated a substantial to an almost perfect value of r for inter-rater reliability, with r demonstrating that the value for scoring reliability could be regarded as substantial. The findings for inter-rater reliability and scoring reliability are presented in Table 6.4.

Table 6.4

Value of Inter-rater Reliability using Pearson's correlation, r, for seven hospice patients, four out-patients and three in-patients

Inter-rater Reliability and Scoring Reliability	**Value of r**

Inter-rater-Reliability:	
Weighted Means: Main Researcher with 8 Staff Raters	.954**
Global Ratings: Main Researcher with 8 Staff Raters	.876**
Scoring Reliability:	
Main Researcher Weighted Means with Global Means	.773**
Staff Raters Weighted Means with Global Ratings	.678**

** $p < 0.01$, N = 21

Test-retest Reliability. Results indicated that the value of Pearson's correlation, r, for the test-retest reliability between the self-report questionnaire item means and the self-report questionnaire item means for the next session was $r = .919$, $p < .01$, with respect to four out-patients and three in-patients. Thus, findings indicate that administering the same samples of patients with the same self-report questionnaire on current and subsequent occasions, provided an excellent reliability. The finding for test-retest reliability is set out in Table 6.5 and Table 6.6 presents the length of therapy in days and individual sessions relating to four out-patients and three in-patients

Table 6.5

Value of Test-retest Reliability using Pearson's correlation, r, for seven hospice patients, four out-patients and three in-patients.

Test-retest Reliability	Value of r
Self-Report Item Means with Self-Report Item Means next session	.919**

**$p < 0.01$, N = 14

Table 6.6

Test-retest Reliability: Length of therapy in days and individual sessions for seven hospice patients, four out-patients and three in-patients

Patient ID	Number of Session	Start Date	End Date	Length of Therapy in Days	Mean Interval Between Sessions
OP1	3	05/12/2023	23/01/2024	49	24.5
OP2	3	09/01/2024	23/01/2024	14	7
OP3	4	30/01/2024	20/02/2024	21	7

OP4	3	07/02/2024	21/02/2024	14	7
IP1	4	11/01/2024	18/01/2024	7	2.33
IP2	2	11/01/2024	16/01/2024	5	5
IP3	2	13/02/2024	15/02/2024	2	2

Note: Mean number of days for 7 patients = 7.83

Convergent Validity. Pearson's correlation, r, was used to assess the convergent validity, that is, the correlation between the self-report questionnaire and the observation measure with respect to seven hospice patients. Results indicated that the values of r were, r = .180 and r = .207 for the main researcher for weighted means and global ratings with self-report means, respectively. Moreover, results indicated that r = .208 and r = .274 for the eight staff raters for weighed means and global ratings with the self-report means, respectively. These values are not statistically significant; the critical value for n - 2 =19 is r = .43. Results for convergent validity are presented in Table 6.7 and are broadly consistent with the results for Study 2.

Table 6.7

Value of Convergent Validity using Pearson's correlation, r, for seven hospice patients, four out-patients and three in-patients

Convergent Validity for Out-Patients & In-Patients	**Value of r**
Main Researcher Weighted Means with Self-report Item Means	.180
Main Researcher Global Ratings with Self-report Item Means	.207
Staff Rater Weighted Means with Self-report Item Means	.208
Staff Rater Global Ratings with Self-report Item Means	.274

N = 21

Selection of variables for case studies. As the values for the global ratings for the main researcher and the eight staff raters were very highly correlated with the weighted mean scores, it was deemed appropriate to focus only on the latter. A further consideration was that, for this study, the values of the global ratings were mostly associated with the upper levels of personal agency on the observation measure, constituting a ceiling effect (Everitt, 2002). Thus, the variance could not be measured or estimated above a certain level (Cramer & Howitt, 2002).

Consequently, in the case studies to follow, the y-axis for each figure represented the self-report item means and the weighted means for the main researcher and staff raters. Table 6.8 indicates the values of the global ratings for the main researcher and staff raters that contributed to the *ceiling effect* (Section 6.2.2), leading to their exclusion from the case study figures.

Table 6.8

Global ratings excluded from the data used to track change over patient sessions

Patient ID	Global Rating	Session 1	Session 2	Session 3	Session 4
OP1	Main Researcher	5.0	6.0	5.5	.
	Staff Rater	5.0	6.0	5.5	.
OP 2	Main Researcher	5.5	5.5	6.0	.
	Staff Rater	5.5	6.0	6.0	.
OP 3	Main Researcher	5.5	6.0	5.5	6.0
	Staff Rater	5.5	6.5	5.5	6.0
OP4	Main Researcher	6.0	5.5	5.5	.
	Staff Rater	6.0	5.5	5.5	.
IP1	Main Researcher	5.0	6.0	6.0	5.5
	Staff Rater	5.0	5.5	6.0	5.5
IP2	Main Researcher	6.0	5.5	.	.
	Staff Rater	6.0	5.5	.	.
IP3	Main Researcher	4.5	5.5	.	.
	Staff Rater	4.5	5.5	.	.

Calculation of critical values for reliable change analyses. Table 6.9 presents the results of the calculation of critical values obtained using standard deviations and test-retest reliability; these values were used in the case studies to follow.

Table 6.9

Calculation of critical values using standard deviation and test-retest reliability

Caseness	Standard Deviation	Test-retest Reliability	Standard Error	RCI =1.96(*)	RCI =1.29(+)
Self-Report Item Means	0.723	0.919	0.291	0.57	0.38

Main Researcher Weighted Means	0.688	0.618	0.601	1.18	0.78
Staff Rater Weighted Means	0.774	0.688	0.611	1.20	0.79

+p < .2, *p < .05

Table 6.10 shows the values that were used to track change over specific sessions. Thirty-six significance tests were carried out, with 4 (11%) statistically significant at p < .05 and 7 (19%) significant at p < .2. The most likely explanation of these results is that the values for IP3 are the most trustworthy, because they replicated across all three measures. The others may be due to chance findings. It can become problematic when many statistical tests are carried out in a single study as, with each test that is run, the probability of finding statistical significance just by chance then increases. That is, it becomes more difficult to identify which are true differences or are due to chance. The level of statistical significance indicates how sure the researcher can be that the results found are not by chance. For example, a sample of participants of a population of interest identified for research, may give rise to a sampling error, the seemingly random differences between the characteristics of a sample population and those of the general population of interest. Sampling errors may arise as samples sizes may be limited; the entire population of interest cannot be included in the research.

Table 6.10

Difference scores obtained over specific sessions used to track change

Patient ID	Change tracked Between …	Self-Report Item Means	Main Researcher Weighted Means	Staff Rater Weighted Means
OP1	Sessions 1 vs 2	0.25	0.95 +	0.75
	Sessions 1 vs 3	0.06	0.60	0.08
OP2	Sessions 1 vs 2	0.56+	0.15	-0.20
	Sessions 1 vs 3	1.25+	0.18	-0.13
OP3	Sessions 1 vs 2	0.25	0.13	0.33
	Sessions 1 vs 4	0.56+	0.13	0.03
OP4	Sessions 1 vs 2	-0.06	-0.60	-0.40
	Sessions 1 vs 3	-0.04	-0.51	-0.51
IP1	Sessions 1 vs 2	0.13	0.42	0.58
	Sessions 1 vs 4	0.13	0.42	0.58

IP2	Sessions 1 vs 2	0.25	0	0.11
IP3	Sessions 1 vs 2	0.63*	2.38*	2.38*

+p < .2; * < .05

The following seven tables and seven figures indicate a) the data used to provide each figure and b) the tracking of patients' personal agency over time.

Out-patient OP1

Out-patient OP1 was a female diagnosed with cancer and lung disease who took part in Study 3, receiving emotion-focused therapy three times over a period of 49 days. There were 14 days between sessions one and two, with 35 days between sessions two and three. Each counselling session was audio-recorded and transcribed. Table 6.11 represents the data used to provide Figure 6.2 that aimed to track change in out-patient OP1. In addition, a narrative for out-patient OP1 is provided.

Table 6.11

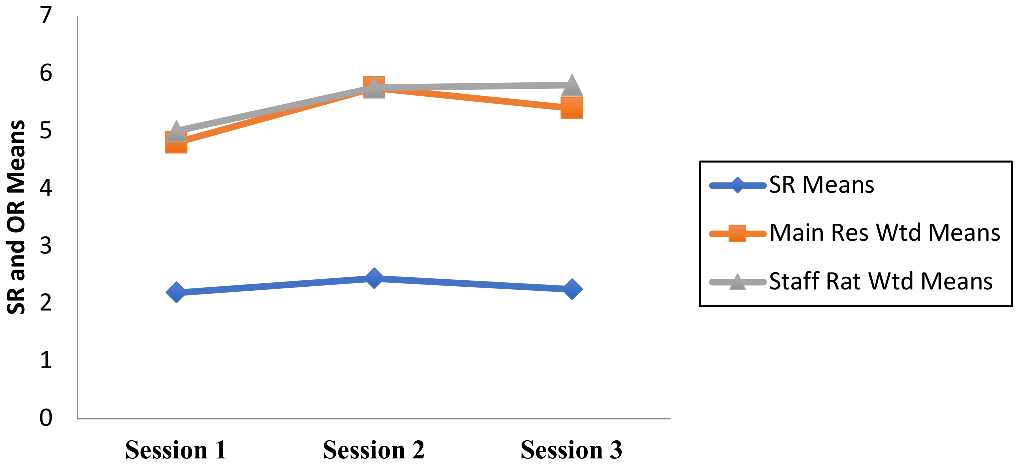
Out-patient OP1: Data for tracking change in personal agency over time

OP1	**RCImin *(p<.05**	**RCImin +(p<.20)**	**Session 1**	**Session 2**	**Session 3**
Self-Report Means	0.57	0.38	2.19	2.24	2.25
Main Researcher Weighted Means	1.18	0.78	4.80	5.75	5.40
Staff Rater Weighted Means	1.20	0.79	5.00	5.75	5.8

Note: RCI represents Reliable Change Index

Figure 6.2

Out-patient OP1: Personal agency scores over sessions



Note: Text in legend for each figure:

SR represents the self-report questionnaire

OR represents the observation measure

SR Means represents Self-report Item Means

Main Res Wt. Means represents Main Researcher Weighted Means

Staff Rat Wt. Means represents Staff Rater Weighted Means

Figure 6.2 indicates that, with respect to the self-report item means, calculated from item responses to the self-report questionnaire, there was a small but positive change in the score of out-patient OP1, that is, before and after the intervention of emotion-focused therapy as exemplified by sessions 1 and 2. Also, a smaller but positive change was experienced over sessions 1 and 3, indicating an overall but small increase from the start to the endpoint. That is, results indicated that whilst out-patient OP1 did experience a small increase in their personal agency, with respect to the self-report item means, the change could not be regarded as statistically reliable. The weighted means for the main researcher and staff raters were calculated from the observer scores on the observation form. Results show that, with respect to the main researcher weighted means, the change in the score from the start to the mid-point, that is, over sessions 1 and two, was statistically significant at $p < .2$. This indicates that over sessions 1 and 2, OP1 did experience a change, in the form of an increase in agency, that was reliable. For, sessions 3 and 4, results indicated that change was not significantly reliable. Thus, results showed that from baseline to end-point, OP1 did experience an increase in personal agency but the overall change could not be regarded as statistically significant with respect to the main researcher weighted means. Results showed that, for the staff rater weighted means, OP1 did experience change over sessions 1 and 2 but that the increase in agency could not be regarded as statistically significant. Results also indicated that over sessions, 1 and 3, OP1 experienced an increase in personal agency that could be regarded as statistically significant at $p < .2$, although this could be due to chance because of the large number of significance tests overall. Thus, the overall results, with respect to the staff rater means, demonstrated that for OP1 the difference between the baseline score and the post-treatment score, that is, change expressed as personal agency, could be regarded as statistically significant at $p < .2$. The change experienced by OP1 is detailed in the following narrative.

Session 1. During, the first session, the patient experienced herself as the troubled self, due to her lack of knowing that she had the illness "… had… while without anyone knowing…" As troubled, the patient's sense of personal agency was represented by a sub-category of the limited self, level 1c. The patient's communication alerted me to aspects of her functioning that might have needed attention. I noticed that the client looked sad and puzzled and thus, continued to experience herself as limited at level 1c. Moreover, her voice was slow, with a thoughtful quality. The patient experienced that the physical effects of the illness could not be stopped, with the illness was more powerful than her ability to stop it, …" can't stop it… out of my power…" At that point, the patient experienced herself as the objectified self, and thus lacking in personal agency as represented by the non-agentic level 0 and specifically level 0a. Her emotions did not fade but were stimulated and activated again as the patient shared her feelings, thoughts and narratives.

As circumstances could not stop, the client was left with the maladaptive feelings of despair and powerlessness and that did not provide adaptive pathways for resolving them. This saw the patient experience herself as the despairing self, objectified and devoid of personal agency as represented by a sub-category, the despairing self, level 0b in the hierarchy of levels of personal agency, "… there is darkness there…” Using exploratory questions and exploratory reflections, I encouraged the patient to attend to how she felt, and she was able to describe her emotional experience. She communicated herself as puzzled, troubled, uncertain self “… got a letter… scan… told me… you’ve got… knowing nothing about it ____ they didn’t ____ know ____ doctors didn’t know”, indicating an increase in agency as represented by the personal agency level 1c. I continued to track the patient’s internal experience as it evolved moment by moment, and not by merely paraphrasing but by being empathically attuned to the patient’s immediate inner experience. Even at this early stage of therapy, the patient was willing to explore and was able to symbolise her experience, allowing me to facilitate differentiation of her experience through empathic understanding and empathic conjecture. The client was able to elaborate about her experience of puzzlement “… doctor… I can’t operate on you… too far gone… can give you chemotherapy”. This indicated that the client remained as the puzzled self at level 1c of the hierarchy of personal agency.

Session 2. I worked with the patient, helping to develop her experience in order to deal with her circumstances. This was accomplished by using the patients’ emotions guiding her to what was important and what she wanted to do. Thus, emotions were the source of action as they were the experiences that provided information about her current state. As an EFT counsellor, I sought to facilitate emotional processing in ways and times that were in keeping with the patient markers and patient readiness. Whilst increasing awareness of emotion is fundamental to therapy, it was only when emotion was felt, did its expression in words allow it to become significant in the awareness of the patient (Greenberg, 2015). The awareness of the “how” and “what” of the experience was important for the patient. Having lost her faith in God, she felt more uncertain of what lay in front of her and remained as the troubled self and experienced at level 1c “… struggle with it all…”. Whilst the patient was the expert of her experience, I helped her to explore and deepen her feelings to discover what hurt her the most. For example, people, even family members didn’t want to talk to her about her circumstances. Both I and the patient affirmed the core pain, and I helped her to stay with and value the information contained in her emotions (Elliott & Greenberg, 2021). As the coping self, level 4b, the patient expressed that she was terrified lest she was “to drop dead when they (grandchildren) were there”. However, on the other hand, she was looking forward to having the grandchildren stay with her at Christmas and thus had constructed herself as the joyfully engaged self, level, 6c. Thus, many emotion schemes were activated, some in harmony while others opposed each other, and it was important that I attended to all of these.

At that point, the patient entered a process whereby her emotions generated the need to drive her in the direction of others who had the capability to help her, “… have anything to ask, I phone…”. That is, as the collective self, and specifically the active collaborating self, level 3b, the patient experienced herself as having a greater sense of agency, using it to help her circumstances. This fits with the ethos of EFT, whereby EFT aims to modify or change responses by accomplishing new skills or altering contingencies (Greenberg & Paivio, 2003). Furthermore, as the coping self, level 4b, the patient recorded that she protested less about the effects of illness… “don’t really make plans… go with the flow…” and, as the moral agent, level 4c, responded more favourably to showing consideration for others “don’t want them upset…”. Moreover, as the moral agent, level 4c, a sense of gratitude, appreciation, and respect “been very fortunate” were communicated, indicating that the patient’s responses were aimed at internal satisfaction, given the demands of her circumstances. The patient was better able to manage her emotions for her well-being, by reducing unpleasant feelings and showing value to others. This demonstrated an increase in self-awareness and an increase in the level of her personal agency, although experienced as internal. Moreover, two main sources of this new internal experience; first, the needs and concerns of the patient were accessed and second, the relationship with the counsellor who was willing to hear, validate and accept, promoted a transformative experience (Greenberg & Paivio, 2003).

As the willing/wanting self, and specifically, the hoping self, level 5b, the patient expressed that “… maybe one day I’ll wake up and it’s all been a nightmare…” When the patient started to take part in the study, she had been actively engaging with family and friends. However, the symptoms of her illness became more severe, and she was “put on palliative care”. At first her thoughts were expressed as unexpected as she experienced the effects of illness on her psychological well-being. This saw the patient at level 1c in the hierarchy of levels of personal agency. However, her thoughts were then directed towards her grandsons, hoping, "… I'm hoping when… on the other side you can see them (grandchildren)… find out how they are doing in life…" (level 5b), going to be with her daughter in the afterlife (fully imagining self, level 5b), expressing concern about how her husband would cope (moral agent, 4c). The patient appeared to have become interested in consoling those she was leaving behind and telling her daughter that she would soon be on her way to meet with her. It was if she was trying to alleviate any distress that might be due to the adversity of her dying. At that point, the patient expressed, "I'm glad to have …this…chat.", experiencing herself as actively collaborating, level 3b. As the patient's symptoms worsened, her ability to attend was greatly restricted.

Session 3. After 5 weeks, the patient did return but her disease had continued to progress, "… appetite is going…", (limited, restricted self, level 1a), with her deterioration visible and the threat to her life heightened," … there's no future…" (despairing self, level, 0-3 of the objectified self, a sub-category of the non-agentic self) and with God becoming important "… get belief's back" (fighting self, 5c). However, the patient expressed that she was not afraid to die and, as such, experienced herself as the fighting self, level 5c, and dealing with circumstances. Also, the patient thought of her family "… wouldn't want them to see me suffering…." On the contrary, she communicated her hoping (level 5b) "…love to see snowdrops"; her on-going enthusiasm for life, "…like to see people, speak to people"; was appreciative of the medication to help her get her "…strength back." and had confidence in helpful others, "… doctors… tablets… give me … strength back" (level 3b). The patient also expressed (to therapist), "… good to get … chat… great… how many more?... that's good. I'll be back next week, hopefully…". However, the client expressed that "… I'm quite philosophical … know it's going to happen… put it to the side… live each day the best I can". As an EFT counsellor, it was important that I acknowledged and attended to the many emotion schemes that were activated in accordance or in opposition with each other.

To sum up, during sessions one and two the patient experienced an increase in her personal agency. On her return to engage in session three, the patient was fully aware that her death was drawing closer than she had previously expected. As a result, the patient chose to exercise her autonomy in ways that she felt were in keeping with her personal circumstances. For the client, it was important that her feelings, thoughts and actions were not only directed to herself but towards family and friends. As an agentic person, the patient did not choose to be unrealistic and as she was aware of her limitations, she validated her limitations and chose to construct herself as the specific selves, moral, hoping, and fully imagining selves. The patient was reflective, acceptant of her givens, appreciative of support and encouragement she had received from helpful others and had the desire to live. The patient and I, as an EFT counsellor, worked together within a therapeutic relationship that, always, upheld, equality, humanity, integrity, empathy, prizing and authenticity. The patient expressed belief in her personal efficacy "I'll take my time. I'll be fine."

Out-patient OP2

Out-patient OP2 was a male diagnosed with cancer and heart disease who took part in Study 3, receiving emotion-focused therapy three times over a period of 21days. There were 7 days between sessions one and two and 7 days between sessions two and three. Table 6.12 represents the data used to provide Figure 6.3 that aimed to track change in out-patient OP2.

Table 6.12

Out-patient OP2: Data for tracking change in personal agency over time

OP2	**RCImin *(p<.05**	**RCImin +(p<.20)**	**Session 1**	**Session 2**	**Session 3**
Self-Report Means	0.57	0.38	1.94	2.50	3.19
Main Researcher Weighted Means	1.18	0.78	5.25	5.40	5.43
Staff Rater Weighted Means	1.20	0.79	6.00	5.80	5.88

Note: RCI represents Reliable Change Index. *p < .05; +p < .2

Figure 6.3

Out-patient OP2: Personal agency scores over sessions

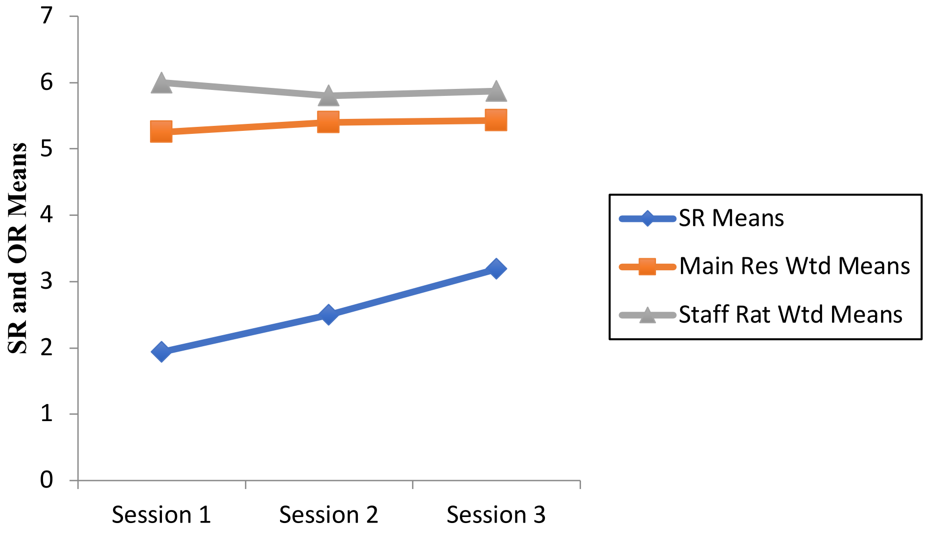


Figure 6.3 indicates that there was a change in the scores of out-patient OP2, before and after the intervention of emotion-focused therapy as exemplified by sessions 1 and 2. This change, expressed in terms of an increase in personal agency, was regarded as statistically significant at p < .2. Also, over sessions 2 and 3, OP2 experienced a change that was regarded as statistically significant at p < .05. Thus, results indicate that from baseline to end-point, and with respect to the self-report item means, the change experienced by OP2 as an increase in personal agency could be regarded as statistically significant at p < .05. Results show that, with respect to the main researcher weighted means, the change in the scores for OP2, from the start to the mid-point and from the mid-point to end-point was very small but positive, showing a very small increase in personal agency. In accordance with the critical values, the changes were not reliable. For the staff rater weighted means, the scores from the start point to mid-point showed a slight amount of negative change indicating a change expressed as a decrease in personal agency. The change experienced by OP2 is detailed in the following narrative.

Session 1. At the first meeting I was aware that the patient was externally focused, finding difficulty in expressing his emotions. Also, I was aware that the patient's voice was quiet and limited, suggesting that he was distant from his experiencing (Elliott et al., 2004). At that point, as an EFT counsellor, it was important that I attended to the patient's voice for clues for unacknowledged emotions. He told his story and expressed that his illness "…interferes". His choice of word indicated that he experienced a psychological impact on his well-being due to illness. This saw the patient unable to exercise any influence over his life and thus, experienced himself as objectified, a sub-category of the non-agentic self, level 0. At that point, the patient was devoid of personal agency and unable to initiate change through his own actions. As an EFT counsellor, it was important that I helped the patient to focus inward. He looked thoughtful. With an increase in awareness, he was able to express how his illness had changed his way of living, "… don't make plans like I used to". This saw the patient experience an increase in his internal personal agency and construct himself as the reactive self and, specifically, the changed self, level 2a.

Session 2. In session 2, as I expressed how hard it must be for him, the patient became quiet and after a few seconds, opened about his experience of having become weak, "… left me weak". This saw the patient construct himself as inadequate and inefficacious and thus, the non-functional self, level 1b, a sub-category of the limited self (level 1). As I validated how he experienced himself, the patient communicated that he was no longer able to do what he once could do, "… I'm not as much…". Again, the patient had constructed himself as ineffective and thus, the non-functional self, level 1b. I was aware that his feelings and thoughts had remained and become a part of his memories and were stimulated and recreated. The patient took the opportunity to re-create memories as "… probably I could be…" the reflexive self and, specifically, the changed self, level 2a. This level of personal agency saw the patient strive for self-preservation and his experience was of an identity that was not representative of him. However, for the patient, this constituted an increase in self-awareness and in personal agency. Again, the patient re-created his memories: "I couldn't go…" suggesting that the patient was helpless as he expressed how he experienced the physical effects of illness, that is, deprived of strength and lacking in personal resources. However, he also expressed that he had got "… used to it (illness) …" and thus, experienced himself as the reacting self and, specifically, the coping self, level 4b.

As an EFT counsellor, I used the patient's inner experiencing to find out what fitted and what felt right (Watson & Rennie, 1994). Also, and in collaboration with the patient, I facilitated emotional processing in ways and times that were in accordance with the patient markers and patient readiness. Thus, I used the more process guiding task of focusing by promoting empathic exploration of his inner experience. As the troubled self, level 1c, a sub-category of the limited self, he expressed, "… bleeding… getting bigger…" Moreover, the patient constructed himself as objectified and specifically as the disappearing self, level 0c, "…this thing's going to grow …till…it bursts… going to kill me…." His voice tapered and became thin. The patient experienced the visible and disagreeable symptoms of his illness and with the knowledge that he could not control these symptoms. This led to the patient as the despairing self, "… there is darkness there…" level 0b, despairing, objectified and lacking in personal agency. Also, the patient expressed that "Life is ...not enjoyable." This saw the client react to his circumstances with an increase in self-awareness and with it an increase in personal agency, namely, the coping self, level 4b.

I listened for the different patient voices to emphasise what sense he had as the creator of his reality. Moreover, using empathic responding, empathic conjecture and imagery, the patient became aware of his voices and what they were saying (Greenberg & Paivio, 2003). This gave rise to the patient gathering information about himself. I asked him, "How does it feel as you talk about this." At that point, the patient realised that how he felt was not inevitable but was determined by himself. He realised that he had to take responsibility for how he created his experience. I was required to attend to the different emotion schemes that were activated at that point. The patient began to realise that he had influence over his experiences. In addition, the patient began to detach from his unwanted experience (Greenberg & Paivio, 2003). The patient's voice changed and expressed that life was important, "… definitely…". This saw the patient communicate an increase in personal agency, constructing himself as the coping self and, specifically, the moral self, level 4c. Whilst the patient's agency was internal, he was more aware that he had the capacity to control what he experienced.

Session 3. As I continued to track the patient's experience as it evolved moment by moment, he was able to enact a change in the form of taking responsibility for his personal agency in the construction of his reality. The patient, as the hoping self, level 5b, a sub-category of the willing/wanting self, expressed, "I'd love to be here… see how they (grandchildren) progress in life…". This indicated that the patient was goal-oriented and sensed an increase in personal agency. Moreover, as the moral agent, level 4c, he communicated that "… been fortunate… I survived…" At that point, the patient's voice became stronger as he constructed himself as fully agentic, level 7. Reflective and motivated, the patient was goal-oriented even in the face of his challenging circumstances and expressed, "…never thought I was going to die… I was determined… get through it…" The patient strongly expressed, "I believed I would get through it." indicating that he had the belief in himself to accomplish a task. The patient and I, as an EFT counsellor, worked together within a therapeutic relationship that provided empathy, respect, and psychological safety. I validated the patient's experience, focusing on his goals and needs to inform action, challenge dysfunctional beliefs and promote and facilitate reorganisation.

To sum up, out-patient OP2 was able to construct himself as the fully agentic self, Level 7 in the hierarchy of levels of personal agency. As an agentic human individual, he was realistic that his illness would overtake his physicality. He became acceptant of his givens and was appreciative of his family, support, was willing to accept help had the desire to live. As he was leaving, the patient expressed, "I enjoyed it (counselling sessions), "… it's nice to look into yourself… thank you."

Out-patient OP3

Out-patient OP3 was a female diagnosed with cancer and received emotion-focused therapy four times over a period of 21days. There were 7 days between each session, with each counselling session audio-recorded to give four transcripts**.** Table 6.13 represents the data used to provide Figure 6.4 that aimed to track change in out-patient OP3.

Table 6.13

Out-patient OP3: Data for tracking change in personal agency over time

OP3	RCI min *(p<,.05)	RCI min +(p<.20)	Session 1	Session 2	Session 3	Session 4
Self-Report Means	.57	.38	3.06	3.31	3.38	3.62
Main Researcher Weighted Means	1.18	.78	5.20	5.33	5.20	5.33
Staff Rater Weighted Means	1.20	.79	5.67	6.0	5.25	5.33

Figure 6.4

Out-patient OP3: Personal agency scores over sessions

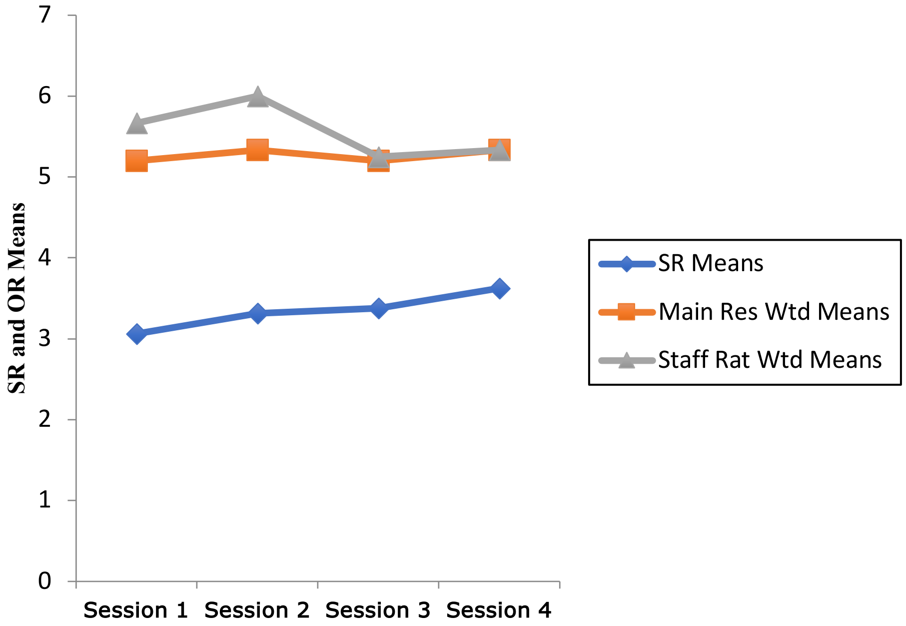


Figure 6.4 indicates that, with respect to the self-report item means, out-patient OP3 experienced a small change over sessions 1 and 2. The change, experienced as an increase in personal agency, was not reliable. Results indicated that from the session 1 to the end-point, OP3 experienced a positive change, expressed as personal

agency, that could be regarded as statistically significant at $p < .2$. For the weighted means for both the main researcher and staff raters, change was small and not reliable. Thus, results indicate that the difference in scores between pre-treatment and the follow up post-treatment scores were not reliable.

Segments of the transcripts of sessions three and four aimed to give an insight into how out-patient OP3 engaged in emotion-focused therapy, with respect to change in personal agency.

Session 3 excerpt 1:

Ruth: I think I look for a good day and I think if I look for a good day it turns out not too bad. (Level 5, Willing/Wanting Self: Believing in Self-Ability to Influence/Succeed)

Therapist: Because you're in control that day?

Ruth: Aye, and see the days you have a bit of control… they're the best days… they are definitely. (Level 5, Willing/Wanting Self: (Believing in Self-Ability to Influence/Succeed)

Therapist: So, I'm just going to ask the question… like do you feel you can increase these amount of days… to be more in control?

As an emotion-focused counsellor, I empathically tracked the patient, observing how she was engaging. This helped me, as counsellor, to choose responses to promote patient work. I guided the process but not as in manipulation but rather, as in promoting openness to the patient's experiences. I was not specifically encouraging the patient to engage in exploration but wanted to show her that I was with her. Through empathic reflection that promotes empathic attunement, I maintained a therapeutic relationship that allowed the patient to continue and elaborate. At that point, the patient was actively collaborating and assessing her capacity for control. The patient re-constructed herself from the actively collaborating self, level 3b, to the motivated, goal-oriented self, level 5a, knowing and wanting what was good for her. That is, the patient did not implement action but wanted to strengthen her personal self-efficacy. Thus, the patient experienced change in the form of enhanced internal personal agency.

Session 3 excerpt 2:

Ruth: Well …

Therapist: In some days there's physical pain I understand that… but you're saying you don't lie down to it?

Ruth: That's a strange one. It's hard to kind of pinpoint… because every day you're reminded of it… the pain'll remind you. (Level 1, Limited Self: Bodily-limited)

Through my training as an emotion-focused counsellor, I was able to use open-edge and growth-oriented responses (Elliott et al., 2004). Open-edge responses helped the patient to reflect while promoting her exploration of more difficult aspects of her experience (Elliott et al., 2004). Moreover, I used growth-oriented responses to highlight what was implicitly implied by the patient with respect to change or growth. I also used empathic conjectures (Elliott et al., 2004) to tentatively guess at what the patient was feeling but had not expressed. Empathic conjectures helped her to deepen and put her distressing experiences into words. A therapeutic relationship that promoted empathy, safety and freedom was important as the patient constructed herself as limited by physical pain, level 1a, that was a constant reminder of her unwanted life-limiting illness. At that point, the patient's personal agency was limited by the effects of her illness.

Session 3 excerpt 3:

Therapist: You respect that it's there?

Ruth: It's there. At one time I couldn't even look at myself when I was getting showered and things… absolutely. I was devastated looking at my body opened up. (Level 1, Limited Self: Troubled by Psychological Effects of Illness)

Therapist: And now?

Ruth: Now, I look at it and go… do you know what… this is my war wounds. I just see it as my war wounds. It was a big fight, and I got through it. (Level 5, Fighting Self: Accomplishing a Task) Yeah… it's nice if somebody can… like you're saying the now. "You've came this far." … and it's nice to hear somebody say that.

There is days you feel look what I've done… and there's not a person who's even said to me. (Level 5, Fighting Self: Need a Reason)

Therapist: Yeah, affirming what you've done and you're here?

Ruth: I have, aye… (Level 5, Willing/Wanting Self: Accomplished a Task)

Therapist: So, it's like saying so… am I motivated to do something tomorrow… I'm here today… this is Tuesday… tomorrow's Wednesday… does it matter how big or small… what am I going to do tomorrow? How does that feel?

Ruth: Aye, that's… it's nice to think that tomorrow will be a good day… like today's a good day. All my Tuesdays are never… they're never hard days for me**.** (Level 5, Willing/Wanting: Enthusiasm)

Therapist: But how would it feel to say Wednesday's a good day?

Ruth: It's nice to think… I could try for Wednesday. I could give it a go and see how we get on… aye, I could**.** **(**Level 5, Willing/Wanting Self: Believing in Self-Ability to Influence/Succeed)

We continued to work together, with open-edge and growth-oriented responses and empathic conjectures helping the patient to intensify her experience and to verbalise her distressing experience. Moreover, the patient expressed a sense of achievement because of accomplishing a task through her own ability to succeed. However, she expressed that there was no validation of her achievement by others. Validation was important to the patient as she used the words, "… was a big fight…" The patient had constructed and re-constructed herself from the specific self, troubled (level 1c) by the psychological effects of her illness to the willing/wanting self, and, specifically, the motivated, fighting self, level 5c, dealing with circumstances and accomplishing tasks. At that point, the patient experienced herself as purposeful and, although not implementing action, experienced her personal agency as action tendencies, approaching her circumstances with the belief that she could exercise influence.

Session 4 excerpt 1:

Ruth: Aye, I think that's the way it's going to have to be. These wee talks have learned me something. I'm important and I need my time too. (Level 5, Willing/Wanting Self: Dealing with Circumstances)

Therapist; *Y*es?

Ruth: And I wasn't doing an awful lot of that before… but I've had time to sit down and think about it and think about what we've talked about and thought… you know I need to have my time. I'm here. I'm a person. I might be you know a mother a wife or whatever but I'm also me**.** **(**Level 6, Enriched Self: Experiencing Excitement for Life)

Therapist: That's right… these are labels?

Ruth: Aye, I need to do things that I want to do… and I'm just going to keep that thought with me and take every day as it comes and hope for the best that it works out. But I'm sure it will. I can control it better. (Level 7, Fully Agentic)

Therapist: You're taking more control?

Ruth: I feel that I can control it a wee bit better definitely… em… it's just pain… if the pain's really bad then I get kind of veered in another direction… but at this moment in time, I'm… (Level 4, Reacting Self: Complaining/Protesting about the impact of negative Aspects of illness on psychological well-being)

Therapist: Does pain make you afraid?

Ruth: Yep, I get scared when it gets too sore, and I try and get up off my seat… using my sticks to get myself up. I think this is dreadful… when is this going to end. (Level 0, Non-agentic Self: Psychological effects of despairing about illness)

Therapist: Yeah?

Ruth: Some days when the pain is really bad it's like oooof… was it worth all that surgery… was it worth this… but I know in my heart that it was worth it… it was worth… (Level 5, Willing/Wanting Self: Accomplishing a task)

Therapist: These thoughts (of pain) disappear?

Ruth: Uhuh, I just think when I've got the pain, I start to maybe feel a bit sorry for myself. I think that's probably when I'm getting down… (Level 4, Reacting Self: Complaining/protesting about the impact of negative aspects of their illness on their psychological well-being)

Therapist: Uhhuh?

Ruth: … but I'll still try and get up and get stuff done… it's like ... (Level 5, Willing/Wanting Self: Believing in self-ability to influence/succeed)

Therapist: Ok, there's still determination and motivation there?

Ruth: Aye, it's still there… I've tried to work my way through the pain but… (Level 5, Willing/Wanting Self: Dealing with circumstances)

Therapist: So, you try and not let these things get hidden?

Ruth: Uhuh, and the family know when I'm in pain because when I'm trying to get up you know… they'll come up and say," I'll give you a wee hand." … and I'll let them help me to get up when the pain's really bad. (Level 4, Reacting Self: Showing Gratitude/Appreciation/Respect)

Therapist: Yeah, you accept the help?

Ruth: I accept help but, in the days, where it's manageable I just get up myself. (Level 5, Willing/Wanting Self: Believing in Self-Ability to Influence/Succeed)

Therapist: You prefer to do it yourself?

Ruth: Yep. (Level 5, Willing/Wanting Self: Believing in Self-Ability to Influence/Succeed)

The patient entered reflection and expressed that she was now seeing herself as a person and not only as an extension of social labels but as a person with needs and wants. In effect, the patient was offering herself empathy and respect and was trusting her own efficacy to deal with circumstances. The patient was fully aware of and acknowledged her illness and its effects. Whilst she did not want to be perceived as a victim of her circumstances, she was willing to accept help when it was needed but where manageable, preferred to do things for herself. As the patient chose to live authentically by being realistic, contented and goal-oriented, she had chosen to construct herself as the full agentic agent, level 7.

Session 4 excerpt 2:

Therapist: Is that a sense of achievement… independence?

Ruth: I think independence plays a big part in it. If I didn't have my independence I don't know how I would be feeling. (Level 4, Reacting Self: Showing Gratitude/Appreciation/Respect)

Therapist: Is like coming here independence… I mean the family are not here it's you.

Ruth: It's me… like I've achieved something on my own out with the family but look at me. Look at what I'm doing. I'm away I'm enjoying myself. I've got arts and crafts whatever… I take my stuff home and it's like look at what I made and … (Level 6, Enriched Self: Experiencing Enjoyment)

Therapist: So, what's important to you now?

Ruth: I don't take life for granted at all… like I did before. (Level 4, Reacting Self: Showing Gratitude/Appreciation/Respect)

Therapist: Yeah?

Ruth: There's so much that is important to me now. I see the sky. I hear the birds. I see the trees. (Level 6, Enriched Self: Experiencing Joy)

To sum up, out-patient OP3 knew what was important to her, namely, independence and achievement. She expressed that, whilst she did not receive validation from others, she was able to offer that to herself. Also, she recognised her personal needs and desires, expressing that she saw the importance of meeting them. In addition, she wanted to enjoy life, no longer took things for granted and was now able to appreciate the natural world around her.

Out-patient OP4

Out-patient OP4 was a female who was diagnosed with cancer and lung disease. She took part in Study 3 and received three sessions of emotion-focused therapy over 14 days. There were seven days between sessions one and two and sessions two and three, with each session audio-recorded to provide three transcripts. Table 6.14 represents the data used to provide Figure 6.5 that aimed to track change in out-patient OP4.

Table 6.14

Out-patient OP4: Data for tracking change in personal agency over time

OP4	**RC1 min** *(p<.05)	**RC1 min** +(p<.20)	**Session 1**	**Session 2**	**Session 3**
Self-Report Means	.57	.38	3.13	3.06	2.75
Main Researcher Weighted Means	1.18	.78	5.8	5.2	5.29
Staff Rater Weighted Means	1.20	.79	5.8	5.4	5.29

Figure 6.5

Out-patient OP4: Personal agency scores over sessions

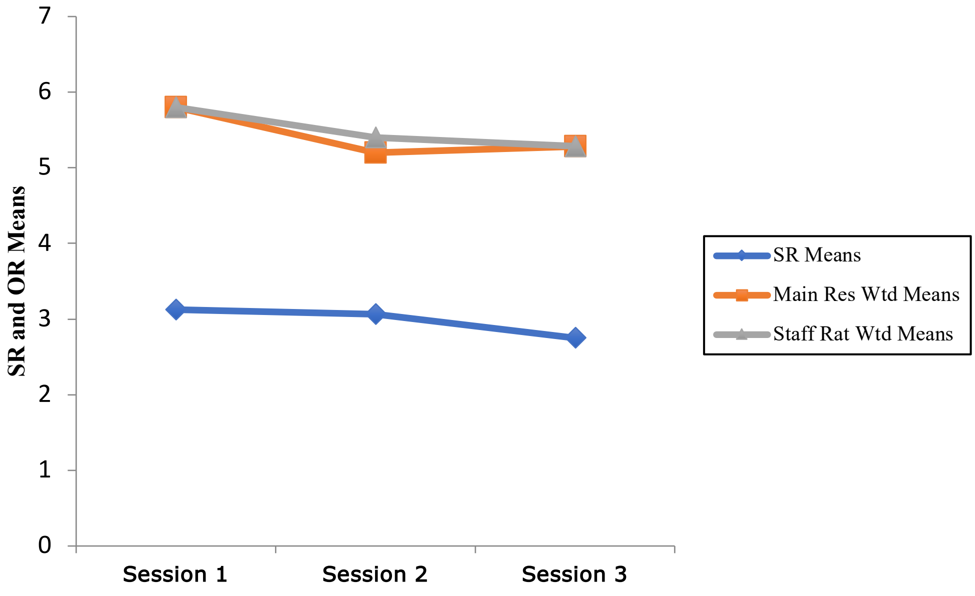


Figure 6.5 shows that, out-patient OP4 experienced change over sessions 1 and 2 and over 3 and 4. Results indicated that all changes, that is, with respect to the self-report item means and weighted means for the main researcher and staff raters, gave

negative values. Thus, results indicated that OP4 may have experienced a slight decrease in her personal agency over the three sessions she received emotion-focused therapy.

It appeared that out-patient OP4 was aware of her diagnosis and prognosis but constructed herself as more of an observer of her circumstances rather than fully acquaint herself with them. The patient's attentional capacity was limited and her emotional disengagement through suppression of expression and distraction appeared to undermine her memory for the emotional experience of diagnosis, treatment, and prognosis (Richards & Gross, 2006). For this patient, emotional disengagement was not adaptive as she was not conducive to adaptation and used distraction as a protection from triggering distressing emotions. The patient did not make lifestyle choices, even although aware of her prognosis.

In-patient 1P1

In-patient IP1 was a female diagnosed with cancer. She completed four sessions of emotion-focused therapy over a period of seven days, with each counselling session audio-recorded to provide four transcripts. There were five days between sessions one and two, with one day between sessions two and three and three and four, respectively. Table 6.15 represents the data used to provide Figure 6.6 that aimed to track change in in-patient IP1.

Table 6.15

In-patient 1P1: Data for tracking change in personal agency over time

IP1	**RC1 min *(p<,.05)**	**RC1 min +(p<.20)**	**Session 1**	**Session 2**	**Session 3**	**Session 4**
Self-Report Means	.57	.38	1.38	1.50	1.50	1.50
Main Researcher Weighted Means	1.18	.78	4.75	5.17	5.33	5.17
Staff Rater Weighted Means	1.20	.79	4.75	5.33	5.29	5.33

Figure 6.6

In-patient IP1: Personal agency scores over sessions

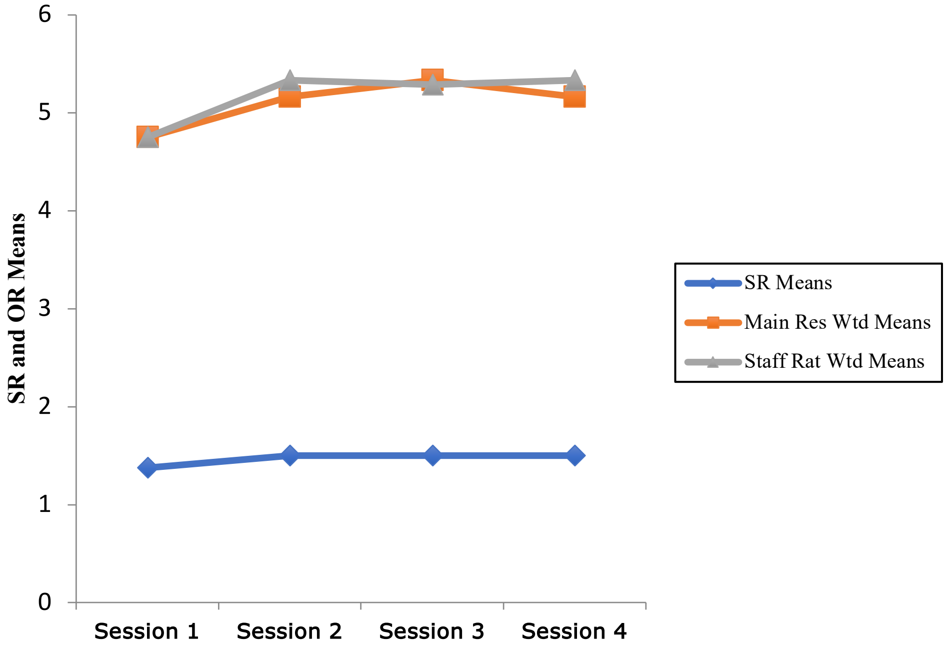


Figure 6.6 demonstrates that, with respect to the self-report item means, in-patient, IP1, experienced the same very small positive change over sessions 1 and 2 and 3 and 4. Results indicate that the change, expressed in personal agency, was not significant. With respect to the main researcher weighted means, the score between the baseline and session 2 indicated a moderate positive change. The results between sessions 1 and 4 were similar. Thus, results indicated there was an increase between pre-treatment and post-treatment but that the change was not statistically reliable. Similarly, for the staff rater weighed means, the scores between the baseline and individual sessions and between the baseline and the end-point were different but the differences were not statistically significant.

Session 1. From the out-set, in-patient IP1 made it known that her illness was not a surprise. She expressed that she had been expecting the diagnosis as her grandmother had died of the same life-limiting illness. "Not really… felt a lump… my grandmother died… was kind of expecting it …" At that point, the patient constructed herself as the reacting self, and more specifically as the coping self, acknowledging and accepting her diagnosis. That is, the patient experienced personal agency at level 4 in the hierarchy of levels of personal agency. Thus, she had a sense of awareness and was able to respond internally to her circumstances by appraising her illness. The patient was able to express what she perceived as helpful, "… was relieved. Now got official medical diagnosis." At that point, I tried to assume what it was like to be her but without identifying with her (Elliott et al., 2004). As an emotion-focused therapist, I provided a safe, empathic, trusting, prizing therapeutic relationship. Also, I was open and honest and attended to what was happening within the session. Moreover, as I was aware of the patient's health status, it was important that I worked actively with the patient as was appropriate.

IP1 communicated that she had recognised her symptoms, "I knew the symptoms my grandmother had… I said, that's me on my way out…". The patient moved from experiencing herself as being able to cope with her circumstances, exemplifying level 4 in the hierarchy of agency, to constructing herself as the disappearing self, with the result that she would no longer exist. The disappearing self is a sub-category of the objectified self, the lowest level of personal agency. Change appeared to take place and quickly. However, the patient again constructed herself as the reacting self, and expressed, "… went on doing what I was doing until it… changed." With that, the patient expressed, "I'm not an emotional person… pragmatist." She then constructed herself as the motivated self and the fighting self, level 5c, dealing with circumstances, "… got this disease… is going to kill me." I was aware that the patient appeared to be able to construct herself back and forth between different levels of personal agency. Also, whilst the patient did acknowledge her circumstances and was aware of the threat to her life, I became more attentive to the possibility that the patient was stopping herself from feeling her emotions through over-regulation (Elliott & Greenberg, 2021). I'As an emotion-focused counsellor, it was important for me to find out whether the patient was blocking her herself from feeling her emotions. This blocking of emotions or self-interruption can see the individual cut off not only from trauma-associated emotions such as fear, but from all emotions (Elliott & Greenberg, 2021).

At that point, the patient constructed herself as the fully agentic self, experiencing unwanted events in her body but realistically deciding to choose to live the best she could for as long as she could. "… I'm basically doing it that way for me. I can live… close as possible… to the same I did before… future… day at a time… how long I've got… could be tomorrow… day at a time… just keep it going that way." As the fully agentic self, the patient did not construct herself as a victim of circumstances but was goal-oriented, realistic and autonomous. As an emotion-focused counsellor, I attended to the vocabulary used by the patient and to the level of her emotional arousal. Moreover, I trusted my inner sense to gauge what I believed was important and meaningful for the patient. Thus, important was the merging of my understanding of human behaviour, my knowledge of theory and my experience of working with clients and personal experiences (Elliott et al., 2004). As an emotion-focused counsellor, I have learned specific ways to help patients to put their feelings into words to make their experience more vivid so that patients become alerted to what their emotions are trying to tell them. However, in-patient IP1 was the expert on her experience and thus knew what was painful, physically, emotionally and spiritually, and moreover, what was disallowed.

Whilst the patient appeared to manage her emotions so that they worked for her benefit, it also became evident that the patient' information- processing helped to remove the affective parts of experience, "I… my philosophy … a practical person… I'm a pragmatist... same all my life… never been emotional… never get upset about… much… like making a will… that brings up your own mortality… I'll face that… better than whoever… untangle… details of estate…" At all times I was acceptant and worked with the patient using empathic conjecture and validation. I attended to the patient's quality of voice. Her voice was strong, and what she expressed was almost as if rehearsed as she repeated things she had said earlier. As we concluded the first session, the patient was acceptant of the positive effects of medication, "(pain) reasonably under control" but highlighted what was for her a limitation, "… in hospital… can't… wander about… put the kettle on if I want… on the other hand… food brought… don't… washing up (laughed)… perks… outweigh…". Again, the patient constructed herself as different selves, changing from one to another, going from the coping self, level 4b, a sub-category of the reacting self to the sub-category, level 1a of limited self, and to the motivated self, and specifically, the enthusiastic self, level 5a. We ended the session with the patient constructing herself as the collaborative self, level 3b, “That’s fine.”

Session 2. The patient constructed herself as the pragmatist, handing her autonomy to those in charge, “I’m a pragmatist… get the green light… disease… it can play up… (waiting)… the most sensible solution.” Practicality appeared to be important to the patient whilst emotion did not appear to be useful. As an emotion - focused counsellor, I was aware that our emotions were our alert system and acted as guides for appropriate action. Moreover, I was aware that our primary adaptive emotions help us cope with current situations (Elliott & Greenberg, 2021). In addition, our secondary emotions protect us from feeling a distressing primary emotion. “I wouldn’t say life has changed… just it’s not going to last as long… no lifestyle change… slowly get shorter… that’ll be it” [T. …. protects you?] “Don’t know if it protects me… protective shield against bursting into tears… not… searching for meaning… practical side of me… organising funeral arrangements…never been anxious… I can’t change what’s happened… I’ll be dead in a few weeks… now final stages… you either laugh or you cry… I’m not a crier.” The patient was using her counselling session to express herself but her coping in the form of emotion regulation, involved not being overwhelmed or debilitated by bad or confusing emotions (Greenberg & Paivio, 2003). The patient did not collapse due to her circumstances.

I continued to work with her using empathic reflection, empathic conjecture and validation. As an emotion-focused counsellor, I was empathically attuned to her and accepted and valued what she was willing to share. She constructed herself as having belief in herself and as such experienced personal agency as the fighting self, level 5c, goal-oriented and with a sense of confidence in her ability to have control over her circumstances as appropriate, “… got what I want … ready… get the right coffin… got... instructions here.” Also, the patient saw death as “… another journey… brain stopped… spirit come out… go… up… down… sideway… never thought about it… doesn’t bother me… think this is all we got.” As the transcending self, level 6c, the patient acknowledged that she would cease to exist but had no notion of what that might be. We ended the session by a mild appreciation from the patient," You're welcome".

Session 3. This session began with the patient constructing herself as the reacting self and, specifically, the coping self, level 4b in the hierarchy of personal agency, acknowledging her illness was "... not exactly (a shock) … my paternal grandparents… paternal Grandfather... great, great Grandmother… died from… I got it… wasn't… surprise… genetics…" Moreover, she acknowledged how the illness had affected her psychological well-being, "… they thought… cure the tumour... aggressive… less susceptible to drugs…I ended up terminal… now … too tired… just lie in bed." However, the patient, as the joyfully engaged self, level 6c, expressed that she did experience joy, "Enjoying the nice blue sky out the window." I listened for different voices but still the patient's voice remained robust and external. I continued to work with her, attending to what she expressed, trying to see the world from her insider perspective. At all times, I provided an empathic validating, and supportive relationship. However, in-patient IP1 did not wish to experience her suffering; on the contrary, she was motivated by her need to avoid distress and the need for mastery over her emotions, "I don't look at it negatively or positively… I deal with it the way I look at things… going to get worse… need stronger painkillers… force myself to live… need stronger painkillers… when it comes."

The patient clearly articulated that she was dealing with circumstances as she constructed herself as the willing/wanting self and, specifically, the fighting self, level 5c. Moreover, with belief in herself, she expressed that, "… I still like living…" However, with a need as if to protect herself, the patient constructed herself as detached from her circumstances. That is, as the limited, detached self, level 1d, the patient experiences herself as emotionally detached from her unwanted circumstances," I don't think I react to anything happy…sad." However, the patient was reminded of the physical effects of her illness, "I'll lie down… legs are sore… pain… down my legs." We ended the session, "If you want to come then?... Yep… any time… after breakfast… medications… so any time after…"

Session 4. This session began with in-patient IP1 expressing that she was, “Wating (for) confirmation (to go home) … it’s getting milder (outside)… allow me … do some things.” The patient constructed herself as the willing/wanting self and, specifically, the motivated self, level 5a, goal-oriented with respect to a greater sense of well-being and fulfilment. She then constructed herself as the enriched self and specifically, the joyfully engaged self, level 6c. [T.” …something you’ll look forward to… the house?] “Yes… a glass of lemonade… that’s the only thing I’m thinking of if I get confirmation, I’m going home…” I continued to work with the patient and with the knowledge that confirmation of going home meant that her participation in the study would stop. However, I was aware the patient was, “… looking forward to… you can go… my stuff’s all ready… get… into going away clothes.” As an emotion-focused counsellor, I promoted and facilitated a shared engagement, and I was fully respectful of her, receptive to her and fully present with her. The patient was looking forward to going home, and was expressing what was in place and what she looked forward to “…pain’s under control… can sleep… district nurses… care package in place… a glass of lemonade… that’s as far… I’ve got… other things…” As I sat with her and listened to her, I tried to put my feet in her shoes. Her constant constructing and re-constructing of herself from the reacting, coping self, Level 4b, moving to level 6c, the joyfully engaged self. The patient then, as the historic self, level 6a, reminisced, seeing her past self as more positive than her present being, “… lucky… past 40 years… achieved… done everything I wanted…terminal cancer… nothing left for me to go for… I was lucky… took it (opportunity).” However, the constant re-constructing seemed as if it helped her to avoid reflecting on her experience of her circumstances, including the existential concerns of loss, finiteness, death, meaning and the anxiety born out of these.

A member of the care team came to inform the patient that she would be going home. I noticed a change in the patient’s voice; it was no longer robust but quiet and thin. I gently commented on her voice and the lowering of her head. As she looked down, she expressed,” Change is inevitable… big lump… if suddenly… not quite as easy… like to be in control… times… you can’t be… basically… practical… deal with practical problems… acceptance… if you can’t change it… pragmatist… don’t sit down… I’m dying.” At that point, as an emotion-focused counsellor, I did not push the patient to express any blocked feelings as I did not want to provoke anxiety. Immediately, her motivation to succeed to decide in to be considerate to others became her priority, “I’m dying… get funeral arrangements organised… sort out… for solicitors… my cousin doesn’t have to sort out when time comes….” The session ended; “I’ll lie here… whatever’s coming” as the ward staff arrived with a time for going home.

To sum up, in-patient IP1 dealt with her circumstances by disallowing herself to express how she felt about her life-limiting illness and its impact on her, including her needs. She acknowledged her diagnosis and prognosis and was aware that she was unable to escape from her givens. She expressed joy with respect to the blue sky and indicated that she still liked living. However, her avoidance of self-reflecting and the constant constructing and re-constructing of herself, helped her to remain at a distance from her circumstances, with the pragmatic part of her enabling her to dwell on the practicalities of her prognosis. Emotion-focused therapy provided an empathic, prizing, validating, non-judgemental and safe relationship wherein, in-patient IP1 could share her beliefs and values.

In-patient IP2

In-patient IP2 was a male diagnosed with cancer and lung disease. He completed two sessions of emotion-focused therapy over a period of five days, with each counselling session audio-recorded to provide two transcripts. That is, there were five days between sessions one and two. Table 6.16 represents the data used to provide Figure 6.7 that aimed to track change in in-patient IP2.

Table 6.16

In-patient IP2: Data for tracking change in personal agency over time

IP2	**RC1 min *(p<.05)**	**RC1 min +(p<.20)**	**Session 1**	**Session 2**
Self-Report Means	0.57	.38	1.56	1.81
Main Researcher Weighted Means	1.18	.78	5.13	5.13

Staff Rater Weighted Means	1.20	.79	5.14	5.25

Figure 6.7

In-patient IP2: Personal agency scores over sessions

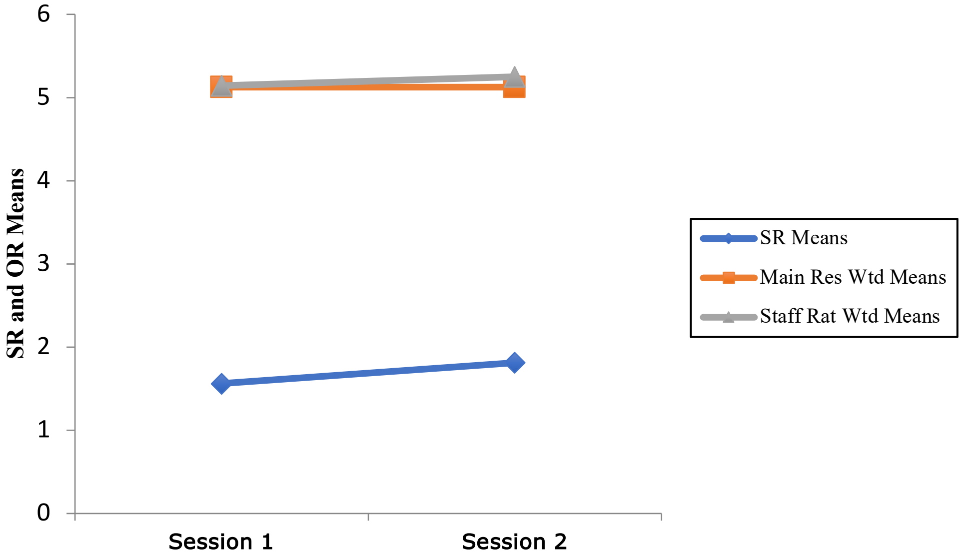


Figure 6.7 shows that, with respect to the self-report item means and the staff raters weighted means, in-patient IP2 experienced very small but positive changes over sessions 1 and 2. However, results show that these changes were too small to be considered significant. Results show that, with respect to the main researcher weighted means, there was no difference between the baseline and the endpoint. Thus, results indicate that the overall change was not statistically significant.

In-patient IP3

In-patient IP3 was a male diagnosed with cancer. He engaged in two sessions of emotion-focused therapy over a period of three days. Each therapy session was audio-recorded to provide two therapy transcripts. Table 6.17 represents the data used to provide Figure 6.8 that aimed to track change in in-patient IP3.

Table 6.17

In-patient IP3: Data for tracking change in personal agency over time

IP3	RC1 min *(p<.05)	RC1 min +(p<.20)	Session 1	Session 2
Self-Report Means	.57	.38	2.25	2.88*
Main Researcher Weighted Means	1.18	.78	2.33	4.71*
Staff Rater Weighted Means	1.20	.79	2.33	4.71*

Figure 6.8

In-patient IP 3: Personal agency scores over sessions

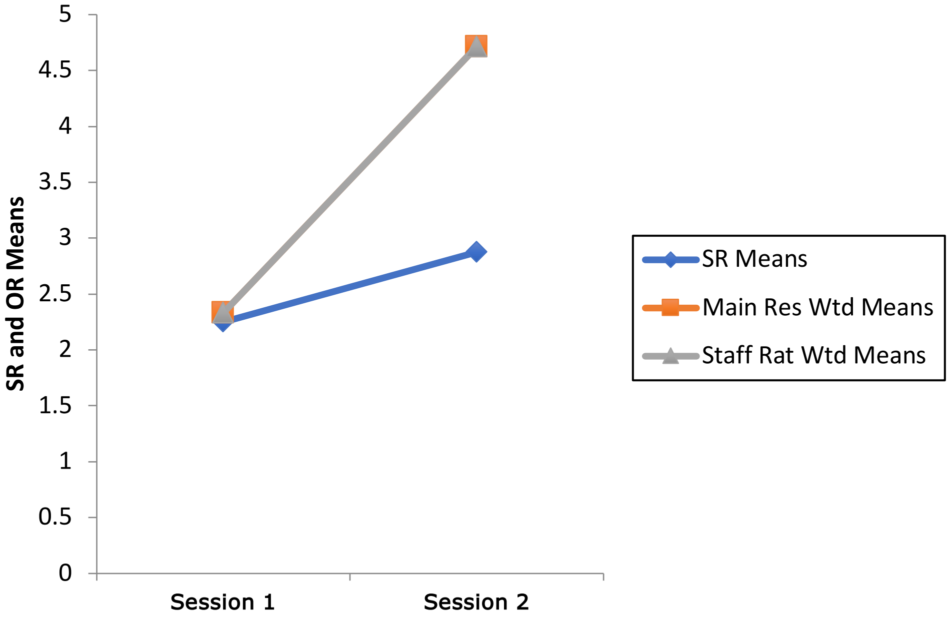


Figure 6.8 shows that for in-patient IP3, and with respect to the self-report item means, the score between the baseline and the end-point were different. Results show that the difference, expressed in terms of personal agency, was statistically significant at p < .05. Moreover, results show that, with respect to the weighted means for both the main researcher and the staff raters, IP3 had experienced a

change, expressed as an increase in personal agency, that was statistically significant at $p < .05$. The change experienced by OP3 is detailed in the following narrative.

Session 1. I was aware of the dysregulation of the patient's emotions, as he became flooded and overwhelmed due to the unexpected, fast deterioration of his physical status. The patient's accessing of emotions was maladaptive and he was visibly in distress and unable to leave his emotional state. As an EFT counsellor, it was important to provide a therapeutic relationship that showed I had a desire to understand with an empathy, sensitive to the patient's moment-by-moment feelings and communications. Moreover, prizing and acceptance were important but that required my understanding, no matter how negative his feelings and thoughts. I promoted freedom and safety in the relationship so that the patient was able to express his fear that was survival-oriented and his anxiety that arose from the threat to his continuity and personal agency. I was aware that he was disabled, with his fear becoming intense anxiety as he anticipated that the disease would very soon overcome his physical body. Crying, the patient expressed that illness had "… turned my world upside down." At that point, the patient experienced himself as having no sense of control and thus, devoid of personal agency. That is, the patient had constructed himself as objectified, level 0a, the lowest level of personal agency, with the imagery of himself brought down by the illness.

As the reacting self, and specifically, the coping self, level 4b, the patient complained about negative aspects of the illness, "could do things with… family… strenuous in me… family". Moreover, as the collective self, and, specifically, the actively collaborating self, level 3b, he was aware that he needed help from others, expressing how he and his family arranged their time together, "We have to work out the morning's to be like… arrange with … daughters… sons-in-law…". As an EFT counsellor, I was aware of the importance of the alliance and safety within the therapeutic relationship. I attended and validated to what he expressed. The patient continued, constructing himself as ineffective due to the physical effects of his illness, "I can't drive anymore… killing me… can't play with the grandkids… can't … play with them." As ineffective, the patient had constructed himself as limited, and, specifically, as the non-functional self, level 1b, that represented him as inadequate, deprived of strength and power, and having no impact on his circumstances. At that point, the patient constructed himself as the despairing self, dispirited and stuck, "…not worked for about 15 years… that was hard to take… devastating." As the despairing self, the patient was disheartened with his unwanted circumstances and so experienced despair that destroyed his sense of agency. Crying, the patient experienced himself as puzzled and confused, level 1c, in relation to the status of his illness, "Surgeon said we'll fix it in six months… you'll be back…"

With IP3 unable to leave his emotional state, the patient and I agreed to stop the recording of the session. However, I did not leave him; I remained with him and helped him to engage in self-soothing. As an EFT counsellor, I was aware that it was only through the experience of the primary maladaptive feelings of the fear of annihilation and insecurity that the patient's emotional distress could be cured. I was acceptant and worked with the patient to access alternate self-schemes (Greenberg & Paivio, 2003) through focusing, empathic conjecture and soothing to allow self-affirmation. At that point, the patient was unable to show empathy to himself while he was experiencing himself as suffering. Thus, for me, my main objective was to make the patient feel safe and prized. Validation helped the patient to know that it was alright to have the emotions and that his feelings were not invalid or wrong. Also, validation allowed the patient to know that it was alright for him to reveal the depth and extent of his feelings without fear or shame. I promoted a collaborative, I-Thou relationship (Schmidt, 1959) to promote safety, trust, humility, and an abundance of empathy. As an EFT counsellor, I was able to help the patient to experience his distress and helped him to look into himself so that he could symbolise his pain and suffering. Once he was able to view himself within an empathic relationship, a processing shift took place, and the patient was better placed to find out what he wanted. A sense of being understood and validated helped the patient to regain composure.

Session 2. I re-united with the patient two days later. He expressed that, "I'm very tired… but slept better…got sleeping tablet… relaxed." That is, the patient, as the limited self, level 1a, expressed that he experienced physical tiredness. However, as the reacting self and, specifically, the coping self, level 4b, the patient experienced an increase in self-awareness as he acknowledged the positive impact of medication on his well-being. Thus, whilst the patient had firstly, constructed himself as the limited self, he re-constructed himself as the coping self. This indicated an increase in internal personal agency. I was aware of a change within the patient. His voice was stronger; he was not crying; he was smiling and laughing. At that point, the patient communicated belief in himself, "I'm getting there…" Thus, the patient had constructed himself as the fighting self, level 5c, goal-oriented and with a sense of personal self-efficacy that indicated an increase in his personal agency. Moreover, whilst the patient was dealing with very distressing problems, he made the decision that would help his personal well-being, "[T. … when things change?] "I just want to go…" The patient appeared to be able to detach from his unwanted experience and experienced himself as demonstrating an excitement for life, "The way I am now …have lunch…sleep… get up… kids… come round… see me… blether… play with them." This indicated an increase in personal agency as the patient became an active initiator, generating novel ways of engaging in life. Moreover, the patient expressed that he would "…struggle on.", constructing himself as the willing/wanting self and, specifically, as the motivated self, level 5a. This saw the patient enter a process of self-evaluation to reinforce his personal efficacy in a drive to achieve his personal goals.

However, the patient was frustrated that he was unable to stop the unpleasant effects of illness and treatment on his body, "… frustrating… so close to the toilet… I'm covered… floor's covered…" Nonetheless, the patient did not allow his circumstances to defeat his awareness of his responsibility to choose to act to achieve change. Also, I was aware that it was important for me to be comfortable with my own and his vulnerability and embarrassment. I helped the patient to listen and attend to his different voices so that he could sense that he was not only the creator of his own experiences but that he could avoid experiences. The patient constructed himself as the joyfully engaged self and, specifically, level 6c, that communicated his purposeful engagement in life to enhance the quality of the time he had left, "… they'll make a joke… I start laughing… family… jokes… I love it… (football)… I hope… pick up the cup…" At that point, the patient attempted to escape from his circumstances, "… if I talk about normal things, it's great". The patient tried to escape from his givens through mentally removing himself from his unavoidable circumstances. He remained enthusiastic by constructing himself as wanting to take part in life and with the hope that something good would happen due to his own efficacy," I'll go for a donner (short walk) … I'll go… have a look."

The overall results show that four patients, three out-patients and one in-patient, experienced change over time, with the change statistically significant at either $p < .05$ or $p < .2$, and with respect to each of the three different variables on the y-axis (SR and OR means). That is, an increase in personal agency experienced by four hospice patients while receiving emotion-focused therapy over a specified number of sessions, could be regarded as statistically significant at $p < .05$ or $p < .2$ with respect to the self-report item means and, or the weighted means for either the main researcher or staff raters. Also, results show that two hospice patients did experience positive change, to varying degrees, but the difference between pre-treatment and post-treatment could not be regarded as statistically significant. In addition, results show that one hospice patient experienced change in a negative direction, suggesting that a decrease in personal agency.

6.4 Discussion

6.4.1 Discussion of the Qualitative Component

The research questions for Study 3 were: a) "Can the new self-report and observation measures of personal agency be implemented for assessing personal agency with a new sample of hospice patients?" and b) "Is Emotion-Focused Therapy associated with the development of personal agency in hospice patients in this sample?" This leads to the discussion of how and to what extent these questions in Study 3 were answered. Results indicated that the eight main categories of personal agency that emerged in this study were the same as for Study 1 and the earlier study (Campbell et. al., 2014). Thus, hospice patients constructed themselves as specific selves, in accordance with the hierarchy of levels of personal agency, ranging from Level 0: *Non-Agentic to Level 7: Fully Agentic.* Similarly, the results showed that whilst the sub-categories of the main categories and their expanded distinctions were the same as for Study 1, the expanded distinctions of sub-categories that emerged in Study 1 were not fully represented in Study 3. It is important to note that, because of illness and treatment, this sample of four out-patients and three in-patients were not able to engage in the full complement of six sessions of emotion-focused therapy, complete six self-report questionnaires or be observed six times. However, results demonstrated that these hospice patients assessed their limitations, appraised their capabilities, and initiated control, with varying effect, on their personal circumstances. Thus, in accordance Study 1, the graded set of categories and sub-categories obtained from hospice patients as “insiders” living with life-limiting illnesses indicated that the capacity of hospice patients to act as agents provides an argument that personal agency is prevalent in human existence and even to the point of death. Results indicated that there is a human capacity to turn life’s negative aspects, such as suffering, into human achievement or accomplishment (Frankl, 2004).

6.4.2 Discussion of the Quantitative Component

With the hierarchy of levels of personal agency supported by this sample of four out-patients and three in-patients, the question was whether the hierarchy, operationalised as the self-report questionnaire and the observation measure, could be implemented with this same sample of hospice patients. Results indicated that the internal consistency reliability for the 16-item revised self-report questionnaire with the combined sample of four out-patients and in-patients was good. This indicated that the items in the self-report questionnaire were measuring the same construct, personal agency. Thus, the interrelationship or homogeneity among the items on the self-report questionnaire could be regarded as good for this sample of four out-patients and three in-patients. As the value of alpha was close to the value of 1, it demonstrated that there was a great deal of covariance among the items relative to variance. Thus, Cronbach’s alpha measured the extent to which the group of items, that is, the items on the scale, were related to each other, providing an estimate of the measurement accuracy, referred to as reliability. The revised 16-item self-report questionnaire allowed data to be collected with respect to how this sample of four out-patients and three in-patients felt, thought, and acted. Thus, it was important to find out whether the questionnaire and observation measures, could be implemented with this sample of patients. On that basis, it was necessary to know the levels of the inter-rater reliability, test-retest reliability and the convergent validity. As in Study 2 (Chapter 5) Pearson's coefficient correlation, r, was elected as the statistical method to assess the levels of the interrater reliability, test-retest reliability and convergent validity. As the number of patients taking part in Study 3 was small, the number of sessions was also small and thus, it was deemed appropriate to combine the sample of four out-patients and three in-patients to carry out the statistical tests.

As with Study 2, it is important to note that the weighted means and the global means of the main researcher and staff raters were used to calculate the levels of inter-rater and scoring reliability (Section 5.4). Moreover, with respect to the inter-rater and alternate scoring of the observation measure, results were consistent with the previous study, indicating very high agreement. That is, results indicated that for weighted means and the global means, the main researcher and the staff raters demonstrated an almost perfect consistency between their judgements of personal agency, indicated by their ratings, as expressed by hospice patients during observation. Thus, as there was a strong correlation between raters, the null hypothesis could be rejected. Thus, this definite relationship supported that the subjective judgement or observations could give confidence that the findings were replicable and not greatly influenced by individual rater subjectivity or biases. Moreover, the reliability for the main researcher and staff raters could be regarded as substantial. That is, raters could be regarded as interchangeable, suggesting that only one rater was required to rate the observation measure during the observing of patients. As with Study 2, raters were provided with a training manual, a protocol that acted as a guide for recording observations, monitoring of data and an opportunity for feedback.

Also, test-retest reliability, the measure of consistency between the self-report questionnaire item means and the self-report item means plus one, was measured using Pearson's correlation, r, to obtain the correlation of the scores of this sample of patients' responses between current and subsequent administering of the self-report questionnaire. Results indicated an excellent level of reliability over time. However, as this test was carried out for one combined sample of patients, the progression of illness was varied and therefore patients experienced different physical and psychological effects of their illness, treatment and surgery. According to literature, if patients experience change on their construct at different rates between test occasions, the correlation between the occasions can be low even if the measurement instrument is precise (Richardson & Jones, 2009). For Study 3, the test was carried out using the same self-report questionnaire with the same sample and the level of test-retest reliability was excellent. A good test-retest reliability signifies the temporal consistency of a test and ensures that the measurements obtained are representative over time.

In Study 3, all patients were diagnosed with a life-limiting illness, and all received palliative care. Moreover, due to their illnesses, patients experienced change, the nature and rate of which was unpredictable and often gave rise to physical, psychosocial, and existential difficulties (Campbell et al., 2014). This might have influenced the measure of reproducibility of the self-report questionnaire, that is, the ability to provide consistent scores over time in a stable population (Aaronson et al., 2002). However, results demonstrated that the self-report questionnaire, was reliable, and little affected by random fluctuations (Kottner et al., 2011). The test-retest provided an understanding of the dependability of the self-report questionnaire within clinical environments, namely, within a hospice environment. As the self-report could be regarded as stable, changes in outcome might be seen as real changes within patients.

Also, according to the literature, test-retest reliability can be influenced by the time interval between tests (Haynes et al., 2018), with the optimal time interval varying depending on the construct being measured, the stability of the construct over time, and on the target population (Evans, 1996). Whilst Backhaus et al. (2002) found test-retest reliability was higher with a shorter time interval, Liao and QU (2010) found that reliability increased with an increase in time interval. Similarly, according to literature, the number of days between tests impacts reliability coefficients. For this sample of hospice patients, the time interval in days between tests ranged from two to five days for in-patients and from seven to 35 days for out-patients. In addition, the smaller the sample size the greater the likelihood of obtaining a spuriously small or large correlation coefficients. As the test was carried out for a sample that consisted of out-patients and in-patients, that may have contributed to the excellent value of r, that is, rather than testing for test-retest reliability with separate samples of out-patients and in-patients, respectively. Also, test-retest reliability can be influenced by the effects of learning, memory, fatigue motivation, sample homogeneity, time interval participant changes and internal consistency.

Furthermore, results suggest that good internal consistency of the self-report questionnaire may allow the measure to be regarded as reliable with respect to this sample of hospice patients. That is, the reliability reflects that items on the self-report are consistent with each other and that the items are measuring personal agency. However, high values of internal consistency may be due to narrowness or item redundancy (Streiner, 2003). Also, as the results for the self-report questionnaire indicate the level of test-retest reliability as excellent, this suggests that the data provided by this measure can be regarded as an accurate representation of patient performance, rather than due to environmental, psychological or methodological processes. That is, an excellent level of test-retest reliability suggests that the identification of differences in performances between the pre-treatment and post-treatment are indeed due to the intervention of emotion-focused therapy and not due to measurement error. Also, an excellent level of test-retest reliability, indicates that the self-report questionnaire can be used in longitudinal studies, with relevance to longitudinal stability and change. In addition, high test-retest reliability has provided a degree of confidence, brought about by the results of Study 3 that do not appear to be influenced by other factors. This suggests that the internal validity of the measures is sound, and results are reproducible. A measure with low test-retest reliability can suppress the true effects of an intervention, such as emotion-focused therapy, resulting in drawing conclusions that may have negative consequences for research questions.

With respect to the observation measure, results demonstrate an almost perfect consistency for inter-rater reliability, suggesting that this high reliability may facilitate the use of the observation measure to measure personal agency and to use the data for further research. Whilst there were eight staff raters in Study 3, it is conceivable that this may have affected the results, but this study allowed the measure of the reliability of the observation measure in a clinical setting using different raters to record data. Also, staff raters had read the same guidelines, suggesting that these were easy to understand and implement without difficulty, supporting the feasibility of this measure. Moreover, an almost perfect inter-rater reliability promotes confidence that results may be replicable, with the influence of individual rater subjectivity or biases having little effect.

Convergent validity*,* the most stringent test of psychometric quality, assesses whether a test that is designed to measure a particular construct correlates with other tests that assess the same or similar construct. Thus, convergent validity is important when the researcher is using two different methods of data collection such as a questionnaire and an observation measure. As in Study 2, the self-report questionnaire and the observation measure, the two formats operationalised to represent personal agency, were analysed for convergent validity using Pearson's coefficient correlation. Moreover, Pearson's correlations were carried out using four different forms of observer measurement. The main researcher's weighted means and global ratings were compared, separately, with the self-report questionnaire item means for the combined sample of seven patients. Also, this was carried out for the staff raters. The values obtained for convergent validity indicated that there was not an acceptable level of convergent validity between the self-report questionnaire and the observation measure.

According to literature (Fornell & Larcker, 1981) convergent validity should demonstrate a value not lower than 0.5. Here, the convergent validity values indicated that the self-report questionnaire that was designed to measure the construct of personal agency did not correlate with the observation measure that was designed to assess the same construct. That is, the scores on the self-report did not correlate with the scores on the observation measure. As, according to current literature, there appears to be no other scales for measuring personal agency in hospice patients, the newly developed measures could not be compared with existing measures. Instead, two newly developed measures were required to be compared with each other. Convergent validity verifies whether the scores of an instrument under study “make sense” in relation to the scores of other related measures. Thus, it was important to examine whether the correlation was able to demonstrate if the measures did capture meaningful information about the experiences of personal agency in this sample of hospice patients. Also, it was important to note that a smaller sample of observations across patients can negatively affect the statistical validity.

In any event, regarding the convergent validity, the results indicated that there was no correlation between the self-report questionnaire and the observation measures. Thus, the self-report designed to measure personal agency in hospice patients, does not correlate with the observation measure designed to measure the same construct. Thus, while these two measures may be regarded as reliable, further research is required to endorse their validity. However, also important for the implementation of the two measures was the tracking of change for each patient over time. This was to identify change in relation to the scores and ratings on the self-report questionnaire and the observation measure over a specific number of sessions. As previously decided, it was deemed appropriate to exclude the global ratings from the tracking of change, due to the ceiling effect. Thus, quantitative data, in the form of self-report item means and weighted means for the main researcher and staff raters, were used to provide seven individual figures to track change. While patients were being tracked, each engaged in emotion-focused therapy, with each session recorded to provide transcripts for analysis.

The reliable change index (RCI)was used to estimate whether change had taken place. That is, the reliable change index, a psychometric criterion, was used to indicate whether a change over time of an individual score (before and after an intervention like emotion-focused therapy) could be considered statistically significant. If a z-score for client change (the reliable change interval or RCI) is greater than 1.96, it denotes a statistically significant difference, that is, reflects reliable change. Moreover, in accordance with Elliott et al. (2009), systematic single case study designs may adopt a more flexible standard of evidence, with $p < .2$

(“preponderance of the evidence”) often a more reasonable and useful standard of proof than $p < .05$ (“near certainty”).

In this study, three out-patients and one in-patient, experienced change over time, with the change statistically significant at either $p < .05$ or $p < .2$, and with respect to each of the three different outcome variables (SR and OR means). This suggests that an increase in personal agency experienced by four hospice patients while receiving emotion-focused therapy over a specific number of sessions, could be regarded as statistically significant at $p < .05$ or $p < .2$ with respect to the self-report item means and, or the weighted means for either the main researcher or staff raters. Also, results show that two in-patients did experience positive change, to varying degrees, but the difference between pre-treatment and post-treatment was small and could not be regarded as statistically significant. In addition, results show that one out-patient experienced change in a negative direction, suggesting that a decrease in personal agency is also possible.

To illustrate variations of personal agency within and across sessions, narratives were provided for out-patients, OP1 and OP2, with part of a transcription and narrative provided for out-patient OP3. Also, narratives were provided for in-patients, IP1 and IP3. Figures and narratives were presented. With respect to answering the research question: “Can the new self-report and observation measures of personal agency be implemented for assessing personal agency with a new sample of hospice patients?” it was deemed justifiable to suggest that, with further investigation, the new self-report and observation measures of personal agency could be implemented for assessing personal agency with a new sample of hospice patients. Also, it is important to note, that four of the seven hospice patients experienced an increase in their personal agency over the time they received emotion-focused therapy, with respect to the variable on the y-axis. Four of the significance tests carried out were statistically significant at $p < .05$, indicating that these tests had the chance of being correct, that is, unlikely to be due to chance. As noted earlier (Section 6.3.2) the most trustworthy results were those for IP3 as all three values were statistically significant across the three variables on the y-axis. Whilst with respect to OP2, one measure, the self-report questionnaire, was significant at $p < .05$ indicating that only 5% was due to chance. OP1 and OP3 were significant at $p < .2$, indicating that only 20% was due to chance. OP2 was significant at $p < .2$, across the self-report questionnaire, indicating that 80% was not due to chance. Seven tests were significant at $p < .2$. With respect to the second research question, "Is Emotion-Focused Therapy associated with the development of personal agency in hospice patients in this sample?", the answer would appear to be yes, in at least one case but not necessarily in the other cases. Three out-patients and all three in-patients were able to project themselves beyond their determinant, a life-limiting illness, and thus, did not only emphasise their circumstances but highlighted their ability to choose what to do about their circumstances. Moreover, three out-patients and two in-patients constructed themselves as the fully agentic selves, level 7, the highest level of personal agency in the hierarchy of levels of personal agency. Whilst this would appear to be a general experience within this sample, these levels are temporary and do not represent post-therapy gains.

As patients experienced a deterioration in their bodies, they had to live with increased physical limitation, growing uncertainty and a shattering of their beliefs that led to the world they knew disappearing (Janoff-Bulman, 1992, 2010). Patients experienced the primary adaptive emotions of fear at threat, of being unsure, and broken due to emotional pain; the primary maladaptive emotion associated with feeling insecure; and the secondary maladaptive emotions associated with feeling helpless, hopeless, vulnerable, and in despair. I worked with patients, helping them to access their primary adaptive emotions and evoke maladaptive emotions to make them more receptive to change by making known new information and experience to them. However, this required patients to have an increased awareness of their emotions as only when they knew what they felt, were they able to reconnect to their individual needs and become motivated to meet them. That is, emotional awareness is about being able to feel the feeling in awareness (Greenberg, 2015). Moreover, being able to attach words to feelings gave patients a sense of control. Thus, symbolisation allowed patients to put a handle on the feeling, allowing them to work with it to create new meaning and narratives. Symbolisation helped patients to create a stronger sense of themselves by being able to denote a feeling that helped them to get a new perspective of the feeling as opposed to just naming the feeling. Also, being able to symbolise their environment helped patients to develop strategies for action (Taylor, 1990).

As an emotion-focused counsellor, I worked with patients within a therapeutic relationship that fostered empathy, prizing, authenticity, trust, integrity and safety. This collaborative alliance aimed to help patients to play a part in who they were motivated to become (Bandura, 1997). Moreover, I interpret evidence here as demonstrating that emotion-focused therapy is associated with the development of personal agency in this sample of hospice patients. Thus, this would suggest that the research questions a) "Can the new self-report and observation measures of personal agency be implemented for assessing personal agency with a new sample of hospice patients?" and b) "Is Emotion-Focused Therapy associated with the development of personal agency in hospice patients in this sample?" have been favourably answered, albeit with a limited sample of participants and with further research recommended.

6.5 Conclusions

The research questions for Study 3 are a) "Can the new self-report and observation measures of personal agency be implemented for assessing personal agency with a new sample of hospice patients?" and b) "Is Emotion-Focused Therapy associated with the development of personal agency in hospice patients in this sample?" More detailed second level research questions are:

e) Is there adequate internal consistency among the items of the self-report measure?
f) Is there sufficient test-retest reliability (self-report and observation measures)?
g) Is there inter-rater reliability between ward staff and researcher observations adequate?
h) Is there sufficient convergent validity between observational and self-report measures?

This study was composed of seven hospice patients, four out-patients and three in-patients, who engaged in emotion-focused therapy, responded to the 16-item self-report questionnaire and were observed by the main researcher and eight staff raters. Findings of that study demonstrate a good level of internal consistency, indicating that there are strong correlations among the items in the self-report questionnaire and suggesting that this measure is reliable. Also, findings demonstrated that for inter-rater reliability, the values of Pearson's r indicate almost perfect agreement. Pearson's r for test-retest indicates that test-retest reliability is excellent. This suggests that the stability of current and subsequent administration of the self-report questionnaire from this sample of patients indicates that test-retest reliability can be assumed. However, results for convergent validity indicate that there is no correlation between the self-report questionnaire and the observation measure for this sample of patients. However, as this was a small sample of patients, it is deemed justifiable to suggest that the self-report questionnaire and the observation measure could be used to assess personal agency in this sample of hospice patients.

Results indicated that three out-patients and one in-patient, experienced change over time and that change was statistically significant at either $p < .05$ or $p < .2$, with respect to one or more than one of the three different variables on the y-axis (SR and OR means). This suggested that an increase in personal agency experienced by three out-patients and one in-patient while receiving emotion-focused therapy over a specific number of sessions, could be regarded as statistically significant at $p < .05$ or $p < .2$ with respect to the self-report item means or the weighted means for either the main researcher or staff raters. Also, results show that two in-patients did experience positive change, to varying degrees, but the difference between baseline and end-point was small and could not be regarded as significant. In addition, results showed that one out-patient experienced change in a negative direction, suggesting a decrease in personal agency. Also, narratives of out-patients OP1, OP2 and OP3, and in-patients IP1 and IP3 indicated how they changed over time.

For this study, analysis was conducted on the seven transcripts obtained from audio-recordings from sessions of emotion-focused therapy. Results indicate that eight main categories of personal agency represent how patients constructed themselves as specific selves: *Level 0*: *Non-agentic, Level 1: Limited, Level 2: Reflexive, Level 3: Collective, Level 4: Reacting, Level 5: Willing/Wanting, Level 6: Enriched and Level 7: Fully Agentic Self.* These categories were the same as was found in Study 1. Also, results indicate that the same sub-categories, and their expanded distinctions of sub-categories, expressed the same subtle nuances of self. The results indicated that, for this sample of patients, the same main categories and sub-categories of personal agency were expressed by most out-patients and in-patients. However, all the expanded distinctions within sub-categories were not fully represented. Results indicated that for this sample of four out-patients and three in-patients the hierarchy represented how patients constructed themselves as experiencing personal agency to varying degrees. I conclude that the research questions have been satisfactorily answered, with the recommendation for further research.

6.6 Chapter Summary

In this chapter I aimed to set out whether the self-report questionnaire and the observation measure could be implemented with a new sample of out-patients and in-patients. Also, Chapter 6 aimed to discover "Is Emotion-Focused Therapy associated with the development of personal agency in hospice patients in this sample?" I outlined the research questions; the design and procedures used to generate and analyse data and provided an overview of the results. In the next chapter, Chapter 7, "Discussion", I explore the findings, interpretation, implications, limitations and recommendations.

Chapter 7: Discussion

7.1 Introduction

The purpose of this thesis, titled "Personal Agency in Hospice Patients" was to discover how and to what extent hospice patients diagnosed with a life-limiting illness, experience their sense of personal agency (Bandura, 2006; Gallagher, 2012; Jeannerod, 2003). Hospice patients are faced with the diagnosis of a life-limiting illness, that is, an incurable disease that they know cannot be put right. Whether caused by an internal or external influence, a life-limiting illness gives rise to the experience of physical and psychological distress and brings about unwanted change, physical, psychological, and behavioural, within the individual. The principal objective of the research programme was to investigate a) how hospice patients expressed their sense of personal agency and b) whether that sense of personal agency could be measured. A secondary objective was to find out if Emotion-Focused Therapy (Elliott et al., 2004) could be associated with the development of personal agency in hospice patients. The overall research programme in this thesis involved a mixed methods research design, consisting of three distinct studies, each with their own research objectives and questions. In this chapter, I initially present the key findings from my three studies and assess the answers they provide to address the research objectives and research questions. That is, the findings of each study will be considered, with focus on personal agency in hospice patients and conclusions will be drawn on whether the research questions were answered. I will identify the implications of my findings for theory and practice, and limitations of this research. Consideration will also be given to recommendations for future research, the original contribution of knowledge, and I will provide some reflections on my learning through the process of this research.

7.2 Summary of Findings

In Chapter 2, I defined personal agency as an inherent capacity that affords the human individual the opportunity to play a part in their self-development and adaptation through their own motivation and self-efficacy (Bandura, 1977, 1989, 1994, 1997, 2008, 2011, 2012, 2018; Gallagher, 2012). Across my three studies I gathered a range of evidence that provided insight into how and to what extent hospice patients experienced their personal agency.

The research question for my first study (Chapter 4) was **"How do hospice patients experience the nature of their control over their thoughts, feelings and actions during their dying process?"**

In this first study (Chapter 4), evidence indicated that hospice patients constructed themselves in accordance with the hierarchy of eight main categories of personal agency, ranging from level 0, non-agentic self to level 7, fully agentic self, that emerged in an earlier study (Campbell et. al., 2014). Also, I found evidence that showed that the same sub-categories, within the main categories, expressed the same subtle nuances as for the earlier study. That is, the categories of agency found in this study, were the same as those used to construct the hierarchy or rational-empirical model of eight graded main categories and sub-categories in an earlier study (Campbell et. al., 2014). As in the earlier study, categories represented individual levels of agency, based on how patients experienced their circumstances.

I further expanded the sub-categories to provide a more extensive understanding of how hospice patients experienced themselves as agentic. Evidence indicated that hospice patients had the ability to initiate control, with varying effect, on their personal circumstances, expressed in the construction of themselves as specific selves in accordance with the hierarchy of personal agency. That is, results indicated that patients' sense of personal agency was experienced at different levels, to varying degrees, with experiences demonstrating shared commonalities. Evidence showed that patients moved between different levels of agency, based on their experiences. Moreover, a cross-case analysis provided evidence that indicated that categories of personal agency were found to be robust and consistent across patients, suggesting that the hierarchy could be used to develop a reliable and valid self-report questionnaire and an observation measure. Thus, the evidence I found in Study 1was able to inform Study 2.

The research question for my second study (Chapter 5) was, **“Can the hierarchy of personal agency be developed into a set of valid and reliable measures (self-report and observation) for assessing hospice patients?”**

In this second study, evidence indicated that, with respect to face validity, the observation measure required no revision. Also, evidence showed a good level of internal consistency for the initial 53-item self-report questionnaire used in a pilot study with a sample of out-patients. Thus, evidence indicated that the items in the questionnaire were related to each other. Using pilot study data to reduce the self-report questionnaire, the findings demonstrated that the level of reliability was good for a sample of out-patients but was questionable for a sample of in-patients. The results also highlighted substantial to almost perfect levels of inter-rater reliability and scoring reliability for both out-patients and in-patients. The level of test-retest reliability was shown as good for out-patients, but not acceptable for the sample of 12 in-patients. Results demonstrated that the convergent validity, the correlation between the self-report questionnaire and the observation measure for 12 out-patients and 12 in-patients, ranged from almost zero to negative correlations. However, these results were the reporting of specific samples of hospice patients and thus, it is deemed appropriate to implement both the newly developed self-report questionnaire and the observation measure with a different sample of out-patients and in-patients.

The research questions for my third study (Chapter 6) were:

Can the new self-report and observation measures of personal agency be implemented for assessing personal agency with a new sample of hospice patients?

Is Emotion-Focused Therapy associated with the development of personal agency in hospice patients?

My third study, Study 3, was a longitudinal, mixed methods, multiple systematic case study design in which a) seven hospice patients were offered up to six sessions of emotion-focused therapy and b) the measurement of the construct, personal agency, was carried out using the revised 16-item self-report questionnaire and the observation measure. Evidence indicated that, with respect to the qualitative component in this study, the main categories and sub-categories of personal agency experienced by this sample of hospice patients supported the hierarchy of levels of personal agency that emerge in Study 1. In addition, evidence showed that whilst the expanded distinctions within sub-categories were not fully represented, they did provide a more extensive insight into how this sample of hospice patients experienced personal agency. Evidence indicated that this small sample of out-patients and in-patients had the ability to initiate action, in different ways and to different degrees, to exert influence over their personal circumstances. Evidence demonstrated that patients constructed themselves in the ways in which they experienced themselves and in accordance with the hierarchy of levels of personal agency. I found evidence that three out-patients and two in-patients did at some point in their sessions experience themselves as the fully agentic selves, the highest level of personal agency within the hierarchy of levels of personal agency. Also, evidence demonstrated that the hierarchy of levels of personal agency was found across cases.

With respect to the quantitative perspective in Study 3, the results indicated that, for the self-report questionnaire, a very good level of internal consistency reliability was obtained with a combined sample of four out-patients and three in-patients. This suggested that there was a good relationship between the items in the self-report questionnaire. Also, with respect to the self-report questionnaire, evidence showed that the level of test-retest reliability was excellent. Thus, the analysis showed that the reliability obtained by administering the self-report questionnaire over current and subsequent administerings was excellent. Also, with respect to the observation measure, I found evidence of almost perfect levels of inter-rater reliability for the main researcher and eight staff raters, with the values for scoring reliability showing substantial levels of reliability. However, the results demonstrated that there was a very small level of convergent validity between the self-report questionnaire and the observation measure. The analysis also highlighted that the level of convergent validity was not acceptable. The study findings indicated that three out-patients and one in-patient experienced change over the time they were tracked while receiving emotion-focused therapy. Evidence also demonstrated that the change was statistically significant with respect to one or more than one of the three different variables on the y-axis (SR and OR means; Chapter 6). Evidence indicated that two in-patients, who also received emotion-focussed therapy, did experience positive change, to varying degrees, but the difference between pre-treatment and post-treatment was small and could not be regarded as significant. In addition, results showed that one out-patient experienced change in a negative direction over the time she received emotion-focused therapy, suggesting a decrease in personal agency.

I believe that the weight of evidence generated by these three studies provides the foundation for proposing that a) the hierarchy of levels of personal agency may be used for measuring personal agency, taking into consideration limitations such as sample size, availability of patients and time and that b) emotion-focused therapy can be associated with the development of personal agency in hospice patients.

7. 3 Implications for Theory

7.3.1 How the Qualitative Components of Studies 1 and 3 Build on Existing Theories

I have identified and set out the main implications for theory arising from this thesis. The qualitative Study 1 (Chapter 4) and the qualitative component of Study 3 (Chapter 6) have similar implications for theory. Likewise, the quantitative Study 2 (Chapter 5) has implications for theory that are shared with the quantitative element of Study 3 (Chapter 6). The findings of Study 1 and Study 3 build on existing theories with respect to personal agency (Bandura, 2006, 2008, 2012, 2018; Gallagher, 2012). These findings reveal a new insight into personal agency, with respect to how it is experienced by hospice patients, out-patients and in-patients. That is, hospice patients construct themselves as specific selves, with each self representing a specific level of personal agency, based on their individual experiences of living every day with a life-limiting illness. Moreover, results demonstrate that patient experience of personal agency can be represented by a hierarchy of levels of personal agency, ranging from 0 to 7, with zero identifying a level of no agency, and level 7 indicating that the patient is fully agentic. This implies that patients adapt to varying degrees, to adversities such as a life-limiting illness. These results fit with the theory of human agency (Bandura, 2006; Gallagher, 2012), whereby hospice patients, out-patients and in-patients, are not merely bystanders of their experiences but are pro-active initiators of action that can influence their own functioning and circumstances.

Moreover, in accordance with Bandura in his ‘Toward a Psychology of Human Agency” (2006), the results of this research are in keeping with the biological, evolutionary, and non-deterministic perspectives. That is, according to Bandura (2006), the genetic endowment of patients provides the physiology that allows them to purposefully influence their functioning and life circumstances. Also, the evolutionary emergence of the ability to symbolise, an ability unique to the human individual, helps patients to re-process their emotions. In keeping with Bandura (1986, 2006, 2018), symbolisation allows hospice patients to embrace new aspects of meaning, giving rise to a sense of control over their living. The findings from this PhD support the theory that as both non-deterministic and biological, hospice patients can experience themselves as both agentic and subject to different determinants (Bandura, 2006; Rogers, 1951, 1959, 1961) such as life-limiting illnesses. Moreover, the results demonstrate that when hospice patients experience an incongruity between themselves and their environment, they try as best they can to alter the ways in which they choose to act (Bandura, 2006, 2008, 2012, 2018; Rogers, 1951, 1959, 1961; Ryan & Deci, 2000). This fits with the theory of Rogers (1967) that maintains that when the person attains a level of self-understanding regarding their emotions, thoughts and actions, they can choose how best to deal with circumstances that give rise to pain and dissatisfaction. Findings indicate that through their capacity for personal agency, out-patients and in-patients become motivated to work out ways to overcome environmental constraints by changing their behaviour to respond to the challenges of their environments.

However, to change their environments, out-patients and in-patients may, in keeping with the theory of collective agency (Bandura, 2006, 2020), seek help from those they regard as helpful experts. Whilst this may see patients hand over their autonomy to or engage in active collaboration, this construction by patients of themselves as the collective self is an indication of an increase in their self-awareness and personal agency, although not necessarily observable from the outside. Results indicate that in line with the concept of collective agency (Bandura,

2020) patients become aware that they need help but, as they may have neither the knowledge nor the expertise required to make decisions about their illness and treatment, they choose to relinquish their autonomy to or to actively collaborate with helpful experts. These actions taken by patients help them to gain information, become motivated and enhance their confidence and ability to become the creators of their experiences. Whilst choice allows patients to have influence over their situation, their circumstances may restrict their choice of options and thus, patients may experience the anxiety coming from what Sartre (1974, 2003) refers to as the accountability of choice. Moreover, the choice made by patients does not always have the desired result and yet, patients are motivated to choose to replace what they experience as bad feelings by feelings that make them feel good (Greenberg, 2015). Thus, whilst patients are pro-active in creating their future, in accordance with Kierkegaard (1941) and Sartre (1974, 2003) they must take responsibility by owning their actions.

The findings of Studies 1 and 3 also demonstrate that the trauma experienced by hospice patients because of their diagnosis, prognosis and the associated physical and psychological effects of their illness and treatment, can give rise to extreme emotional arousal, leaving them overwhelmed by feelings of panic and fear and with vivid memories frequently arising in their experience. This fits with the theory of trauma of Greenberg and Paivio (2003), who posit that trauma can bring about the break-down of fundamental beliefs about self and others, the loss of the capacity to self-soothe and the intrusion of memories, feelings and thoughts associated with the trauma. However, the findings of Studies 1 and 3 also demonstrate that hospice patients are driven towards growth and self-enhancement (Angyal, 1941; Goldstein, 1939; Jeannerod, 2003; Joseph & Linley, 2008; Rogers 1951, 1959; Ryan & Deci, 2000; Seligman, 2011; Tedeschi & Calhoun, 2004) through an innate capacity to become more and more of their potentialities. This supports that growth is not disorganised but rather has directionality (Bandura, 2006; Gallagher, 2012; Rogers 1951, 1959) and is in keeping with the theories of post-traumatic growth of Joseph & Linley (2008), Rogers (1951) and Ryan & Deci (2000). However, post-traumatic growth does not result from the trauma itself, but through the struggles and efforts of patients in their dealing with their cruel, unwanted and unavoidable adversity. The findings in Studies 1 and 3 demonstrate that following a traumatic event like a life-limiting illness, out-patients and in-patients experience new-found understandings, create new meaning, renew or alter life priorities, have a greater appreciation for life, new possibilities, new beliefs, and experience an increase in their sense of personal agency (Campbell et al., 2014; Cordova et al., 2001; Jeannerod, 2003; Joseph & Linley, 2008; Rogers, 1951; Ryan & Deci, 2000; Seligman, 2011; Tedeschi & Calhoun, 1995, 2004, 2006, 2014).

Whilst the concepts of resilience and post-traumatic growth may be viewed as similar, resilience involves a return to the baseline level, with post-traumatic growth involving a positive change that goes beyond the previous level of psychological functioning (Layne et al., 2014). Findings show that hospice patients can adapt in the face of adversity, and this resonates with the theory of Davidson (2000). Moreover, Fredrickson (2001) maintains that adaptation takes place through the overturning of the impact of painful or distressing emotions, with Greenberg and Watson (2006) proposing that it is through the transforming of their emotions that the person can experience themselves as resilient. Also, according to Stockwell and Charney (2012), resilience is likely to exist on a continuum that may present itself in differing degrees across multiple domains of life. Thus, resilience is relative and dependent on the circumstances, including the environment. Findings indicate that hospice patients adapt in different ways and at different rates, constructing themselves as specific selves dependent on their experiences that fluctuate and can alter.

However, hospice patients can feel threatened by the fear of annihilation, giving rise to death anxiety. The theory of terror management (Greenberg et al.,1986, 2008) posits that the person may feel threatened by their own death and therefore adopt worldviews that protect their self-esteem and sense of worthiness, allowing them to believe that they have an important role in a meaningful world. Whilst, according to the theory of Greenberg et al. (1986, 2008) the awareness and management of death can give rise to behaviour that may be disagreeable, Vail et al. (2012) maintain that death awareness can give rise to the promotion of personal growth that is experienced as rewarding for the person. The findings of Studies 1 and 3 agree with both of these theories. Moreover, the results show that patients work hard to give meaning to their lives (Syet et al., 2023) and when patients choose to live authentically, findings indicate that they are better prepared to face their death. Also, the studies reveal that when hospice patients sense that their locus of control is internal, they experience themselves as more agentic, with action initiated by them "*... I can do this myself... I'm in a good place just now*." Thus, depending on the locus of control, hospice patients may believe that an outcome is decided by their personal actions. This is in line with the existing theory of Rotter (1966) who refers to locus of control as a person's perception about the underlying significant causes of events in their lives. Furthermore, findings of Studies 1 and 3 fit with the theories of Yalom (1980, 2008) and Solomon (2015). That is, death-anxiety may result in adaptive action as patients look for ways to change their experience in order to seek meaning, tranquillity, contentment, resilience, a sense of relatedness and become less fearful as their death approaches (Frankl, 2004). A search for meaning provides patients with an understanding of the nature of their existence and provides them with the sense that their lives are significant and purposeful, allowing them to interact authentically with others (Frankl, 2004).

Moreover, the findings of this research show that out-patients and in-patients believe that, through their own personal ability, they can exert the influence needed to bring about their desired outcomes. Moreover, hospice patients demonstrate their self-efficacy with varying effects on their living, with those patients who demonstrate confidence in their self-efficacy better able to face and challenge their adversity. These findings support the theory of self-efficacy as proposed by Bandura (1977, 1989). Also, my findings indicate that patient desire to live is promoted by hope. Through hope, patients consider what can be, with reasonable confidence that they can realise what they desire. That is, patient motivation sees them continue to work toward a future, even in the face of a challenging life-limiting illness. In his theory of hope, Snyder (2010) suggests that hope is composed of three main components; the approach to life in a goal-oriented way; pathways that enable different ways to achieve those goals; and agency, the belief that change can be instigated and goals chieved. For Snyder, hopeful thinkers are perceived as those individuals who have clear goals, imagine workable options towards achieving these goals and persevere even when faced with adversities. Moreover, Snyder maintains that hope may be perceived as a human defence mechanism, that is, a state of mind that can help the individual to deal with the life adversities, allowing the individual to move in a positive direction. For example, patients in Study 1 (Chapter 4) expressed as follows: “hopefully is (research) going to help lots of other people” (out-patient OP2); “maybe able to get to and from the bathroom.” (in-patient IP3). In Study 3 (Chapter 6) patients communicated thus: out-patient OP1, “… blood clot _____ it could move… still sitting… a number of months… so hopefully…” (out-patient OP1); “I’d love to be here… see how they (grandchildren) progress in life.” (out-patient OP2).

7.3.2 How Might Emotion-Focused Therapy Promote Personal Agency in Hospice Patients?

The concept of personal agency is pivotal to this research, and, from a humanistic perspective, patients are basically free to choose what to do and how they construct their world. That is, as an agent, the human individual can exert influence over their functioning and the course of events through their own actions (Bandura, 2011). However, a limitation, like a life-limiting illness, can stifle agency, with the patient not able to make meaningful choices. In this research, the treatment of choice was Emotion-Focused Therapy (EFT). All hospice patients, eight out-patients and seven in-patients, who took part in Studies 1 and 3 received EFT as the treatment. EFT was chosen because this kind of therapy upholds that emotions are at the core of human existence. Elliott et al. (2004) posited that the emotions of the person are the regulators of their mental functioning, facilitating both thought and action, with Greenberg (2015) proposing that emotions are the main reference system by which the person orients themselves in the world. The principal premise of emotion-focused therapy is that emotion is significant to the construction of the self and an essential determining factor in the process of self-development (Elliott et al., 2004).

That is, emotions inform the person about what is important to them, with the knowledge that is made available important for helping them to assess their circumstances and act in a way that appropriately meets their needs and desires. Emotion is a brain phenomenon greatly different from thought and has its own neuro-chemical and physiological basis (Greenberg, 2015). Moreover, as regulators of mental functioning, emotions firstly establish goal priorities and organise the person for specific actions (Frijda, 1986). Secondly, emotions set the goals for cognitions and action to accomplish. In essence, emotions inform the person that an important need, goal, or value may be enhanced or damaged in a situation. Thus, as emotions act as a guide as to what the person needs or wants, affect is a key influence in human conduct (Elliott et al., 2004; Pascual-Leone, 1992). As an affective state, tension can be associated with dissonance, instability, or uncertainty. Thus, when associated with distressing emotions like fear or emotional pain, it may be accompanied by discomfort and uneasiness that may create a desire for more stable and consistent states and feelings of expectation (Lehene & Koelsch, 2015). This may see the person seek relief through talk and action. That is, emotion is basically about motivation and action, setting goals and preparing the person for action. Alternatively, cognition is about knowledge and action.

For the most adaptive outcome of action, the person needs cognition to help them make sense of the situation, and, by way of reasoning, the individual can decide which option to enact to best achieve their goal or resolve their circumstances (Elliott et al., 2004). Moreover, the person, in enhancing their environment, challenges themselves to maintain a sense of coherence and strives to become more complex. This helps the person to respond more confidently and flexibly in their pursuit of life projects important to them. Gaining an understanding of their emotional states, level of motivation and performance provides the person with guidance for self-regulatory control. Thus, EFT was elected as the therapy to help out-patients and in-patients to change by enabling them to make sense of their emotions through awareness, expression, regulation, reflection, and transformation (Greenberg, 2015). With its humanistic beginnings, EFT supports the humanistic principles of a) experiencing, b) agency and self-determination, c) wholeness, d) pluralism and equality, e) presence and authenticity, and f) growth (Elliott et al., 2004).

Moreover, as an intervention, EFT informs how emotion organises experiencing through *emotion schemes* (Greenberg, 1993; Greenberg & Paivio, 2003), the basic psychological unit of emotional experience and meaning, and how emotional processes function in the human individual. Emotion schemes are constructed from the person's inherent mode of responding and their past experience (Greenberg & Paivio, 2003). These interact with the current circumstances and generate current experience. However, emotion schemes are not only the basis of normal human functioning: they may be a source of human dysfunction. The function of emotion schemes is to discern incoming information from the environment to give direction to the emotional sense of the individual and their position relative to the world. Whilst emotion schemes are not straightaway accessible in awareness, they can be accessed through the experiences that they generate. However, to be identified, emotion schemes are firstly required to activate an experience relating to a particular person or situation. Once activated, it is important that these experiences are explored and expressed before reflected upon (Greenberg & Safran, 1987).

In addition, activation gives rise to emotion schemes that are continually constructed and reconstructed as the individual interacts with their circumstances. Hence, over time, emotion schemes are liable to change or vary across individuals and even within the same individual. As such, emotion schemes are highly individual, resulting from emotional memories, hopes, expectations, fears and knowledge acquired from lived experience. On that basis, a personal or emotion scheme represents a record of subjective lived experience and is a construction of the individual's own experience and action. Thus, as well as emotion, the combined elements of affect, cognition, motivation, and action, provide each individual with a unified sense of themselves and the world. Based on that premise, the emotion scheme is not a static construction but, instead, is an idiosyncratic, active process that in time is action-oriented, having effect on experience, behaviour and interaction with respect to a particular situation.

However, whilst it is emotions, an adaptive form of information-processing and action readiness, that informs patients of their circumstances to facilitate their wellbeing (Greenberg & Safran, 1986, 1989), it is the unpleasant emotions that bring attention to the person's needs and desires. Thus, emotions can give information that may be useful or detrimental. Information is useful if the emotion fits the circumstances, like the fear of threat to existence due to life-limiting illness, as this can help the person to meet their needs (Elliott et al., 2004). Emotions that give detrimental information such as helplessness and vulnerability are maladaptive and require to be changed. However, when these disagreeable emotions last and the circumstances that gave rise to them become intense, the patients sense themselves as disconnected from an adaptive and meaning-making system (Frijda, 1986; Izard, 1991).

In his theory of person-centred therapy, Rogers proposed that a facilitative climate in the form of a helping, connected relationship, may be necessary for the process of development and growth (Rogers, 1951, 1957, 1961). Thus, whilst the capacity to respond to a life concern, like a life-limiting illness, lies within the person, facilitation through a therapeutic relationship can provide the sufficient and necessary conditions required to allow psychological freedom and safety, enabling the individual to experience personal power and move towards growth (Angyal, 1941; Goldstein, 1939; Rogers, 1957, 1961). The provision of psychological safety through an “I-Thou” meeting (Buber,1958; Schmidt, 2000, 2001) can help to facilitate the moment-by-moment processing of patients’ experience. As an intervention, EFT provides a therapeutic relationship, with the therapist following and guiding the client’s emotional processing in different ways at different times. When the client can experience an empathic, safe, and genuine connection with the therapist, centres in the brain that process emotions, are affected and new possibilities are made accessible for the client Greenberg, 2015).

In therapy, the client is encouraged by the therapist to attend to their moment-by-moment experiencing to promote the development of more adaptive functioning. This is achieved through the therapist helping the client to focus on their felt sense and emotions and, initially, change involves acceptance of, for example, emotional pain. Emotions are connected to the needs of the individual and working through them within a curative relationship helps the individual to change emotion with emotion (Elliott, 2016; Greenberg, 2015). Emotional change is crucial for lasting cognitive and behavioural change. Moreover, EFT proposes that first the individual feels and then they think, that is, “I feel, therefore I am’. Attainment of personal standards provides the individual with self-satisfaction (happiness in EFT terms) whilst failing to meet those personal standards sees the individual feeling discontent and disapproval, even anger at self or shame. Progress can take the form of a) changing goals; b) perseverance toward their original goal; c) lowering of their goals or expectations; or d) deciding on a more challenging or relevant goal.

Moreover, the person can be motivated to set goals by attending to and clarifying concerns through emotional expression (Greenberg, 2015). However, people do not fully access their experiencing until they can express it, verbally or non-verbally. In the current studies, bodily sensations and nonverbal expressions help patients to discover and own what they felt (Elliott et al., 2004). Also, it was important for patients to regulate their emotion, so that they could tolerate, be aware of, express in words, and use emotions adaptively to regulate distress and to promote needs and goals (Greenberg, 2002). According to Rennie (1992), it is the person's capacity to symbolise their inner experience, that is, to know and to understand it better, that promotes self-regulation and control. Thus, conscious experience is created and transformed by representing it in words (Taylor, 1990); in this way experience can be altered. However, the person assesses and responds to information about their environment at a preconscious level. Thus, unverbalised experience is less available to conscious awareness, symbolisation and reflective scrutiny (Watson & Greenberg, 1996).

Distressed emotions were experienced by some patients as under-regulated and thus they experienced themselves as overwhelmed. Others were over-regulated, becoming distant from their emotions. From an EFT perspective, it is self-reflection that allows the person to stand back from their experiencing and make sense of the situations that gave rise to the emotions. When patients began to reflect, they were able to develop new narratives to explain their experience (Greenberg & Angus, 2004). Based on this, patient circumstances could be understood in new ways, leading to the re-evaluation of experiences that gave rise to new views of themselves and the world. Developing a new outlook on what was important for the hospice patients, involved fundamental change in attitude and for hospice patients, reflection on their close-to-death experiences, which brought about changes in their approach to life. Moreover, in accordance with the EFT perspective, a safe therapeutic relationship characterised by affect attunement, validation of patient experiences and empathic responses (Elliott et al., 2004) allowed painful emotions to be made accessible and to be changed by adaptive emotions.

In EFT, change or transformation is the changing of emotion with emotion and specifically transforming maladaptive emotions like helplessness with other adaptive emotions (Greenberg, 2002). This requires patients to be able to remove an emotion by "an opposed, stronger emotion" (Spinoza, 1967, p. 195). That is, another feeling is used to change or undo it. Thus, and in accordance with Elliott et al., (2004), maladaptive emotions require to be replaced or changed by accessing primary emotions to obtain their adaptive information and ability to organise action. EFT tries to change the focus by emphasising the role of the experience of adaptive and maladaptive emotion in therapeutic change. In time, the co-activation of the more adaptive emotion, along with its response to the maladaptive emotion, helps change the maladaptive emotion. Thus, therapy involved the changing of the emotional experience and the narratives of patients in which their experience was embedded (Greenberg & Angus, 2004).

7.3.3 Emotion-Focused Therapy and the Hierarchy of Levels of Personal Agency

As an EFT therapist, I see each out-patient and in-patient as the expert on their personal experiences and as the agent who constructs the meanings through which they live their life. As results indicated, hospice patients, both out-patients and in-patients, constructed themselves as specific selves based on how they experienced their circumstances. Faced with physical and emotional pain, patients experienced that their autonomy was stifled or even destroyed, giving rise to a lack of agency, communicated as a lack of control. Within the lowest category in the hierarchy, that is, *non-agentic*, hospice patients expressed an experience of themselves as having no capacity to initiate change through their own actions to generate alternative ways of constructing their experience. Words used by most patients communicated a sense of being reduced to the status of an object and thus *objectified* and non-agentic. Patients expressed similar experiences of becoming profoundly discouraged about their world, with patients in despair due to the loss of hope and experiencing defeat, devastation, helplessness and powerlessness.

These emotions are maladaptive (Greenberg & Paivio, 2003) and hinder patients from coping constructively (Elliott et al., 2004). This may see the patients become stuck and see no other possibilities, with the construction of alternatives disrupted. Moreover, secondary reactive emotions (Elliott et al., 2004) may result in the primary adaptive emotion being hidden by their reaction to the primary reaction. This can lead to actions that are not relevant for the current circumstances, with patients experiencing helplessness and isolation becoming stuck in a maladaptive state of uncontrollable helplessness. As an EFT counsellor, I tried to help patients to change their experiences of maladaptive emotions into primary emotions. That is, my goal was to help patients to acknowledge and experience the primary adaptive emotions and needs that they previously avoided or did not symbolise (Greenberg & Watson, 2006). However, it is the need and action tendency associated with the primary emotion that gives rise to adaptive action, promoting motivation and direction for change and a new way of responding.

For all out-patients and in-patients life had changed, and they had become more physically restricted, sensing themselves as *limited*. Consequently, they experienced themselves as troubled, puzzled, and uncertain. However, as out-patients and in-patients experienced themselves as *reflexive*, they sensed an increase in their self-awareness and in their internal agency, albeit an internal agency that was not translated into observable action. For example, with their increase in self-awareness and in personal agency, patients pursued self-preservation as they became displeased with their new circumstances, including their new identity. Patients acknowledged their identity had changed or even been replaced by an unknown other. This gave rise to a lack of personal control. For example, in Study 1 (Chapter 4) patients expressed as follows: (out-patient OP5*), "Oh, it changed my life completely... completely... I really do miss it"*; (in-patient IP1), "*I just feel... I don't feel me*." Similarly, in Study 3 (Chapter 6) (out-patient OP3), "*I... see changes… accepting… I canny (cannot) go as fast… I used...*" As a result of experiencing troublesome and disruptive change, patients became defiant, resisting to comply with their illness and self-defeating attitudes. Instead, patients aimed to maintain their independence by standing up to illness and death and by avoiding emotional disengagement. This is illustrated in Study 1 as follows (out-patient OP2*), "I'm here... I'm not a memory; "Something in me fires me... You've had enough of me... you are not going to win."* Similarly, for Study 3, (out-patient OP3), "*I look in the mirror… it's still me.*"; (in-patient 1P1*), "protects me… could be being a realist a pragmatist ... protective shield against…"*

Also, an increase in personal agency saw all out-patients and most in-patients intentionally try to generate ways of constructing their experience. Through the self-representation of the *collective self*, patients chose to either relinquish their autonomy to experts knowledgeable in their illness and treatment, or to engage in meaningful collaboration with them. As patients sensed an increase in their personal agency, they became more proactive in their living. Whilst most out-patients and in-patients did sense an increase in their self-awareness, their agency continued to be experienced as internal. Results indicated that patients had similar experiences of themselves as the *reacting self*, reacting in ways that they believed helped them to better influence what was happening to them.

As self-awareness increased, reacting as avoiding gave way to reacting in the forms of coping, and of evaluating the self from a moral standpoint. Results indicated that at this level of agency in the hierarchy, there was a deepening sense of self-awareness, with out-patients and in-patients expressing similar experiences of dissatisfaction with their circumstances. As patients were not content to live their lives shaped by a life-limiting illness, they communicated the desire to become motivated to make changes in their living and chose to construct mental imagery and anticipated desired future experiences. Out-patients and in-patients were no longer mentally dominated by their unwanted circumstances but, instead, chose to attend to narratives that were influenced by them. Through wishing, hoping, and wanting, patients worked towards a future that, if even it could not be realised, promoted a new, more positive way of thinking. Whilst out-patients and in-patients represented themselves as *willing and wanting,* and goal-oriented, they did not implement action but experienced their personal agency in the form of action tendencies. These action tendencies urged patients to carry out behaviours that are associated with specific emotions. For example, when patients experienced fear, the associated action tendency involved an urge to escape from what was causing fear. Thus, as action tendencies helped patients to move towards their goals, they expressed a desire to live and believed in their own self-efficacy.

Results indicated that as the *enriched selves*, most patients felt a need to re-connect with their past selves; saw nostalgia as a stimulus for promoting wellbeing; and accepted that life was finite, with many patients contemplating the concept of an afterlife. Also, out-patients and in-patients chose to take part in life, communicating a sensed increase in their self-confidence and, by further assessing what was important for them, they turned their attention to intrinsic goals, sensing eagerness, achievement, and self-fulfilment. Whilst patients knew and accepted that they could not escape from their diagnosis and prognosis, they generally made the decision that their *givens* would not get in the way of their choice to live as the *fully agentic selves*. That is, hospice patients chose not to be victims of their diagnoses and prognoses, but rather, optimistically and realistically, chose to engage in life to their best ability. The findings of Studies 1 and 3 both indicate that most out-patients and in-patients were able to construct themselves as fully agentic. In Study 1, (out-patient OP5), *"I have achieved a lot... haven't I?... I... have done well... mentally and physically... both... not just the one... drugs will control the pain... but it's up here... it's yourself... now I feel I'm in control up here now too... no fear up here anymore... no fear now... the cancer in the legs and that... I never think about it... I'm a happier person now... I really am... and I want to do things now that I didn't"*; Study 3, (in-patient IP1), *"… future… day at a time… never know… disease… kill you… complications with drugs… infections… viruses… how long I've got... could be tomorrow… I take a day at a time… just keep going that way.*

The expanded sub-categories provided more discerning distinctions of personal agency as experienced by hospice patients. These distinctions indicated not only the extent to which patients reflected on the experiences of their circumstances but how they chose to communicate these additional nuances using metaphor and reification (Morrison, 2009) the changing of something abstract into something more real, to represent their experiences as more concretely. For example, out-patients and in-patients expressed how the experience of being disempowered, ignored, and discarded left them feeling weak, forsaken, and unable to have influence over their circumstances. Out-patients and in-patients communicated that the effects of illness and treatment affected them physically (pain, exhaustion, sickness, loss of hair) and psychologically (helpless, vulnerable, and ineffective). This suggested that patients were able to look closely at what was happening to them. All out-patients and most in-patients were able to communicate that the experience of their illness had resulted in their identity becoming either transformed or even replaced with another. Results indicated that both out-patients and in-patients did experience themselves as trying to mentally escape from or play down their illness and associated effects through their use of defence. For example, in Study 3, (out-patient OP1), *"I joke about it…"* while (in-patient IP3), "*I talk about normal things*."

However, as patients assessed their personal resources, physical, psychological, and social, they were able to assess what held value for them. They communicated that their experience of the effects of illness and treatment or surgery did not only give way to dissatisfaction and protestation (affected badly, aggrieved) but gave rise to positive, helpful experiences (improvement, looking after themselves) and from both physical and psychological perspectives. Results indicated that out-patients and in-patients showed respect for others (didn't want to worry anyone) through expressions of gratitude (help), and appreciation (thanks). In addition, out-patients and in-patients indicated that they did have regrets (things could have been avoided). As dissatisfaction grew, most patients, through the use of 'I", and exemplified as the *fighting self,* communicated a sense of being able to deal with their circumstances and accomplish tasks through their own ability. As out-patients and in-patients experienced achievement, they were able to experience joy, find enjoyment in engaging in activities and to experience an eagerness, an enthusiasm and a willingness for life and living.

During the process of change, I helped patients to access new subdominant emotions (e.g., sadness from loss) by shifting attention to different aspects of the circumstances and by focusing on what was needed. Also, I used imagery to help them access new emotion to change how they saw things. This helped patients to undo their previous way of processing, allowed them to challenge their perception of themselves with respect to the maladaptive emotion, with the result that its hold on them became less. For all patients time was limited, and they were aware that, whilst they could neither avoid nor change their circumstances, the choices they made could enhance what time they had remaining, providing a sense of dealing with their circumstances and accomplishing a task. This illustrates how the human individual is autonomous and competent, promoting self-development, adaptation and change (Bandura, 2012). However, this was influenced by the patient's personal self-efficacy that was able to affect the direction of their development. A basic tenet of emotion-focused therapy is that the human individual has an inherent tendency toward maintenance, growth, and mastery (Greenberg et al., 1993; Rogers, 1959).

7.3.4. Development of a Self-report Questionnaire and an Observation Measure for Assessing Personal Agency in Hospice Patients, Building on Existing Theory

Study 2 was able to bring together existing theory for the development of two new measures for assessing personal agency in hospice patients, a self-report questionnaire and an observation measure. The first link to existing theory was with that of personal agency, defined as an inherent capacity that allows the human individual to play a part in their self-development and adaptation through their own motivation and self-efficacy (Bandura, 1977, 1989, 1994, 1997, 2006, 2008, 2011, 2012, 2018). The aim of the study was to design valid and reliable measuring instruments that could assess how hospice patients experienced personal agency in relation to having influence over their experiences and circumstances. That is, through the development of a self-report questionnaire and an observation measure hospice patients would be able to respond to items on the self-report questionnaire and be observed. As the scores from these measures represented how hospice patients experienced their circumstances, the data could be used to inform clinicians of their needs. Thus, by developing these two measures, clinicians would be able to track personal agency in hospice patients with a view to implementing treatment plans. This aim was consistent with the theory of measurement whereby measuring a particular topic and expressing it in numbers provides knowledge about the topic

(William Thomson, Lord Kelvin, 1889). Moreover, the theory of logical positivism, empiricist and anti-realist approaches to the theory of measurement supported *representability* (Krantz et.al., 1971; Luce et. al., 1990). This characterised measurement as the mapping between two relational structures, an empirical one and numerical one (Krantz et.al., 1971; Luce et. al., 1990). Representational theories of measurement advocate an abstract framework for scale construction and meaningfulness of representation (Narens, 2002).

The development of the two measures began with the discovery of the hierarchy of levels of personal agency (Campbell et al., 2014). This hierarchy represented eight levels of personal agency, ranging from Level 0, the non-agentic self to Level 7, the fully agentic self as expressed by hospice out-patients. However, this hierarchy was a conceptual representation of the latent concept of personal agency. As personal agency is an abstract concept, it could not be quantified directly and, thus, this study looked to the theory of psychometrics that measured and numbered the operations of the mind (Rust & Golombok, 2009). Psychometrics as a scientific discipline is concerned with how psychology research measures of designated phenomena arrive at meaningful conclusions (Jones & Thissen, 2007). Psychometrics involved the theory and method of psychological measurement that enabled the concept of personal agency to be quantified (Jones & Thissen, 2007) and that required making personal agency measurable. To be measured, the research linked to the theory of conceptualisation and operationalisation. That is, conceptualisation and operationalisation, the first two steps in the measurement process, defined personal agency according to existing literature.

However, there appears to be no existing literature regarding the measurement of personal agency in hospice patients. The conceptual definition provided a precise definition of personal agency that saw the human individual not just as a product of their givens but as pro-active, motivated and with belief in their personal self-efficacy. The operational definition set out specificity, type of instruments to be developed and, the statistical tests that would ensure reliability and validity and thus, promote accurate research. Operationalisation paved the way for the design of this research, based on my worldview perspective, as researcher. That is, my assumptions of ontology, and epistemology informed the research to reflect how personal agency was experienced by hospice patients. This led to a mixed methods research (MMR) design, with its focus on trying to provide an insight into the understandings of the experiences of hospice patients in a real-world context. That is, in accordance with the theory of MMR, quantitative and qualitative approaches complemented each other by helping to negate potential weaknesses and limitations through the obtaining of only one form of data. In line with a quantitative approach, the available choices of quantifying personal agency were a self-report questionnaire and an observation measure. Thus, this exemplified another uniting of theory through the election of a Likert-type scale that provided a way of looking at the nature and ways of how hospice patients experienced personal agency. The election of a 5-pont Likert-type scale, allowed hospice patients to respond to items that were based on intensity as opposed to “agree, disagree”. Moreover, responses to items quantified the intensity of experiences, ranging from zero to four. In addition, the theory underpinning the Behaviourally Anchored Rating Scale (BARS) that provided the basis for the observation measure, defined behaviours and offered concrete, specific examples of actions at varying levels of personal agency. Also, items in the self-report questionnaire and descriptors in the observation measure were verbatim responses provided by out-patients in the earlier study. All these theories, referred to in existing literature, were brought together in the creation of two measures and, in accordance with the theory of a pilot study, the measures were tested to ensure they were valid and reliable.

7.3.5 Implementation of the Self-report Questionnaire and the Observation Measure Bringing Together Existing Theory

Study 3 was a mixed method, multiple systematic case study design that brought together the theory associated with mixed methods research and multiple systematic case studies. A case study is a detailed description and assessment of a specific situation in the world created for the purpose of deriving generalisations and other insights from it (Yin, 2018). When one study contains more than a single case, here a hospice patient, the study is a multiple case design. The evidence from multiple cases can be taken as more robust but it is important that each case retains its uniqueness. Also, case studies are said to be "naturalistic" as cases are studied in their natural contexts. Moreover, case studies within mixed methods research, allow the researcher to address more complicated research questions and to collect a rich and strong array of evidence than can be achieved by any one method alone. A systematic case study involves the gathering of data from multiple sources such as self-report questionnaires, observation measures and counselling sessions and are a method for developing research evidence-base (Widdowson, 2011). For example, systematic case studies provide valuable information on the effectiveness of change of interventions.

This current PhD extended the work of an earlier study (Campbell et al., 2014) by seeking to discover whether the abstract concept of personal agency in hospice patients could be measured within a brief course of therapy. With respect to a search of existing literature, it appeared that this current study was the first investigation of measuring personal agency in hospice patients. Moreover, this research used existing theories in a creative way to add to existing knowledge and, as prior research studies relevant to this thesis could not be found, it was necessary to develop a relevant research typology as in the naming of categories. Thus, this research has tried to expand knowledge by attempting to address the research gap, the unanswered questions relating to personal agency in hospice patients, a field with a lack of existing research. Moreover, this study has attempted to demonstrate that personal agency experienced by hospice patients could be measured through the newly developed self-report questionnaire and observation measure.

7.4 Implications for Practice

The findings from this research have the potential to affect practice within a hospice setting. For example, the hierarchy of levels of personal agency was shown to be a useful basis for two measures for assessing personal agency in out-patients and in-patients within a hospice environment: a self-report questionnaire and an observation measure. These two measures showed their potential to provide a common language for information exchanges among healthcare professionals within an inter-disciplinary team, promoting the implementation of treatment plans as appropriate. In addition, these two measures showed their potential for tracking the degree of change in personal agency as reported by patients, based on moment-by moment experience of their life-limiting illness. Grounded in the illness experience, embodied and relational, both measures have the potential to assess outcome by providing on-going evaluation of change along a continuum of agency. Thus, care providers could attend to the needs and case formulation, personalised to the patient's unique situation. Moreover, as the hierarchy provides a visual representation of the concept of personal agency as experienced by hospice patients, it has the potential to be used in the training programme of clinicians and counsellors.

The self-report questionnaire was evaluated by hospice patients as easy to read, understand and use; was not too long; did not give rise to fatigue. Also, as part of their evaluation, patients communicated that the format of the self-report did help them to ask questions and enter discussion about their circumstances, including how they prepared for their end-of-life. Moreover, staff raters evaluated the observation measure as easy to understand and implement; it was not time-consuming. Raters supported the concept of personal agency in hospice patients and were interested to understand the purpose of the research. Moreover, raters from both the out-patient and in-patient units expressed that taking part helped them to gain a deeper insight into how patients experienced and communicated their life-limiting illnesses.

Emotion-Focused Therapy appeared to be useful as a treatment for developing personal agency in hospice patients. The case studies provided evidence that EFT may promote personal growth in a difficult situation. It also appeared to give rise to new attitudes and views in patients; enabled them to deal with stressors; encouraged self-soothing/self-validation; helped them enhance their self-efficacy and face challenges and existential issues including meaninglessness, loss and death.

7.5 Implications for Policy

The implications of the findings of this research for influencing policy could be implemented through active co-operation with key decision makers within hospice settings. The use of the hierarchy of levels of personal agency could be adopted by policy makers for use by clinicians and counsellors. Also, the use of the two measures could be extended by their adoption by policy makers in other palliative care settings, such as palliative care units in hospitals and in social care environments, to inform decision-making for treatment plans and case formulation. Both the self-report questionnaire and the observation measure have the potential to be used by healthcare professionals as they are evidence-based and aimed at improving the well-being of hospice patients. Moreover, the self-report questionnaire may be used to assist during discussions about diagnosis, prognosis, treatment, and surgery. In addition, the self-report questionnaire may be used to assist with difficult discussion with family members.

7.6 Research Limitations and Strengths

This research is subject to some limitations. The first limitation concerned how the confounding variables of severity and progression of illness, levels of anxiety coming from physical and psychological impact of the effects of illness and treatment/ surgery, fatigue, and hospital appointments affected the availability of patients and consequently the gathering of data. The availability of patients, out-patients and in-patients, as potential participants to be identified to take part in the research was limited. Moreover, having given consent to take part, meeting with patients within an arranged schedule was not always feasible and sometimes resulted with the agreed number of six sessions having to be shortened and or reduced. This sometimes resulted in obtaining data from only one, two or three sessions with some of the patients, leading to the reduced access of data and the need for the identification of other patients as was appropriate. Also due to the fluid nature of their illness, patient responses were not always consistent and had an implication for the results obtained from statistical testing. For example, error variance or unexplained error indicates how much random variance is expected within scores. Extraneous variables such as patient mood, personality traits (Cuijpers et al., 2010), time of day a test is administered (Fleeson, 2001) can influence the error variance and can determine what is statistically significant or is due to chance. This type of variance cannot be predicted when the study is being carried out. Also, there may be a decrease in statistical power, the likelihood of a significance test not detecting an effect when there is one, due to a small sample of participants or a high standard error (Button et al., 2013). The standard error represents the variability of a sample population and thus, identifies whether sample data is an accurate indication of the entire population. A high standard error indicates that the sample means are spread around the population mean and thus the sample is not representative of the population.

However, it is important to note that the data of Study 1 provided the basis of Study 2. Nonetheless, as the sample size was small, the number of sessions was small and in Study 3, a limited sample of patients meant that statistical tests were carried out with the combined sample of four out-patients and three in-patients. Also, the ability to track the change in patients' experiences became more difficult. A small sample size can result in insufficient statistical power to answer the research questions, and a statistically non-significant result can be due to the small sample size. For example, some statisticians agree that a sample size of 100 is the minimum needed to carry out factor analysis and to obtain meaningful results (Mundfrom et al., 2005). An unforeseen limitation was due to the major refurbishment of the research site. As this required the re-scheduling of time to travel to an alternative site, fitting with patient personal and medical care was not always feasible. Thus, engaging with patients did often require additional re-scheduling of time. This meant that for some patients who were in the hospice for respite care, went home without being able to complete their participation in the study and thus, they were unable to provide more data.

A second limitation was time. As it became evident that many patients experienced poor prognoses, time became a salient factor as the end of their lives became apparent. In line with that, patients required time with their family members, giving rise to the limitation of time in relation to the actual carrying out of research. In addition, the requirement for additional care and hospital appointments had the implication for rescheduling research time. However, it is important to note that all in-patients and out-patients were willing and eager to always take part in the research as their physical circumstances allowed. Whilst delay in time due to patient circumstances was not entirely unforeseen, it compounded the time constraints with regards to the time allowed to carry out research as PhD student and part-time counsellor, within the timeline of a PhD research programme. Moreover, the restrictions imposed due to COVID-19 led to the suspension of data collection for over one year. As a result, my research stopped and with no indication that I would be able to re-start. Other time delays arose from changes in the members of management and in clinical staff, refurbishment of the entire hospice and from unforeseen personal events. These limitations had negative impact on my research and on myself as a person, giving rise to personal anxiety.

A third limitation centres on the generalisability of case study designs and the extent to which data can explain phenomena. Yin (2014) supports "analytical generalisation", that is, where the researcher compares or "generalises" case study data to existing theory. The point of a case study is to learn as much as possible about an individual or a group so that the information can be better generalised to many others. At the same time, case studies tend to be highly idiosyncratic and so can be difficult to generalise findings to a larger population. That is, the conclusions drawn from the study of an individual may not apply to the larger population. In health-related research, generalisation is important as findings are applied to people and time-frames other than those in a particular study. Thus, it is important that the sample accurately represents the broader population. The hierarchy of levels of personal agency was found to be the same across three samples of hospice patients. Thus, a general experience of the phenomenon, personal agency, was experienced, allowing a move from idiographic to nomothetic. However, further investigation with new, larger samples is needed so that conclusions drawn from the research may be applied from the sample population to the general population.

7.7 Recommendations for Future Research

With life-limiting illnesses experienced throughout the world, this research represents an initial step on the path to measuring personal agency in hospice patients. This research topic provided the opportunity to bring fresh and original ideas that have the potential to add to existing knowledge regarding personal agency and to give a new insight into a previously unexplored area, personal agency in hospice patients. This study was a process that united novel ideas and innovative methodology in the creation of two new measures, a self-report questionnaire and an observation measure, that have positive value. Whilst the hierarchy of levels of personal agency was supported by three different samples of hospice patients, it is recommended that future research builds on the findings by using a larger sample of hospice out-patients and in-patients to include more different types of life-limiting illnesses. This recommendation may require that further research is carried out in multiple sites, that is, within palliative care settings, in hospices, hospitals and in social care. Also, multiple sites may allow the recommendation for further research to include patients of different chronic life-limiting illnesses such as Parkinson's disease and multiple sclerosis.

Considering the research findings, it is recommended that, whilst the study did fit with the definition of a longitudinal study, the study time be extended. In this research, the study did allow for the collection of data over repeated observations and tracked the same type of information on the same descriptors in the observation measure. However, an extended longitudinal study would better address the limitation of patient availability, access to data and the concern of time constraints, in relation to effects of illness and student timelines. That is, this recommendation of an extended longitudinal study would allow the identification of a larger sample of participants and, with that, a greater access to data. A larger sample size might increase the statistical power, increasing the chance of detecting a true effect and thus, allowing the drawing of accurate conclusions about a population, using sample data. Moreover, an extended longitudinal study would facilitate the tracking of hospice patients over a longer time frame, as appropriate. As life-limiting illnesses are experienced worldwide and this research represents an initial step in the measuring of personal agency in hospice patients, it is recommended that future research builds on the findings of this study. Thus, for researchers having an interest in this field of research, this research programme may provide the motivation for further investigation to further address the gap that currently exists in this domain. Further research would help to generate additional findings that may promote a point toward generalisation.

7.8 Original Contributions to Knowledge

A key contribution of this research is that it has provided a deeper understanding of how hospice patients live with a life-limiting illness. Also, an original contribution to knowledge was a differentiated and validated definition of levels of personal agency with respect to hospice patients, including the creation of a new typology regarding categories and sub-categories. A useful contribution of this present research is the development of two new measures, self-report questionnaire and observation measure, including a body of psychometric research on them, evidenced that personal agency can be measured in hospice patients. The self-report questionnaire to be administered to patients to allow them to report their responses to items representing levels of personal agency. In addition, the observation measure is for use by observers to rate the levels of personal agency during the observation of hospice patients. Also, evidence supports the proposition that personal agency exists to the point of death. A key contribution of this research is that it illustrates how EFT can facilitate a deeper understanding of how hospice patients experience living with a life-limiting illness, potentially offering a voice to patients and opportunities for collaboration with clinicians, counsellors, family, and clergy.

7.9 Personal Reflection

Finally, I share the impact of this research on me as a person, counsellor and researcher. First, as a person, I feel privileged that patients allowed me to enter their private perceptual world (Rogers, 1961), sharing their fears, despair, moments of courage and hopes. As a researcher and counsellor, I accompanied each out-patient and in-patient on their search for meaning; there were tears and moments of joy. I appreciate and respect the impact of finiteness, maladaptive emotions and defence mechanisms. However, as a person, researcher and counsellor, I was anxious about the research; especially in the face of counter-intuitive results and null hypotheses, along with time and practical constraints. At various points I asked myself why I was doing this research. Why was it important? As a person, this research allowed me to reflect on what it was like to have the diagnosis of a life-limiting illness; as a counsellor, it provided me with an opportunity to help others to make changes in their lives; and as a researcher, this research provided me with an opportunity to study an unexplored concept, to be creative, whilst attending to my self-discipline and self-awareness. However, research can be lonely and a responsibility. Research is rewarding but requires the necessary and sufficient psychological strength, sensitivity, empathy, humility, integrity, authenticity, confidence while engaging in EFT tasks, and an abundance of perseverance. I have gained a better understanding of the concept of perseverance as only when physical symptoms proved too much for patients did, they require to re-schedule their taking part in the study.

As a result of carrying out this research I have identified changes within my practice. For example, I can truly enter the experiencing of patients and be with them in their distress. Consequently, I can attend, not only to those aspects of experiencing that strive for positive movement, but to those that push for caution, validating both the over-regulated and the under-regulated. Also, as a person, researcher and counsellor I take stock of me and I appreciate my family, old, young and in-between. An unexpected outcome of this thesis is that I may want to increase my knowledge of statistics, because, quoting Rogers (1961, p.25), “Facts are friendly.”

7.10 Conclusion

This comprehensive investigation has demonstrated that hospice patients, out-patients and in-patients, experience their personal agency in accordance with a hierarchy of eight main levels, sub-levels and expanded distinctions of personal agency, ranging from level 0, non-agentic self to level 7, fully agentic self. Also, it has confirmed that agency exists even to the point of death. Moreover, using mixed methods research design, the hierarchy was developed to create two new measures, a self-report questionnaire and an observation measure for assessing personal agency in hospice patients. The investigation confirmed that the measures, with additional research, had the potential to be reliable and valid. The two measures were implemented with a new sample of out-patients and in-patients. In addition, Emotion-Focused Therapy was the treatment received by patients and could be regarded as developing personal agency in hospice patients. These findings have significant implications for theory, practice and policy, which I have set out in this chapter. Finally, I have presented a summary of the original contributions to knowledge made by this thesis and shared some personal reflections.

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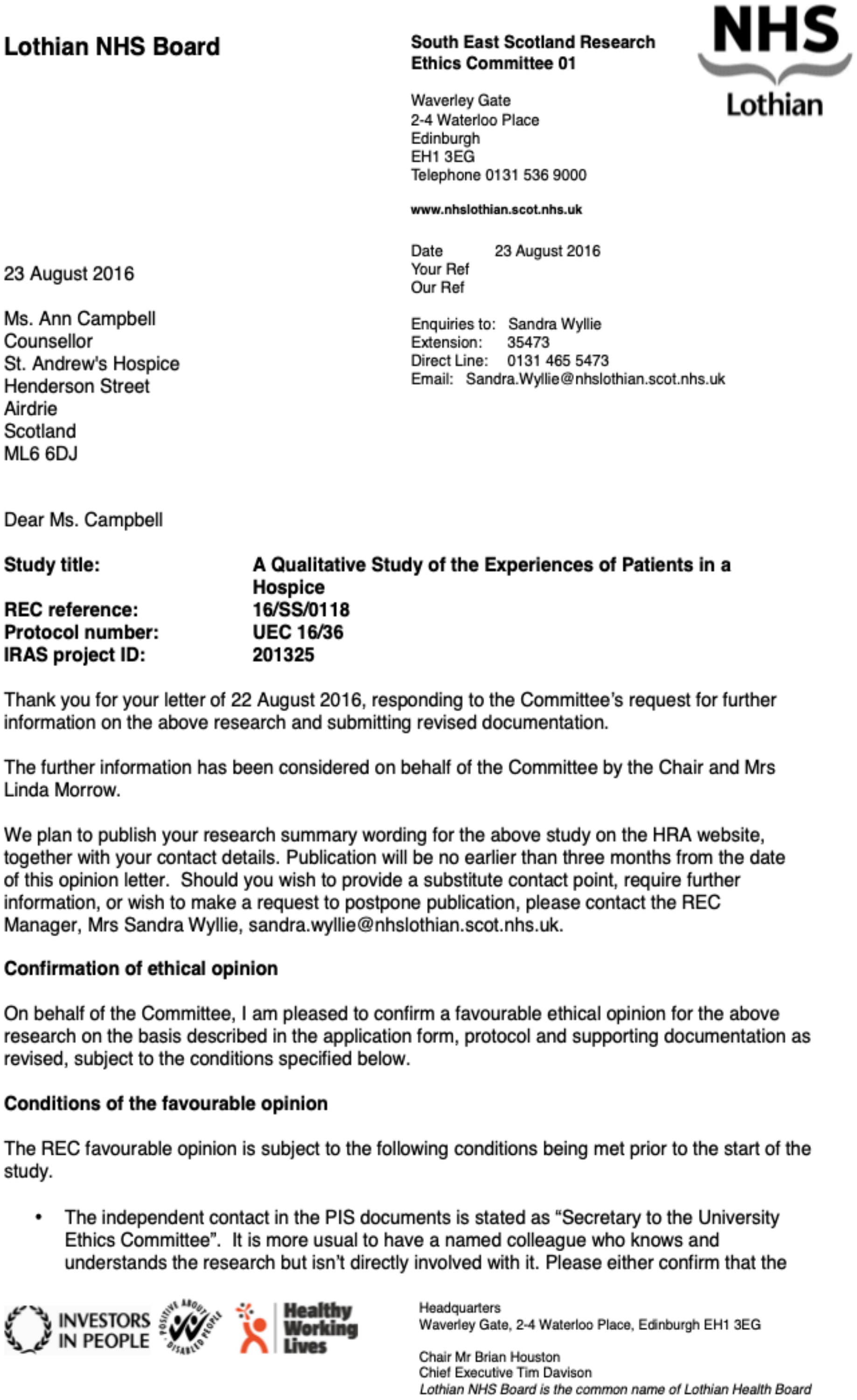
Appendix A: Ethical Approval of Research from NHS Ethics Committee for Study 1



Lothian NHS Board

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Date 23 August 2016
Your Ref
Our Ref

Enquiries to: Sandra Wyllie
Extension: 35473
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23 August 2016

Ms. Ann Campbell
Counsellor
St. Andrew's Hospice
Henderson Street
Airdrie
Scotland
ML6 6DJ

Dear Ms. Campbell

Study title: **A Qualitative Study of the Experiences of Patients in a Hospice**
REC reference: **16/SS/0118**
Protocol number: **UEC 16/36**
IRAS project ID: **201325**

Thank you for your letter of 22 August 2016, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chair and Mrs Linda Morrow.

We plan to publish your research summary wording for the above study on the HRA website, together with your contact details. Publication will be no earlier than three months from the date of this opinion letter. Should you wish to provide a substitute contact point, require further information, or wish to make a request to postpone publication, please contact the REC Manager, Mrs Sandra Wyllie, sandra.wyllie@nhslothian.scot.nhs.uk.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

Conditions of the favourable opinion

The REC favourable opinion is subject to the following conditions being met prior to the start of the study.

- The independent contact in the PIS documents is stated as "Secretary to the University Ethics Committee". It is more usual to have a named colleague who knows and understands the research but isn't directly involved with it. Please either confirm that the

Headquarters
Waverley Gate, 2-4 Waterloo Place, Edinburgh EH1 3EG

Chair Mr Brian Houston
Chief Executive Tim Davison
Lothian NHS Board is the common name of Lothian Health Board

Secretary is aware of this study and is able to answer any patient queries, or supply and amend to include the contact details of a more appropriate person.

- After the sentence "Any decision you make to withdraw (or to decline to be involved in the first place) will not affect the care you receive from any relevant service." please add just to reinforce the point that the audio recording is the study "You will still be offered counselling sessions but they will just not be recorded"

You should notify the REC once all conditions have been met (except for site approvals from host organisations) and provide copies of any revised documentation with updated version numbers. Revised documents should be submitted to the REC electronically from IRAS. The REC will acknowledge receipt and provide a final list of the approved documentation for the study, which you can make available to host organisations to facilitate their permission for the study. Failure to provide the final versions to the REC may cause delay in obtaining permissions.

Management permission must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements. Each NHS organisation must confirm through the signing of agreements and/or other documents that it has given permission for the research to proceed (except where explicitly specified otherwise).

Guidance on applying for NHS permission for research is available in the Integrated Research Application System, www.hra.nhs.uk or at http://www.rdforum.nhs.uk.

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of management permissions from host organisations

Registration of Clinical Trials

All clinical trials (defined as the first four categories on the IRAS filter page) must be registered on a publically accessible database within 6 weeks of recruitment of the first participant (for medical device studies, within the timeline determined by the current registration and publication trees).

There is no requirement to separately notify the REC but you should do so at the earliest opportunity e.g. when submitting an amendment. We will audit the registration details as part of the annual progress reporting process.

To ensure transparency in research, we strongly recommend that all research is registered but for non-clinical trials this is not currently mandatory.

If a sponsor wishes to contest the need for registration they should contact Catherine Blewett (catherineblewett@nhs.net), the HRA does not, however, expect exceptions to be made. Guidance on where to register is provided within IRAS.

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

Ethical review of research sites

NHS sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

Document	*Version*	*Date*
Covering letter on headed paper [L16025 Cover Letter 06/06/2016]	V1	06 June 2016
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [University of Strathclyde Personal Indemnity]		31 July 2016
GP/consultant information sheets or letters [Letter to GP]	Version 1	22 March 2016
Letter from sponsor [Letter Regarding University of Strathclyde Insurance Policies]		26 May 2016
Letters of invitation to participant [Letter of Invitation to Take Part in a Research Study: Day Hospice Patients]	Version 2	04 April 2016
Letters of invitation to participant [letter of Invitation to Take Part in a Research Study: In-ward-Patients]	Version 2	04 April 2016
Other [University of Strathclyde Employers' Liability]		31 July 2016
Other [Personal Liability]		18 September 2016
Other [Personal Liability]		18 September 2016
Other [Employer's Liability]		03 March 2017
Other [Email confirming that participants identified via a NHS contract]		22 June 2016
Other [Letter of Reference from Professor Robert Elliott]	Version 1	30 September 2014
Other [Providing an Understanding of what is involved in the Counselling Sessions]	V1	07 July 2016
Other [Response Covering Letter]		22 August 2016
Other [Amended "Detailed Method of Description" in Protocol]	V9	16 August 2016
Participant consent form [Consent Form: Day Hospice]	V2	09 August 2016
Participant consent form [Consent Form: In Ward]	V2	09 August 2016
Participant information sheet (PIS) [Participant Information Sheet for Day Hospice Patients]	V4	08 August 2016
Participant information sheet (PIS) [Participant Information Sheet for In-ward Patients]	V4	08 August 2016
REC Application Form [REC_Form_06062016]		06 June 2016
Summary CV for Chief Investigator (CI) [CV for Chief Investigator]		15 March 2016

Summary CV for supervisor (student research) [CV for Academic Supervisor]		04 September 2015
Summary, synopsis or diagram (flowchart) of protocol in non technical language [Summary of PhD Proposal]	Version 1	26 May 2016

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Reporting requirements

The attached document *"After ethical review – guidance for researchers"* gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The HRA website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

User Feedback

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website: http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance/

HRA Training

We are pleased to welcome researchers and R&D staff at our training days – see details at http://www.hra.nhs.uk/hra-training/

16/SS/0118	**Please quote this number on all correspondence**

With the Committee's best wishes for the success of this project.

Yours sincerely

Dr Chee-Wee Tan
Chair

Email:sandra.wyllie@nhslothian.scot.nhs.uk

Enclosures: "After ethical review – guidance for researchers

Appendix B: Participant Information Sheet: Out-patients, Study 1

Participant Information Sheet
Approval: REC 16/SS/0118; UEC 16/36

Title of Study: What can I control in my life when I am a hospice patient? (V1)

Study: Qualitative: Counselling Sessions: Day Hospice Patients

Chief Investigator: Ann Campbell, B.Sc. (Hons) Psych., M.Sc. Counselling, PG Dip. Counselling, MBACP (ann.campbell.100@strath.ac.uk)

Academic Supervisor: Professor Robert Elliott, Ph.D. (0141 548 3703; Robert. Elliott@ strath.ac.uk)

Invitation to take part
We'd like to invite you to take part in our research study. Joining the study is entirely up to you. Before you decide we would like you to understand why the research is being done and what it would involve for you. The Chief Investigator will go through this information sheet with you, to help you decide whether or not you would like to take part and answer any questions you may have. Please feel free to talk to others about the study if you wish.

What is the purpose of the study?
In this study we are trying to find out how hospice patients deal with having an illness that cannot be cured. That is, we want to learn about how much hospice patients feel they can help themselves in their everyday living through their own feelings, thoughts and actions. An earlier study was carried out at St. Andrew's Hospice. We found that when patients were able to influence their own feelings, thoughts and actions, they better dealt with their circumstances. For example, they were able to decide what was important for them and make choices. This allowed them to live the best they could, for as long as they could and in ways that felt right to them.

Also, we want to find out how well the results of the earlier study will hold up with a new sample of patients (male and female) with diagnoses of different illnesses that are life-limiting. Illnesses may include cancer, chronic obstructive pulmonary disease, multiple sclerosis and motor neuron disease. Patients presenting symptoms of dementia will not be invited to take part. The study will take place in St. Andrew's Hospice and is sponsored by the University of Strathclyde. Doctors from St. Andrew's Hospice will identify four patients from Day Hospice, based on their medical records and on specific eligible and non-eligible criteria (See below). A letter of invitation and PIS will be given to patients at the same time by the doctors/care team. Only English-speaking patients will be invited to be potential participants. There are no translation services available.

We will work with you respectfully and offer you 6 sessions (each session lasting 40 minutes) of counselling called Emotion-Focused Therapy. This kind of therapy can help you to react to the distressing experiences of your circumstances. The study will last for 6 weeks.

We will ask you to give permission for your counselling sessions to be audio-recorded and for permission to keep the recordings of these sessions for the purpose of this research. We will transcribe the recordings to be analyzed. We hope to find out whether the results of the earlier study are supported by this study or require elaborating or modifying. We will also ask you to give permission for publication/conference presenting of results.

This study is both relevant and important for participants/patients and the public. That is, it may achieve change and make improvement about what concerns you as a patient within the study. Improvement may then be brought into general knowledge and used to enhance services and make changes in practice that would benefit all.

Why have I been invited and am I eligible?

We invite you to take part in this study because you have been diagnosed with an illness that cannot be cured. This means that you live every day with an illness that is life-limiting. The study asks how hospice patients experience themselves as being able to have influence over their feelings, thoughts and actions. We invite you to take part to find out how you experience this ability and whether it is helpful in your everyday living.

You are eligible to take part in the study if you:

- Are diagnosed with an illness that is life-limiting
- Are attending Day Hospice in St. Andrew's Hospice
- Are over the age of 18 years
- Are interested, willing and mentally and physically able to undergo a series of counselling sessions.
- Are able to give informed consent, voluntarily.

You are not eligible to take part in the study if you:

- Have physical inability due to progression of disease, pain or chronic fatigue
- Have diminished cognition due to illness or medication
- Have inability to give informed consent, voluntarily
- Are known to the researcher
- Are presently engaged in other counselling or research

Do I have to take part?

The answer is “No”. Taking part is entirely up to you. Also, you are free to withdraw at any time during the study without giving a reason and without your medical care, access to counselling or legal rights being affected.

What should I do if I am interested in taking part?

If you express an interest in taking part, then all you need to do is to sign your name in the box on the invitation. This will give permission for you to be contacted by the researcher for discussion of the study and taking consent.

What does taking part in the study involve?

- Having a face-to-face discussion with the researcher to go over the information about the study, including your involvement in it and giving your consent. We will welcome and answer any questions about the study so that you will feel adequately informed and able to decide whether or not you want to take part. Also, we welcome you to share the information given to you with others important to you (e.g. family, friends, GP). This meeting should last 25 minutes, as appropriate. We will agree to meet one week later.

- Meeting with the researcher one week later. We will ask if you understand the information. Also, we will answer any further questions you may have about the study. If you decide to take part we will ask you to sign the Consent Form. This meeting should last 5 minutes. Taking part will be completely up to you.

- Taking part in counselling sessions: You will be offered 6 sessions of counselling with the researcher who is also the counsellor. Each session will last 40 minutes and will take place on the day you attend Day Hospice and over 6 weeks. We will audio-record the counselling sessions and the recordings will be transcribed to create written copies called transcriptions. Counselling sessions are part of standard care and the transcription of these is for the purpose of research. It is important for you to know that if you choose not to take part in this study then the care and counselling sessions you receive will not be affected. Counselling may take place in either a room in Day Hospice or in the researcher’s room. Both are in St. Andrew’s Hospice. You can decide which is more suitable to you.

- During the counselling sessions, you will be asked to talk about how you experience and deal with your illness in your everyday life and about how much you are able to have the experiences you want to have.

- At the end of each session, there will be time for debriefing when you will be given the opportunity to reflect on your experience of the counselling.

Are there any possible disadvantages or risks from taking part?

You may find that taking part in research may cause you discomfort. Being audio-recorded may make you feel shy or inhibited. Then you may find it

- difficult to talk about deeply personal matters. We will welcome questions and address your concerns about the study at any time. If you did not want to be recorded, you would still continue with your counselling session as part of routine care.

- You may experience increased emotional distress due to addressing difficult experiences and challenging issues in your life. If you become distressed, we will work actively with you to help you hold and soothe any painful feelings that you experience. We will help you to take part in self-soothing in the form of relaxing, self-supporting and self-caring. Relaxing, pausing and taking a breath will allow you to stay with your vulnerability. Then you can continue to explore your experiences when you feel ready.
- You may experience an increase in fatigue due to your illness by taking part in the study. At all times we will be mindful of the concern of physical and emotional fatigue. If you tell us that you experience fatigue, then research would be stopped and take place later, as appropriate. The direct care team will be on site if assistance is needed during the study.

How will information about me be kept confidential?

- The original copy of your Consent Form will be placed in your medical records. A second copy will be given to yourself. A third copy, with your "Patient Identification Number", will be held in the researcher's office in a locked filing cabinet, in a locked room in the University of Strathclyde, to which only the researcher and the academic supervisor will have access.
- Codes instead of names will be used to identify your audio recordings. The audio recordings will be transported in a securely locked container from St. Andrew's Hospice to be encrypted within the secure cloud storage system, in the University of Strathclyde. This system is backed up twice daily. Only the researcher and her academic supervisor will have access to your recordings. They will be retained for the purpose of this research, publication and the writing of the academic thesis.
- Only the researcher and her academic supervisor will have access to your study data (audio recordings, transcripts and analysis). Your study data will be retained securely for 5 years to allow later checking of transcripts while the study is still in progress. After 5 years data will be securely deleted.
- Responsible members of the University of Strathclyde or the NHS organization or other authorities may be given access to your data for monitoring and/or audit of the study to ensure that the research is complying with applicable regulations.
- In order to identify you, doctors of St. Andrew's Hospice will have access to your medical records. Only members of the direct care team will have access to your medical records. The researcher and the academic supervisor will not have access.

- Your demographic information: gender, age in years, occupation, ethnicity, status (single or otherwise), diagnosis and prognosis will be extracted from your medical notes by a member of the direct care team.

What are the possible benefits of taking part?
We do not know what the outcome of the study will be and this is why we are conducting the research. However:

- You will have the opportunity to talk about things that are important to you like how you deal with the circumstances brought about by your diagnosis of a life-limiting illness.

- You may find an increase in your self-esteem through helping yourself and others by contributing more knowledge and understanding about a life-limiting illness.

- You may maximize your use of counselling towards your own self-empowerment and decision-making, leading to improved quality in your remaining life. The earlier study suggests that participants did experience an improved quality of life through taking part.

- At the end of the study, you may discover that further counselling would be helpful for you. You can discuss this with the researcher.

Will my General Practitioner/family doctor be informed of my taking part?
We will send a letter to your GP to let him or her know that you have agreed to take part in this study. We will respect your confidentiality.

What will happen if I don't want to carry on with the study?

- Your taking part in the study is entirely voluntary and you can change your mind at a later stage.

- Any decision you make to withdraw (or to decline to be involved in the first place) will not affect the care you receive from any relevant service. You will still be offered counselling sessions but they will just not be recorded.

- If you withdraw, all your identifiable personal information will be destroyed. Your data collected up to your withdrawal will be used for the purpose of research for which your consent has already been given.

What will happen to the results of this study?
This study is a part of PhD research. We will write up the results as a thesis and hopefully, present at conference, appear in peer reviewed scientific journals and make available through the University library system and the library within St. Andrew's Hospice. When publishing the results, we will anonymize all of your written data. We will also use pseudonyms to further lessen your identification.

You may want to know the results of the study in which you have taken part. If you request to know them we will discuss this with you. This will provide feedback to you on the outcome of the research to which you have contributed. Also, results will show relevance of the findings to future care. We will provide you with a link to a website from which you can get information about the study.

What happens if something goes wrong?
If you have a concern about any aspect of this study, you should ask to speak to the researcher who will do her best to answer your questions (Telephone 0141 548 4971) or Academic Supervisor (Telephone 0141 548 3703). If you remain unhappy and wish to complain formally, you can do this by contacting your local NHS Lanarkshire Complaints' Officer. http://www.nhslanarkshire.org.uk/ContactUs/Pages/default.aspx.
Health Rights Information Scotland (HRIS) will provide you with accurate and up-to-date information about your health rights. http://www.hris.org.uk/patient-information/.

Independent Contact: Helen Baigrie, Secretary to the University Ethics Committee Research and Knowledge Exchange Services, University of Strathclyde, Graham Hills Building, 50 George Street, Glasgow, G1 1QE. (Tel 0141 548 3707)

Sponsor: The University of Strathclyde has appropriate insurance in place in the unlikely event that you suffer any harm as a direct consequence of your participation in this study.

Site of Research: St Andrew's Hospice, where the research will be conducted, is the employer of the researcher, and is covered by a Certificate of Employers' Liability Insurance.

Researcher: Is covered by a Personal Certificate of Professional Liability Insurance.

How have patients and the public been involved in this study?
Prior to the earlier study, we could not find recorded and analysed information about how hospice patients deal with a life-limiting illness. This study views the patients as experts who are able to provide knowledge and experience. In the earlier study, the categories of a sense of being able (or not) to deal with a life-limiting illness emerged as a result of patients taking part in counselling sessions.

Who has reviewed the study?
All research studies are looked at by an independent group of people, called a Research Ethics Committee, to protect your safety, rights, wellbeing and dignity. The South East Scotland Research Ethics Committee 01 has granted approval for this study.

Thank-you for considering taking part.

Appendix C: Participant Information Sheet: In-patients, Study 1

Participant Information Sheet
Approval: REC 16/SS/0118; UEC 16/36

Title of Study: What can I control in my life when I am a hospice patient? (V1)

Study: Qualitative: Counselling Sessions: In-patients

Chief Investigator: Ann Campbell, B.Sc. (Hons) Psych., M.Sc. Counselling, PG Dip. Counselling, MBACP (ann.campbell.100@strath.ac.uk)

Academic Supervisor: Professor Robert Elliott, Ph.D. (0141 548 3703; Robert.Elliott@ strath.ac.uk)

Invitation to take part

We'd like to invite you to take part in our research study. Joining the study is entirely up to you. Before you decide we would like you to understand why the research is being done and what it would involve for you. The Chief Investigator will go through this information sheet with you, to help you decide whether or not you would like to take part and answer any questions you may have. Please feel free to talk to others about the study if you wish.

What is the purpose of the study?

In this study we are trying to find out how hospice patients deal with having an illness that cannot be cured. That is, we want to learn about how much hospice patients feel they can help themselves in their everyday living through their own feelings, thoughts and actions. An earlier study was carried out at St. Andrew's Hospice. We found that when patients were able to influence their own feelings, thoughts and actions, they better dealt with their circumstances. For example, they were able to decide what was important for them and make choices. This allowed them to live the best they could, for as long as they could and in ways that felt right to them.

Also, we want to find out how well the results of the earlier study will hold up with a new sample of patients (male and female) with diagnoses of different illnesses that are life-limiting. Illnesses may include cancer, chronic obstructive pulmonary disease, multiple sclerosis and motor neuron disease. Patients presenting symptoms of dementia will not be invited to take part.

The study will take place in St. Andrew's Hospice and is sponsored by the University of Strathclyde. Doctors from St. Andrew's Hospice will identify four patients from the In-ward area, based on their medical records and on specific eligible and non-eligible criteria (See below). A letter of invitation and PIS will be given to patients at the same time by the doctors/care team. Only English-speaking patients will be invited to be potential participants. There are no translation services available.

We will work with you respectfully and offer you 8 sessions (each session lasting 15 minutes) of counselling called Emotion-Focused Therapy. This kind of therapy can help you to react to the distressing experiences of your circumstances. The study will last for 3 weeks.

We will ask you to give permission for your counselling sessions to be audio-recorded and for permission to keep the recordings of these sessions for the purpose of this research. We will transcribe the recordings to be analysed. We hope to find out whether the results of the earlier study are supported by this study or require elaborating or modifying. We will also ask you to give permission for publication/conference presenting of results.

This study is both relevant and important for participants/patients and the public. That is, it may achieve change and make improvement about what concerns you as a patient within the study. Improvement may then be brought into general knowledge and used to enhance services and make changes in practice that would benefit all.

Why have I been invited and am I eligible?
We invite you to take part in this study because you have been diagnosed with an illness that cannot be cured. This means that you live every day with an illness that is life-limiting. The study asks how hospice patients experience themselves as being able to have influence over their feelings, thoughts and actions. We invite you to take part to find out how you experience this ability and whether it is helpful in your everyday living.

You are eligible to take part in the study if you:

- Are diagnosed with an illness that is life-limiting
- Are an In-ward patient in St. Andrew's Hospice
- Are over the age of 18 years
- Are interested, willing and mentally and physically able to undergo a series of counselling sessions.
- Are able to give informed consent, voluntarily.

You are not eligible to take part in the study if you:

- Have physical inability due to progression of disease, pain or chronic fatigue
- Have diminished cognition due to illness or medication
- Have inability to give informed consent, voluntarily
- Are known to the researcher
- Are presently engaged in other counselling or research

Do I have to take part?

The answer is “No”. Taking part is entirely up to you. Also, you are free to withdraw at any time during the study without giving a reason and without your medical care, access to counselling or legal rights being affected.

What should I do if I am interested in taking part?

If you express an interest in taking part, then all you need to do is to sign your name in the box on the invitation. This will give permission for you to be contacted by the researcher for discussion of the study and taking consent.

What does taking part in the study involve?

- Having a face-to-face discussion with the researcher to go over the information about the study, including your involvement in it and giving your consent. We will welcome and answer any questions about the study so that you will feel adequately informed and able to decide whether or not you want to take part. Also, we welcome you to share the information given to you with others important to you (e.g. family, friends, GP). This meeting should last 25 minutes, as appropriate. We will agree to meet two days later.

- Meeting with the researcher two days later. We will ask if you understand the information. Also, we will answer any further questions you may have about the study. If you decide to take part, we will ask you to sign the Consent Form. This meeting should last 5 minutes. Taking part will be completely up to you.

- Taking part in counselling sessions: You will be offered 8 sessions of counselling with the researcher who is also the counsellor. Each session will last 15 minutes and over 3 weeks. We will audio-record the counselling sessions and the recordings will be transcribed to create written copies called transcriptions. Counselling sessions are part of standard care and the transcription of these is for the purpose of research. It is important for you to know that if you choose not to take part in this study then the care and counselling sessions you receive will not be affected. Counselling may take place in the In-ward area or in the researcher’s room, depending on your mobility. Both are in St. Andrew’s Hospice.

- During the counselling sessions, you will be asked to talk about how you experience and deal with your illness in your everyday life and about how much you are able to have the experiences you want to have.

- At the end of each session, there will be time for debriefing when you will be given the opportunity to reflect on your experience of the counselling.

Are there any possible disadvantages or risks from taking part?

- You may find that taking part in research may cause you discomfort. Being audio-recorded may make you feel shy or inhibited. Then you may find it difficult to talk about deeply personal matters. We will welcome questions and address your concerns that are relevant to the study at any time. If you did not want to be recorded, you would still continue with your counselling session as part of routine care.

- You may experience increased emotional distress due to addressing difficult experiences and challenging issues in your life. If you become distressed, we will work actively with you to help you hold and soothe any painful feelings that you experience. We will help you to take part in self-soothing in the form of relaxing, self-supporting and self-caring. Relaxing, pausing and taking a breath will allow you to stay with your vulnerability. Then you can continue to explore your experiences when you feel ready.

- You may experience an increase in fatigue due to your illness by taking part in the study. At all times we will be mindful of the concern of physical and emotional fatigue. If you tell us that you experience fatigue, then research would be stopped and take place later, as appropriate. The direct care team will be on site if assistance is needed during the study.

How will information about me be kept confidential?

- The original copy of your Consent Form will be placed in your medical records. A second copy will be given to yourself. A third copy, with your "Patient Identification Number", will be held in the researcher's office in a locked filing cabinet, in a locked room in the University of Strathclyde, to which only the researcher and the academic supervisor will have access.

- Codes instead of names will be used to identify your audio recordings. The audio recordings will be transported in a securely locked container from St. Andrew's Hospice to be encrypted within the secure cloud storage system, in the University of Strathclyde. This system is backed up twice daily. Only the researcher and her academic supervisor will have access to your recordings. They will be retained for the purpose of this research, publication and the writing of the academic thesis.

- Only the researcher and her academic supervisor will have access to your study data (audio recordings, transcripts and analysis). Your study data will be retained securely for 5 years to allow later checking of transcripts while the study is still in progress. After 5 years data will be securely deleted.

- Responsible members of the University of Strathclyde or the NHS organization or other authorities may be given access to your data for monitoring and/or audit of the study to ensure that the research is complying with applicable regulations.

- In order to identify you, doctors of St. Andrew's Hospice will have access to your medical records. Only members of the direct care team will have access to your medical records. The researcher and the academic supervisor will not have access.

- Your demographic information: gender, age in years, occupation, ethnicity, status (single or otherwise), diagnosis and prognosis will be extracted from your medical notes by a member of the direct care team.

What are the possible benefits of taking part?
We do not know what the outcome of the study will be and this is why we are conducting the research. However:

- You will have the opportunity to talk about things that are important to you like how you deal with the circumstances brought about by your diagnosis of a life-limiting illness.

- You may find an increase in your self-esteem through helping yourself and others by contributing more knowledge and understanding about a life-limiting illness.

- You may maximize your use of counselling towards your own self-empowerment and decision-making, leading to improved quality in your remaining life. The earlier study suggests that participants did experience an improved quality of life through taking part.

- At the end of the study, you may discover that further counselling would be helpful for you. You can discuss this with the researcher.

Will my General Practitioner/family doctor be informed of my taking part?
We will send a letter to your GP to let him or her know that you have agreed to take part in this study. We will respect your confidentiality.

What will happen if I don't want to carry on with the study?

- Your taking part in the study is entirely voluntary and you can change your mind at a later stage.

- Any decision you make to withdraw (or to decline to be involved in the first place) will not affect the care you receive from any relevant service. You will still be offered counselling sessions, but they will just not be recorded.

- If you withdraw, all your identifiable personal information will be destroyed. Your data collected up to your withdrawal will be used for the purpose of research for which your consent has already been given.

What will happen to the results of this study?
This study is a part of PhD research. We will write up the results as a thesis and hopefully, present at conference, appear in peer reviewed scientific journals and make available through the University library system and the library within St. Andrew's Hospice. When publishing the results, we will anonymise all of your written data. We will also use pseudonyms to further lessen your identification.

You may want to know the results of the study in which you have taken part. If you request to know them we will discuss this with you. This will provide feedback to you on the outcome of the research to which you have contributed. Also, results will show relevance of the findings to future care. We will provide you with a link to a website from which you can get information about the study.

What happens if something goes wrong?
If you have a concern about any aspect of this study, you should ask to speak to the researcher who will do her best to answer your questions (Telephone 0141 548 4971) or Academic Supervisor (Telephone 0141 548 3703). If you remain unhappy and wish to complain formally, you can do this by contacting your local NHS Lanarkshire Complaints' Officer. http://www.nhslanarkshire.org.uk/ContactUs/Pages/default.aspx.
Health Rights Information Scotland (HRIS) will provide you with accurate and up-to-date information about your health rights. http://www.hris.org.uk/patient-information/.

Independent Contact: Helen Baigrie, Secretary to the University Ethics Committee Research and Knowledge Exchange Services, University of Strathclyde, Graham Hills Building, 50 George Street, Glasgow, G1 1QE. (Tel 0141 548 3707)

Sponsor: The University of Strathclyde has appropriate insurance in place in the unlikely event that you suffer any harm as a direct consequence of your participation in this study.

Site of Research: St Andrew's Hospice, where the research will be conducted, is the employer of the researcher, and is covered by a Certificate of Employers' Liability Insurance.

Researcher: Is covered by a Personal Certificate of Professional Liability Insurance.

How have patients and the public been involved in this study?
Prior to the earlier study, we could not find recorded and analysed information about how hospice patients deal with a life-limiting illness. This study views the patients as experts who are able to provide knowledge and experience. In the earlier study, the categories of a sense of being able (or not) to deal with a life-limiting illness emerged as a result of patients taking part in counselling sessions.

Who has reviewed the study?
All research studies are looked at by an independent group of people, called a Research Ethics Committee, to protect your safety, rights, wellbeing and dignity. The South East Scotland Research Ethics Committee 01 has granted approval for this study.

Thank-you for considering taking part.

Appendix D: Invitation to Take Part in a Research Study: Out-patients, Study 1

Invitation to Take Part in a Research Study

Approval: REC 16/SS/0118; UEC 16/36

Having a life-limiting illness can be scary and leave people feeling powerless and out of control. We would like to invite you to take part in a research study, in St. Andrew's Hospice, on coping with this sense of powerlessness. We are trying to understand more about hospice patients' sense of personal control, that is, the sense you have of yourself as having control over your thoughts and actions so that they can help you in your everyday living with a life-limiting illness. In an earlier study, also carried out at St. Andrew's Hospice, we found that having this control helped patients to better deal with their circumstances so that they were able to decide what was important for them and make changes that helped them to live to the best of their ability and for as long as they could in the ways that felt right to them

This study, called "What can I control in my life when I am a hospice patient?" seeks to build on the earlier research. This study has been developed in collaboration between St. Andrew's Hospice and the University of Strathclyde and will be carried out by Ann Campbell (a counsellor at St. Andrew's and a PhD student at University of Strathclyde) and with assistance from a Ward Sister of St. Andrew's Hospice. The study will be supervised by Professor Robert Elliott of the University of Strathclyde and monitored by Bruce High, Chief Executive Officer of St. Andrew's Hospice.

Taking part in the study will be entirely your decision. The counsellor will offer you 6 sessions of counselling. Each session will last for 40 minutes and will be recorded. If you choose to take part, you will have the right to withdraw from the study at any point and without any part of your care being affected.

If you would like to take part, we would like you to write your name in the box provided.

The doctors of St. Andrew's Hospice will identify you and Ann will meet with you to explain, clearly, the purpose of the study and what you would be asked to do. Ann will be very happy to answer any questions or concerns you may have about the study.

Appendix E: Invitation to Take Part in a Research Study: In-patients, Study 1

Invitation to Take Part in a Research Study

Approval: REC 16/SS/0118; UEC 16/36

Having a life-limiting illness can be scary and leave people feeling powerless and out of control. We would like to invite you to take part in a research study, in St. Andrew's Hospice, on coping with this sense of powerlessness. We are trying to understand more about hospice patients' sense of personal control, that is, the sense you have of yourself as having control over your thoughts and actions so that they can help you in your everyday living with a life-limiting illness. In an earlier study, also carried out at St. Andrew's Hospice, we found that having this control helped patients to better deal with their circumstances so that they were able to decide what was important for them and make changes that helped them to live to the best of their ability and for as long as they could in the ways that felt right to them

This study, called "What can I control in my life when I am a hospice patient?" seeks to build on the earlier research. This study has been developed in collaboration between St. Andrew's Hospice and the University of Strathclyde and will be carried out by Ann Campbell (a counsellor at St. Andrew's and a PhD student at University of Strathclyde) and with assistance from a Ward Sister of St. Andrew's Hospice. The study will be supervised by Professor Robert Elliott of the University of Strathclyde and monitored by Bruce High, Chief Executive Officer of St. Andrew's Hospice.

Taking part in the study will be entirely your decision. The counsellor will offer you 8 brief sessions of counselling. Each session will last for 15 minutes and will be recorded. If you choose to take part, you will have the right to withdraw from the study at any point and without any part of your care being affected.

If you would like to take part, we would like you to write your name in the box provided.

The doctors of St. Andrew's Hospice will identify you and Ann will meet with you to explain, clearly, the purpose of the study and what you would be asked to do. Ann will be very happy to answer any questions or concerns you may have about the study.

Appendix F: Consent Form: Out-patients, Study 1

CONSENT FORM

Approval: REC 16/SS/0118; UEC 16/36

Patient's Identification Number for this study: ☐

Title of Study: What can I control in my life when I am a hospice patient? (V1)

Study: Qualitative: Counselling Sessions: Day Hospice Patients.

Name of Chief Investigator: Ann Campbell, Counsellor

If you agree, please initial box

1. I confirm that I have read and understand the Participant Information Sheet dated 23-08-2016 (Version 5) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐

2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care, access to counselling or legal rights being affected. ☐

3. I understand that only the direct care team will have access to my medical notes. The Chief Investigator and Academic Supervisor at the University of Strathclyde will have access to my relevant demographic information, which the Chief Investigator will obtain from the direct care team. ☐

4. I understand that this study may be externally monitored by individuals (not the researchers) from the Sponsor (University of Strathclyde) or from the NHS organization or other authorities. This might involve looking at relevant sections of my medical notes and data collected during the study, to make sure that the study is being conducted properly and that my rights are being protected. I give permission for these individuals to have access to my records. ☐

5. I understand that the Chief Investigator and the Academic Supervisor at the University of Strathclyde may use relevant data collected during the study. ☐

6. I agree to my GP being informed of my participation in the study while I attend Day Hospice at St. Andrew's Hospice. ☐

7. I agree to take part in the above study. ☐

Name of Participant	Date	Signature

Chief Investigator	Date	Signature

Appendix G: Consent Form: In-patients, Study 1

St. Andrew's Hospice

University of Strathclyde Glasgow

CONSENT FORM
Approval: REC 16/SS/0118; UEC 16/36

Patient's Identification Number for this study: ☐

Title of Study: What can I control in my life when I am a hospice patient? (V1)

Study: Qualitative: Counselling Sessions: In-patients.

Name of Chief Investigator: Ann Campbell, Counsellor

If you agree, please initial box

1. I confirm that I have read and understand the Participant Information Sheet dated 23-08-2016 (Version 5) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐

2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care, access to counselling or legal rights being affected. ☐

3. I understand that only the direct care team will have access to my medical notes. The Chief Investigator and Academic Supervisor at the University of Strathclyde will have access to my relevant demographic information, which the Chief Investigator will obtain from the direct care team. ☐

4. I understand that this study may be externally monitored by individuals (not the researchers) from the Sponsor (University of Strathclyde) or from the NHS organization or other authorities. This might involve looking at relevant sections of my medical notes and data collected during the study, to make sure that the study is being conducted properly and that my rights are being protected. I give permission for these individuals to have access to my records. ☐

5. I understand that the Chief Investigator and the Academic Supervisor at the University of Strathclyde may use relevant data collected during the study. ☐

6. I agree to my GP being informed of my participation in the study while I am an In-ward patient in St. Andrew's Hospice. ☐

7. I agree to take part in the above study. ☐

Name of Participant	Date	Signature
Chief Investigator	Date	Signature

Appendix H: Complete Record of the Analysis of Study 1

A Complete Record of the Analysis of Study 1

Title of Phase 1: A Qualitative Study of the Experiences of Hospice Patients.
Construction of Self as an Active Agent within the Hospice Process: A Cross-Case Analysis
Examples of statements as expressed by out-patients and in-patients, respectively.

Participant Identification Codes: Out-patients: OP1; OP2; OP3; OP5
In-patients: IP1; IP2; IP3; IP4

Level 0: The Non-Agentic Self

This category represents the lowest level of personal control, with patients experiencing themselves as incapable of initiating change through their own actions. Faced with emotional pain and devoid of a sense of personal agency, patients lack the ability to construct their experience in alternative ways that would allow them to self-organise, self-regulate, or self-reflect. Categories in this level are characterised by differences in intensity and immediacy, with 0a, the *Objectified Self*, being the most intense. Further analysis of categories reveals additional knowledge about the profound experiences of patients as non-agentic.

0a: Objectified Self

Due to the direct and indirect effects of their incurable illness, participants are reduced to the status of an object, with objectification either a destructing or stifling their autonomy. This gives rise to an inertness that points to a lack of agency and, even if that inertness is temporary, patients experience that their feelings become unimportant due to a denial of subjectivity. Within the sub-category of the *Objectified Self*, patients communicate their sense of lack of control due to 1) the effects of their illness and 2) the challenge of their treatment and 3) the involvement of others who they perceive as having influence with respect to their circumstances.

Oa-1: By the Effects of Illness

Using metaphors, both out-patients and in-patients are able to describe a strong image, although not literally true, that helps to provide a straightforward explanation and understanding of how their illness has deprived them of their ability to exercise any influence over their personal life circumstances. Participants also communicate that the effects of illness have impact on both their physical and psychological well-being.

The physical effect is powerfully described by *"Unforgettable and excruciating"*. The psychological impact of the illness is captured in their choice of harsh-sounding words that present the image of being brought down with no sense of control. In addition, their use of the past participle, *"devastated"* supports the sense of a lack of control imposed on them.

0a-1.1: Physical Effects of Illness

Out-patients

OP1-139: But all of a sudden... it's... it's came.

OP1-216: Oh no... no. It just comes on you.

OP2-18: Unforgettable and excruciating

OP3-97: That's it started.

OP5-91: It just hits you like that.

OP5-93: I don't feel right... it just hits you like that.

OP5-114: It just hits you like that...

OP5-162: ... it never leaves you.

In-Patients

IP1-1: It hit me with three ____ infections.

IP1-186: Then you get hit.

IP2: (No data)

IP3: (No data)

IP4: (No data)

0a-1.2: Psychological Effects of Illness

Out-patients

OP1-14: I was devastated.

OP1-22: Oh, I was devastated.

OP1-42: The daughter started crying... I was too numb to get to that stage.

OP1-91: ... completely gone... just scavage (rubbish)

OP1-111: I was shocked.

OP2-26: ... an emotional wreck.

OP3-162: This breathing is driving me round the bend.

OP3-168: I feel this has taken over my whole life... whole life... everything."

OP3-251: It's too much for me.

OP5-8: Ah, boy... that floored me.

OP5-9: ... was in a shock... total shock.

OP5-12: ... and this (diagnosis) just stopped... defeat for me.

OP5-54: Oh, it takes over your life.

OP5-57: It was too much for me.

OP5-67: This is just wearing me down.

OP5-110: I was stunned.

OP5-170: I feel I've been defeated.

In-Patients

IP1-28: I was hitting the roof.

IP1-49: … and I'm... like a rabbit in the headlights.

IP1-88: Every... every piece of my life stopped.

IP1-100: So, it was quite devastating.

IP1-164: We were devastated.

IP2: (No data)

IP3-56: so that frightened the life out of me... totally finished any kind of faith I had.

IP3-98: ... it gets too much.

IP4-87: I think it told you... it told you.

0a-2: By the Effects of Treatment

The patients communicate that the treatment is bothersome, *"tubes everywhere"*, and distressing, rendering them devoid of feeling and leaving them unaware of what is going on around them for some time. The extent of the lack of sense of control is heightened by the feeling of, at times, as though they are guinea pigs. Participants recognised that their treatments were intended to help them, but they are vexed by the loss of perceived control. They communicate that the effects of treatment affect them both physically and psychologically.

0a-2.1: Physical Effects of Treatment

Out-patients

OP1-12: Took the full day to put in... tubes everywhere... out of it for 10 to 15 days.

OP1-119: ... the stuff they were giving me was knocking me out altogether.

OP2-59: I couldn't go out. For six months I had (treatment)... was never out the door... I wasn't fit.

OP3: (No data)

OP5-104: It (treatment) leaves me... take me to the end of the week to recover.

In-Patients: (No data)

0a-2.2: Psychological Effects of Treatment

Out-patients

OP1-21: Because you're killing me... because it (treatment) was very severe.

OP1-38: The treatment just destroyed all feelings you had for anything.

OP2: (No data)

OP3: (No data)

OP5-90: You just feel as though at times you're a guinea pig.

In-Patients: (No data)

0a-3: By the Involvement of Others

Whilst the involvement of others is intended to benefit patients, patients sometimes feel that, on particular occasions, they are not given the opportunity to influence their own circumstances. When patients sense that their feelings and experiences are not considered then then they felt *disempowered*, "*been passed from pillar to post", ignored, "nobody told me", or discarded "took me off his list."* Devoid of a sense of control, participants become objectified and lacking in agency and subjected to actions without responding or initiating an action in return.

0a-3.1: Feeling Disempowered

Out-patients

OP1-2: ... "I'll see you in my office and get your family along with you."

OP1-190: They (Family) won't allow me to be on my own.

OP2: (No data)

OP3-136: I've just "been passed from pillar to post".

OP3-139: ... and then they passed me to the hospice.

OP3-194: I get passed from pillar to post... and I've ended up here.

OP3-232: ... she's passed me on.

OP5-187: Yeah... he doesn't matter... I don't matter.

In-Patients

IP1-166: No, I didn't... I didn't feel treated as a person.

IP2: (No data)

IP3: (No data)

IP4: (No data)

0a-3.2: Feeling Ignored

Out-patients

OP1-33: "We'll have a discussion with doctors that's treating you." … they came back to me... "We'll reduce the dose."

OP2: (No data)

OP3-141: ... doctors come and stand at the end of your bed... speak to people round about... didn't speak to you.

OP3-142: One said you're getting home... nobody told me... they'd spoken to each other.

OP5-81: I was rushed back in... put in isolation... put on the drip...

OP5-88: I got put into a room... evening... sat in that room...till the morning...nobody come near me... no one come near me.

In-Patients: (No data)

0a-3.3: Feeling Discarded

Out-patients

OP1: (No data)

OP2: (No data)

OP3-19: ... then he took me off his list.

OP3-138: I used to go and see the __ nurse in the hospital... she refuses to speak to me now... I used to see Dr ___... he took me off his list.

OP3-197: You're just a number... definitely just a number.

OP3-203: I've been left... discarded... uh huh that's true.

OP3-224: They've all brushed me off their hands... left me to it... more or less left in the dark.

OP5-111: I'm just a number... just one of many...

OP5-128: ... didn't engage in conversation... never looked at your notes before you went in... on the computer to have a look... I'll see you in... there's your tablets... make an appointment.

In-Patients: (No data)

0b: Despairing Self

Participants are cast into the undesirable circumstances of a life limiting illness that destroys their sense of agency. With the reality of their new, unwanted circumstances, patients experience profound unhappiness and become discouraged about their world. With patients unable to make their lives personally manageable, let alone worth-while, they experience horror, awfulness, and loss of hope. Within the sub-category of the *Despairing Self*, participants communicated that their experience of despair is due to 1) the effects of their illness 2) the harshness of their treatment.

0b-1: Despair due to Illness

Participants are disheartened, deprived of hope and enthusiasm as they must live with the truth about their physicality. Discouraged and dispirited, participants experience deep emotional suffering *"Oh God... can't take it away; very dark... a hole... no ladders to climb... no light."*

0b-1.1: Physical Effects of Despairing about the Illness

Out-patients

OP1-93: ... you're suffering... severe suffering.
OP2-19: I bubbled and cried.
OP2-51: Just kept crying.
OP3: (No data)
OP5: (No data)

In-Patients

IP1-29: I think it was ____ long when they got it (tumour)
IP1-135: But it's very aggressive... they said.
IP1-160: [Doctor], "There's nothing... You're not fit enough for anything."
IP1-162: "There's nothing we can... nothing we can do."
IP1-163: No treatment... so... just came away.
IP1-242: Oh God... can't take it away.
IP2: (No data)
IP3: (No data)
IP4-97: It really hurt.

0b-1.2: Psychological Effects of Despairing about the Illness

Out-patients

OP1: (No data)
OP2-17: That was terrifying.
OP2-22: It was horrendous. It was horrendous.
OP2-53: ... was horrific... horrific... horrendous.
OP2-85: I was terrified...
OP2-90: It's very lonely. It's a lonely, lonely place.
OP2-91: I'll just go to sleep... no reason now... might as well just give up now.
OP2-92: I can't do this... I'm climbing the walls... I'm going down.
OP2-94: Very scary... very dark... a hole... no ladders to climb... no light.
OP2-103: ... back into... black hole... down and down

OP2-134: Terrified...

OP2-169: It was a terrifying experience... hard... really hard.

OP3-5: It was a very, very bad time.

OP3-6: But it was a difficult time.

OP3-25: Scary

OP3-27: and it's scary...

OP3-29: it's ... frightening.

OP3-32: ... it is hard.

OP3-53: It's difficult.

OP3-55: It's a nightmare... it really is a nightmare.

OP3-62: It's hard ... it's really hard.

OP3-68: But it's hard... It is hard.

OP3-70: ... it is really a nightmare.

OP3-72: ... and it's frightening...

OP3-75: Oh, it is... it is very... it's very frightening.

OP3-93: ... but as I say it's really, really frightening.

OP3-98: ... and I know it's just a nightmare.

OP3-107: It's a nightmare.

OP3-122: It's very, very hard.

OP3-157: But it's difficult... it definitely is difficult.

OP3-163: ... it's getting worse and worse.

OP3-164: Oh, very scary.

OP3-167: It is very scary... it really is...

OP3-170: ... it really is... it's frightening.

OP3-190: ... there's just nothing...

OP3-191: It's so frustrating... so frustrating.

OP3-214: It's difficult... very difficult.

OP3-229: ... it's really frustrating.

OP3-245: ... so, it's very difficult.

OP5-1: ... awful

OP5-2: ... it was terrible.

OP5-19: Oh, terrible...

OP5-25: Oh, it was terrible... Oh, it was really terrible.
OP5-163: ... and it's terrible.
OP5-268: oh, dark... very dark.

In-Patients

IP1-41: Kept thinking of my Mum... Oh my God... this is coming to me now.
IP1-87: … it's scaring me to think... God...
IP1-121: I feel I can cry saying that.
IP1-174: It's terrible.
IP1-216: It's awful... it's terrible.
IP1-222: It's just awful.
IP1-226: Oh, it's a horrible... horrible... horrible... horrible disease.
IP1-227: It's scary.
IP1-228: It's a very lonely place.
IP1-244: It's heart-breaking... heart-breaking.
IP1-248: Really... it's been awful.
IP2-65: It's horrendous.
IP2-85: ... it's very difficult...
IP3-14: ... was the scariest thing ever
IP3-94: ... I was kind of like... Oh, my God... Oh, my God...
IP4-18: Nothing…
IP4-72: It's hard... to talk.

0b-2: Despair due to Treatment

Whilst patients recognise that their treatments are intended to help them, the treatments that they receive do not always bring about their desired outcome. In addition, participants experience their treatment as cruel and gruelling. The effects of treatment see participants despondent and dejected and often unable to continue with treatment despite the threat to their existence, *"Didn't shrink the tumour; Soul-destroying."*

0b-2.1*:* Physical Effects of Despairing about the Treatment

Out-patients

OP1-97: They (tablets) are not working...

OP2: (No data)

OP3: (No data)

OP5: (No data)

In-Patients

IP1-64: Didn't shrink the tumour... didn't do anything for the tumour really.

IP2: (No data)

IP3: (No data)

IP4: (No data)

0b-2.2*:* Psychological Effects of Despairing about the Treatment

Out-patients

OP1-32: I says, I'll need to stop because I can't take much more of it.

OP1-47: … Soul-destroying... getting these pumped into you.

OP1-64: One after that one... going to go through the same again with this...

OP1-74: Got to go through this again... No... I know what I've been through.

OP1-98: Couldn't cope with it much longer.

OP1-113: Dreading if it's the same... dreading if it's coming back... same treatment.

OP1-152: ... was horrendous.

OP1-156: I cannot go through that again... it was very severe... very severe.

OP2-107: I can't cope with this. I can't cope with this.

OP2-168: I can't do it.

OP3: (No data)

OP5-63: It was absolutely terrible... oh, terrible.

OP5-66: After seven sessions I said, "Can't take any more of it. Had enough."

OP5-79: ... was terrible... really... really terrible.

OP5-80: Oh, it's terrible... Oh, it was terrible.

OP5-89: I said, "Oh, this is ridiculous. That's terrible."

OP5-111: I thought it was terrible.

OP5-141: I've been to hell and back... yeah... that's how it feels.

In-Patients: (No data)

0c: Disappearing Self

Participants are faced with the reality of an identified, incurable illness that is threatening their existence. As they experience disruption of their body through disease the fragility of their lives is uncovered. Whilst they are becoming more aware of their circumstances, participants are aware that they lack control over their circumstances and so cannot prevent the inevitable. Within this sub-category, participants communicate a) how the illness affects their physical existence and b) how that threat to their existence affects them from a psychological perspective.

0c-1: The Sense of Disappearing due to the Effects of Illness

The reality of participants is that their illness cannot be stopped, with the result that they, as individuals, will disappear by no longer existing, *"I'm not going to be here; go home... sort out your ... you don't have long."*

0c-1.1: Physical Effects of Disappearing due to Illness.

Out-patients

OP1-73: … I'm going to die...
OP2-46: ... it has spread.
OP2-47: It's incurable.
OP2-49: It's incurable. It's not operable.
OP2-72: It's still in there... and it's growing.
OP2-78: The longer I'm not on treatment... the longer it's attacking.
OP2-81: There's a delay... delaying... giving it (cancer) extra... boost.
OP2-82: I'm not going to be here.
OP2-232: I won't be here to know.
OP3: (No data)
OP5-17: Your thoughts immediately went ... not going to be here. I'm dying.
OP5-265: You actually thought you were dying.

In-Patients

IP1-47: It's (tumour) just working away... get this taken out... before something happens.
IP1-53: It had travelled through... into... very quickly... very aggressive… very complex.

IP1-99: Got told... tumour now travelled from the... ___ up... into my _____

IP1-241: But I’m not going to be here soon.

IP2-3: ... and then progressed...

IP2-5: ... a cancer tumour... is attacking my spine...

IP2-30: I’m terminally ill.

IP2-38: I think the cancer is attacking... in several places.

IP2-39: It started in the spine, and it started to migrate because it’s aggressive.

IP3-29: Initially was told... go home... sort out your ... you don’t have long.

IP4-3: It (illness) will kill me.

0c-1.2: Psychological Effects of Disappearing due to Illness.

Out-patients

OP1: (No data)

OP2: (No data)

OP3-12: Since then, I’ve just gradually gone downhill.

OP3-30: I will not wake in the morning.

OP5-35: As far as I was concerned, I was on the road out.

OP5-165: I can’t fight this for ever.

OP5-266: All I could think about was dying.

In-Patients

IP1-31: I knew my life was over... and oh my God I’m going to die.

IP2: (No data)

IP3-17: ... yeah... I think it’s... thinking this is the beginning of the end.

IP4: (No data)

Level 1: Limited Self

Participants take stock of their own personal sense of control and as they cannot escape from their diagnosis of a life-limiting illness, they become susceptible to unwanted limitations that interfere with and diminish the quality of their every-day living. Participants communicate their experience of limitations regarding their a) physical body, b) capacity to be effective, c) lack of ability to make sense about what is happening to them and d) emotional disconnect from their circumstances.

1a: Bodily-Limited Self

Patients are aware that their bodies provide the opportunity for active exploration of their environment. However, their bodies, are defenceless against the harm caused by illness, with the result that their physicality becomes unresistant to disease and pain, giving rise to giving rise to limitations. Participants try to assess the limitations of their personal agency within their circumstances.

1a-1: Physical Effects of Illness

Patients communicate that the physical effects such as pain, tiredness, and mobility issues, limiting their ability to move about freely and easily, *"I had to crawl on my hands and knees; I was gripping on to the walls; so tired all the time; so tired all the time; I'm weak in the legs; I took sweats and shivers."*

1a-1.1: Physical Pain

Out-patients

OP1-5: Oh, I could feel the pain.

OP1-114: ... the pain is still there... still there... The pain is still there.

OP1-122: It feels sore. The arm is sore.

OP1-131: It is sore.

OP1-207: I take mini strokes... take angina pains as well.

OP1-211: I've had a lot of angina over the weekend.

OP1-224: It's painful... when I do anything... Painful when I breathe even.

OP1-227: Then the armpit started... it was very painful.

OP2-21: I never felt pain like it.

OP3: (No data)

OP5-4: no appetite... constipated... couldn't eat anything... terrible pain

OP5-20: I was in so much pain.

OP5-39: I was still in a lot of pain.

OP5-41: ... a pain in my side... in my rib cage... constant... walking the floor

OP5-46: I had to crawl on my hands and knees.

OP5-53: Then the pain started on this side... in my back... in my spine.

OP5-188: I told him about pains in my legs... pains in my side.

In-Patients

IP1-12: Oh, I was in agony … in pain.

IP1-15: ... sore... I was gripping... on to the side of things... gripping on to the radiators.

IP1-17: I can't walk in here... I was gripping on to the walls.

IP1-44: I was in pain.

IP1-131: When I'm sore... that's exhausting.

IP1-195: Oh, it's sore.

IP1-207: Woke up this morning...in so much pain

IP1-211: The pain is unbelievable.

IP1-213: (Tearful) Sore... Oh God... it's sore.

IP1-236: ... pain I had... was unbelievable.

IP1-256: I'm still sore... so sore... it's sore.

IP2-2: Illness started... it was a groin pain...

IP3-134: ... I was in a lot of pain this morning.

IP3-162: You mind (remember) where I'm sitting? It's a bit sore.

IP4-27: Still as sore...

IP4-103: I'm all sore and all that...

IP4-104: I was all sore... the last time I went to...

IP4-116: ... the old pain kicked in.

1a-1.2: Physical Tiredness

Out-patients

OP1-169: I feel tired... have a sore ear... had it (cold) for about a month.

OP1-203: I've got more tired... oh yeah tired.

OP2: (No data)

OP3: (No data)

OP5: (No data)

In-Patients

IP1: (No data)

IP2: (No data)

IP3-153: I felt exhausted.

IP3-169: I’m just so tired all the time.

IP3-173: ... it’s a tiredness... I can’t really sleep.

IP4: (No data)

1a-1.3: Mobility

Out-patients

OP1-116: I’m getting slower... with the walking stick.

OP2-163: I had balance problems.

OP3: (No data)

OP5-49: I couldn’t move my legs.

OP5-105: I’m weak in the legs... if I go out for a walk... have to take a stick with me.

OP5-119: My legs were swollen.

OP5-151: Having a lot of bother with my legs.

OP5-264: There’s concerns it’s the bones with me.

In-Patients

IP1-66: Took me a wee bit to get back on my feet again.

IP1-72: When I went back to see him... I wasn’t walking.

IP1-106: I couldn’t get up.

IP2-4: ... to actually both... in my bottom limbs

IP2-19: I started to lose the legs again.

IP3-61: My knees are kind of bouncy... still a wee (little) bit bouncy...

IP3-67: ... because the vertebrae in my back being kind of crumbly.

IP4: (No data)

1a-1.4 Body Temperature

Out-patients

OP1: (No data)

OP2-61: I took sweats and shivers, and I was frozen.

OP3: (No data)

OP5: (No data)

In-patients

IP1: (No data)

IP2: (No data)

IP3: (No data)

IP4-28: I was warm this morning... am feeling a bit cold.

IP4-30: But I'll not take long in heating up again.

IP4-31: People say coming in... "This room's warm." I cannot... I don't feel it warm... no.

IP4-32: [T. "You feel the cold easily?"] Mm... all the time... yeah.

1a-1.5: Other Physical Effects

Out-patients

OP1-197: The eyesight is beginning to go... glaucoma for about 15 years.

OP2: (No data)

OP3-7: I took a heart attack.

OP3-16: I started getting this breathlessness.

OP3-23: And it (breathlessness) just gets worse.

OP3-24: When I move... start getting this wheezing.

OP3-42: I'm still getting breathless.

OP3-91: ... and my lips are very dry as well.

OP3-219: This past week I've had a head cold... and I've had a lot of phlegm.

OP5: (No data)

In-Patients

IP1: (No data)

IP2: (No data)

IP3: (No data)

IP4-11: The blood cells are very low… the white bells cells are very low…

IP4-75: There's another wee (small) change... slurring, slurring.

1a-2: Physical Effects of Treatment

Participants communicate that treatment can bring constant, unpleasant side-effects like sickness, headaches and hair loss. Unwanted as these side-effects are, participants are not able to stop them occurring or even diminish them "*constant sick; hair fell out.*"

1a-2.1: Sickness/Headaches/Diarrhoea

Out-patients

OP1-13: You feel violently sick... headaches... diarrhoea...

OP1-23: ... diarrhoea and sickness all the time... headaches

OP1-94: Well, you're sick all the time... headaches.

OP1-102: Just constant... constant sick...vomiting

OP2-37: I felt sick... felt as if I was going to lose everything in my stomach.

OP2-188: I don't feel very well... I feel kind of sick.

OP2-249: ... splitting headache... and... feel sick.

OP3: (No data)

OP5-59: ... sickness and diarrhoea... diarrhoea was terrible... the sickness.

OP5-62: ... the diarrhoea was the worst.

OP5-74: Couldn't stop being sick... couldn't eat anything... constant diarrhoea.

In-Patients

IP1: (No data)

IP2: (No data)

IP3: (No data)

IP4-43: It can make you feel sick and drowsy.

IP4-92: I felt a bit... oo... and nausea.

1a-2.2: Loss: Hair/ Toenails/ Appetite

Out-patients

OP1: (No data)

OP2-54: Lost the skin from my face... lost my fingernails... lost my toenails... had ulcers.

OP2-102: ... hair's coming out...

OP3: (No data)

OP5-61: ... the hair fell out.

OP5-121: Your appetite goes.

OP5-214: My toenails... they were dead and discoloured.

In-Patients: (No data)

1b: Non-Functional Self

Participants, deprived of strength and power due to both their illness and their treatment, discover that their resourcefulness is wanting and so perceive themselves as a) helpless b) vulnerable and c) ineffective, with no ability to act or react. Within this sub-category, participants describe how the feeling of being non-functional affects both their physical and psychological well-being.

1b-1: Patients Experiencing Themselves as Helpless

As participants do not experience a sense of being in control, they are unable to do anything to help themselves, "*I'm no fit to look after myself; I collapse in the chair.*"

1b-1.1: Due to Physical Effects of Illness

Out-patients

OP1-206: I've no energy. I've no energy. I cannot...

OP1-223: There's nothing else you can do about it.

OP1-235: So, I am restricted... I cannot...

OP2: (No data)

OP3-38: ... because I can't walk.

OP3-84: I had to keep stopping and holding on to something... sit until I get my breath back.

OP3-96: And I'm standing there panting.

OP3-121: I collapse in the chair.

OP3-154: I can't do any exercise... I start panting... I get breathless.

OP3-182: Can't go out very often... can't walk about... can't go out with my friends.

OP5-44: I still couldn't do things I was used to doing... stop playing golf... no energy to walk... lived in a flat... couldn't climb the steps... effort to get out and back in.

OP5-45: I had no energy.

OP5-50: ... no energy whatsoever.

OP5-82: I hadn't eaten for three days... just drinking water.

OP5-97: Oh, you can't... you're housebound.

OP5-139: ... couldn't play to the standard... don't have the same strength... don't have it anymore.

In-Patients

IP1-39: … sent home from work too much.

IP1-108: I was exhausted.

IP2-83: I found it difficult to speak...

IP2-108: [T. "But would you be able to go outside?"] No... no... bed to walker.

IP3-19: ... because I'm no fit to look after myself.

IP3-59: I was struggling... trying to get them to move.

IP3-66: ... my back... I can't bend to pick... things off the floor... if I stand, I get ten minutes... then I need to be back on the bed again.

IP3-68: ... it's really difficult... so... jobs... I need them to do.

IP3-120: It was more or less everybody pushing me in a wheelchair.

IP3-135: I was trying to go to the bathroom... was too difficult... I sit there for ages.

IP3-161: I miss just not getting out of bed.

IP3-164: Fine in the wheelchair... as long as someone to push me all the time.

IP4: (No data)

1b-2: Patients Experiencing Themselves as Vulnerable

Participants communicate that they feel exposed to harm and so do not experience themselves as safe, physically, or emotionally, *"couldn't leave the house; I held on to her hand and couldn't let go*."

1b-2.1: Physical Effects of Vulnerability due to Illness

Out-patients

OP1-55: It took about a year for me to get discharged from the cancer doctors.

OP1-150: I can't go abroad now. That would kill me.

OP1-201: I was taking these turns and... losing the place... it's split seconds.

OP1-237: I'll no go anywhere now... couldn't cope on my own. I need someone with me.

OP2: (No data)

OP3-51: It's slightly up hill... I've to stop a couple of times... I have ... to stop.

OP3-74: I've got to sit... take all these deep breaths.

OP3-161: I feel light-headed.

OP5-64: ... you couldn't leave the house... couldn't leave the house.

In-Patients

IP1-73: I took a time to heal... absolutely awful... a complex thing.

IP1-89: I don't go out anymore... panic attacks... don't even go shopping.

IP2-6: two sections of my spine... impacting on my spinal cord... affects the functioning of my legs.

IP3-156: I don't think they'll let me outside.

IP4: (No data)

1b-2.2: Psychological Effects of Vulnerability due to Illness

Out-patients

OP1-246: No. I need... I cannot do this. I need to stop.

OP2: (No data)

OP3-4: I found it difficult at the beginning... on my own.

OP3-73: ... it's really frightening... because I'm on my own.

OP5: (No data)

In-Patients

IP1-102: Had that (Dying alone in the night) in my mind... most of the night.

IP2: (No data)

IP3-8: My daughter came... I held on to her hand and couldn't let go.

IP4: (No data)

1b-3: Patients Experiencing Themselves as Ineffective.

Participants express that they experience themselves as inefficacious, inadequate, "*I can do absolutely nothing; couldn't seem to grasp what was actually happening*."

1b-3.1: Physical Effects of Feeling Ineffective due to Illness.

Out-patients

OP1-37: There's nothing else I could do... that's how it treats you... the illness.

OP2: (No data)

OP3-77: I can't do anything... I can do absolutely nothing.

OP3-104: I mean I can do absolutely nothing in the house now.

OP3-117: ... now I can’t ... I can’t get up.

OP3-124: I can’t do that now.

OP3-125: I can’t get up that hill.

OP3-126: I can’t go anywhere.

OP3-129: ... and I just can’t do anything.

OP3-179: I can’t go down there... it’s too far.

OP3-217: I can’t do these things.

OP3-236: I can’t... I can’t walk about.

OP5-55: You cannot do...

OP5-77: But I can’t play golf or do things I used to do.

OP5-120: Nothing you can do.

OP5-154: ... but I can’t... can’t walk as far as I... I can’t do that just now...

OP5-171: I can’t do that... definitely... I can’t do it.

In-Patients

IP1-27: … I couldn’t... I couldn’t even tolerate it (pain)... could not tolerate it.

IP2: (No data)

IP3-112: But I’m not able to do that... anymore.

IP4: (No data)

1b-3.2: Psychological Effects of Feeling Ineffective due to Illness.

Out-patients

OP1-15: to tell the truth... cause I didn’t know what to do.

OP1-99: You’ve no control.

OP1-223: There’s nothing else you can do about it.

OP1-235: So, I am restricted... I cannot...

OP2: (No data)

OP3-243: ... and now you know you can do absolutely nothing.

OP3-249: I just can’t do it.

OP5-28: I just couldn’t look at it.

OP5-33: I just couldn’t cope with it all.

OP5-34: Couldn’t take anything in that they were telling me.

OP5-247: I couldn’t do... couldn’t for the life of me.

In-patients

IP1-18: I said, "I can't do it."

IP1-212: I cannot...

IP2: (No data)

IP3-12: ... couldn't seem to grasp what was actually happening.

IP4: (No data)

1c: Strongly Puzzled Self

Participants perceive themselves as not knowing or understanding what is happening to them or what is being done to them and so they feel puzzled, troubled, and uncertain in the world in face of missing personal resources. They experience that they function differently under life circumstances that have changed and so find it difficult to form judgements that provides them with clarity of their experiences.

1c-1: Patients Experiencing Themselves as Troubled

Due to their illness and treatment, participants experience themselves as troubled, at a loss, as they are beset with problems, "*hotspots... How many? What's a hotspot? This can't be the only life*; *tablets and things I'm on... they don't seem to be doing any good; Scared to go to sleep."*

1c-1.1: Troubled by Physical Effects of Illness

Out-patients

OP1-58: Same feelings I was getting in this leg.

OP1-100: You have to go to your bed... that didn't work... had to get up again.

OP1-115: ...it's always there... always there... painkillers don't help... don't help.

OP1-121: I have... to see one of the doctors... got a pain under my armpit... been going on for a number of days... felt a lump...

OP1-134: But this (new pain) is about 3 or 4 days now.

OP1-225: It is there. I know it's there. I can feel it.

OP1-228: I know there is a swelling under there as well.

OP1-230: I can feel. I can feel the swelling.

OP-2: I thought it's a bit sore. It's not comfortable. So, I went to see my GP.

OP2-36: You got hotspots... hotspots... How many? What's a hotspot? Is that something else... is that cancer?

OP2-127: Took a cold... Why is this not stopping? ... a cold or something else... I couldn't kick this one.

OP3-102: Why are you making me walk this distance?

OP5-11: I was as fit as a fiddle... never smoked... never drank... in my life... worked all my life... retired... five days I was out on the golf course... loving my life... I really was.

OP5-129: ... somebody tell me something... explain something to me.

In-patients

IP1-9: Went on holiday and... like... the blood was so visible.

IP1-34: But even with that all my (tests) coming back fine... coming back absolutely fine.

IP1-161: I just says, "Why... why... why am I not able to?"

IP1-187: And then you think "Why?"

IP2-95: ... things like that... not going to have room (time) for.

IP3-6: I got up and went to the toilet... came back and lay on my bed... and I don't know.

IP4-17: They can't get the… they can't get it they've tried...

IP4-60: I mean I was supposed to die, and I didn't.

1c-1.2: Troubled by Psychological Effects of Illness

Out-patients

OP1-138: [T. "And you're not in charge of that?'] No... no... I thought I would be but I'm not.

OP2-16: Something inside me told me that this wasn't a cyst.

OP2-27: ... how to handle this?

OP2-28: How am I going to keep him (husband) up and keep myself up?

OP2-34: No, it doesn't feel... it doesn't feel routine. It doesn't feel normal.

OP2-50: I'm sitting with a ticking time bomb in me... contain it?

OP2-192: Had all different scares... it keeps coming... what's the next stage...

OP3-145: ... is this where they feel they can't do anymore... just let her go there and that's it.

OP3-231: What's the point of being here?

OP3-235: ... just been left to just carry on...

OP5-13: My sister was with me...I just remember grabbing her hand... and looking at her... Good God...

OP5-30: I was scared to look at it (results). I really was.

OP5-131: No one else to go to... all I've got... don't have any other options.

OP5-145: Oh, no... I don't... I wouldn't like to think so...

OP5-147: [T. "What would it have meant... if people had known?"] I don't know... don't know how they are going to... [T. "... treat you ?"] Yeah... that's what you're scared of.

OP5-186: You're nervous... you're concerned... what he's going to tell you.

OP5-212: That was a fear.

OP5-261: [T. "What... makes you not tell people?"] You're scared in one way... I don't know whether they'll ignore you.

OP5-262: ... they'll stay away from him... he's got the plague... a leper... you just don't know.

In-patients

IP1-11: Definitely it was causing alarm signs even without that happening.

IP1-16: They told me... I knew it wasn't all these things they were telling me.

IP1-80: After a year... I think... God... after a year... how this just hit me.

IP1-175: I never thought I'd be planning mine (funeral). [

IP1-179: This can't be the only life.

IP1-181: [T. "The leaving?"] Uh huh... The leaving her (daughter)...

IP2: (No data)

IP3-9: I didn't want her (daughter) to leave me... every time she went to move away I'd go... "Nope... stay there."

IP3-11: So, that was upsetting me all the more.

IP3-55: I don't know... I don't know... I really don't have a...

IP3-82: I am frightened that we go off the rails... frightened that they just don't know how to cope.

IP3-84: I'm frightened that they're not doing what they need to be doing (studies) ... that's my biggest fear.

IP3-111: It's almost she's abandoned me... who does that to their child?

IP3-131: [T. "What would you say to her if she was here?"] Oh... I've no idea.

IP3-150: I don't know if anybody's staying or if... if at all there's going to be anybody here... (at the end)

IP4-4: I've been told... because they've got nothing to fight it.

IP4-52: Sometimes it's kind of hard to say. (That no treatment can help).

1c-1.3: Troubled by Lack of Effectiveness of Treatment on Physical Body

Out-patients

OP1-101: You get the treatment... you're on steroids... to help stop the sickness... but it wouldn't stop.

OP1-202: They (doctors) don't seem to know... stepped up my ____ tablet thinking it was that... it's not that.

OP2: (No data)

OP3-187: What I'd like to say... "Is there nothing you can do... nothing you can give me that would help?"

OP3-193: I feel somebody should be able to do something... But what?... that's the thing...

OP3-195: Why I don't know... who has referred me... nobody told me.

OP3-200: Is there anything else they can give me that would help a bit?... Could somebody look into that?

OP3-227: I feel... no matter how many different tablets and things I'm on... they don't seem to be doing any good.

OP5-84: ... the medication... bringing down the level... but this is every three or four weeks... this is what's happening to me.

OP5-230: He (doctor) doesn't believe it's being caused by these pills... he's not convinced... maybe he's right... I don't know.

In-patients

IP1-209: Medication... not worked... what else is there?... Is there something else to get?

IP2: (No data)

IP3: (No data)

IP4-94: I don’t know if the anti-sickness drugs I was taking before it or not... I don’t know if that did it or not... or had anything to do with it.

1c-1.4: Troubled by Lack of Effectiveness or Inappropriateness of Treatment on Psychological Well-being

Out-patients

OP1: (No data)

OP2-80: Knowing I wasn’t getting any treatment.

OP2-140: Taking that step... into the unknown.... fear

OP2-141: I accepted the diagnosis... but there must be a cure... somewhere down the road.

OP2-172: Brings it all back... just brings it back.

OP3-180: It’s just... oh, I don’t know...

OP3-192: And I feel... what’s the point?

OP5-85: ... that’s what I weighed... that’s what I’ve lost since I started... on this medication... this is what’s worrying me now.

OP5-99: Scared to go to sleep... stuck between the rock and the hard place.

In-patients: (No data)

1c-2: Patients Experiencing Themselves as Puzzled and Confused by their Current Status of Illness and Treatment

Patients are muddled and so find difficulty in understanding their new-found circumstances, “*What do you mean? ... nothing we can do; What do I do with this? Well, I don’t know what I want to do; just pure poison… going into you.”] … I said, “Why are you giving me them?” … [Doctor] “If we don’t ... you will die*; *quite baffling that it’s happened.”*

1c-2.1: Puzzled and Confused by the Current Status of Illness, from a Physical Perspective

Out-patients

OP1-56: They never told me once I was in remission... I kept asking... they never said... wouldn’t tell me.

OP1-65: They couldn’t explain why it came in this other leg... they were astonished it came there.

OP1-127: If I can see one of the doctors... got a scan a fortnight ago... don’t know why it’s taking so long.

OP2-48: What do you mean? ... nothing we can do. What do I do with this?

OP2-87: I was ill... really ill.

OP3-15: I don’t know whether it has healed itself or not...

OP3-17: I didn’t know what it was.

OP3-132: ... how could this big change happen?

OP3-134: is it my... is it that...? I don’t know.

OP3-137: No one is telling me anything... explain... this is what’s happening...

OP3-172: ... but what if it doesn’t calm down... Do I use my emergency thing?

OP3-186: Nobody will sit down and talk to me.

OP5-22: “You need to get straight down here.” They’d been looking for me.

OP5-83: ... took all the samples... came back... don’t know what it is.

OP5-270: I just don’t know how I got it. I still don’t know.

In-patients

IP1-14: ... this has been about a year I’ve been feeling like this.

IP1-35: It’s just... agony... sheer pain from this and I knew that you could really get bad --- infections … if they weren’t treated well.

IP1-40: … when I wasn’t going into work.

IP1-48: I didn’t even know on that day why I was going in. (to hospital).

IP2-53: I don’t smoke... I don’t drink... I like to think I eat healthy.

IP2-54: ... you don’t know... they find it... it spreads or how you’ve got it.

IP3-5: Uh huh... something happened... but I don’t know what.

IP3-7: I’m really not sure what happened after that.

IP3-152: Got no idea whatsoever... over the past three or four days... at least.

IP3-168: ... just how tired I am... I don’t know why?

IP4-13: Really baffled … because I’ve not been on any medicine or anything to do with that…

IP4-15: No… it’ll go back down again.

IP4-16: It’s done it once before… went back down again… it rose a bit…

1c-2.2: Puzzled and Confused by the Current Status of Illness, from a Psychological Perspective

Out-patients

OP1: (No data)

OP2-101: I... don't figure it out... whatever it is ... it keeps me.

OP2-191: Because I'd had so many good results... when does the bad result hit me... was quite shocked at getting that (secondary cancer) ... I did believe it... there must be something coming I don't like.

OP2-230: I bubbled (cried)... bubbled (cried)... I couldn't stop, and I didn't know why.

OP2-239: I don't need to tell people I've got a wig... so why broadcast it?

OP2-240: I don't know if it'll change... don't know if that will ever change.

OP2-241: Do I need to tell them I've got secondary? Do I look I've got secondary?

OP3-20: I don't know why... he didn't tell me.

OP3-22: [T. "So, you didn't really know where you were at that point?"] No, No... That was me.

OP3-60: ... but nobody seems to...

OP3-160: ... and I don't know... whether it's my imagination or not...

OP3-183: So, what is there to do?

OP3-225: I don't know.

OP3-233: I don't know... I don't know.

OP5-242: Whether he'll be there or not... I don't know.

In-patients

IP1-22: I never got to speak to... they were... taking your symptoms over the phone.

IP1-24: I wasn't even seeing anybody... waiting times... trying to get appointments.

IP2-48: Nobody will sponsor you as a cancer patient (for work) ... nobody seems to want to use that word.

IP2-116: ... I get totally mixed up.

IP3-2: ... still wasn't sure what was real... what wasn't real... what was actually happening.

IP3-22: I didn't know where I was or what was going on...

IP3-81: I don't know.

IP3-92: The other night at visiting I sat there and just burst into tears and no apparent reason... and still don't know why.

IP3-107: I don't understand why she's doing this.

IP3-109: I don't understand...

IP3-114: ... and that totally confused it all the more.

IP3-115: I don't know whether it was a case of... or whether they had kind of...

IP4-10: No, it's because I'm where I'm at.

IP4-14: It just done it... which is quite baffling that it's happened.

IP4-38: It sounds silly... but that's just the way I feel.

IP4-39: I don't think it's silly either... but it sounds silly.

IP4-127: It's probably a normal thing... I don't know.

1c-2.3: Puzzled and Confused by the Physical Effects of Treatment on the Current Status of Illness

Out-patients

OP1-48: [Doctor, "... just pure poison… going into you."] … I said, "Why are you giving me them?" … [Doctor] "If we don't ... you will die."

OP2: (No data)

OP3-188: What about all the tablets I've been on for months...

OP3-189: ... and nobody says to me... "I think we'll try this, or we'll try...."

OP3-223: I know I had problems with my heart... but nobody has said... just kept giving me different tablets and different things.

OP5-40: The pills I was on... the mixture of pills... it just wasn't working...

OP5-72: He (doctor) said, "That's the only thing I can give you. If you don't take them the ____ is just going to keep going up."

OP5-96: ... they just let it continue and continue... entirely... pure liquid... liquid all the time.

In-patients: No data

1c-2.4: Puzzled and Confused by the Psychological Effects of Treatment on the Current Status of Illness

Out-patients

OP1-95: Half of the time you don't know where you are.

OP1-110: I don't know how I felt.

OP2-167: I don't know why I have... but I have.

OP3-202: Well, I don't know what I want to do...

OP5-124: No, I don't know.

OP5-125: When you get (treatment)... you could phone with any problems to discuss ... if you weren't sure... nothing with this... no helpline... nothing... just take them (tablets) and that's it.

In-patients

IP1: (No data)

IP2: (No data)

IP3: (No data)

IP4-78: Medication does a lot of things to you... physically and mentally.

1c-3: Effects of the Unexpected

Participants find difficulty in absorbing what has become reality, the unforeseen, unplanned diagnosis of a life limiting illness and effect of treatment, "*Doctors says, "It will come back." ... I says, "It will come back; I could not believe it; wasn't something I was expecting.*"

1c-3.1: Physical Effects of the Unexpected due to Illness

Out-patients

OP1-4: For to get told I had _____ and ____ ... cancer doctors to get in contact … as soon as possible... because it was progressing.

OP1-40: I thought it was just (only)... was inoperable... couldn't operate to take it out... impossible to operate.

OP1-57: (Pause)... this year it started in this leg... I was getting swellings.

OP1-62: Doctors says, "It will come back." … I says, "It will come back?"

OP2-73: It's like chalk and cheese... getting the results... I've got secondary... then... the results saying I'm normal.

OP2-178: If somebody had told me last year that I would be sitting... I would have told you. "No." ... If someone had said to me... "You'll be here next year. You'll be doing all this." ... I don't think so.

OP3-92: ... so I go through these things for moisturising your lip... I don't know how many of those I've gone through.

OP5-7: They told me there and there... "You've got ___ cancer... has spread to your __.

In-patients

IP1-61: … he [Doctor] … "I can't operate." … I'm like "What?" … [Doctor] "It's inoperable... inoperable." I said, "My Goodness."

IP1-159: Doctor said, "... I can't give you anymore treatment. I can't give you anymore." I'm like, "Right."

IP2-51: ... had a little bit of treatment... operation was good... recovered from that five years... low and behold... this node pops up.

IP2-52: I was only 43... the first time I got it.

IP3-3: [T. "... what's happening to me?"] Uh huh because it's the first time.

IP4-12: This week for some apparent reason they took a jump up.

IP4-106: ... because you don't expect that...

1c-3.2: Psychological Effects of the Unexpected due to Illness

Out-patients

OP1-9: It was ____ and ____ ... oh yeah … it was shock.

OP1-10: He [Doctor] says, "It's very progressive... has to be treated immediately." So that was a shock... yes... a shock to me.

OP1-39: I didn't realise what I was going to get... what was in front of me. OP1-45: But I didn't know what I was going into.

OP1-49: Unknown to me I didn't know what was in front of me... bang... bang

OP2: (No data)

OP3: (No data)

OP5-10: I wasn't expecting that. That was the last thing in my mind.

In-patients

IP1-30: I could not believe it.

IP2-50: (Doctor) "I've got to give you the bad news." Told me it was cancer. [T. "Could you believe it?"] No... because... this started... in January... started prior to that... seven years prior ... I had ___ cancer at 43... yeah... I got through that.

IP3-46: I can't even remember why it happened ... I was speaking to someone ... burst into tears ... that still happens.

IP3-86: I've always taken responsibility for that (parenting)... so the last thing I was expecting was... such a massive... support.

IP4-8: No… it doesn't… there's nothing that can build you up.

1c-3.3: Psychological Effects of the Unexpected due to Treatment

Out-patients

OP1-171: I thought they were doing good but... hanging (fragile) a bit.

OP2-146: It wasn't something I was expecting.

OP3-11: So, I thought... I'll be fine.

OP5: (No data)

In-patients: (No data)

1c-4: Patients Experiencing the Effects of Uncertainty

Participants do not have sure knowledge about what is going to happen to them and so they are unclear with respect to their future. Illness and treatment both give rise to uncertainty and their effect is both physical and psychological, "*my longevity or whatever; Maybe at the end of the day it doesn't help you.*"

1c-4.1: Physical Effects of Uncertainty due to Illness

Out-patients

OP1: (No data)

OP2-11: I did say, "Could this be cancer?" I did ask.

OP3-78: (No data)

OP5: (No data)

In-patients

IP1-3: I was nurse myself... and am testing my own ___ and there was signs it was an infection.

IP1-95: It might be a month... it might be a month.

IP2-101: ... my longevity or whatever...

IP2-103: ... whether they can intervene in any way...

IP2-121: I don't know what it's going to be like tomorrow. I don't know... the weather will be like tomorrow?

IP2-129: I don't know what time. It's in the morning.

IP3-78: ... at first, I wasn't sure.

IP4-98: I'm saying to myself... "Is this the kind of thing that's going to be happening to you... are you going to get these infections at any time?"

1c-4.2: Psychological Effects of Uncertainty due to Illness

Out-patients

OP1-54: Not knowing what's in front of you.

OP1-89: You're wondering what the outcome is going to be... if it's going to start... again.

OP2-12: You come out of the surgery and you're on your own... you sit... you're walking.

OP2-52: I says, "I don't know what's going to happen?"

OP2-88: You don't know what's going to happen.

OP2-131: The unknown... a change... somethings happening... don't know what it is?

OP2-226: I think uncertainty... in the secondary... creep in now and again

OP3-171: Knowing that I'm on my own... What's going to happen?

OP5-26: Not knowing what you're going to be told.

OP5-87: I don't know what's going to happen.

In-patients

IP1-77: [T. "... uncertainty?"] Yep … blood clots... just all sorts of stuff.

IP2: (No data)

IP3-122: ... and so I don't know.

IP4-68: They maybe won't but they could get better... there is a difference between getting better and could get better.

1c-4.3: Psychological Effects of Uncertainty due to Treatment

Out-patients

OP1-92: ...about for two weeks... you don't know where you are.

OP2-71: Waiting on treatment... what if? ... what's happening? ... no getting treatment...

OP2-187: It's the uncertainty...

OP3: (No data)

OP5-94: You don't get an information pack... nothing available... don't know what's going to happen here.

OP5-100: I don't know if because I've missed (medication) these five days... my ___ number will go up or if it will stay... I'm betwixt and between.

OP5-113: You're lying in bed at night... you're saying, "Is this going to start tomorrow?"

OP5-122: I've got it in my head... whether it will or not...

In-patients

IP1-50: And I'm saying … and I'm thinking … am I getting (treatment)?

IP2: (No data)

IP3: (No data)

IP4-81: Maybe at the end of the day it doesn't help you... .

1d: Detached Self

As participants receive information about what is happening to them, they appear to have some degree of awareness of experiencing themselves as emotionally detached from their unwanted state of affairs. They make reference to what is happening to them but, at the same time, the happening appears independent of them and not part of their lived experience, "*It took me a bit of time to digest…* "

1d-1: Detached due to Psychological Effects of Illness

Out-patients

OP1-41: It was hard to take in... sitting there.

OP1-109: Was unbelievable at the time... didn't ... sink into me.

OP2-60: I didn't know that I was ill.

OP2-89: There's a lot of information... don't think a lot of people take the information in... I know I didn't to an extent.

OP2-190: It took me a bit of time to digest...

OP3: (No data)

OP5-32: I can't remember an awful lot of it.

OP5-58: Oh, I was... was just out of this world.

In-patients: (No data)

Level 2: Reflexive Self

Participants are becoming more self-aware and experience an internal sense of agency that sees them strive for self-preservation, despite their incurable illness. Participants feel dissatisfied that their identity before their diagnosis has become

different or even replaced by another identity, bringing with them the feelings of loss and lack of personal control.

2a: Changed Self

As the *Changed Self,* participants communicate a halt to their usual selves, with their identity prior to their illness becoming transformed during their illness.

2a-1: Participants Experience Themselves as having Become Different

Patients feel that they are recast in a new identity that does not represent their self-image, self-esteem, or individuality. The change in identity is perceived as troublesome and disruptive, "*I know I've changed; I'd never felt like that before."*

Out-patients

OP1-25: I don't know because I'm not an angry person.

OP1-35: I'm not an angry person.

OP1-240: I can't do things I used to.

OP2-45: I've changed. I know I've changed.

OP2-151: It changed me... it has changed me.

OP2-221: There's a change in me.

OP3-65: But I don't cook very much now.

OP3-242: ... it's so frustrating... when you know what you used to do.

OP5: (No data)

In-patients

IP1-145: I used to go swimming... used to go swimming with my friend.

IP1-184: Because I've always been so independent... do things on my own.

IP1-190: I used to take my daughter... used to

IP1-191: We (patient/daughter) loved doing that... enjoyed doing that.

IP2-43: I'm not a teary person.

IP2-88: It's had a big impact on my life.

IP3-13: ... I'd never felt like that before.

IP4-74: I'm finding it hard to get things out now... before it was free flowing.

2a-2: Participants Experience Themselves as having Become Replaced

Patients feel that their familiar identity has been removed and another, unknown to them, has taken its place. Patients communicate that they are not comfortable with their new selves, "*old me died... a new one was developing; I don't feel me.*"

Out-patients

OP1-163: [T. "You become like another person?"] Yeah... oh yeah... you do.

OP1-165: ... used to sit together and talk... laugh and joke.

OP2-105: It wasn't me. It was a person with cancer.

OP2-111: ... so, I'm not that same person.

OP2-118: She's coming back as a different person.

OP2-217: … old me died... a new one was developing.

OP2-245: I feel like a different person.

OP3-131: When I think back to what I was like... and I see myself now...

OP3-240: My life has changed completely.

OP5-143: Oh, it changed my life completely... completely... I really do miss it.

OP5-176: And that was never me.

In-patients

IP1-204: I just feel... I don't feel me.

IP2: (No data)

IP3-119: This time I'm not fit to do that.

IP4: (No data)

2b: Defiant Self

Even if illness results in dramatic changes in their living, patients don't experience themselves as defeated, resisting to accept or comply with their illness and self-defeating ways of feeling and thinking about their circumstances.

2b-1: Participants Resist to Accept/Comply with their Illness.

Patients are non-defeatist, experiencing themselves with increased self-determination, aiming to maintain independence and continuity by standing up to illness and death, "*I'm here... I'm not a memory; I'm not ready to go... I don't feel it's my time.*"

Out-patients

OP1-195: They want to be the parent to me... not going to allow that as long as I'm still here.

OP1-247: As long as I space it out... manage to get it done. It may take longer.

OP2-29: I just have to get on with it.

OP2-67: I need to go... I've still to do my own thing.

OP2-129: I'm not ready... I'm nowhere ready.

OP2-144: I just go... No, You're not... You're not doing this.

OP2-171: I'm here... I'm not a memory...

OP2-193: I've got to kick my backside and say, "No."

OP2-219: I don't see the victim anymore.

OP3: (No data)

OP5-38: I'm not ready for snuffing it yet.

OP5-273: I'm not ready to hang up my clogs yet.

In-patients

1P1-122: I'm not ready to go... I don't feel it's my time.

IP2-32: I'm not going through any more scans.

IP2-35: [T. "So, these treatments you didn't go through with?"] No... no.

IP3: (No data)

IP4-110: I don't care...

IP4-62: [T. "What does that do to you as a person?"] As a person... nothing... no it's just a saying you know.

IP4-63: No... I don’t think like that.

IP4-65: No, I don’t.

IP4-110: I don’t care...

2b-2: Participants Resist to Accept/Comply with Self-defeating Attitudes.

As patients experience a greater sense of control, albeit an internal sense of control, they avoid emotional disengagement due lack of self-regulation, “*Something in me fires me... You’ve had enough of me... you are not going to win; You just have to face it.”*

Out-patients

OP1-117: I just need to keep going.

OP1-178: Just got to plod away. You just got to keep going.

OP1-221: I just need to plod on.

OP1-252: You’ve just got to survive.

OP2-42: I have to be one step ahead of this.

OP2-95: Something in me fires me... You’ve had enough of me... you are not going to win.

OP2-109: ... you are not going to beat me... I’m going to beat you...

OP2-128: Part of me goes, “You (cancer) is not winning this.”

OP2-147: I got back at you. You didn’t win.

OP2-212: No, you’re not on... I can do this.

OP3-10: But I managed.

OP5: (No data)

In-patients

IP1: (No data)

IP2-40: [T. “When you’re talking... how difficult...talking about myself?”] It’s not a problem... not a problem... no.

IP2-47: [T. “Were you ready... to face it?”] Yeah... yeah.

IP2-55: You just have to face it.

IP3: (No data)

IP4-20: [T. “So, you don’t avoid?”] No…

IP4-70: I don’t think so no... I don’t think so.

IP4-90: Not really... no.

IP4-100: … no... no I wouldn't say stops it... no.

Level 3: Collective Self

Patients' experiences of their incurable illness limit or even prevent them from making their own decisions about their circumstances; as a result, they may seek what they need through collaboration with others.

3a: Relinquishing Self

Participants, as the *Relinquishing Self*, are not actively engaged in decision-making but, rather, allow themselves to pass their autonomy to appropriate others who they expect will respond prudently to their needs.

3a-1: Handing Over of Autonomy with respect to Illness.

Participants are confident that the relevant others, who have knowledge, expertise, and experience, will respond with wise and well-judged decision-making, "*they're trying to stop me bleeding to death. I left it to them; He (Doctor) got me out of my bed and he made me walk."*8

Out-patients

OP1-159: I just let them carry on... they're trying to stop me bleeding to death. I left it to them.

OP1-199: They don't allow me. Oh no... oh no way... that's what I'm told.

OP2: (No data)

OP3-9: When I was in hospital... They told me... Right... That's it... no more (smoking).

OP3-143: I got referred to come... to the day centre.

OP5-135: I'll just have to wait and see.

OP5-195: No, I've never asked questions... I just take... I'm a bit in awe of these people... they've got knowledge of these things... I think these people are a step above me.

In-patients

IP1-6: … believed my doctor

IP1-38: … and I was sent home from work.

IP1-67: [Doctor] … he’s very straight down the line: “Get up out of your bed.” Do this... do that... bla... bla... bla

IP1-69: He (Doctor) got me out of my bed and he made me walk.

IP2-110: I won’t cook... someone else will cook...

IP2-137: And this was the place selected. [T. “You selected it?”] No... my ___ nurse.

IP3: (No data)

IP4-5: That’s why I’m being cared for overnight…

IP4-21: They come right out and tell you and there’s no ifs or buts or in-betweens in it… they tell you…

IP4-88: When you start getting... bone marrow...taken out of you they’re talking along the lines ... they start talking about ___ and all that.

3a-2: Handing Over of Autonomy with respect to Treatment.

Participants are confident that the relevant professionals will choose the treatment that best meets their needs, “*They managed to get it dissolved... the tumours... destroyed them; They did that... a 13-hour operation,”*

Out-patients

OP1-11: They started me on [treatment] … very severe... get it every month.

OP1-46: They told me the results... they decided to go ahead with this treatment.

OP1-61: They managed to get it dissolved... the tumours... destroyed them.

OP1-154: They (doctors) telling me I need to keep going (With treatment)

OP1-170: Went to the doctor... gave me a spray for my ear... antibiotics

OP1-226: He’s sending me for a scan... he doesn’t think it’s... I can’t take the chance... Had it three times.

OP1-231: They’ll... do something about it... send me back to (hospital) maybe.

OP2-20: We are going to do biopsies. I got six.

OP2-125: They will take blood tests again.

OP2-234: I had to go to the hospital to get this eye...

OP3-13: ... and they diagnosed... they... decided to take it out.

OP3-80: I had an appointment at the chiropodist at the Health Centre.

OP5-5: Doctor seen me... and said he was sending me for a biopsy.

OP5-197: They said they'll have to cut the dose... I just accepted it... got on with it... I accepted the fact that they knew what they were doing.

In-patients

IP1-46: I was admitted there (hospital) … and straight into an operation.

IP1-65: They removed all round about. They did that... a 13-hour operation.

IP1-208: The doctors changed... changed the dosage.

IP2-8: ... they had a solution... they had various scans.

IP2-21: ... the way they (doctors) work is... starts you off high and they gradually reduce the dose... at a fairly rapid pace until you're off them.

IP2-24: They agreed they were going to keep us kind of going with that for a little bit longer... at this higher rate... was their advice.

IP2-77: Had the doctor... saying the medications... keeping at the level that normally keep while in here... to take home with me.

IP3: (No data)

IP4-25: I know that if they can make me really well… they would tomorrow… I know that.

IP4-76: I was told that's from the medication I was taking.

3b: Active Collaborating Self

The experience of a significant life event like a life-limiting illness prevents the participants from living their lives in individual autonomy and thus they choose to take part in meaningful co-operation with others, including helpful professionals, family, and friends.

3b-1: Collective Agency/Efficacy with Helpful Others

Patients willingly engage in collaboration with others, who they believe, can help them in their decision-making, regarding their circumstances, "*I... asked my doctor, "Do I need to go and book a bed in the hospice; you've kind of opened my eyes a little bit... I don't feel so frightened... What do I feel more?... feel calmer; The girls helped me with the housework... my dogs...things like that; He [Reverend] is coming... he'll help me with details of the funeral.*"

3b-1.1: Healthcare Professionals

Out-patients

OP1-8: She referred me to the (hospital) … I told them about it... they say... "We'll do a scan."

OP1-67: They say I'm getting physiotherapy... physiotherapist is trying to help

OP1-219: They've given me an inhaler because I went to see the nurse about it and she said, "I'll recommend that you get an inhaler to help you."

OP2-5: I told the doctor... doctor, "I'll have a look."

OP2-189: Nurse, "I've got the results." ... I went... She says... and I'm going...I've got that trust in her.

OP2-200: If I've got any problems... I'll speak to the nurse... she'll know.

OP2-237: I went in ... to see him (doctor)... and I... and he went... and I said...

OP3-18: I used to go and see a heart specialist down at the hospital.

OP3-21: ... heart failure nurse... every month... every six weeks... she was looking at the tablets... I was asking her how I was doing... we'll change this and do that.

OP3-140: I said to them... "I don't want... I would rather...." They referred me... doctors... speak to you on a one-to-one basis...

OP5-21: They give you a card, so you can phone this number... I phoned the number and spoke.

OP5-24: The phone rang... hospital saying... a cancellation... Would I like to go... I went... got bone scan... got another call... come down to speak to... they had the result of the... scan.

OP5-36: I... asked my doctor, "Do I need to go and book a bed in the hospice?" She asked me if I wanted a ____ nurse... I said, "I'll take all the help I can get."

OP5-42: Got a phone call... can you come in today... I went... seen the doctor... gave them all my medication... doctors said... what we want you to do.

OP5-60: I went back... to tell the doctor... he went on to the computer and said, "We... to give you a lower dose."

OP5-86: So, I spoke to....

OP5-95: You just phone an ambulance... go… to the hospital.

OP5-102: I spoke to ___ ... she's going to get me an appointment with Dr ___ she's excellent... she was really good when I was in the last time.

OP5-106: I'll go in the car.

OP5-190: I went... to see Dr ___.

OP5-192: Doctor phoned me... telling me that Dr ___ had been in touch with him...they'd discussed my case... they decided... another tablet... try this... I said, "That's great... I'll do that."

OP5-198: When I saw that doctor... she was very, very good... It's great when someone sits like I'm talking to you... explains everything to you.

OP5-199: I definitely feel a lot better since I spoke to Dr _____... I know now … something getting done… .

OP5-213: ... I went to the podiatrist and got my toenails cut.

OP5-215: She said they (toenails) would grow again... I'm quite happy with that... "Come back... we'll file them down again."

OP5-241: I go and see the consultant on Friday.

OP5-243: But I have to go anyway to get the drugs... results of my ___ test.

In-patients

IP1-19: So, I went to (get help) … got another antibiotic.

IP1-20: I took that one along with a load more pain killers.

IP1-21: Went back again when the antibiotic was finished.

IP1-51: So, we got it out... operation... the tumour went...

IP1-54: The top surgeon there... so I went... they offered me surgery.

IP1-56: We had a meeting.

IP1-57: He says I could be a candidate for a trial.

IP1-62: ... did the (treatment)... done that... went back to the surgeon.

IP1-76: Because they're learning as well... everybody's learning.

IP1-116: We were going to hold it back from her (daughter) until we seen the hospital doctor... in case there was a plan.

IP2-9: We managed to recover my legs by the use of steroids.

IP2-14: They come in and make sure my legs are functioning...

IP2-23: But we had to recover this plateau for the steroids.

IP2-104: ... specialists will also be coming... doctors... care team... the__ nurse... all come to the house... all got access... key-safe at the door.

IP3-62: ... but I was able to get myself off the bed with a wee (little) bit of help.

IP3-63: My issue was getting back on the bed... we're working on that today.

IP3-65: She's coming back... gives me exercises for my feet... I think each time I do it... it gets a wee (little) bit stronger.

IP3-158: [T. "You'll ask them?"] I'll ask anyway.

IP4-24: I know there are one or two of the doctors that I really... get on with…

IP4-131: I had a talk with the doctors... they were saying to me... if anything goes wrong... come back up here again.

3b-1.2: Therapist

3b-1.2.1: Therapist: Mild Appreciation

Out-patients

OP1: (No data)

OP-2: (No data)

OP3-69: Could that do for now? [T. "Yes... yes... thank you."]

OP3-148: [T. "... important... when you feel you've had enough... you tell me to stop."] Well... think that's probably enough for today.

OP3-218: I think that'll do just now. [T. "Yes... thank you... thank you."]

OP3-252: That's me... (panting). [T. "I can hear... we'll stop... thank you."]

OP5: (No data)

In-Patients

IP1-2: You know what I mean?

IP1-23: You know what I mean?

IP1-42: Do you know what I mean?

IP1-96: You know what I mean?

IP1-129: Do you know what I mean?

IP1-132: She (Therapist) is learning from me and I'm kind of telling her my problems... my woes.

IP1-156: So, you plan to pop in if you like... if you are here...

IP1-220: You know what I mean?

IP2-67: You understand? [T. “Yeah.”]

IP2-68: I’ve no more to tell... lunch is coming shortly... [T. ... let you get on.”]

IP2-73: [T. “... I thank you.”] You’re welcome. [T. “Thank you.”]

IP2-117: [T. “I understand...”] So, that’s where we are. [T. “OK... see you tomorrow... Is that OK?”] See you tomorrow... definitely.

IP2-118: Chap the door and there’s a space and we’re good to go. [T. Thank you.”] You’re welcome. [T. “Thank you.”]

IP2-120: So, I’ll put that at the side (to talk). [T. “OK.”]

IP2-122: [T. “The weather?] Yeah. [T. “... it’s dry, today.”] It’s dry, today.

IP2-124: [T. “It’s not... too cold outside.”] Good, good yeah. It’s coming on now for that time of year, yeah.

IP3-18: ... if you know what I mean... [T. “I understand.”]

IP3-70: [T. “... we’ll end there today... alright...?”] That’s absolutely fine... thanks very much. [T. “Thank you for that.”]

IP3-102: [T. “... I respect you talking to me... thank you.”] No problem (tired voice). [T. “... tired?”] I am. I’m getting tired. [T. “We’ll stop... Thank you.”]

IP3-147: (Patient coughing) [T. “Do you want more water?”] Yes... please.

IP3-151: [T. “I just want to say thank you...”] You’re very welcome.

IP3-176: [T. “I’ll not tire you out... I’ll say cheerio ... see you on Monday if that’s OK with you?’] That would be lovely. [T. “... I look forward to it.”] Thank you very much.

IP3-177: (Therapist and client shake hands). [T. “My hands are a bit cold.”] Oh, that’s OK... mine are roasting. [T. “Thank you.”] You’re very welcome. [T. “Take care.”] “You too.”

IP4-130: Sometime in the morning (going home) ... Is there a problem?... Do you still want to talk to me?

IP4-133: [T. “I could come back late in the afternoon if that’s OK. “] ... after half-past four... that’ll be fine. [T. “OK... that’s great... that’s great.”]

3b-1.2.2: Therapist: More Heart-felt Appreciation

Out-patients

OP1-194: [T. “What’s it like sharing these thoughts?”] It’s nice to put them out... talk to somebody else.

OP2-243: I can pick up the phone... phone here... come here...

OP2-251: It helps me... talking about all the stuff I’ve been through... I’m, actually, kind of seeing myself in a different light. It’s probably taken me to do this... see who I have become... get a chance to sit down and talk... it has helped... I know it has helped.

OP3: (No data)

OP5-200: ... two weeks ago after I spoke to you... I actually felt a lot better.

OP5-217: ... since coming here... meeting you... don’t know how long ... two months... I feel a lot better up here... mentally... definitely up here I’ve felt a lot better... bodily I feel better... If I hadn’t come here... meeting you... I wouldn’t have bought a new car... I wouldn’t have met Dr ___ This has all happened the last six... four... five weeks.

OP5-233: I feel a lot better... definitely... I’m quite pleased with myself... you’ve played a part in it... [T. “We’ve explored...”] Yeah, I have.

OP5-236: Coming here has been a big help.

OP5-252: I’m glad you’re here... I can share it with you... I can talk to you in confidence... a big thing is when it all finishes here...I can come back and see you... if it’s three months down the line ... I can come over and ask to see you... I know I can do that... I can phone you... that’s a big thing for me... knowing I’ve got you to fall back on... certainly.

In-patients

IP1-198: It’s absolutely fine speaking to you about it... feel fine and relaxed.

IP1-203: I’ve been glad to get it off my shoulders... with you... definitely.

IP1-259: It helps... speaking to you... So, it does. It helps us with feelings as well... helps us with our feelings... what we bring.

IP2-42: [T. “How is it sharing with me... ?”] It’s OK. [T. “I thank you.”]

IP2-58: What is it you call it? ... when you leave something?... to your kids. Yeah... inheritance... I keep forgetting that word...

IP2-69: Yeah... yeah... it was good to talk about these things.

IP2-71: Open... yeah... that's the word. [T. "... honest?"] Yeah... I am honest.

IP3-83: We've done enough to allow them the freedom to ask anything.

IP3-110: I'm sorry (crying)... [T. "... don't apologise... it seems quite hurtful."]

IP3-130: Do you ever do that where you have arguments inside your own head... somebody that's not actually stood in front of you...

IP3-133: [T. "I'm not going to push you on this subject... ?"] "OK." [T. "... when I come back... if you want to talk more about it... that's OK with me... if it's OK with you."] "OK... yep."

IP3-170: ... you've kind of opened my eyes a little bit... I don't feel so frightened... What do I feel more?... feel calmer... I don't feel so claustrophobic. I was getting really claustrophobic at times.

IP4-1: [T. "If I asked... what is your prognosis… How does that feel to you…? Is that too much...?"] "No… no…"

IP4-73: It's not hard to talk to you.

3b-1.3: Family Members

Out-patients

OP1-7: I told my daughter... I've got a swelling... she says, "We'll need to go to the doctor about it."

OP1-19: He (Son) stayed with me through... through all these treatments.

OP1-198: I don't drive much anymore. My daughter drives me anywhere I want to go.

OP2-185: I listen to my body, and I listen to my husband... you rest... do what your body tells you... He's (Husband) taught me a lot.

OP2-228: Husband says... nurse says... I says, ...

OP3-43: I do my big shopping at the.... my sister takes me.

OP3-90: ... then I got him (Nephew) to take me... to the shop... he got a couple of packs of... that'll last me for a wee (short) while.

OP5-14: My sister said to me, "Come and stay with me... You're coming to stay with me." ... I went and stayed with my sister.

OP5-69: I always listen to my sister... she was with me all the time.

In-patients

IP1-43: [Partner] "Come on... you're going to the hospital... we're not waiting." I said, "Right, that's what we'll do."

IP1-45: He (Partner) phoned the ambulance... we went over to the hospital...

IP1-60: So, the two of us (Patient and Dad) went away in (hospital).

IP1-93: And they'll (Family) explain the money side.

IP1-140: Me and my Dad... we will tell everybody.

IP2-111: They'll (family) will be in and out.

IP3-21: The girls helped me with the housework... my dogs...things like that.

IP3-24: ... we decided, "Right, we need to phone somebody now. We need to get this dealt with."

IP3-34: ... it was really me and their Dad... working on them from losing it

IP3-36: We need you to stay on track... do what you're doing with university...

IP3-40: ... me and their Dad had a couple of days (to digest things)

IP3-48: We have made plans for afterwards... arranged what's going to happen with them ... they're going to stay with Dad.

IP4-132: ... my sisters are coming...

3b-1.4: God/Friends/Clergy

Out-patients

OP1-145: Pray to God... pray to the Saints for help. They do help.

OP2-108: I phoned my friend... she said, "Right...come... tomorrow morning and we'll do it."

OP3-46: ... and number of people have actually stopped me and said to me, "Are you alright?" I said, "Yes... am just getting my breath back."

OP3-100: I get picked up at the door... I get into the van.

OP3-119: And the number of times people will stop and say, "Are you OK?" ... I'll say, "Yeah... I'm just having a rest."

OP3-211: I say to her (friend)... "Just you walk on and I'll take my time." I go and sit in a café... she comes... we get a taxi.

OP3-237: They pick me up and I come here.

OP5-258: I go to Mass every morning when I can.

In-patients

IP1-172: He [Reverend] is coming... he'll help me with details of the funeral.

IP1-201: ... my minister's stuff... got that today... see what he says... I'll be maybe... be... clearer... at things.

IP1-223: ... the minister... got a lot off my chest to him as well.

IP2: (No data)

IP3: (No data)

IP4: (No data)

Level 4: Reacting Self

Participants, through an increasing sense of awareness, can internally respond to their individual circumstances, and to carefully appraise their illness.

4a: Avoiding Self

Participants react to their circumstances in ways which help them to better control their anxiety in the face of the reality of what is happening to them. That is, patients try to mentally distance themselves through psychological strategies brought into play by the unconscious mind.

4a-1: Patients try to Escape form their Stressor.

Patients try to escape from their diagnosis/prognosis by mentally removing themselves from their difficult situation, "*I try and put it away from my mind; I don't want to know about it... get on with it.*"

Out-patients

OP1-71: I try and put it away from my mind.

OP1-157: So, try and avoid that if I can.

OP2-3: The doctor will see you... if you want to sit. I said, "If I go home, I won't come back." ... because you put... I don't want to know.

OP2-133: It's just a cold... I tried to push it away.... push it away.

OP3-3: I just could not be bothered.

OP3-66: I just can't be bothered.

OP5-3: couldn't be bothered.

OP5-15: I didn't want to go out... wanted to hide... didn't want to tell anybody.
OP5-29: I didn't want to know.
OP5-31: I just shut my eyes. I didn't want to know.

In-patients

IP1-4: I completely believed... it was an infection.
IP1-10: I didn't tell my partner.
IP2: (No data)
IP3: (No data)
IP4-86: I don't want to know about it... get on with it... and that's the end of it.

4a-2: Patients Playing Down their Stressor.

Patients use defense mechanisms, such as minimising, rationalising and distracting, to protect themselves from psychological damage arising from the reality of the diagnosis of a life-limiting illness, "*Doctors said there was a risk, but I didn't think it was that high; keeping it simple... don't go too deep.*"

Out-patients

OP1-75: What do you do? … just carry on... try and put it to the back.
OP1-126: I have got arthritis... so... I don't know if it's that causing this.
OP1-130: You do want them (doctors) to have a look... to check...
OP1-161: Doctors said there was a risk, but I didn't think it was that high.
OP2-1: I found a lump... I thought OK... keep an eye on it... fortnight passed.
OP2-8: No, don't think about it. It's going to be fine.
OP2-126: There's two sides... I'm alright but always that bit that you think... sits at the back of your head... law of averages... is there... might not... don't let it come forward... stays at the back.
OP2-148: You have to find things you can do that you don't sit and think.
OP3: (No data)
OP5-6: I just thought it was constipation... went to the doctor... "I'm suffering from constipation."
OP5-23: I didn't want to face anybody... tell them. Didn't know how they would react... how I would react... couldn't face telling anybody.
OP5-27: She (doctor) put it on the screen. I never looked at it.

In-patients

IP1-5: I was using the... testing... I completely believed... definitely.

IP1-7: … then we went on holiday... we thought maybe a break we needed.

IP1-8: … not being away for eight or nine years on holiday... need a holiday.

IP1-237: I was just working away... been ill for one year... Pal says, “You’ve been ill for two and a half years.”

IP1-238: [T. “... the pain will go away?”] Yeah... will go away... That’s exactly what I thought.... my usual thinking (smiles)... I could fix it.

IP2: (No data)

IP3-97: ... keeping it simple... don’t go too deep...

IP3-101: I keep it as simple as possible.

IP3-103: ... but without going into it too much...

IP4: (No data)

4b: Coping Self

Patients consciously take stock of their physical, psychological, and social resources, in relation to their circumstances. Whilst their coping remains an intra-personal process, from the perspective of selves to their circumstances, they selectively affirm those aspects of their illness they perceive as positive, whilst complain and protest about those they identify as negative.

4b-1: Patients as Complaining /Protesting

Patients experience a drastic change in their every-day living and so feel aggrieved, expressing angry irritation through complaining and protesting.

4b-1.1: Patients Complaining/Protesting about Aspects of their Illness that they see as Negative.

With full awareness, patients react by expressing their feelings of dissatisfaction and annoyance brought about by the physical effects of their illness, “*it used to get worse as the day went on but now it’s there from first thing; I shouldn’t be sitting like this at this stage (of life).”*

Out-patients

OP1-6: So, I had to give up driving because of that... can’t drive anymore...

OP1-77: Plus, I’ve got glaucoma... my eye sight’s not too good... I’ll need to stop the driving.

OP1-82: I don’t want to die in pain.

OP1-118: I was always quite nippy on my feet... now I’ve slowed down... have to accept that.

OP1-234: If I’d been a bit better... didn’t have these problems, I would probably have been going along (on holiday) with him.

OP2-104: Looked in the mirror and it’s like looking at cancer... I don’t know what cancer looks like... but that’s what I looked like.

OP2-106: Didn’t like who I seen... No, I didn’t like who I seen... it’s too much a reminder that you’ve got it.

OP3-26: Especially at night... I lie and read for a wee (short) while... then I get up... and breathless...

OP3-52: When I get into the house... before the jacket comes off... I sit down... I’ve to get my breath back.

OP3-54: I lie in the couch... and I’m fine... no problem... but walking through to the kitchen and walking back... I can’t even... I have to sit.

OP3-71: ... used to be it got worse as the day went on... but it’s there from first thing in the morning when I get up.

OP3-83: Should have done in about two minutes... took me about ten minutes.

OP3-85: Once I get there and I’m calmed down I’m fine... the minute I start to move I get this...

OP3-94: I’ve to sit on the edge of the bed for about five minutes to get my breath back before I can actually get into bed...

OP3-99: It’s everyday... all the time... it used to get worse as the day went on but now it’s there from first thing.

OP3-103: Just a few steps... fine just sitting here... minute I move... that’s me.

OP3-106: Number of times... had to stop... takes forever to do a job like that.

OP3-111: I’ve got cleaners come in once a fortnight.

OP3-118: I’ve to go the other way... just flat... a bit longer... takes me forever.

OP3-153: ... the weight is piling on because I’m not getting any exercise.

OP3-159: I've noticed sometimes... if I go up the stairs... I get very breathless, and I feel I'm hot... a temperature... I've to sit ... get my breath back.

OP3-169: I'm getting to the stage... I know what's going to happen... breathlessness started again.

OP3-204: I come here but somebody picks me up and takes me home... that's it... the minute I'm in the door... that is me.

OP3-207: Because of the weather... I was not out... I was frightened... the high wind would take my breath away.

OP3-212: Walking is a nightmare because I've to keep stopping.

OP3-220: This phlegm...I spit it out... I lie down... gathers again... toss and turn... don't sleep at all... doesn't really help... not been a good week.

OP3-244: Could go ___ on the train... couldn't walk about... just don't go...

OP3-246: I just don't get out at all... or very rarely.

OP3-248: Past few years I've had problems... stairs... hills... now... can't walk from my living room to my kitchen without heavy breathing.

OP3-250: As the day goes on it (breathing) gets worse and worse... uh huh... oh, definitely... definitely... it gets worse as the day goes on.

OP5-138: Biggest effect on my life... before I took the cancer... was a good golfer... played in the club team... I could still play but... I would have to sit in the buggy.

In-patients

IP1-78: I feel it's been something every month... had to go to hospital every month for something.

IP1-85: I shouldn't be sitting like this at this stage (of life).

IP1-101: We had to tell immediate family last night.

IP1-130: Physically sometimes I feel It's my time because I've not got any energy… I'm exhausted.

IP1-210: ... don't want to lie in pain.

IP2-1: Illness has affected me from the beginning of January of this year.

IP3: (No data)

IP4-58: Not possible at the moment... not the way things going at the moment.

4b-1.2: Patients Complaining/Protesting about the Impact of Negative Aspects of their Illness on their Psychological Well-being

Patients, with full awareness, come to understand that what has negative impact on their physical being also has a negative effect on their psychological well-being, “I say to myself sometimes... “*The mental side of it... lying in bed at night... making your will... picking the hymns for the church service... who I was leaving everything to; tomorrow going to be the same... like ‘Groundhog Day’... the same thing every day.”*

Out-patients

OP1-1: It’s not very pleasant getting told it (diagnosis).

OP1-59: I wasn’t looking forward to getting it again.

OP1-63: I said, “Well that’s something to look forward to isn’t it... something to look forward to.”

OP1-84: I just worry about these... worry about these things.

OP1-123: I don’t want... I don’t want the cancer to come back.

OP1-140: It’s more worrying the second time... first one was bad enough... bad enough... but to feel it again.

OP1-253: Made me think a lot more about God...things like that. Hard to explain how it has affected me. ... you know you’re going to die sometime but you wonder how it’s going to come... cancer or hit by a bus or something. You’ve... to try... get this in your head... you don’t want to put it in there. Don’t want it there... would drive you mad. You don’t want to do that.

OP2-6: I think when I walked into the (doctor’s) room... I thought... fear... Do I really want to be here? ... Fear was everywhere.

OP2-7: When I start to think about it... the tears start to come.

OP2-23: It was painful... that sticks in my head every day. If I think about it... it brings a lot of stuff back... so, I try to put it out of the way.

OP2-24: It makes me agitated... kind of angry... having to go through it... deal with something I don’t want to deal with... hurting more than pain...

OP2-30: Not until you have cancer you realise how destructive it can be. I would say more emotional... can destroy people's relationships... way people look at you... changes completely the way you look at life.

OP2-31: Husband says, "Are you alright?" I went, "Yep. I told you." That was the angry bit coming out in me.

OP2-33: Went for bone scans... terrifying because you don't know what is involved... fear... a bone scan can find something in your bones.

OP2-38: Maybe if I am sick... the cancer will be away. These are thoughts going through your head when you're lying.

OP2-66: Sometimes (motivation) slips a little bit now and again... if I focus too much on the cancer side.

OP2-99: It changes you as a person... a burning feeling or empowerment.

OP2-174: It creeps in now and again... it creeps... just silently... silently... and if you're not aware of it creeping it can overtake... very quickly.

OP2-207: I just thought... Why have I not done this... years ago? Why did it take me to have secondary (cancer) to do all these things?

OP2-229: People... say, "Oh, you're in remission." Don't get remission with secondary... you've always got it... get containment... completely different... makes me angry... having to stand there and explain... live on these drugs for the rest of your life... keeps it contained... I don't want to go there... I done that... explaining to people.

OP2-235: I must be renowned for having things that don't go away... have... the rest of my life.

OP2-238: But I don't want to have to tell people every time I've got secondary cancer... [T. "... become... a part of your name or...?"] Yeah... a middle name... surname... I would like to take that out... I know I've got it... I know I'll never lose that... Why should I have that label? ...

OP2-244: If I told people I've got secondary... I know I have to prove... (Pause)... that you can live with secondary... you can have a life... put make-up on... do your hair... prove to other people... let other people know... I'm available to go for a coffee... a night out... go out for lunch... prove you can survive... you can live.

OP2-247: [T. "... this... need to tell people...."] It's actually a weight off your shoulder. I can just be myself... people that need to know... already know... I don't need to tell anybody else... so, why broadcast it any further... I don't need to excuse myself... don't need to do that.

OP2-248: It hurts... your best friend sees that (cancer) and doesn't see me... Can't change how people see me... or see what they are trying to see or not trying to see... I can't change it.

OP3-28: ... when you're on your own... everything goes through your head.

OP3-31: Somebody find me the next morning... lying in my bed...that is frightening... everything goes through your mind.

OP3-34: ... because I don't have much of a life at all.

OP3-56: And I say to myself, "Is it worth it... being here?"

OP3-135: Everybody seem to be passing me on... saying... "I can't do anymore... I'll pass you on to so and so." ... they do see me for a wee (short) while... "Nothing I can do. I'll pass you on to someone else."

OP3-173: ... I say to myself sometimes... "I'd be as well away "(Dead).

OP3-178: It's not living... definitely not... just existing... it's just existing.

OP3-184: Very difficult... because there is nothing, I can do... I know it's not going to get any better.

OP3-196: It's... where they don't communicate with you... that is frustrating...

OP3-198: I feel people should communicate with you... tell you... if there's nothing, they can do... tell you that... what's the point of all this... if there's nothing they can do.

OP3-209: I was bored... sitting in the house all day... it's a long, long day...

OP3-228: So, as I say... I'm just left in the dark...

OP3-230: ... I was always so active... can't do anything now... is a big hurdle...

OP5-16: The mental side of it... lying in bed at night... making your will... picking the hymns for the church service... who I was leaving everything to.

OP5-18: When you hear the big 'C' ... when I heard the number... I'll never forget it.

OP5-140: I'd rather not play (golf) at all than... I'm embarrassing myself...my clubs are still lying in the locker... can't bring myself... go down and take them away... really miss that (golf)... was a big part of my life... social life... lots of friends... miss that badly... really do... couldn't go... watch other people play... rather just have a complete break altogether... maybe I've lost friends because of it.

OP5-142: I've had it all... all these illnesses... but the worst thing... me not being able to play golf... that's the worst thing... worse than the (treatment)... that's the biggest change that's really hard to accept... if you didn't have the illness... yeah... as we progress in years then you not be able to play at the standard you were at... that's different... I would definitely accept that... [T. "... this is like being forced upon you...?"] Forced... yeah... definitely... I blame the illness for it... definitely... that's the worst of it... that was the killer for me... worse than anything... not being able to play golf.

OP5-144: Oh, no... I never for a minute thought this would happen to me... it wasn't in the family. Didn't smoke... didn't drink... was very, very active... played golf every day... went to ___ on a golfing holiday... I said, "Something wrong here." ... because everybody knows their own body... you think when you retire... got a great life now... what I dreamt of... no worries... problems... no hassle... no stress... what I worked for all my life... what I wanted... saved for... I just feel it's been all taken away from me...

OP5-146: It made me I think... more withdrawn... when I got the (treatment) ... lost all your hair... didn't want to go anywhere... wouldn't take my hat off... when my hair came back... got a bit more confidence... it definitely shatters your confidence... just want to hide... well I did... went to live with my sister... didn't want anybody to see me... talk to anybody... didn't want to tell anybody... didn't want anybody to know...If I'm up here staying with you...I can hide...

OP5-168: I'd like to buy a new car... is it worth my while... I buy a new car every three year... always done that... what's the point... am I going to be here in three years' time... it's the illness that does it... if a doctor could say to me, "You'll definitely be here in three years' time." ... I'd be straight down to the car show room... any other time I would have done it by now... have had a new car...

OP5-175: The first time it was two weeks... the second... the third... You're watching the calendar... Yeah... you're watching all the time... Everybody knows their own body you know when you get up in the morning... or when you're sitting... I'm alright now... I'll make it through today... up here the problem... if you could stop thinking...

OP5-177: You just lost interest... can't be bothered... try and sleep... to pass the time... do crosswords... got the laptop... put it on in the morning... look at headlines in the paper... put it off... that's it for today... not interested... lack of interest.

OP5-178: [T. "How are you with change?"] That's a difficult one... you know how to ask them... (chuckle)... It's hard... compared to what I was doing four years ago... was as fit as a butcher's dog... had my life in front of me... had many plans... going to do many things... I feel that it's all been taken away from me.

OP5-180: If you'd asked me five weeks ago... when I was lying in the (hospital)... I would have said, "No chance... I'll never be here."... because it's that bad you felt... take me away out of this.

OP5-204: If I could play (golf) and not embarrass myself I'd be quite happy... if I could get out and enjoy it... the standard that I was before... and I've got to accept... I mean if I could get to play golf... I would know that I've came to terms with it...

OP5-208: ... it's been a long road... yeah, yeah... definitely.

OP5-211: Definitely... it was in my head that I would never play (golf) again... the pain in my legs... that the cancer had spread to my legs... because this is where the pain was.

OP5-267: I was planning funerals...hymns... where I was going to be buried... who was going to carry my coffin... this how I spent two weeks.

OP5-271: I wasn’t angry... I was disappointed... really disappointed that my whole lifestyle had to change. Going for walks and things I just wasn’t able to do... was hard to accept that... hard to accept that... after coming through the (treatment) and all the rest of it.

In-patients

IP1-33: [T. “But that’s not what you’re thinking... ?”] No... no, definitely not because my Mum passed away with cancer.

IP1-68: I could have... went crazy with him.

IP1-90: You need to repeat again... repeat again... repeat again. Yeah, yeah, It’s the explanation of everything... all the time.

IP1-91: It does scare me... scares me... I’m going to leave my daughter.

IP1-107: That was my news yesterday... was a bit of an upset.

IP1-110: Two or three in the morning... I woke up... was thinking about it.

IP1-120: I don’t feel ready to go... ready to go.

IP1-158: [Doctor] “What can I do for you?” [Patient] “Had a referral.” (Doctor) “Well hold on.” ... looked at scan. Thought a bit blasé...

IP1-165: ... felt it was a bit blasé about the whole thing.

IP1-183: [T. “... losing independence?”] Oh, I hate it... absolutely hate it.

IP1-185: God give me a break.

IP1-188: Completely... yeah... completely unfair (Tearful).

IP1-200: (Tearful)]... I shouldn’t be planning things like this for my age.

IP1-214: (Tearful)... is this the way you’re going to go on... be like this all the time... Is this going to be it to the End?

IP1-215: [T. “Are you frightened?”] (Tearful) Uh huh... I am... I just feel... things are coming quick... not getting time to adjust.

IP1-217: I just think... tomorrow going to be the same... like ‘Groundhog Day’... the same thing every day.

IP1-218: It’s like never ending... feel it’s never ending...

IP1-219: (Tearful) Don’t tell me I need to go through this tomorrow again...

IP1-229: It really makes you think about things... gives you all the senses... emotions like anger and guilt.

IP1-230: You’ve worked hard in life... some people abuse... that annoys me... it’s unfair... you try to do your best.

IP1-233: It puts things into perspective... definitely... puts life into perspective.

IP1-234: Every day... I feel a bit of sadness from it... really do... sadness it has come to this...

IP1-235: I just knew... I wasn’t in a good place... felt as if the disease... had gone on... on... as it had... too much pain... pain was far too much.

IP1-249: It (life) grinds all day... the same... in pain... every day in this hospital.

IP2-41: It’s a problem that I’ve got to try and repeat the story to everyone... all the time... try and get it in the right order.

IP2-49: When I was first diagnosed with cancer... I felt so low.

IP2-63: Job done (life over) ... but it’s such a young age... young age sixty-one.

IP2-64: We shouldn’t be here... shouldn’t be in this position.

IP2-66: Internally... you feel alone.

IP2-80: Some things I don’t need help with... they’re treating me, a 61-year-old man, as if I’m somebody that’s 80 or 90.

IP2-89: I had to retired early... I had to give up my job which I loved.

IP2-115: When I’m in here I don’t know what day it is... I’m just staring at a screen here... don’t know what day it is...

IP2-130: But I don’t know what time. That’s OK.

IP2-131: (Long pause) Glad to leave this hospice. (pause) I haven’t liked it... I haven’t liked it. Too... far too attentive.

IP2-132: [T. “Attentive? Would you like some time on your own?”] Yeah.

IP3-1: When I first came in (the ward) I was very confused.

IP3-4: Most of the time I’m able to be in control of what’s going on... Start off my day thinking as positive as I possibly can... keeping things as normal as possible for my daughters... eh... from the evening into the early morning I wasn’t able to do that... I really got upset about nothing.

IP3-15: I had always been adamant I didn’t really want to come to hospice... because I thought initially... you go into hospice... you don’t go home.

IP3-16: was frightening for me initially

IP3-39: I think we'd had maybe about a day or two... digest a few things... I wouldn't say accept things.

IP3-45: [T. "... and acceptance?"] Not yet... not yet... still a lot of things that...

IP3-77: I lost my brother and sister. I was really young... you didn't talk about death in my family... it was only the adults... really difficult because you were never able to come to terms with anything... don't talk about that in front of the kids... was it for my benefit? I couldn't see it that way... I just saw it as it's not your business... nobody there to ask....

IP3-:91: Physically, not afraid... now I know what can happen. Emotionally... a lot harder... that's the hard bit to deal with... emotion rather than the physical side... emotionally, I can be up and down.

IP3-96: [T. "Did you ever get angry about a diagnosis?"] Not really... but my daughters did because the initial diagnosis we thought I had...

IP3-104: I get angry. (about family dynamics)

IP3-106: I've seen her (family member) twice in the last year and a half... I feel really angry about it.

IP3-108: And I think at this stage... and that's not what I want.

IP3-113: I'm too angry with her (family member)

IP3-118: It's just the way things have worked out.

IP3-123: So, initially, I felt totally abandoned by her (family member).

IP3-124: ... and she hasn't dealt with it... not at all... no.

IP3-125: [T. "Would you like to contact her?" (family member] Not now.

IP3-126: I feel now... it'll be the last gasp... when I'm ready to go... give all her excuses... (family member).

IP3-127: And I don't know if I can handle her (family member) being here.

IP3-129: I can't talk about my Mum without getting upset.

IP3-146: (Coughing) [T. "Is that sore coughing?"] Yep... and it hurts my girls (to hear it).

IP4-7: That's about all I can take you know (infections).

IP4-112: It's very emotional when you get there (stop treatment) ... very emotional...

IP4-114: I can still remember it yet...

IP4-125: And I felt like these people are gawking at me and looking at me...

4b-1.3: Patients Complaining/Protesting about Aspects of their Treatment that they see as Negative.

With full awareness, patients react by protesting about the physical effects of their treatment, "*You're killing me with this treatment; Your memory is not the same... sleep pattern is out.*"

Out-patients

OP1-20: I was only supposed to get 6 sessions, but I told them... after 4... "You'll need to stop."

OP1-31: You're killing me with this treatment.

OP1-90: Treatment... affected me badly... 6 to 8 months it lasted... alright once you got it... ten days later you were away (incapacitated)...

OP1-153: I wouldn't go through (treatment) again... too severe... never lasted.

OP1-158: If they say I need (more treatment) I need to refuse it. Take... tablets... help pain... won't take that again... been through that much.

OP1-210: I couldn't go through that again... couldn't work for a year after it. It was that bad.

OP1-233: I told them last time. "I'm not taking more." I don't want anymore.

OP2: (No data)

OP3: (No data)

OP5-70: Boy, was I glad when it (treatment) was finished... really glad... getting these pills... the weight is... steroids... went from a __ waist to __ I hated that... oh, really hated that.

OP5-116: It limits you... you know... it definitely does...

OP5-118: Your memory is not the same... sleep pattern is out... if you can sleep for two hours, you're doing well... you wake up... sleep for another two hours...

In-patients

IP1-225: I could be talking... and drift off quite easily... drugs and everything.

IP2-16: Morphine dries my mouth... hear it on the recorder. I'm very dry.

IP2-20: When you use steroids, doctors don't want you to stay on steroids... like you to be weaned off... weaned-off effects... started to take affect...

IP2-26: The steroids just kind of keep it for a while.

IP2-31: ... there's no medical means that they can make me better...

IP2-81: It's (dry mouth) always kind of awkward you know.

IP2-84: ... so, by the time you go to do an activity... I run out of water to moisten myself... I'm having to mouth gestures more.

IP2-87: Not getting tired as such... the drugs are making me tired some days... which I expected.

IP3: (No data)

IP4-46: I've heart medication to take over and above all the rest of the medication that I've got to take... it's an everyday thing.

IP4-91: It was fine up to the last two (Treatment sessions).

IP4-99: So that was that... that was binned. (Treatment)

4b-1.4: Patients Complaining/Protesting about the Impact of Negative Aspects of their Treatment on their Psychological Well-being

Patients, with full awareness, communicate that what they perceive as negative aspects of their treatment have also impacted negatively on their psychological well-being, "*the mind's terrible... I think the mental side of it is worse than the physical side of it; I'm definitely aggrieved.*"

Out-patients

OP1: (No data)

OP2: (No data)

OP3: (No data)

OP5-71: Oh, it was a disappointment. (_____ count increased)

OP5-101: I just feel if I was to say to the doctor, "I want to stop these. I don't want to take any more." He would just say, "Well there's nothing more I can do for you. Away you go." [T. "Are you afraid of hearing that?"] Yeah... yeah... I just feel I can't because... he's all I've got... I don't have another option.

OP5-161: It's all up here in the mind... the mind's terrible... I think the mental side of it is worse than the physical side of it... You're thinking... is this going to start tomorrow... it gets to tomorrow... the diarrhoea and sickness... is it going to start again... a constant thought in your head all the time...

In-patients

IP1: (No data)

IP2-29: I'm definitely aggrieved. ...

IP2-34: The oncologist you see is an interventionist... in terms of prolonging your quality of life... the action would have been ____ and ___ would have been bad... even worse losing your hair...

IP2-37: ... the callers can see something... they see the fact that I look better and if they had the offer of ___ ... because they saw me getting well... there's still something in the background.

IP2-86: ... things like that make it awkward...

IP3: (No data)

IP4-44: I probably need it (treatment)... not getting it for nothing... so, I probably need it.

IP4-93: ... no I was expecting a lot more (treatment sessions) ... but no I'm fine.

IP4-96: The reality... I was going just the week before I took that right bad infection... that hurt because I couldn't go (see his grand-daughter).

4b-2: Patients as Acknowledging/Accepting

Patients react, with full awareness, by allowing themselves to no longer turn away from their feelings but to be open and choose to face the truth.

4b-2.1: Acknowledging/Accepting Physical Aspects of Illness Perceived as Positive

Patients acknowledge their life-limiting illness, actively affirming those perceptions that activate constructive, helpful experiences of themselves in the context of their illness, "*I was watching for it... what to expect... been through it before; I honestly think I can handle pain... must be able to handle pain ... it's been so bad.*"

Out-patients

OP1-66: I’m not looking for it... I’m trying my best, but the pain is still there... that’s why I need the walking stick.

OP1-137: I have deteriorated... bit slower... more aches and pains... could be the illness.

OP1-187: The family keep saying to go to the (hospital doctors). I’m not going. I’m not at that stage yet.

OP1-200: I don’t mind. It’s (family looking out for him) for my own benefit.

OP1-208: Sooner or later I’ll probably need to go and see them (doctors).

OP1-212: I had to take my heart spray.

OP1-213: I was watching for it... what to expect... been through it before.

OP1-217: I know when it is coming. I’ve got a good idea because I’ve been through it all.

OP2: (No data)

OP3-76: Takes a wee (short) while for me to calm down... get my legs back up (on the couch) again... once there... settled ... calmed down... I’m fine.

OP3-101: I’m so used to it now that I know it’ll calm down.

OP5-164: [T. “When I go... you live with every day or... a long way off?”] Oh, no, ... every day... think about that every day... I wake up... I say, “Oh, well I’m here for another day.” ... because you just don’t know.

OP5-206: If I can walk in a straight line... I can do that now... I used to say, “I’m staggering here... people will think I’m drunk.” I can walk in a straight line now... my balance is a lot better... improved a lot...

In-patients

IP1-37: … then I knew.

IP1-82: I honestly think I can handle pain... must be able to handle pain … it’s been so bad.

IP1-118: Rather than say... she’s in hospice... she’s had a good day... they can actually say... well she’s not had a good... day.

IP1-133: But... eh... I don’t feel as if I’m a person that’s dying at the moment.

IP2-7: ... so that (improvement) happened about midyear...

IP2-75: I had a relatively peaceful night last night.

IP2-107: I'll be able to get out and about... toilet... on the ground floor... be able to go from bed to my walker.

IP3-71: A hairdresser suggested this shampoo... they tell you ... it works...it actually works... growing an awful lot since I've been using it.

IP3-73: ... you end up with blue hair... ha, ha... I'm too young for blue rinses...

IP4-64: Not at the moment anyway... I've never been violently ill or anything that would constitute to say... that you're ready to go.

IP4-115: So, I had a few days where I wasn't that good...

4b-2.2: Acknowledging/Accepting: Psychological Impact on Physical Being

Patients come to understand that what has impact on their physical being also affects them psychologically, "*I have to live round it because it's in here; Where's the point of being afraid... what's going to happen is going to happen... regardless.*"

Out-patients

OP1-3: Well, I knew then it was something... something drastic here happening.

OP1-51: I'm not looking forward to dying but if it comes... it comes... just prefer it a natural way.

OP1-52: You've just to resign yourself to that (dying).

OP1-70: So, there's nothing else I can do... just live with it

OP1-72: I don't dwell on it... if you done that you'd be in the 'Loony Bin'

OP1-76: These things you have to live with.

OP1-81: It doesn't bother me dying but it's the way it's going to happen.

OP1-148: It (dying) doesn't mean anything to me. Oh, no.

OP1-151: I have to live round it because it's in here.

OP1-160: If they (treatment) could help... fair enough... If they couldn't help... I would need to go (die).

OP1-164: I don't want to do that again. I'll heed their warning the next time... rather take the road out. Yeah... I'd rather take the road out.

OP1-167: When you're out... it (cancer) doesn't exist then... only when you go back home again... got to take the tablets.

OP1-168: Of course, ... You’ve got to respect it (cancer)... look after yourself.

OP1-179: I have had my share of illness... there’s every possibility it will come back but, I’ve got to keep positive and try to work at it.

OP1-189: In the last couple of years, I prefer to be on my own.

OP1-241: Things are slowing me down now but it’s a relief when I say, “I did that myself.”

OP1-242: You can’t let people help you when you can (do it). But sometimes you need help. Sometimes you need help.

OP1-244: I didn’t think I would reach 80... with the troubles... back and fore to hospital... survived it.

OP1-245: [T. “How difficult is it to accept limitation?”] It’s beginning hard now to accept it... becoming hard now to accept it... (pause) I know I cannot do it anymore. I have to pace it now. I have to pace it now.

OP2-4: But I knew. I had a kind of a feeling I had cancer. I don’t know why... when I found the lump... I thought... I’ve got __ cancer.

OP2-9: My initial reaction when the doctor said there was a lump... I thought ... at least I know I’m not imagining it. My imagination is not running away with me.

OP2-10: I don’t think it frightened me as such because I kind of knew. I think... I thought... the doctor’s going to say that word anyway.

OP2-13: A big part of me was going, “How do I handle my husband?” It wasn’t how to handle myself because I ... knew it was ___ cancer.

OP2-14: There’s some kind of relief that I didn’t imagine...

OP2-77: You sometimes tend to forget you’ve got it... I’ve still got it... kicks in now and again... got to respect it... respect what’s inside.

OP2-110: I seen a cancer victim, and I did for a long time. It’s only recently... this is me... told other people who I was before the diagnosis did.

OP2-115: No, no... I can’t avoid it... it has a bad habit of creeping up on you if you avoid it... if you hit it on the face... can deal with it quicker...

OP2-120: If I have too much time to think... I can go back to the hole... and I think... I’m not going to make this... I’m not going to be here next year... as long as I don’t think too long, I’m fine.

OP2-135: It's like another person inside... an unwelcome visitor or guest... but I've got to learn to live with this guest and I've got to let it live to the extent but not too much...

OP2-139: [T. "So, there's a kindness to yourself...?"] Yes. That's a big part of it... can push too much... probably get more harm than good... depends on the day... how the body... how the mind... the mind is not always clicked to do... what you want the body to do... the mind is not always there...

OP2-154: When you have cancer and secondary as well... I think you tend to spend more time on yourself... Don't beat myself up as much... If I don't get something done... so, what? ... don't beat myself up now.

OP2-158: If it eventually does win... it's had a good battle with me.

OP2-162: This (scrapbook) helps with my diagnosis... you think of the people... who are not here... Why can't I enjoy my life as much until my time's here... seeing photos like that... probably helps me.

OP2-180: I think my confidence came back when I got my diagnosis. I hit rock bottom and it's went up... up... still going... I can now walk into a room without saying to someone... "You go in first." ... Now I go in first. It took the diagnosis of cancer to do this.

OP2-213: If I get stressed and I'm worrying about stuff... my mood nose-dives... it does nose dive... that would be a big disadvantage to me... balance what's right and what is not.

OP2-214: I'm a lot more confident now... I can walk into places now... I used to say, "You go in first."

OP2-218: I didn't like the one that was developing because I liked the old one... don't like the old one now... I like the new one... I look in the mirror and I like who I am.

OP3: (No data)

OP5-78: That's why I like coming here... because I can talk to other people that's going through the same thing or had been through it...

OP5-223: ... so, there's definitely a lot of confidence coming back...

OP5-244: I'm quite confident whereas before I was nervous...

OP5-246: I'm not nervous about it at all... before I started to see you... I used to take a taxi over to the (hospital)...I was nervous... anxious about it... not now... drive myself over... drive myself back... a big, big plus for me... I'm in a better frame of mind when I go in... now I'm quite focused... more focused in these situations... than I was months ago.

OP5-254: I've got a bit more energy... definitely my confidence is really up.

OP5-263: But I just wonder... They're both (friends) dead... I am still sitting here. I must have been doing something right... or doing the right thing... or maybe they left it too long...

In-Patients

IP1-79: I've come to the point now where I feel... it's just hit me... psychologically.

IP1-81: I've had my low points psychologically... definitely had my low points.

IP1-109: I didn't play on my mind or anything.

IP1-112: It's made me stronger.

IP1-136: Speaking about it... doesn't harm me to speak about it... whoever's in... we speak about it.

IP1-139: We're going to need to tell her because the following week could be totally different... last week... there was nothing in any major organs.

IP1-148: So, everyday has been a bit of improvement.

IP1-152: I take each day as it comes.

IP1-154: But I need to take a day as it comes.

IP2-12: [T. "So, the independence came back?"] Yeah. It came back.

IP2-36: I was aware that it would shorten my time.

IP2-44: ... I've got two children... grown-up... well-sorted in their life... I'm gone so what... Dad's gone... Mum's still alive...

IP2-46: I suppose everyone has to face it at some time... pain.

IP2-56: I'm young enough to face it.

IP2-74: Things today are OK.

IP2-96: Emotionally... (Pause)... it's not really done things to me emotionally...

IP2-99: [T. "Is it hard for you to accept...?"] No, it's not hard.

IP2-105: ... most of the time I'll be on my own... I think... that's OK for me.

IP2-109: [T. “Is that (limited mobility) OK?”] That’s OK... yeah.

IP2-136: It was necessary (to come to the hospice) at the time... yes.

IP3-26: ... which was a big 180 degree... it was a big turnaround. (agreeing to go to hospice)

IP3-60: But I felt a lot stronger.

IP3-138: I don’t see the point in having fears anymore.

IP3-140: Where’s the point of being afraid... what’s going to happen is going to happen... regardless.

IP3-142: [T. “... it’s hopes and wishes?”] Yeah... that’s more the way I kind of look at it.

IP3-171: [T. “I notice... you don’t use your curtains (around the bed) anymore?”] No, I am quite happy to have my friends and family in without having the curtains shut.

IP4-2: My prognosis is not good… but it’s not bad either… I’m living with the thought of my next infection…

IP4-19: I’ve no feeling about it… they just tell you straight.

IP4-26: That’s what I feel… I just feel that sometimes you know.

IP4-35: I ... I like to be comfortable and cosy... you know within myself.

IP4-36: [T. “... it’s an emotional thing?”] Well yeah... yeah... very much.

IP4-37: ... feeling of security... you know you’ve the security of the hospice... the security of the hospital... feel secure with that round about me.

IP4-40: [T. “There’s a safety and a warmth?”] Um... definite.

IP4-47: No... never feel like that... no... I don’t hold a grudge either.

IP4-48: No... not much point... what’s the point of bearing a grudge... it’s happened.

IP4-51: I think will power has a lot to do with it. I think will power is the most to do with it.

IP4-55: I’m OK today...

IP4-71: I think could is a good word to use... hope’s always a good word to use.

IP4-77: So, I believe that.

IP4-89: You know what’s wrong with you.

IP4-108: I think we're going back to the will power thing again...

4b-2.3: Acknowledging/Accepting the Impact of the Positive Aspects of Treatment /Surgery

Patients communicate their experience of treatment /surgery as positive, with both aiming to keep them alive, "*if I hadn't taken the treatment, it would have killed me; The medication... I think is doing its job.*"

Out-patients

OP1-108: ...if I hadn't taken the treatment, it would have killed me.

OP1-209: I don't reckon I could go through surgery again. No. The heart operation was big... success at the time... done its job... given me another 10 years...

OP2-176: It's due to the medication...I sit and balance that because of the benefits... if I was not on that medication... I wouldn't be sitting here telling you this. I've got to remember that... with side effects like this... there are more benefits.

OP3: (No data)

OP5-109: Still not recovered... fully... but every day it's getting better.

OP5-115: ... no warning no nothing... here it comes... anywhere at any time... seems to be every third or fourth or fifth week... I take a note of it...

OP5-123: I asked, "Will I ever come off these." ... she (nurse) said, "No. You're on these until.... same with the injection... on that for life." ... the rest of my life.

OP5-134: Every day you feel a bit stronger... but... boy oh boy... always in the back of your mind... that it's going to happen again.

OP5-156: [T. "So, what you get... is helping you?"] Oh, yeah it (treatment) does. I would miss it... I really would miss it.

In-patients

IP1-149: So, we think something's working in the medication... we think something's working.

IP1-196: The medication... I think is doing its job.

IP1-197: It's just getting rid of the pain... the dopiness... and balancing everything out.

IP2-15: So, what solved it was... made a difference... was the use of steroids and morphine.

IP3: (No data)

IP4-9: It's something to do with the immune system… it's (name of drug) I'll always be on...

IP4-41: ... no, just my normal medication in the morning... there's plenty of it... a lot of medication.

4b-2.4: Acknowledging/Accepting the Psychological Impact of Positive Aspects of Treatment

Patients acknowledge that what they perceive as positive aspects of their treatment have positive impact on their psychological well-being, "*It had reduced... that's what the injections had done... I was jumping for joy; Got mobile again with the use of steroids... is very good... and me on my own... was very good.*"

Out-patients

OP1-43: We will just need to put up with it.

OP2: (No data)

OP3: (No data)

OP5-37: It had reduced... that's what the injections had done... I was jumping for joy.

OP5-43: I had no pain whatsoever... It was great... I felt really good.

OP5-75: I'm happy with that... it won't go any lower... if I keep taking them it will stay... if I stop... would go up again. Quite happy to take them. I remember all the numbers... never forget them.

OP5-153: This (treatment) is what's causing... it's the side effects... One of the many side effects... this is just what you've got to live with.

In-patients

IP1-168: Just knowing... just knowing I was out of there.

IP1-173: ... won't have to worry about everything.

IP2-10: Got mobile again with the use of steroids... is very good... and me on my own... was very good.

IP3: (No data)

IP4-80: That's what you're used to taking... it's not there because they want to give you it... it's there because it's to help you.

4c: Morally Evaluating Self

Patients, as human beings, hold standards of right and wrong that serve as counsel. Hence, they consciously engage in the process of self-regulation, monitoring and assessing how they react to their circumstances to keep track of what they feel is appropriate within their specific circumstances. Moreover, they reveal how they would conduct themselves by translating their moral thoughts into moral conduct, aided by wisdom and by up-holding what they perceive as right.

4c-1: Patients Showing Consideration for Others

Patients show kindness by considering the feelings, thoughts and needs of others, "*I'll look after them. That's my purpose... yeah... that's my purpose in life... keep them safe and well; I don't want somebody standing at a headstone when you could be on a beach remembering the nice stuff... the nice holidays.*"

Out-patients

OP1-129: The doctors... you don't want to take them away from their patients... if they're dealing with really sick patients.

OP1-132: I can turn to my family, but I don't want to worry them.

OP1-143: I should depend on my family more, but I try to leave them out of it.

OP1-177: I've got to look after my sons... daughter... grandchildren... great-grandchildren... that's top of my list... why I'm still here... yes... I've got to make sure I'm still here for them.

OP1-181: And the thought of leaving them here... and me going... you don't want to do that... don't want to leave them... I don't.

OP1-188: It's not fair on them (family). They've got to come and visit in hospital... It's not fair. I'm not going to put them through that. They've got their own lives to lead.

OP1-196: I'll look after them. That's my purpose... yeah... that's my purpose in life... keep them safe and well.

OP1-215: I don't get them involved if I can help it. They've seen enough. They don't need anymore. They've been through it all with me.

OP1-236: They say, "You can come along with us." I say, "I don't want to burden you with me."

OP1-254: You're more now considering other people... yeah... more care...

OP2-96: She said, "Why didn't you buzz...?" I said, "I don't want to disturb people. I don't want to put on people."

OP2-97: I don't like disturbing people if they're busy. They've a lot of people apart from me.

OP2-231: Husband not having anybody to help him. Hopefully, he'll be alright.

OP3-127: ... and I don't want to keep them my friends... to hold them back.

OP3-175: I just don't want to be a burden to anybody.

OP3-176: I don't want to lie and take up a bed.

OP5-117: I just don't want to... I could go... and waste it for other people.

In-patients

IP1-32: My partner is not clued up with things like that... trying to assure him.

IP1-83: I'm scared to leave my daughter.

IP1-92: Everything is all done for her... for handing over to her.

IP1-117: She's [daughter] nearly 22... no point in keeping anything from her... she's an adult... she's as well knowing what we all know... be truthful.

IP1-137: Me and my daughter... I maybe keep somethings (back).

IP1-138: You know she's (daughter) scared to break down in front of me... and vice versa... you're scared to say things.

IP1-141: We will be honest and tell everybody what has happened.

IP1-199: [T. "Thank you for sharing."] You're very welcome. Sometimes, I break down when I talk to you... must be hard for you to listen.

IP1-240: (Crying) It's affecting everybody else now. Affecting me with pain and affecting everybody around me.

IP2-28: So, I don’t know if that in some way kind of gives you an idea of where we are?

IP2-57: In terms of the family... I’ve put things in place out there to secure...

IP2-59: ... left them an inheritance... it’ll be divided up between them.

IP2-70: I’ve been blunt (open) with you in terms of some of my answers... sorry... blunt is a cheeky word.

IP2-102: Speak to the kids... tell them if I’m getting worse or bad... getting worse or happy...

IP2-133: [T. “... you find it difficult to say that?”] Yeah. [T. “Is it like... you’re not supposed to say it?”] It is... oh yeah.

IP2-134: It’s not in everyday language.

IP3-10: I was really conscious of how frightening... must have been for them.

IP3-27: I thought I didn’t want the girls to have to take on this type of care.

IP3-28: [T. “... it was for the girls rather than for yourself?”] Uh huh... yep...

IP3-32: The more I know... more I can help my daughters... more I can keep them informed.

IP3-37: I can’t imagine how it would be in their situation... I know how I feel... but to be in their situation... people say... oh, my Gran... my uncle died... and you’re like... “Nope.” ... this is my Mum.

IP3-38: I said to them as well, “Remember, I’m not the only one with cancer.” ... affects all of us... so there’s no point in... we don’t talk about that in front of ___ if we don’t then nothing gets said... nothing gets done and everyone bottles things up... going to be so much harder.

IP3-42: ... And... I didn’t want to bring that up and it affect (a family event)

IP3-47: At home because I try to force myself into control ... I’m aware I’m at home with the girls and I don’t want them to see that ... then it’ll help them be a bit stronger and deal with it.

IP3-54: Well, I feel standing at a grave-side and grieving like that... I don’t think... it’s just personally me... that would prolong the healing of it... I think if they don’t stand crying at a graveside...

IP3-57: What I keep saying to the girls... "See if you live your life and treat people the way you would like to be treated yourself... that's the best you can do." You can't do any better than that...

IP3-58: I do have a conscience and so I wouldn't... I would never ridicule anybody. I would respect what other people believe.

IP3-75: I don't want somebody standing at a headstone when you could be on a beach remembering the nice stuff... the nice holidays...

IP3-79: That's the thing... I don't want them to think there's anything they don't know, and I've told them that if there's anything at all you want to ask me... please ask me... if what I'm doing by wanting to go and be on a nice beach upset you then I need to know that too.

IP3-80: [T. "When... you talk about the beach... there's a sense of freedom?"] Uh huh... yep... that's what I think. Letting go of the hard stuff... that's going to cause them (family) pain... away from people who try to... comfort them in a way that maybe is too over the top. Makes me really happy that they can go together... can be a release for them.

IP3-85: As time has gone on we (family) do Christmas together... birthdays... holidays... and it's all for the benefit of the girls.

IP3-95: ... it was straight into... How do I do this?... How do I talk to the girls?... How do I help (daughter)?... trying to keep everybody sorted and in the loop because I said to my daughters, "If there was anything that you need to ask me... please ask me... don't leave it... don't try to make me feel better because that's not going to work."

IP3-121: Both she (Mum) and my Dad have lost... children... I'll be the third one... So, I can see how hard that would be.

IP3-128: No... sorry... I'm very emotional today.

IP3-148: So, if it (the end) goes quickly and easily and doesn't hurt the girls...

IP4-22: A lot of people wouldn't like that… I think it's a decent thing to do.

IP4-134: It'll save you rushing about.

4c-2: Patients Showing Gratitude/Appreciation/Respect

Patients communicate that they are thankful for the help and support received from others and, indeed, hold these others in high regard. Also, patients are grateful for the positive effects of their care/treatment, communicating that they experience a sense of enhanced personal well-being, *"(life)... very precious... every day's precious; Just let's say that's eight of my nine lives away... ha ha ha... I had a reprieve... yeah... that's a good way to put it."*

Out-patients

OP1-26: He (son) wouldn't even retaliate... wouldn't answer back... I apologised every time when I felt better.

OP1-27: I apologised to him (son) about it... same thing would happen next month... I had to apologise again.

OP1-29: He (son) was looking after me... preparing the meals... stayed with me... didn't need to stay with me.

OP1-107: He's one of these (sons)... wouldn't hold it against you... he knew it was the toxins...

OP1-251: I never thought I'd ever reach this age... no way in my life... the trouble I've been in... illnesses and things like that.

OP1-255: You begin to get very appreciative of other people.

OP1-257: I appreciate life now.

OP2-121: Got good news... tumours shrunk... brilliant... great news... looked up and... Thank You very much... got a cup of tea...

OP2-152: ... appreciation has gone up.

OP2-161: It's to give him something... when I'm not here... So, he's got this.

OP2-184: After having a good day... I thank my guardian angels... I don't forget them... thank you for another day... keeping me safe and healthy... if you could possibly do me another day tomorrow... I would much appreciate it... I don't ask for too much.

OP2-208: (life)... very precious... every day's precious... uh huh.

OP3-47: But it's good them to do that.

OP3-147: It's good to just speak about it to somebody... and somebody maybe that could understand how I feel... nobody else does.

OP3-206: ... because it's door-to-door, it helps.

OP3-208: ... and he's very good... he drops me at the end of the road.

OP3-213: Quite often... people will stop me and say, “Are you alright?” It’s nice of them... it’s nice that they do that.

OP5-107: But I’m glad to be home.

OP5-148: I found that out... (people) very understanding... find out who your real friends are... ones that look after me... taking me to hospital... taking me for (treatment)... phoning me... see that I’m alright... be here in five minutes... between them and my two sisters... great support group... neighbours checking on you all the time...

OP5-182: I don’t know how hard I’ve been on the people that love me... my sisters... can have a hard time... I’ve put them through... I don’t know... but I’m glad they’ve been there... to support me.

OP5-183: I’ve been fortunate enough I was born into a family that’s always stuck together... always supported one another.

OP5-194: So, I really feel good now that somebody’s doing something about it... that it’s being investigated.

OP5-238: When I saw some of the other poor souls... really quite fortunate.

OP5-249: Everything seems to be going in the right direction.

OP5-250: Oh, thank you very much... Oh... I thoroughly enjoy this.

OP5-259: I feel as though I’ve been kept for a reason. I don’t know what it is... maybe this is just my faith that does this... I’m getting a second bite of the cherry.

In-patients

IP1-115: And I’m glad she (daughter) was here last night.

IP1-170: Things you would not appreciate... before

IP2-18: ... got me (legs) both operational. I was absolutely delighted about that... I mean about eight weeks from June going into October.

IP2-79: They’re very, very helpful... they can’t do enough for you.

IP3-69: Here... somebody actually comes and gives me my food and deals with feeding me... help me get washed and dressed... it’s been lovely and they’re all so nice... they really are... they’re so nice.

IP3-87: I couldn’t fail him (husband). He does everything for me... it’s really endearing... we can still be that way... good for the girls to see that.

IP3-174: It (foot) is looking much better today... not red... this one's good.
IP4-23: At least you know where you are… where you stand you know.
IP4-61: Just let's say that's eight of my nine lives away... ha ha ha... I had a reprieve... yeah... that's a good way to put it.
IP4-84: You've got to show some respect for the people that's looking after you... trying to help you do these things. I've a lot of respect for them.
IP4-105: I got a lot of care and attention on the plane. They kept coming over and asking me... and they gave me some treatment on the plane.
IP4-119: I've never been on a holiday for ten years... twelve years... spoiled myself with going business class... so that made a big difference.
IP4-120: You get picked up at the door and dropped off at the door... albeit you pay for it... [T. "... makes thing easier?"] Oh, yeah... my God... yeah.
IP4-121: You just sit in a big limousine... get taken to... get taken right into...

4c-3: Patients Showing Regret

Patients express that they experience themselves as sad, repentant, and disappointed as a result of feeling 'sorry about' something that they have either done or not succeeded in doing, "*I was a smoker. I didn't smoke a lot. It's beginning to catch up on me now. I can't help that; But it's my own fault... (Pause)... It's out of my hands now... My life has been taken right out of my hands.*"

Out-patients

OP1-16: My son... was looking after me... he got the worst of it... I couldn't help it... I couldn't tolerate people.
OP1-17: I treated him as if it was his fault.
OP1-18: I treated him (badly) every month when it came to that... he just sat quiet … he knew what was coming.
OP1-24: Anger and things like this... he was getting the worst of it.
OP1-28: It wasn't fair on the boy... He's (son) a young man... was doing his best … he got the worst of it.
OP1-30: Sad for me to treat him this way... he...doing it for the best intentions.
OP1-34: I felt sorry for him... I knew what he was going to get... pure anger.
OP1-36: But I'm sorry for him... I'm sorry for doing it to him.

OP1-220: I was a smoker. I didn't smoke a lot. It's beginning to catch up on me now. I can't help that.

OP1-222: You don't want to be breathless. You caused it yourself. There's nobody else to blame.

OP2: (No data)

OP3-8: I think it (heart attack) was... at that time I was a smoker.

OP3-63: And I feel... I'm not getting any exercise... the weight is piling on... not going to help.

OP3-128: One of them... she's a year younger than me and she is still so active... I'm so envious of her... she's still getting out and about...

OP3-130: It's really frustrating... that she can do it... one year younger than me... she's able to do it.

OP3-181: I just don't feel as if life's worth living now... what kind of life do I have?... not a lot...

OP3-239: But I feel I'm not getting any exercise... the weight is piling on... because I'm not doing anything.

OP5: (No data)

In-patients

IP1-231: Then the guilt... can't get up... help people... when the buzzer is going.

IP1-239: (Crying)... Terrible... that I'm leaving them behind... it's something may have been fixed... Somebody have done something about it.

IP1-243: I've learned the hard way again. This has been one of the hardest things. Something that could have been avoided.

IP1-245: Guilt with myself... because I feel my daughter doesn't deserve this... She deserves me to be here longer... My partner... sisters... brothers... all the family... shouldn't be this way.

IP1-247: But it's my own fault... (Pause)... It's out of my hands now... My life has been taken right out of my hands.

IP2: (No data)

IP3: (No data)

IP4-122: Some people are... and they're looking at you as you walk into.... and I'm just a normal person like them...

IP4-129: I couldn't turn around and say to these people, "This is what's wrong and that's what's wrong."

Level 5: Willing/Wanting Self

Dissatisfied with their circumstances, patients become proactive and purposeful, experiencing the desire or need to initiate action. They know and want what is good for them and experience themselves as goal oriented. However, whilst patients do not implement action, they nevertheless experience their agency in the form of action tendencies that organise them toward internal actions and move them toward their goals.

5a: Motivated Self

Participants, from the perspective of wanting to continue their identity and activities and reduce uncertainty about themselves, communicate their drive to strengthen their own efficacy through the expression of their own personal needs and wishes. As *Motivated Selves,* patients are goal-oriented, with the active process of wanting, providing a channel for intrinsic motivation and a greater sense of well-being and fulfilment. Also, patients indicate that the *Need / Reason*, *Willingness* and *Enthusiasm* are key components in the drive to achieve their goals.

5a-1: Need/Reason

Patients engage in a process of self-evaluation that results in better understanding of themselves, providing them with the motivation to reinforce their personal effectiveness and efficacy in order to resist changes in their perceived self-concept, "*Re-adjust, re-value... work out if I'm still doing it the right way; It definitely... makes me think of things... put things into place.*"

Out-patients

OP1-87: I've got to look after myself... I feed myself... I look after myself...

OP1-96: You're taking tablets for to try and help with the sickness.

OP1-205: But I'll need to get something to get me out of this.

OP1-232: I have to get it done. If it's cancer again... I'll need to get it done.

OP2-69: I like to know. I like to hear. So, can I get the results of...

OP2-86: I need to survive.

OP2-116: Got to deal with it.

OP2-145: Re-adjust, re-value... work out if I'm still doing it the right way...

OP2-165: I have to get this done... I have to do this.

OP2-173: I have to kick my backside... kick it again.

OP2-175: I have to be... have got to...

OP3-108: I know it's got to be done.

OP3-110: Well, you know you've got to.

OP3-158: I need to watch what I'm doing.

OP5-56: You're keeping your diary... got to go here... there... got to go there.

OP5-166: I asked, "Will I be on these tablets... will I ever be off them?" So, I'll just have to take them.

OP5-228: No, no I wouldn't wait so long now.

In-patients

IP1-86: I'm trying to find memory boxes... funeral to organise... when you have children you should start doing it.

IP1-94: And I can sort my funeral out.

IP1-111: I'm going to ask... I'm going to ask questions... I need to.

IP1-123: I'll speak to the (hospital doctors).

IP1-125: I just feel it's not my time.

IP1-128: I just feel it's not my time yet.

IP1-171: It definitely... makes me think of things... put things into place.

IP1-202: I've been meaning to message him... meaning to up to church.

IP1-224: I need to concentrate on myself... uh huh.

IP1-246: I don't feel ready to go... I don't... I don't feel ready...

IP2-17: Once I take a drink of water I'm fine. I can keep talking again.

IP2-123: My coat needs lifting (to take home). Well, see... for tomorrow.

IP3-20: Really important to me... was able to do as much for myself as I could.

IP3-41: I tried to explain it.

IP3-49: Sort of a ... just so that everything's (sorted)

IP3-100: ... But still discuss it...

IP3-117: I had to practically drag... make sure she got there... make sure everything was alright.

IP4-85: Yeah, I've asked.

5a-2: Willingness

Patients are prepared to persevere and remain resilient in the face of their adversity, and they recognise willingness as a resource, crucial for their desire to continue their identity, "*It means a lot to me to persevere; I just get on with it.*"

Out-patients

OP1-53: … try to get yourself cured as quick as possible.

OP1-112: I knew it had to be done... get through it.

OP1-125: [T. "When you feel something new... a change.?"] Yes... oh yeah... I have to watch things like that.

OP1-141: You just need to try and work through it.

OP1-229: We'll (I) get that sorted.

OP1-239: It means a lot to me to persevere.

OP1-243: I don't really ask them. I'd rather persevere and do it myself even if it takes me longer.

OP2-55: I knew I had to do (treatment) and I knew that I wanted to do...

OP2-58: I never refused (treatment)... I've no intentions of knocking back (treatment)...

OP2-132: I have to try and work it out... compute it... kick it to the side or carry on... persevere.

OP2-209: Still working on keeping me going.

OP3-210: If I can manage to get out... even for a couple of hours... I'll do that.

OP5-68: I decided to carry on.

OP5-157: I'll take any help I can get.

OP5-185: ... but I'll take any help I can get.

OP5-203: I'm the type... I definitely will try it.

OP5-257: I'm ready to go.

In-Patients

IP1-58: I think we'll go for the surgery and get all removed.

IP1-74: I was to get this radical treatment.

IP1-251: ... start writing my daughter that letter I’ve been wanting to write.

IP1-252: Start doing things... get writing a personal letter from me to her (daughter)... So, I will... put in a personal box.

IP2-82: [T. “And... you are able to... voice?”] I do say to her... yeah.

IP3-159: ... small party this afternoon for residents... have to be fit to do that.

IP4-42: I just take it all at once and get it over and done with.

IP4-49: I just get on with it.

IP4-53: (will power) ... helps me with everything... everything...

IP4-82: Still take it (medication).

IP4-83: Which I believe you’ve got to do. (Take medication)

5a-3: Enthusiasm

Patients are goal-oriented, eagerly wanting to embrace life, and with an expectancy that something especially good will happen as a result of their own efficacy, “*I’ll get up in the morning... where are we going? ... what are we doing? First goal is to get home... my own home... get settled... take it from there...* .”

Out-patients

OP1-44: Try our best.

OP1-146: So, got to keep going.

OP1-162: I thought... get it done.

OP2-40: I planned for swim wear.

OP2-62: I was planning for the next session.

OP2-65: I had to get out of bed in the morning... make a cup of tea... get dressed... dog to walk. The motivation never ever... it’s never went away... never will... it will never go away.

OP2-119: I’ll get up in the morning... where are we going? ... what are we doing?

OP2-250: I’ll come and get you... I’ll tell you...

OP3: (No data)

OP5-253: I try and walk as much as I can.

OP5-255: Counting the weeks... since I was in hospital... way I feel just now there's no way I'll be in hospital this week.

In-patients

IP1-84: It's just everything... getting everything sorted.

IP1-103: Thought I would do it (take pain relief) before I went out in the wheelchair.

IP1-113: When you go today I'm making up a memory box for my daughter.

IP1-114: Things like that are giving me motivation and it's making me...

IP2-100: First goal is to get home... my own home... get settled... take it from there...

IP2-106: I've got remote controls... ha... ha... for the TV... my lights... I can switch my lights off and on... So, I can control any of the lights...

IP2-119: Yes, I'm just preparing to go home, yeah. Put my clothes into bags...

IP2-124: [T. "It's not exactly too cold outside."] Good, good yeah. It's coming on now for that time of year, yeah.

IP2-125: So, I'll get all my clothes in these bags early tomorrow.

IP2-126: Get up early, for a wash of course.

IP2-127: Breakfast... the last... before I take my final intake of pills...

IP2-139: Yes... so, that's me almost set (for home)

IP3-31: ... don't hold back.

IP3-72: ... kind of... grey looking... so, I bleached it (hair)... and I used a...

IP3-90: I say," See if you can't bring positivity into this wee (small) room."

IP3-154: Going to see if me an____ are allowed to go for a short wander about.

IP4-101: Oh, without a doubt... oh without a doubt...

IP4-107: But I'll go... I'll go... (To see granddaughter)

IP4-109: Uh huh... I'll go.

5b: Imagining Self

Participants communicate specific future goals that they want to achieve and express these through imagination. Imagination and fantasy see patients create images in their minds and they reflect on these images and associated feelings.

Through *wishing*, *hoping*, *wanting* and *constructing mental pictures,* patients are able to think of themselves in the future.

5b-1: Wishing

Patients express their desires, however, what they desire cannot or probably will not happen as what they wish for is not realistic. However, wishing allows patients to muse on what could happen, what could be, thereby giving rise to a degree of excitement, even if temporary, "*I just wish someone would tell me if they can do anything for this; That it goes quickly..." (Pause) (Tearful) Quickly and easily.*"

Out-patients

OP1-175: I'm too young to die yet (smiling). There's another good... I hope... 20 years in me yet.
OP2-137: ... hoping that I can call the shots for a long time.
OP3-58: I just wish someone would tell me if they can do anything for this...
OP3-226: If somebody would just sit down and speak to me and tell me...
OP5-221: I would love to go on holiday again... even if it was only for four or five days or for a week.
OP5-240: ... just hopefully... maybe in two weeks... I'll have had my game of golf... weather permitting... hopefully...

In-patients

IP1-189: Christmas is a goal.
IP1-192: I hope and pray... I can get my Christmas Tree up... Uh huh.
IP1-205: Just give me a chance to get up and walk on my feet...
IP1-221: I mean... tell me something different is going to happen... Please.
IP2-97: ... four or five years before that would eventually happen...
IP2-112: ... hopefully... I'll be able to greet them at the front door.
IP3-116: All it would have taken was a phone call... (from family member) that would have been fine.
IP3-145: [T. "What do you wish for... for yourself?"] Me?... That it goes quickly..." (Pause) (Tearful) Quickly and easily.
IP3-155: I was thinking... outside.

IP3-157: I’d like a short... I’d like to have a short jaunt outside.

IP3-175: I’m going to have two actual feet soon... That I can walk on both.

IP4-102: Could actually go tomorrow (see grand-daughter) ... wouldn’t think twice about going.

5b-2: Hoping

By hoping, patients consider what could be, with reasonable confidence that what they desire can be realised. Patient motivation is strengthened and so they continue working toward a future in the face of adversity, “*I had 13 brothers... 2 sisters... like to see them again… I hope they are waiting for me; God there must be... I hope… must be something after this.*”

Out-patients

OP1-68: I just need to hope it doesn’t come back... hope it doesn’t come back.

OP1-149: I hope to meet them again... I hope they’ve gone to the same place I want to go... hope to meet my brothers... sisters... mother...

OP1-250: I had 13 brothers... 2 sisters... like to see them again. I hope they are waiting for me...

OP1-256: I hope I have given you more information.

OP2-170: I hope I go before him.

OP2-205: I hope what they see is not sad things.

OP2-227: Results... barely visible and I’m hoping it stays there.

OP2-236: ... hoping they don’t get an infection...

OP2-252: ... hopefully is (research) going to help lots of other people.

OP3-59: Exactly... exactly... yeah... if someone could even say to me...

OP3-133: If people would just tell me what it is that’s wrong...

OP3-174: ... and I hope if anything happens I just go quickly.

OP3-185: If people would say to me... you’ll just have to...

OP5-98: And you just hope you can make...

OP5-103: ... so, hopefully she can do some investigation.

OP5-108: I just hope it’s a help to you.

OP5-127: I’m still waiting on the appointment... hopefully... I’ll be able to...

OP5-130: I just wish somebody would sit down and explain all this to me.

OP5-132: So, hopefully... I'll be able to talk to...

OP5-149: ... hopefully... they'll get something sorted out for me.

OP5-150: I hope it's help to you...your studies.

OP5-155: ... just... hopefully it will pass.

OP5-173: I just hope I can stay out of hospital.

OP5-174: My body can accept these tablets... get used to them... my hope.

OP5-181: Yes, I hope to be here in three years' time talking to you.

OP5-184: Hopefully... I get some good news tomorrow when I see (doctor).

OP5-207: ... long may it continue.

OP5-232: I can accept old age... I can accept that... but please let me stay the way I am for a... bit longer.

OP5-251: I just hope it's helpful for you.

In-patients

IP1-63: Praying, praying... the (treatment) would work and shrink something.

IP1-97: Hopefully there's a plan... I hope so... I just hope so.

IP1-98: I hope they will tell me today if there's a plan or if there's no plan.

IP1-124: … and hopefully there's a plan.

IP1-178: God there must be... I hope... must be something after this.

IP2-60: ... he's interested in gymnastics... I always said he would be fantastic.

IP3-33: Thought I would be able to tackle the whole scenario if I was better informed.

IP3-64: ... maybe able to get to and from the bathroom.

IP3-143: I hope that everything goes well for the girls (afterwards).

IP3-144: I hope it's (the end) all going to go better than I'm expecting it to go.

IP3-165: [T. "Would... (wheelchair) take you to the party?"] Uh huh, it would.

IP3-166: If somebody's able to take me... (to hospice party) ... make things easier.

IP3-167: It would be good to go... (to the hospice party) Yeah.

IP3-172: I would love a... sleep... ha, ha.

IP4-45: I would say, "To keep me stable."

IP4-57: Oh well I hope so.

IP4-59: I believe it could change.

IP4-67: Things could get better...

IP4-69: There is hope with could... yeah there's hope with could.

5b-3: Wanting

Patients want to take action in order to achieve their goals and, as the *Imagining Selves,* the act of imagining provides a new direction for thinking. Through their increasing capacity as agents, patients choose to initiate change by generating alternative ways of constructing their experience through imagining, "*I want 40 years... if I get 39 1/2... I've won... 2 years; I don't want to feel like this... don't want this.*"

Out-patients

OP1-50: I didn't want to die... I'm too young to die yet.

OP1-204: I said, "No, no. I want to do it myself... if I can."

OP2-57: I want to be here. I want to live.

OP2-79: My biggest wish was to have my birthday... I want to do my birthday.

OP2-153: I want to live... I want to be here.

OP2-155: There is a strong... a very strong... wanting to be here.

OP2-156: I don't want this cancer to win.

OP2-164: I want... to go to the dog home and see if I can get a dog.

OP2-166: This is what I want to do.

OP2-182: I want 40 years... if I get 39 1/2... I've won... 2 years.

OP2-196: I wanted to celebrate.

OP2-202: I want a week.

OP2-206: I always wanted to go and see a musical. I want to do a musical.

OP2-223: I want to be seen... I'm here to be counted.

OP3-112: Well, it's not way I would want to do it.

OP3-113: I don't want people coming...

OP3-177: I want to come to the hospice... than hospital if anything happens.

OP5-126: I don't want to stop taking them.

OP5-133: I definitely don't want to stop taking it (medication).

OP5-136: I'm not going to stop taking the drug... that would be foolish.

OP5-158: I just want someone to tell me what's causing all this.

OP5-209: I want to play golf.

OP5-226: I would call... want to stay the way I am... I want to stay like this.

OP5-231: My body will stay the way I am and that's the way I want to be.

OP5-248: That was all I wanted to do (drive himself).

In-patients

IP1-193: Get four-hour pass... get (Christmas Tree) decorated... come back in.

IP2-90: I was looking forward to eventually retiring officially.

IP2-135: Would like to say to you... you to hear but swear words in it.

IP2-138: I can say cheerio to it (hospice) tomorrow.

IP3-23: ... and I wouldn't let my daughter leave my side.

IP3-25: I actually went, "I want to go to the hospice."

IP3-30: ... I said that I wanted to know.

IP3-43: I wanted her to have her communion...

IP3-50: I want to be cremated.

IP3-51: And I don't want a service as such.

IP3-52: I want to be taken on a nice wee (short) walk to a nice beach... scattered on a nice beach.

IP3-89: Avoid arguing with them (daughters)... not going there... completely ignore her... get into a fight... I just don't want to be in that...

IP3-141: [T. "Do you set... aims or goals?"] ... it's not aims as such... it's more... I don't want to feel like this... don't want this... .

IP3-163: ... to see if I'm able to be up and about... to go to the party.

IP4-95: I plan to go to Abu Dhabi.

IP4-111: ... I want to see my grandkids... I want to see her (granddaughter) ...

IP4-123: ... I wanted to go (travel) by the style I wanted to do...

5b-4: Fully Imagining

As patients can to some degree direct and control what they experience, they deliberately choose to focus on a particular script. Their script, whilst stimulus-driven, is under the control of their will. With a shift from the abstract to the more concrete, the construction of mental imagery is more than exploring options and is seen to anticipate possible desired future experiences, "*If you could stay the same... same age... didn't get older... no illnesses; picking the kids up from school.*"

Out-patients

OP1-69: Not looking for the pleasure of having same thing happening with this leg.

OP1-128: Good news if they don't contact you.

OP1-185: I've had one or two scares since... so I must be going to live for a long time yet. Touch wood (smiles).

OP1-214: If it had gone down into the arm I would phone for an ambulance.

OP1-249: If you could stay the same... same age... didn't get older... no illnesses.

OP2-142: They can't cure it... can contain it for...three years... or four or five... whatever... you feel by then that's another step... got to be hope.

OP2-198: I'll get my forty years and that's where I' heading.

OP3-155: Oh, don't tell me I'm going to be one of these big, fat people.

OP3-165: Oh, dear don't tell me I'm going to stop breathing here (alone).

OP3-166: What if I'm lying here (alone)... something happens... nobody here?

OP3-201: Get a fresh... somebody looks at my case notes and say, "Right, I think we can try this." Somebody who could assess me...

OP5-179: I'd like to think I'd be here in three years' time... just now... I feel as though I'll be here in three weeks'... sorry... three years.

OP5-189: Right now, I feel as though... I'll be here in three years' time.

OP5-202: I got the new car... the next thing... to hit the golf course... ha, ha.

OP5-219: If I could just play a game of golf once a week... something to really look forward to...

OP5-220: I would really, really enjoy that... I'm convinced it's coming... that's really my next goal.

OP5-222: I could go on holiday... get a... change of scenery for a week.

OP5-224: A nice holiday... game of golf... that would please me... that would do me... I'd really love that...

OP5-229: I've learned... definitely learned... I wouldn't suffer what I went through... if it is ever to happen again... phone straight away...

OP5-239: I just look forward to the next step now.

In-patient

IP1-55: Great... I can get surgery and get all of this removed... this is fantastic.

IP1-59: Like... oh my God... this is great... they can take this away.

IP1-75: … am I a guinea pig and it's going to work... or am I a guinea pig and I'm going to die from this?

IP1-153: I have got goals... Christmas... then my daughter's graduation.

IP2-33: [T. "What's it like... to make decision like...?"] Very easy for me. I knew it was coming.

IP2-78: I'm looking forward to going home... seriously looking forward.

IP2-91: Buying a dog... I always wanted... having a dog in my semi-little house... taking a dog for a walk.

IP2-92: ... picking the kids up from school...

IP2-93: ... intervening where my son and daughter would ask... "Dad can you do this... Can you do that for me?"

IP2-94: And I felt (would) proud... walk the kids back home.

IP2-98: They know I'm not going to be around to pick up the kids... things like that...

IP2-113: I'm going home in an ambulance... an ambulance stretcher... onto my tripod... into the house... onto a bed like this... has all the functionality.

IP2-114: I'll be at home... yeah... and I'll know what day it is...

IP2-128: I'll just be waiting for the ambulance.

IP3-35: And I was like... nobody goes off the rails... nobody... once I'm gone you... don't just go off the rails.

IP3-53: The kids to take that time along with their Dad... a holiday away from everybody wanting to give them condolences.

IP3-76: ... just want to avoid the whole (funeral thing) ... standing at a graveside... because I never enjoyed doing that.

IP3-88: My fear would... that somebody said something stupid... that was the last thing they said... I said... frightens me they end on a really bad note.

IP3-105: I thought it would be nice if she (family member) came... have a wee (small) coffee... and a wee (small) chat... a ten-minute visit.

IP3-132: I'd probably get really angry with her (family member) ... [T. "Questions to ask her?"] Yeah.

IP3-139: I don't see the point... It would just make matters ten times worse.

IP3-160: ... and to be running about daft... ha, ha. Oh yeah.

IP4: (No data)

5c: Fighting Self

With a strong sense of self-efficacy, patients remain goal-oriented in the face of their demanding circumstances. They approach their situation with the assurance that they can exercise control and so they set themselves challenging goals and try to maintain commitment to them. In addition, patients communicate that their fighting self appears more evident at this particularly significant phase in their life, with impact on their level of motivation, sense of worth and personal achievement.

5c-1: Believing in Self-Ability to Influence/Succeed

Participants experience a strong sense of confidence in their own ability to influence the circumstances that affect their life, "*You're pushing to help to save yourself... trying to stop you dying... keep yourself alive; I... say to myself this is not going to beat me.*"

Out-patients

OP1-104: I had to persevere and get it done.

OP1-120: You're pushing to help to save yourself... trying to stop you dying... keep yourself alive.

OP1-133: I'd rather do it myself if I can. Oh yeah... oh yeah... if I can help it.

OP1-135: We'll get there... get there... eventually... one way or other.

OP1-142: No, never give up... been a fighter all my life... look after yourself.

OP1-155: I am keeping going... my own way... I don't need anyone else.

OP1-172: I had to go... wasn't getting out of the bit with this cold. I had to get it seen to... didn't want it to develop into something else... didn't want to go into hospital.

OP1-173: You have to do it... you have to. No point waiting on them. You have to do it yourself.

OP1-174: I depend on myself. I make sure I'm fine.

OP1-184: The illnesses I've had... nearly killed me... I came through that... It's been trying to get me... but it's not going to get me.

OP1-186: Got a lot to do. That's why I fight all these illnesses the best I can.

OP1-238: "No, I'll manage... made a pig's ear of it... I'll manage. I have to.

OP2-32: I can do this. I can do this. I can beat this.

OP2-63: It was always there. I t was always there. From the diagnosis of the secondary ___ cancer... I can deal with this. I've got to do it.

OP2-64: The more (treatment) I got... the more ill I got... took a lot to keep pushing myself up.

OP2-74: I can function. I can live.

OP2-84: This is my time to change... prove I can fight... that I can do things myself.

OP2-93: I'm fighting this on my own. It's me that's fighting this... me.

OP2-100: I can do this... this is me... I can win this...

OP2-112: Before the diagnosis... had very little confidence. I had to push myself... getting the cancer... if it wasn't there then I wouldn't be doing what I'm doing today... but he's got to behave.

OP2-114: I'll face anything... have a good go... will face it... give it a good go.

OP2-130: The illness is not winning... I'm not ready to let you have another bit of me... so, sit there.

OP2-136: I rule the roost. I call the shots.

OP2-149: I'm ill but I'm not out... I'm here... still here... I can still do this...

OP2-197: I said, "It's not the treatment that's shrinking them... it's me." My positivity is shrinking them... along with the medication.

OP2-220: A fighter... uh huh... that's who I see now.

OP2-246: I'm a survivor.

OP3-41: I try and walk from ____ down to ___.

OP3-49: I say that to myself... "Just have a wee (short) rest and then have a wee (short) wander round." ... make my way down to the...

OP3-78: Well, I try... I try and get the bus.

OP3-86: Definitely... I would hate to be stuck in the house... so I really try.

OP3-89: ... and it's just a matter of crossing the pavement and going in.

OP3-114: I meet a friend once a week and I deliberately make it that we go into ____ ... gets me out.

OP3-115: I try to get the bus to pick me up... take me to the supermarket.

OP3-116: Just cross over to... get a coffee... come back down... get bus back.

OP3-215: I feel as if I need to keep going... keep trying to get out... even although it's difficult.

OP5-48: I said "I'll still be here in the morning. Never thought for a minute that I wasn't going... make it through the night. I said, "I'll be alright."

OP5-137: ... the day might come when I'll say, "I've had enough." Not yet.

OP5-216: Oh, I take part in it... I definitely take part in it... no, no... definitely take part in it.

OP5-218: It's by me coming here... I took part in it... I didn't say, "No, I'm not going to the hospice... No, I don't want to see the counsellor... I'll go and see the counsellor."

OP5-227: I'm taking charge of the situation.

OP5-237: Everything's moving in the right direction for me I feel... not feeling sorry for myself anymore... definitely not... I'm not the poor me.

OP5-245: Won't let it get me down... I'm determined... won't let it get me down.

OP5-260: I'm going to make the most of this.

In-patients

IP1-71: It was grand... a big turnaround... I was on top of myself.

IP1-127: I feel with it. Uh huh... considering the amount of drugs I am on.

IP1-134: I've got a lot more to give.

IP1-150: It's having that positivity to get up and do it.

IP1-151: I will have days where I will be down but it's staying positive.

IP1-176: I'm going to try... like things done properly... I know it's done by me.

IP1-177: If it's my mistake then... I'll clear it up.

IP1-182: I've ordered that... I've started... I'll do something...

IP1-194: (Laughing) I don't trust anyone else to put it up (Christmas Tree).

IP1-250: I'm going to... do my magazine... crossword... get back into that mind frame... writing again... rather lying and thinking...

IP1-253: I'll try to get up and have a bath... get a bath... try to get the pain way.

IP2-76: Things are arranged for Friday... so I've had a bit of activity... you know... on the phone.

IP3: (No data)

IP4-33: At home I'll sit with blankets round about me.

IP4-34: I did that for a comfort thing...

IP4-54: I… say to myself this is not going to beat me.

IP4-56: You just cannot have two or three pills put in you and that's it. You got to have the belief that they're going to work for you... or at least help you... that's my belief... it's what I've got belief in.

IP4-66: I've got this belief in myself.

5c-2: Dealing with Circumstances

Patients do not avoid difficult challenges but, instead, communicate that their belief in their self-efficacy enables them to deal with their testing situation by giving it attention and making decisions that can enhance their personal well-being, "*Oh yeah... had to do it... either that or you go home and die; I've been dealing with pain from day 1. It's not another thing to deal with. It's something I deal with in a regular basis.*"

Out-patients

OP1-78: You just have to keep going... not going to lie down and die... that's the last thing on my mind.

OP1-105: Oh yeah... had to do it... either that or you go home and die...

OP1-106: Oh no... there was no option... oh no.

OP1-124: I'm trying my best to keep it at bay.

OP1-136: Of, course... I must fight... I must fight... to keep alive.

OP1-176: Push yourself... I'm doing that. It's no problem. I've got to do it.

OP1-180: I've got to get through it... must get through it. That is a must. I've got to... I've got to keep going... no matter what happens.

OP2-15: I have got it... I can sort that bit now... relief... now we deal with this.

OP2-25: This is something that I will fight all along.

OP2-39: I am there. So, don't tell me to wait. I'm here. I need all this now.

OP2-43: I have to have everything I need in place... knowing where I'm going... what I'm doing... what I'm getting... to win.

OP2-56: I knew that this was my only hope... giving me some life... so, I've got to... got to do it to survive... got to do it... .

OP2-83: I decided... I needed to fight.

OP2-122: Keep going... keep fighting.

OP2-138: It makes me all the more determined... all the more determined...

OP2-194: You take this one... and you work on this one.

OP2-233: I am fine... I'm positive... I'm fighting... I'm here.

OP3-33: Trying to live...

OP3-35: I try not to sleep during the day.

OP3-36: And I try to get out.

OP3-37: I use more taxis recently...

OP3-45: I stop there and lean on the box and try and get my breath back.

OP3-48: I walk round and into ___ and sit on their windowsill.

OP3-61: [T. "You would be willing to try?"] Yes... Yes... definitely.

OP3-64: Well... I try...

OP3-67: I try... buy a wee (small) pack of fruit...

OP3-79: ... so I use taxis most of the time.

OP3-87: Oh definitely... definitely... it (trying) lets me get out.

OP3-95: ... now I've... started taking the housecoat off... putting it on the bed.

OP3-120: I stop... take a couple of breaths... wait till I get my breath back... then I walk on and go into the house.

OP3-221: I try and get rid of it because I don't want it to gather in my chest.

OP5-51: I had to learn to walk again... the 'Zimmer' first... and the sticks... learn to put on my clothes... two weeks you know.

OP5-52: So, I went to _____ for the (treatment)

OP5-65: I still went back.

OP5-73: I'll take them because I want to be here... as long as I can... So, I took them.

OP5-112: I'm still taking... yeah... I'm taking the tablets.

OP5-160: I can't stop the tablets... I know that... there's no way can I stop these tablets... no way under the sun... I'll just have to get on with it... I'll just have to get used to them.

OP5-191: So, I took the pills... I took them...

OP5-193: So, I started that this morning.

OP5-196: And I went back.

In-patients

IP1-13: I was taking all sorts of painkillers just to get through.

IP1-26: … and so I went to the hospital.

IP1-36: I tried to drink plenty of water... plenty juice... eh... get good sleep.

IP1-52: I came back in (hospital).

IP1-157: I went away on Friday to the hospital.

IP1-232: [T. "Does that guilt stop you from buzzing... for help?"] Sometimes... but at certain times I need to... I've learned... I need to buzz... when I need it.

IP2: (No data)

IP3-93: I've been dealing with pain from day 1. It's not another thing to deal with. It's something I deal with in a regular basis.

IP4-6: Watching the weather… standing next to various people and all the rest of it… I'm taking these wee (small) precautions.

IP4-29: So, had to put the window down...

IP4-50: You know... try and make the most of it.

IP4-79: Aw there's no doubt you take it... regardless.

IP4-128: I didn't want to go business class but that's the way I went because I was sore.

5c-3: Accomplishing a Challenge

Patients communicate their personal achievement of successfully accomplishing challenges that need great mental and/or physical effort. An increase in self-belief in their own efficacy sees patients less beset with self-doubts. This allows them to set goals for themselves and plan courses of action designed to attain their aims and aspirations. Throughout their communications relating to *Accomplishing a Challenge*, patients use the first-person singular pronoun, reinforcing that they are more reliant on their own capacity to exercise control, "*I turned the tables on the cancer. I turned it. I'm living; I managed to get my pyjamas off today.*"

Out-patients

OP1-60: I went back to the [hospital] and I got 18 treatments for this.
OP1-103: Yeah... yeah... I chose to continue (treatment) myself.
OP1-144: I keep myself tidy and clean... and spiritually as well.
OP1-183: It's a must to be here. I cannot leave. I refuse to leave. Refuse point blank.
OP1-191: So, I'll just keep going to the end of the road.
OP1-192: The end of the road has been near two or three times. I have stepped back from the end of the road... stepped back from there.
OP1-218: Just use your will power. I stopped (smoking) overnight...
OP2-75: I turned the tables on the cancer. I turned it. I'm living.
OP2-76: I'm living with cancer and boy am I living.
OP2-98: I took charge of the cancer. I took charge of it.
OP2-124: Go to hospital every three weeks... check-up... how I am... doing.
OP2-157: So, if I can keep doing what I'm doing then it won't (win).
OP2-160: I was determined I was going, and I walked in.
OP2-222: Would have sat back in the corner... don't stay in the corner anymore.
OP3-14: I have been watching... I don't eat cheese now... I don't eat eggs... I buy the skimmed milk.
OP3-39: I come here on a Monday.
OP3-40: A Tuesday... I take... a taxi to ____ and get a couple of things there.
OP3-44: I've walked down the lane... and crossed the pedestrian crossing.
OP3-50: I get a wee (small) bus...
OP3-81: I got a taxi up.
OP3-105: I changed my bed yesterday.

OP3-109: I can put a washing in no problem... take them out and hang them.

OP3-152: I don't eat a lot of biscuits and things.

OP3-156: ... so... I watch what I'm eating.

OP5-76: I just get on with it now.

OP5-152: I came ... for a massage.

OP5-167: When I was diagnosed... I made a bucket list... I did the things I wanted to do... I've done them all.

OP5-205: I test myself if I'm out walking.

OP5-210: [T. "So, there's something you've overcome?"] Yeah... definitely.

OP5-256: Yeah, definitely... I've got the better of this.

In-patients

IP1-25: I finally got another appointment.

IP1-70: Well, I was swimming... I was walking... Yeah... I was only on paracetamol.

IP1-119: I managed to get my pyjamas off today...

IP1-143: I managed to walk with the tripod... round to the bathroom… walked all the way round.

IP1-144: Managed to get into the bath without the hoist... into the bath with my feet... my own legs.

IP2-13: ... and every Tuesday the physiotherapy I do...

IP3-44: Sat the girls down... one of the hardest things I've ever done... difficult time... really difficult... [T. "Did it help, talking...?"] It helped me.

IP4-118: [T. "It was worth the effort?"] Without a doubt.

IP4-124: I've had all these illnesses... I've saved up... (to go on holiday)

IP4-126: I would probably say, "There you are."

Level 6: Enriched Self

Patients engage in a dialectical process, confronting the difference between the partial restoration of their normal or historic, past self, and the accepting/transcending future self. As *"Enriched Selves",* patients also experience enhanced value and significance in their present living.

6a: Historic Self

With patients experiencing an incongruence between their past self and their present self-concept, they want to return to their former self, namely the self before their diagnosis. They recognise that their new present self gives rise to different understandings of themselves, and so they reconnect with their past self through recalling past events, influenced by their personal schemas.

6a-1: Incongruence Between Patients' Past and Present Selves

Patients make comparisons between their past and present selves, with the self in the present experienced as less efficacious. This causes disequilibrium and is experienced by the patient as frustration and so they may reminisce or try to restore to their former selves. Patients' need to reduce the incongruence between their normal and transformed self-concepts serve as the motivation towards change and maintenance, "I just hate it now. When I think what I used to be like."

Out-patients

OP1: (No data)

OP2-41: I want to go back to swimming.

OP3-149: Gone are the days when I used to make soup every week.

OP3-150: My family used to come on a Sunday. I would spend Saturday making home-made soup... think about it... Sunday I would make a casserole... so we had a big dinner on a Sunday... never thought anything about it... it was one of those things that you did.

OP3-151: But gone are the days... I just don't cook now.

OP3-216: I just hate it now. When I think what I used to be like...

OP3-241: I was called Mrs N__ ... I was always out and about somewhere... I used to go away to ___ ... always somewhere... theatre... cinema... always doing something.

OP5: (No data)

In-patients

(No data)

6a-2: Rosy Retrospection

Patients remember their past selves with a "rosy retrospection", perceiving their past selves as more positive than they judge their present being. Nostalgia makes them feel happier, more self-confident, and closer to people around them, "*I used to come last year... I enjoyed it... the atmosphere is nice... the people are very nice*."

Out-patients

OP1: (No data)

OP2: (No data)

OP3-1: Well... eh... for a start... I used to be known as Mrs. N____... Mrs. N___... My friends... we used to go to the theatre... used to go to the cinema... we'd go away for days out.

OP3-2: Tuesday was my day and I used it to go somewhere... just to get out and about... suit myself... I enjoyed that... could stop when I wanted... look in any shops I wanted...

OP3-123: I was out and about... couple of times a week... I was up at... down to... you name it I used to go... I loved it.

OP3-144: I used to come last year... I enjoyed it... the atmosphere is nice... the people are very nice.

OP5: (No data)

In-patients: (No data)

6a-3: Restoring to Past Self

Patients are frustrated with who they have become and want to restore themselves to their past selves who they see as more positive, "*The (me) I lost last year is coming back... slowly...; Go to the hairdresser... get my eyebrows done... something... make me feel like me.*"

Out-patients

OP1: (No data)

OP2-117: The (me) I lost last year is coming back... slowly...

OP3: (No data)

OP5: (No data)

In-patients

IP1-126: I'm sitting talking to you... and I'm like... I feel normal.

IP1-206: Go to the hairdresser... get my eyebrows done... something… make me feel like me.

IP2: (No data)

IP3: (No data)

IP4: (No data)

6b: Accepting/Transcending Self

Patients accept that they are finite beings, acknowledging that their physical bodies will cease to exist. Some patients choose to transcend that finiteness through belief in a form of afterlife, freed from the limitations inherent in matter and having an existence outside the created world.

6b-1: Accepting Life as Finite

By accepting that the human being is finite, the individual acknowledges that they have a time-limited existence. Although the human individual does not represent a deterministic organism, devoid of goals and plans, they accept that they do not have the ability to avoid death which may be perceived as a means of escaping from their pain, physical and emotional, "*It (dying) means getting away... no more pain... no more worries; This is the End... going home... yes*."

Out-patients

OP2: (No data)

OP3: (No data)

OP5: (No data)

In-patients

IP1: (No data)

IP2-61: [T. "Do you believe this is the End or...?"] This is the End... going home... yes.

IP2-62: [T. "... is there something... When you are no longer here... is that the End?"] Yeah... my mother's dead... sister's dead... that's it... job done.

IP3: (No data)

IP4: (No data)

6b-2: Believing in the Power of a Higher Being/After Life

Patients communicate their belief that there must be something, undefined and beyond this earthly world, that has a power greater than themselves. In addition, patients express that there may be, without specification, an after-death existence that may see the reuniting of people separated by death, "*It must be good up there (Heaven)... I'd love that... That's OK to me. That's fine for me; This is a journey. It's just a matter of finding each other... when you've crossed that path.*"

Out-patients

OP1-79: He [God] will make the decision whether I go... this week or next... or maybe in another 20 years' time.

OP1-80: When I'm over a 100... He [God] might decide... well you've had enough... you'd better come up here... so we'll do it that way.

OP1-147: It must be good up there (Heaven)... I'd love that... That's OK to me. That's fine for me.

OP1-248: I believe there's a Heaven and hell. I do think a lot of Heaven and Earth... especially Heaven. You hear people, "You're going to a happier life."

OP2: (No data)

OP3: (No data)

OP5-169: I'm not scared of going... if somebody could tell me... my mother would be there waiting for me at the other side... I would be absolutely delighted... If I thought my mother was... standing there at the Pearly Gates... waiting on me... I'd be quite happy... if somebody could tell me that.

OP5-269: In my opinion it's out of my hands... whatever happens... it's up to You up the stairs... when you come into this world... your name goes in the book when you come in and when you go out.

In-patients

IP1-180: This is a journey. It's just a matter of finding each other... when you've crossed that path.

IP2: (No data)
IP3: (No data)
IP4: (No data)

6c: Joyfully Engaged Self

As patients become fully aware of their finiteness, they purposefully engage in living, enhancing the quality of life in the time they have left. Confronting their own deaths provides patients with the opportunity to live true to themselves and recognise what is really important to them. Hence, they choose to turn their attention towards internal satisfaction.

6c-1: Patients Experiencing Joy

Patients experience a sense of being one with the world, countering the feeling of being isolated from the world and rising above the barriers that blocked their aims and desires. Their joy is constructed form their own accomplishments or progress towards their goals, "*It's a good day... a good day... because it's another day I'm here... another day to celebrate... so, it's a good day; I was out yesterday in the fresh air in the wheelchair... it was great.*"

Out-patients

OP1-193: I count my blessings every day... I'm still here. I count my blessings every day.
OP2-68: It's a good day... a good day... because it's another day I'm here... another day to celebrate... so, it's a good day.
OP2-186: Feeling amazing... feeling amazing
OP2-199: ... over the moon...
OP2-203: [T. "... life right now?"] Brilliant... absolutely awesome... fantastic... it's just unbelievable.
OP3: (No data)
OP5-201: I spoke to you on the ___ on the ___ I had a new car... You cost me ... ha, ha... Oh, I love it... highly delighted... made a difference to me... yeah, ha, ha... really did... I really felt a lot better...
OP5-234: What's next for me... I love my car... got a good deal... I like haggling... enjoyed that part of it... I really feel a lot better.

In-patients

IP1-105: Oh... there was... I got to see them... father deer... mother... baby deer.

IP1-147: I was out yesterday in the fresh air in the wheelchair... it was great.

IP2-22: Low and behold... legs return... yeah... back to being mobile.

IP2-140: ... just to get settled into the bed... get settled into bed... be a relief.

IP3-149: They've (daughters) enjoyed their couple of nights (in Mum's hospice room). Had pizza... they had the small dog in to play... The second night one of them just wanted to lie about and play with her phone... watch telly... lay in bed... both slept in that bed... So, that was good... was lovely for them to do that... nurses made us a pot of tea to go with the pizza... It was lovely. It was really nice.

IP4-113: She's such a papa's girl (grand-daughter) ... I can say that without laughing... it was really beautiful.

6c-2: Patients Experiencing Enjoyment

Patients communicate great pleasure and happiness brought on by the success and satisfaction as a result of taking part in an activity that provides interest and, in some instances requiring physical and/or mental effort. By participating in activities, patients experience a greater a sense of achievement and self-fulfilment, " *Live... take each day as it comes... enjoy it... looking... plants for the garden... trees... take more time to see things... take more in... now I enjoy doing things; Got up this morning... had a lovely fried breakfast… So, I did… lovely."*

Out-patients

OP1-166: I play dominos... enjoy mixing with the guys... play in a domino league.

OP2-211: (Life)... couldn't be better... couldn't be any better... got a car...

OP2-225: Live... take each day as it comes... enjoy it... looking... plants for the garden... trees... take more time to see things... take more in... now I enjoy doing things...

OP3-82: I met a friend... I was meeting her in this café... not that far away.

OP3-146: I love it when I get the... massage... makes you feel good... the people that come are nice.

OP3-234: I enjoy coming here... I really do... the staff are all so nice and you get a lovely lunch... I love the massage... so relaxing... I love it.

OP3-247: Was out last night. Service in one of the churches... carols... my friend and I went. I enjoyed that.

OP5-92: Took my sister to... went home... had my dinner and was looking forward to the football match... sat and watched.

In-patients

IP1-142: Got up this morning... had a lovely fried breakfast… So, I did… lovely.

IP1-146: The bath is absolutely brilliant for me... get out of the bath... I dry myself.

IP1-167: It was great... getting fresh air... to get in the fresh air... fresh air was like... brilliant... so it was.

IP1-254: Get in the bath and hopefully it will be good... hopefully it will be good bubble bath... bubbles... come back to bed ... get an afternoon nap

IP1-257: Look at the small birds outside... tweet... tweet.

IP1-258: It was nice yesterday... I went out... it was windy... a windy heat.

IP2: (No data)

IP3-136: Had my oldest daughter staying last night... youngest one stayed the night before... she brought my small dog up for a wee (short) while... it was nice to have her here and the wee doggie (small dog).

IP3-137: I think my young daughter and her Dad’s coming... one of the other dogs is coming... don’t know what dog they’ve decided on... please don’t let it be the puppy... ha, ha, ha... she runs amok.

IP4: (No data)

6c-3: Patients Experiencing Excitement for Life

Within this level, patients experience themselves as pro-active, generating novel ways of constructing their experience, indicating an increased power of agency. As active initiators, patients engage in their every-day living with a sense of excitement, marked by enthusiasm and eagerness, “*Every day is a dream... just when you get up every day and you go... I’m here... I’m here; I just put the lights on in the motor... sat* *in the car... went... had a look round the landmarks... enjoyed myself... still enjoyed myself."*

Out-patients

OP1-182: [T. "Is life precious?"] Oh yeah to me it is... yeah... It's like a diamond to me... or a ruby... it's more than money can buy... is life.

OP2-70: I went out that ward on cloud nine... really did... met husband... lunch.

OP2-123: Doing alright... doing great... normal routine... shopping and whatever... definitely.

OP2-150: I'm living... and loving life... I get up and I think... I'm here... and I'm living it and loving it.

OP2-177: Every day is a dream... just when you get up every day and you go... I'm here... I'm here.

OP2-195: I don't think my feet touched the ground (laughing)... running around in circles.

OP2-201: Joined the gym... circuit training... exercising twice a week... walking the dog... booked a holiday... hot tub (laughing)...

OP2-215: Go out every Saturday night... go to... up dancing... loving it.

OP2-224: I've got the holiday... went to football... going to do more musicals... out... different nights... live basically.

OP3-57: My Grandson... see every couple of weeks... he comes and takes me out for lunch... nice to see him... My daughter was up to see me...

OP3-88: My Grandson came over last week... he took me out for my lunch... we've discovered this café... and it's really nice.

OP3-205: Tomorrow, I'm meeting a friend for lunch... I'll need to get a taxi... I'll try... get bus down to supermarket... get a couple of things... cross the road and go have a coffee... back down and get the bus.

OP3-238: My Grandson ... takes me out for my lunch... I see my friends once a week... we go out for lunch... taxi or get a bus on Friday... drops me outside my Grandson's... go for a coffee... get the bus back.

OP5-172: I 've met a lot of new friends... we have lunches... days out... our quiz nights.

In-patients

IP1-104: That (tablets) helps me... really quick... then I can go on to the wheelchair and get out and a wee (short) walk... get fresh air.

IP1-169: I go out for a walk... going to rain... don't care ... sometimes you appreciate... the rain on your face... wind on your face.

IP2-11: Oh... it was brilliant... put on my socks... and I drove my car again.

IP3-74: [T. ... had your nails..."] Yeah... I'm really pleased because my toes are that colour... I tried to get it the same colour... my daughter brought me artificial flowers that are that colour.

IP4-117: I just put the lights on in the motor... sat in the car... went... had a look round the landmarks... enjoyed myself... still enjoyed myself.

Level 7: The Fully Agentic Self

Faced with the diagnosis of an incurable illness, patients are aware of themselves as vulnerable, finite beings and experience events within their physical body that limit their sense of control. Whilst aware of their *givens,* they optimistically but realistically, choose to actively engage in life to their best ability. Thus, determined not to be the victim of their *limit situation*, patients decide to live authentically by accepting their freedom to make choices, owning their personal decisions and actions.

As "*Fully Agentic Selves*", and from an existential perspective, patients experience themselves as optimistic, realistic, goal-oriented, contented, autonomous individuals, "*I have achieved a lot... haven't I?... definitely... give myself a pat on the back... I really have done well... mentally and physically... both... not just the one... the drugs will control the pain... but it's up here... it's yourself... now I feel I'm in control up here now too... no fear up here anymore... no fear now... the cancer in the legs and that... I never think about it... I'm a happier person now... I really am... and I want to do things now that I didn't; There's nothing nobody can do about it... nothing can change it... to be angry all the time... really silly... takes up so much energy... for me it's best to accept what's going on... try and muddle... through it.*"

Out-patients

OP1:85: Just got to plod away... do things at your own leisure... own speed … that's all I can do... doing my own time... no one will push me along.

OP1-86: I have to be in control because if you let it get on top of you... you're finished... kaput... keep going the way you are... have to be positive.

OP1-88: I'm doing no bad myself...keep going... just keep going... keep going to the end of the road... the End... that's what I'm intending to do.

OP1-258: Got to hold on to it (life) as far as I can... hold on to it as far as I can.

OP2-44: Taking charge of it... do it my way... I'll know when it's too much. I am strong... can be a strong character... more so since I have got this.

OP2-113: No, I'm living with this cancer... I'm going to live as long as it lets me... live... and if you've got that in there (head)... you'll get... God willing... ten...twenty years...

OP2-143: You actually look at things now... more aware of colours... purple... more vivid... more intense... trees... robin... seagull... take note of everything that's about... same with people... appreciate it more... see more... do more... opens doors... I've not tried that before.

OP2-159: And I'll give it all I've got, and I'll keep giving it all I've got. I can't do anymore... when that time is right... But it's a long way down the road... I've got too much damage to do.

OP2-179: I am... and I continue... completely different turn around... like being reborn again... a second chance to be and do... as much as I can... to do as much as I can and make the most of what I've got now.

OP2-181: Half of the stuff I dreamed of doing... I'm doing now... taking me to places that I didn't think I could do... realising I can do... I'll go with the flow... push boundaries... see if I can... believe more in myself and I believe more that I can win... more I do... more I win.

OP2-183: I just take it a day... a day... going on holiday... plan the birthday party... put things in place... If there's not anything in place..., what am I going to do now? ... everyday...I get up every day... I'm fine today... good a new day.

OP2-204: All my hard work... my positive thinking... didn't always have it... paid off... It is working... if I keep that going... I should keep going.

OP2-210: If I don't do what I'm doing... is it going to start progressing? ... if I keep doing what I'm doing... it doesn't... there's a balance I've got to find... I'm alright the now... I have to be sensible...

OP2-216: It's what I want... I'll try if it's not life-threatening or it's going to injure or damage me in any way... don't smother me... I am capable... I'm here... can do it... know when to stop. Get up in the morning, "Right, what's on today?" We're doing... or chilling.

OP2-242: Tell her not to be stupid... don't broadcast it... you're alright... you're surviving... then you get sympathy... don't want sympathy... never wanted sympathy... don't treat me as a cancer victim... I'm still me... don't treat me as a cancer patient... when I go to the hospital that's what I am... when I leave that hospital... I leave it there... I'm me... cancer dealt with today.

OP3: (No data)

OP5-225: I feel now it's (living) achievable... two months ago... I gave up all hope of it... I said to you... "What's the point of me buying a... I'm not going to be here in three years' time... I feel now... nothing to stop me from being here in three years' time... That's the way it is now... I want to be here in three years' time... a big change... yeah.

OP5-235: I have achieved a lot... haven't I?... definitely... give myself a pat on the back... I really have done well... mentally and physically... both... not just the one... the drugs will control the pain... but it's up here... it's yourself... now I feel I'm in control up here now too... no fear up here anymore... no fear now... the cancer in the legs and that... I never think about it... I'm a happier person now... I really am... and I want to do things now that I didn't.

OP5-272: I never think of dying anymore... never crosses my mind... don't lie at night... is this my last night... don't think about arranging a funeral... never think... to what it was three years ago... I'm in a far better place than where I was... back then, I had no one to talk to...

this is the best place that I’ve been for a long, long time... I just hope to stay here... I know it’s got to come to an end at some point... maybe you can fight this forever... I’ll be running to the (hospital) every... month... gladly do that... as long as I’m here.

OP5-274: Life is changing for me... definitely feel I’m a happy chappy (fellow)... I definitely feel a lot better... doing a lot more... I feel more independent... my sister changes beds... does ironing... want all that stopped... I can do this myself... I’m in a good place just now.

In-patients

IP1: (No data)

IP2-25: Going to disregard (advice)... going to start dropping it (steroids) ... there’s not any more... quality of life... going to stay with the morphine... stay with the morphine.

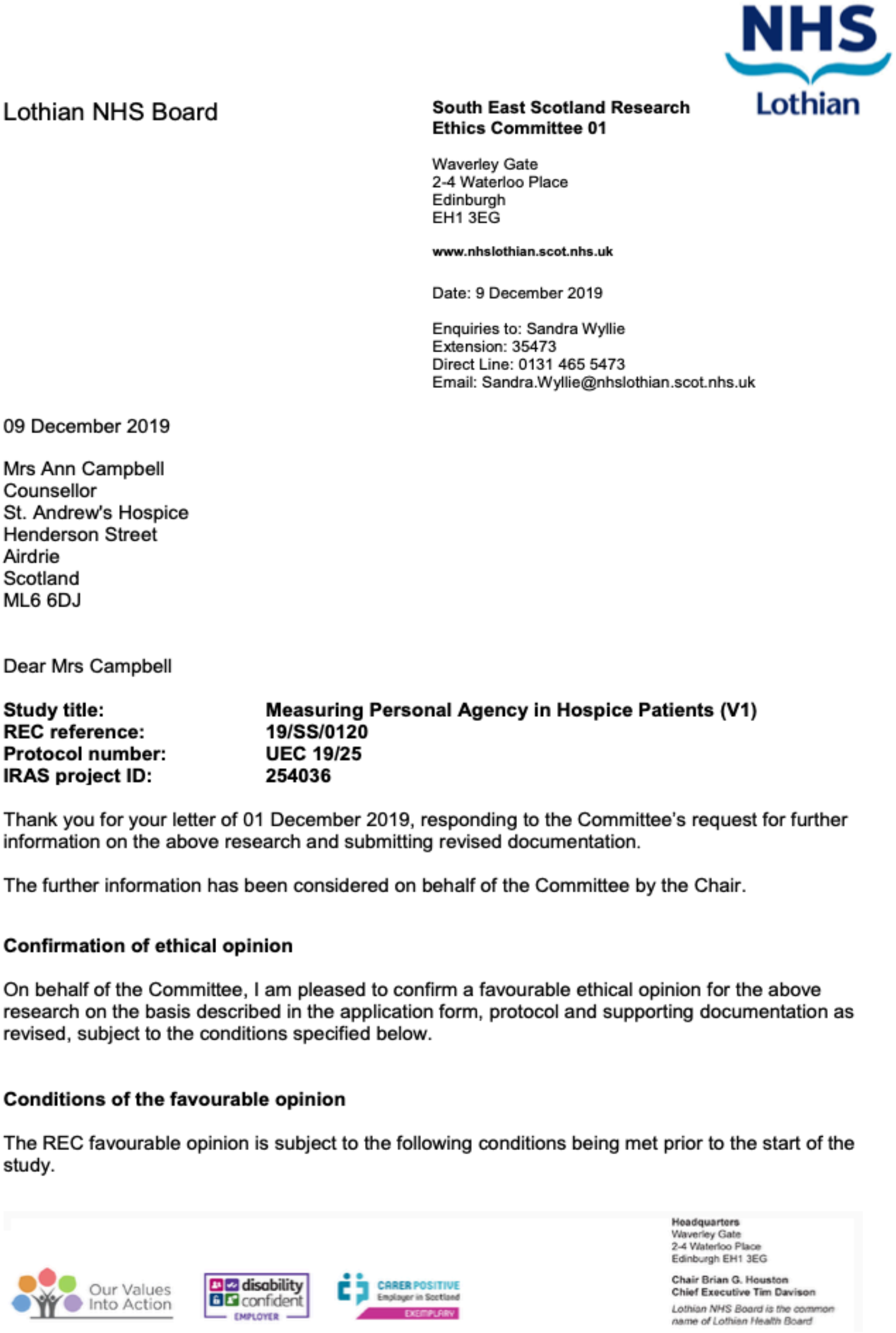
IP2-27: I’ve still got the use of my legs... I can go home... can move about... end my days with my family at home. End my days at home... rather than in here... that’s why I’m going home (chuckle).

IP2-45: ... to my own house... yeah... that’s good... family’s all sorted out... care package all sorted out. I’m going home to one of these beds... to lie as long as possible... move about... I can’t in here the same way.

IP3-99: There’s nothing nobody can do about it... nothing can change it... to be angry all the time... really silly... takes up so much energy... for me it’s best to accept what’s going on... try and muddle... through it...

IP4: (No data)

Appendix I: Ethical Approval of Research from NHS Ethics Committee for Study 2



NHS
Lothian

Lothian NHS Board

South East Scotland Research
Ethics Committee 01

Waverley Gate
2-4 Waterloo Place
Edinburgh
EH1 3EG

www.nhslothian.scot.nhs.uk

Date: 9 December 2019

Enquiries to: Sandra Wyllie
Extension: 35473
Direct Line: 0131 465 5473
Email: Sandra.Wyllie@nhslothian.scot.nhs.uk

09 December 2019

Mrs Ann Campbell
Counsellor
St. Andrew's Hospice
Henderson Street
Airdrie
Scotland
ML6 6DJ

Dear Mrs Campbell

Study title:	**Measuring Personal Agency in Hospice Patients (V1)**
REC reference:	**19/SS/0120**
Protocol number:	**UEC 19/25**
IRAS project ID:	**254036**

Thank you for your letter of 01 December 2019, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chair.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

Conditions of the favourable opinion

The REC favourable opinion is subject to the following conditions being met prior to the start of the study.

Confirmation of Capacity and Capability (in England, Northern Ireland and Wales) or NHS management permission (in Scotland) should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements. Each NHS organisation must confirm through the signing of agreements and/or other documents that it has given permission for the research to proceed (except where explicitly specified otherwise).

Guidance on applying for HRA and HCRW Approval (England and Wales)/ NHS permission for research is available in the Integrated Research Application System.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of management permissions from host organisations

Registration of Clinical Trials

It is a condition of the REC favourable opinion that **all clinical trials are registered** on a publicly accessible database. For this purpose, 'clinical trials' are defined as the first four project categories in IRAS project filter question 2. Registration is a legal requirement for clinical trials of investigational medicinal products (CTIMPs), except for phase I trials in healthy volunteers (these must still register as a condition of the REC favourable opinion).

Registration should take place as early as possible and within six weeks of recruiting the first research participant at the latest. Failure to register is a breach of these approval conditions, unless a deferral has been agreed by or on behalf of the Research Ethics Committee (see here for more information on requesting a deferral: https://www.hra.nhs.uk/planning-and-improving-research/research-planning/research-registration-research-project-identifiers/

As set out in the UK Policy Framework, research sponsors are responsible for making information about research publicly available before it starts e.g. by registering the research project on a publicly accessible register. Further guidance on registration is available at: https://www.hra.nhs.uk/planning-and-improving-research/research-planning/transparency-responsibilities/

You should notify the REC of the registration details. We will audit these as part of the annual progress reporting process.

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

After ethical review: Reporting requirements

The attached document "After ethical review – guidance for researchers" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study, including early termination of the study

- Final report

The latest guidance on these topics can be found at https://www.hra.nhs.uk/approvals-amendments/managing-your-approval/.

Ethical review of research sites

NHS/HSC sites

The favourable opinion applies to all NHS/HSC sites listed in the application subject to confirmation of Capacity and Capability (in England, Northern Ireland and Wales) or management permission (in Scotland) being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

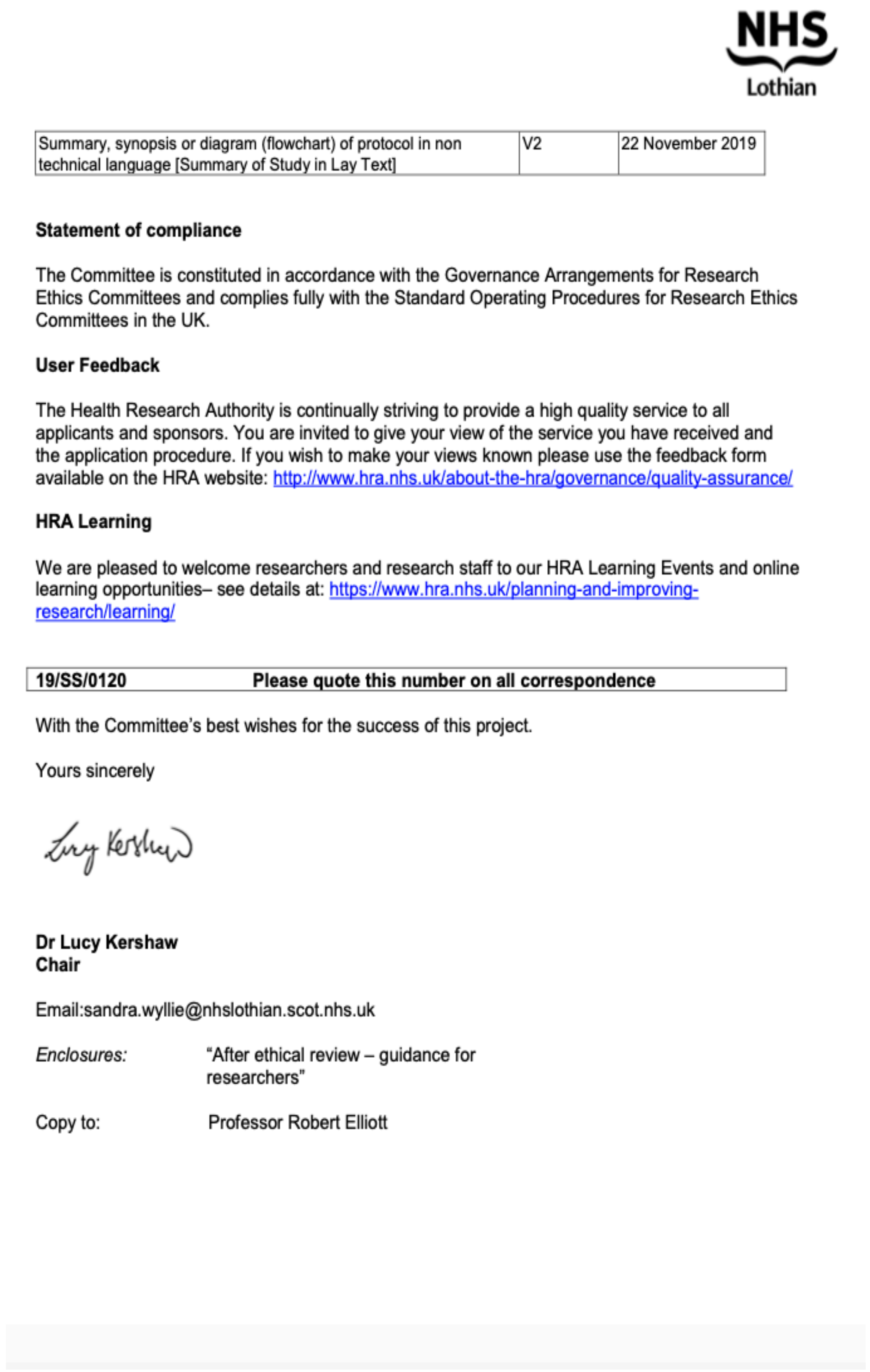
Non-NHS/HSC sites

I am pleased to confirm that the favourable opinion applies to any non-NHS/HSC sites listed in the application, subject to site management permission being obtained prior to the start of the study at the site.

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

Document	*Version*	*Date*
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [Uni of Strathclyde Professional Indemnity]	V1	01 August 2019
GP/consultant information sheets or letters [Letter to GP Phase 2]	V2	13 March 2019
IRAS Application Form [IRAS_Form_24102019]		24 October 2019
Letter from statistician [Statistician Report]	V1	03 December 2018
Letters of invitation to participant [Pilot Study Invitation]	V3	23 November 2019
Letters of invitation to participant [New Sample Invitation]	V3	23 November 1993
Non-validated questionnaire [Non-Validated Self Report Questionnaire]	V5.4	15 November 2019
Other [Appendix A Detailed Description of Method]	V2	22 February 2019
Other [Reference Letter from Supervisor]	V1	03 December 2018
Other [Employers' Liability Insurance]	V1	04 March 2019
Other [Towergate Professional Liability]	V1	19 September 2019
Other [Letter showing my responses to actions required by REC 01]		01 December 2019
Participant consent form [Consent Form Pilot]	V3	22 November 1987
Participant consent form [Consent Form New Sample]	V3	22 November 2019
Participant information sheet (PIS) [Pilot Study PIS S2]	V4	22 November 2019
Participant information sheet (PIS) [New Sample PIS S2]	V4	22 November 2019
Research protocol or project proposal [PhD Proposal Phase 2]	V2	19 December 2018
Summary CV for Chief Investigator (CI) [CV Ann Campbell CI]	V1	12 September 2019
Summary CV for supervisor (student research) [CV Prof Robert Elliott]	V1	03 December 2018



Summary, synopsis or diagram (flowchart) of protocol in non technical language [Summary of Study in Lay Text]	V2	22 November 2019

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

User Feedback

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website: http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance/

HRA Learning

We are pleased to welcome researchers and research staff to our HRA Learning Events and online learning opportunities– see details at: https://www.hra.nhs.uk/planning-and-improving-research/learning/

19/SS/0120	**Please quote this number on all correspondence**

With the Committee's best wishes for the success of this project.

Yours sincerely

Lucy Kershaw

Dr Lucy Kershaw
Chair

Email:sandra.wyllie@nhslothian.scot.nhs.uk

Enclosures: "After ethical review – guidance for researchers"

Copy to: Professor Robert Elliott

Appendix J: Participant Information Sheet: Out-patients, Pilot Study, Study 2

Participant Information Sheet
Approval: REC 19/SS/0120; UEC 19/25

Title of Study: Measuring Personal Agency in Hospice Patients. (V2)

Pilot Study: Day Hospice Patients

Chief Investigator: Ann Campbell, B.Sc. (Hons) Psych., M.Sc. Counselling, PG Dip. Counselling, MBACP (ann.campbell.100@strath.ac.uk)

Academic Supervisor: Professor Robert Elliott, Ph.D. (0141 548 3703; Robert.Elliott@ strath.ac.uk)

Invitation to take part

We'd like to invite you to take part in our research study. Joining the study is entirely up to you. Before you decide we would like you to understand why the research is being done and what it would involve for you. The Chief Investigator will go through this information sheet with you, to help you decide whether or not you would like to take part and answer any questions you may have. Please feel free to talk to others about the study if you wish.

What is the purpose of the study?

In this study we are trying to learn to measure how hospice patients feel they can help themselves in their everyday living through their own feelings, thoughts and actions. An earlier study was carried out at St. Andrew's Hospice. We found that when patients were able to influence their own feelings, thoughts and actions, they better dealt with their circumstances. For example, they were able to decide what was important for them and make choices. This allowed them to live the best they could, for as long as they could and in ways that felt right to them. Also, we want to test the usability of the self-report and observation measures that will be used in this study.

The study will take place in St. Andrew's Hospice and is sponsored by the University of Strathclyde. The direct care team from St. Andrew's Hospice will identify ten patients from Day Hospice. A letter of invitation and PIS will be given to patients at the same time by the care team.

We will work with you respectfully and ask you to fill out a self-report form with questions on it six times, either by yourself or with assistance of the researcher.

Each self-report will take about 10 minutes to fill out. On the same day, the researcher or a member of the direct care team will fill out a different form that will try to evaluate your sense of control, based on the same topic, by observing you. Each observation session will last 15 minutes. We will ask you to do this once a week when you attend. The study will take place in Day Hospice and last for 6 weeks.

We will ask for your permission to keep your self-report and observation forms for the purpose of this research. We will also ask you to give permission for publication/conference presenting of results.

Why have I been invited?

We are inviting you to take part in this study because you have been diagnosed with an illness that cannot be cured. This means that you live every day with an illness that is life limiting. The purpose of the study is to develop useful measures that can show how much hospice patients experience themselves as having a sense of influence over their feelings, thoughts and actions. We invite you to take part to help us to find out whether we can measure your experience of this ability and how we can improve how we do so.

Do I have to take part?

The answer is "No". Taking part is entirely up to you. Also, you are free to withdraw at any time during the study without giving a reason and without your care, or legal rights being affected.

What should I do if I am interested in taking part?

There will be a box entitled "Ann's Study" in Day Hospice. If you are interested in the study and want to be contacted to learn more about it, write your name on the invitation letter and place in the box. If you are not able to do this by yourself, you can ask a member of the direct care team to do this on your behalf. This will give permission for you to be contacted by the researcher for discussion of the study and taking consent.

What does taking part in the study involve?

- Having a face-to-face discussion with the researcher to go over the information about the study, including your involvement in it and giving your consent. We will welcome and answer any questions about the study so that you will feel adequately informed and able to decide whether or not you want to take part. Also, we welcome you to share the information given to you with others important to you (e.g. family, friends, GP). This meeting should last 15 minutes.

- We will check back with you one week later. We will ask if you understand the information. Also, we will answer any further questions you may have about the study. If you decide to take part, we will ask you to sign the Consent Form (Appendix III). This meeting should last 10 minutes. Taking part will be entirely up to you.

- You will be asked to fill out a simple self-report form at a total of six occasions, either by yourself or with assistance of the researcher, using pen and paper. Each self-report will take 10 minutes to fill out. On the same day, the researcher or member of the direct care team in Day Hospice will also fill out a different version of the form by observing you, using pen and paper. Each observation session will last 15 minutes. Both of the forms will be filled out in Day Hospice. We will ask you to do this once a week when you attend. It is important for you to know choosing to take part or not will in no way affect the care you receive.

- During the observation it is OK for you to talk with the observer but there is no requirement that you do so.

- At the end of each session, there will be time for debriefing when you will be given the opportunity to reflect on your experience of filling out the self-report form and being observed.

Are there any possible disadvantages or risks from taking part?

- The first main risk in this study is emotional distress from filling out the self-report form due to you facing the reality of your circumstances rather than avoiding them. If you feel that you might get too upset as a result of filling out the self-report form, then the researcher will encourage you to not take part in the study. If you agree to take part and find yourself more upset than you thought you would be, then you may be encouraged to stop taking part. The researcher will work with you, helping you to comfort yourself by pausing, relaxing and taking a breath. After filling out the self-report form, the researcher will discuss with you any concerns you may have about your illness or taking part. If, later, you experience any emotional distress, the direct care team will contact the researcher who will meet with you to provide the help needed. If the researcher is not available, the direct care team will ask another member of the counselling team to provide the necessary help. The direct care team will be on site to provide the necessary care that you may require. The researcher will support your withdrawal from the study, validating that the choice you have made is right for you.

- The second main risk associated with filling out a self-report form is feeling pressurized to take part. However, you are allowed to withdraw from the study at any time.

- A third risk of filling out self-report forms is that of fatigue due to illness. If you tell us that you are experiencing fatigue, then the giving of forms will be stopped and put off to another time, as appropriate. The direct care team will be on site if assistance is needed during the study.

- With respect to the observation form, we will be open about the observation, but you may experience a feeling of uneasiness/self-consciousness through being observed. However, you will be familiar with those collecting the data as it will be either the researcher who administered the self-report or a member of the direct care team from Day Hospice. You will be asked for verbal consent before starting each individual observation so that the observer will know whether or not that particular time is suitable and appropriate for you.

- We welcome questions and will be happy to address any concerns about the study at any time.

How will information about me be kept confidential?

- The original copy of your Consent Form will be placed in your medical records. A second copy will be given to yourself. A third copy, with your "Patient Identification Number", will be held in the academic supervisor's office in a locked filing cabinet, in a locked room in the University of Strathclyde, to which only the researcher and the academic supervisor will have access.

- Codes instead of names will be used to identify both your self-report and observation forms. The forms will be transported in a securely locked container from St. Andrew's Hospice and stored securely in a locked filling in the academic supervisor's locked room in the University of Strathclyde. Only the researcher and her academic supervisor will have access to your forms. They will be retained for the purpose of this research, publication and the writing of the academic thesis.

- Only the researcher and her academic supervisor will have access to your study data (self-report/observation forms and analysis. Your study data will be retained securely for 5 years to allow later checking of the forms while the study is still in progress. After 5 years data will be securely deleted.

- Responsible members of the University of Strathclyde or the NHS organization or other authorities may be given access to your data for monitoring and/or audit of the study to ensure that the research is complying with applicable regulations.

- In order to identify you, members of the direct care team St. Andrew's Hospice will have access to your medical records. Only members of the direct care team will have access to your medical records. The researcher and the academic supervisor will not have access.

- The researcher will request that you provide your demographic information: gender, age in years, occupation, ethnicity, status (single or otherwise), diagnosis and prognosis directly to her. Only the minimum amount of information required will be collected.

What are the possible benefits of taking part?

We do not know what the outcome of the study will be and this is why we are conducting the research. However:

- You will be given the time and opportunity to create space for self-reflection. Some previous participants have reported that this was useful for them.

- By taking part in the study, you may help others by contributing more knowledge and understanding about a life-limiting illness.

- During or at the end of the study you may discover that you may want to engage in counselling. You can discuss this with the researcher.

Will my General Practitioner/family doctor be informed of my taking part?
We will send a letter to your GP to let him or her know that you have agreed to take part in this study. We will respect your confidentiality.

What will happen if I don't want to carry on with the study?

- Your taking part in the study is entirely voluntary and you can change your mind at a later stage.

- Any decision you make to withdraw (or to decline to be involved in the first place) will not affect the care you receive from any relevant service.

- If you withdraw, all your identifiable personal information will be destroyed. Your data collected up to your withdrawal will be used for the purpose of research for which your consent has already been given.

What will happen to the results of this study?
This study is a part of PhD research. We will write up the results as a thesis and hopefully, present at conference, appear in peer reviewed scientific journals and make available through the University library system and the library within St. Andrew's Hospice. When publishing the results, we will anonymize all of your written data. We will also use pseudonyms to further lessen your identification.

You may want to know the results of the study in which you have taken part. If you request to know them. we will discuss this with you at the end of your participation. This will provide you with feedback on the research to which you have contributed. Emerging findings may also show relevance to future care. We will provide you with a link to a website from which you can get information about the study.

What happens if something goes wrong?
If you have a concern about any aspect of this study, you should ask to speak to the researcher who will do her best to answer your questions (Telephone 0141 548 4971) or Academic Supervisor (Telephone 0141 548 3703). If you remain unhappy and wish to complain formally, you can do this by contacting your local NHS Lanarkshire Complaints' Officer.
http://www.nhslanarkshire.org.uk/ContactUs/Pages/default.aspx.

Health Rights Information Scotland (HRIS) will provide you with accurate and up-to-date information about your health rights. http://www.hris.org.uk/patient-information/.

Independent Contact: Angelique Laverty, Secretary to the University Ethics Committee Research and Knowledge Exchange Services, University of Strathclyde, Graham Hills Building, 50 George Street, Glasgow, G1 1QE. (Tel 0141 548 3707)

Sponsor: The University of Strathclyde has appropriate insurance in place in the unlikely event that you suffer any harm as a direct consequence of your participation in this study.

Site of Research: St Andrew's Hospice, where the research will be conducted, is the employer of the researcher, and is covered by a Certificate of Employers' Liability Insurance.
Researcher: Is covered by a Personal Certificate of Professional Liability Insurance.

How have patients and the public been involved in this study?
The items used in both forms were derived from a previous patient interview study; thus, the previous participants contributed to the design of the research. In addition, participants who will take part in the pilot study will be involved by helping to revise both self-report and observational forms, to be used in the main part of this study. However, participants will not be involved in the management of the research.

Who has reviewed the study?
All research studies are looked at by an independent group of people, called a Research Ethics Committee, to protect your safety, rights, wellbeing and dignity. The South East Scotland Research Committee 01 has granted approval for this study.

Thank-you for considering taking part.

Appendix K: Invitation to Take Part in a Research Study: Out-patients, Pilot Study, Study 2

Pilot Study

Approval: REC 19/SS/0120; UEC 19/25

To revise both the Self-Report and Observation Questionnaires

Invitation to Day Hospice Patients to take part in this Study

Having a life-limiting illness can be scary and leave people feeling powerless and out of control. We would like to invite you to take part in a research study, in St. Andrew's Hospice, on coping with this sense of powerlessness. We are trying to understand more about hospice patients' sense of personal control, that is, the sense you have of yourself as having control over your thoughts and actions so that they can help you in your everyday living with a life-limiting illness. In an earlier study, also carried out at St. Andrew's Hospice, we found that having this control helped patients to better deal with their circumstances so that they were able to decide what was important for them and make changes that helped them to live to the best of their ability and for as long as they could in the ways that felt right to them.

This study, called "Measuring Personal Agency in Hospice Patients", seeks to build on the earlier research. This study has been developed in collaboration between St. Andrew's Hospice and the University of Strathclyde and will be carried out by Ann Campbell (a counsellor at St. Andrew's and a PhD student at University of Strathclyde) and with assistance from members of the direct care team of St. Andrew's. The study will be supervised by Professor Robert Elliott of University of Strathclyde and monitored by Bruce High, Chief Executive Officer/Clinical Governance at St. Andrew's Hospice.

Opting-in to the study will be entirely your decision. The researcher, Ann, will ask you to fill out a simple self-report form each form taking 10 minutes to fill out. On the same day, you will be asked to be observed by the researcher or member of the direct care team in Day Hospice, with each observation lasting 15 minutes. We will ask you to do this, 6 times over 6 weeks. If you choose to take part, you will have the right to withdraw from the study at any point and without any part of your care being affected.

The direct care team will supply a PIS Form along with this Letter of Invitation. There will be a box entitled "Ann's Study" in Day Hospice. If you are interested in the study and want to be contacted to learn more about it, write your name below and place the letter of invitation in the box. If you are not able to do this by yourself, you can ask a member of the direct care team to do this on your behalf. This will give permission for you to be contacted by the researcher for discussion of the study and taking consent. If I don't hear from you I will not contact you.

The direct care team of St. Andrew's Hospice will identify you and Ann will meet with you to explain, clearly, the purpose of the study and what you would be asked to do. Ann will be very happy to answer any questions or concerns you may have about the study.

Appendix L: Consent Form: Out-patients, Pilot Study, Study 2

CONSENT FORM

Approval: REC 19/SS/0120; UEC 19/25

Patient's Identification Number for this study: ☐

Title of Study: Measuring Personal Agency in Hospice Patients (V2)

Pilot Study: Day Hospice Patients

Name of Chief Investigator: Ann Campbell

If you agree, please initial box

1. I confirm that I have read and understand the Participant Information Sheet (Appendix II, V4, 22/11/2019) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐

2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care, access to counselling or legal rights being affected. ☐

3. I understand that only the direct care team will have access to my medical notes. I give permission for the Chief Investigator to request relevant demographic information directly from me. Only the minimum amount of information required will be collected and shared with the Chief Investigator and her Academic Supervisor at the University of Strathclyde. ☐

4. I understand that this study may be externally monitored by individuals (not the researchers) from the Sponsor (University of Strathclyde) or from the NHS organisation or other authorities. This might involve looking at relevant sections of my medical notes and data collected during the study, to make sure that the study is being conducted properly and that my rights are being protected. I give permission for these individuals to have access to my records. ☐

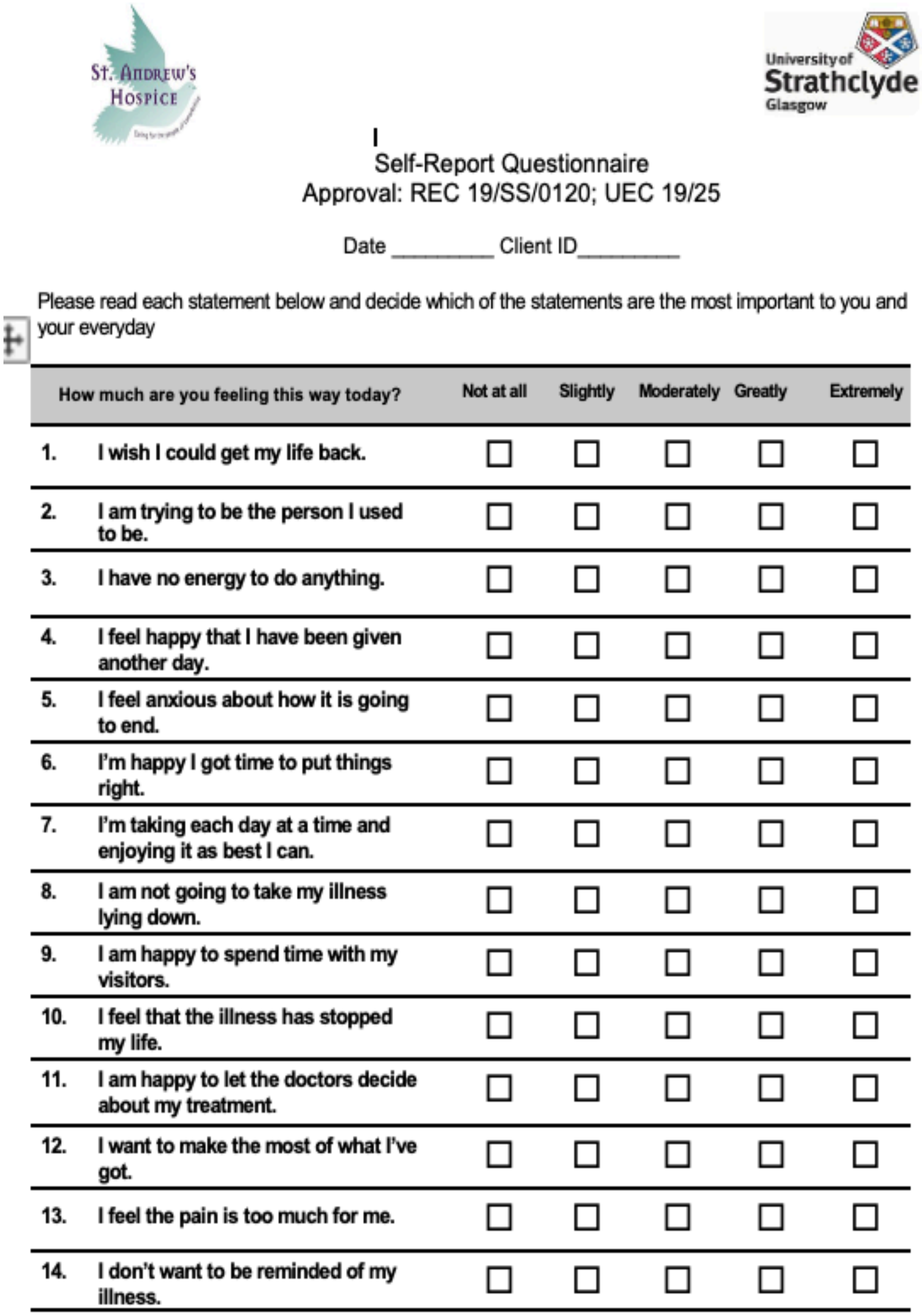
5. I understand that the Chief Investigator and the Academic Supervisor at the University of Strathclyde may use relevant data collected during the study. ☐

6. I agree to my GP being informed of my participation in the study while I am a patient at St. Andrew's Hospice. ☐

7. I agree to take part in the above study. ☐

Name of Participant	Date	Signature
Chief Investigator	Date	Signature

Appendix M: Self-Report Questionnaire 53-Item, Pilot Study, Study 2



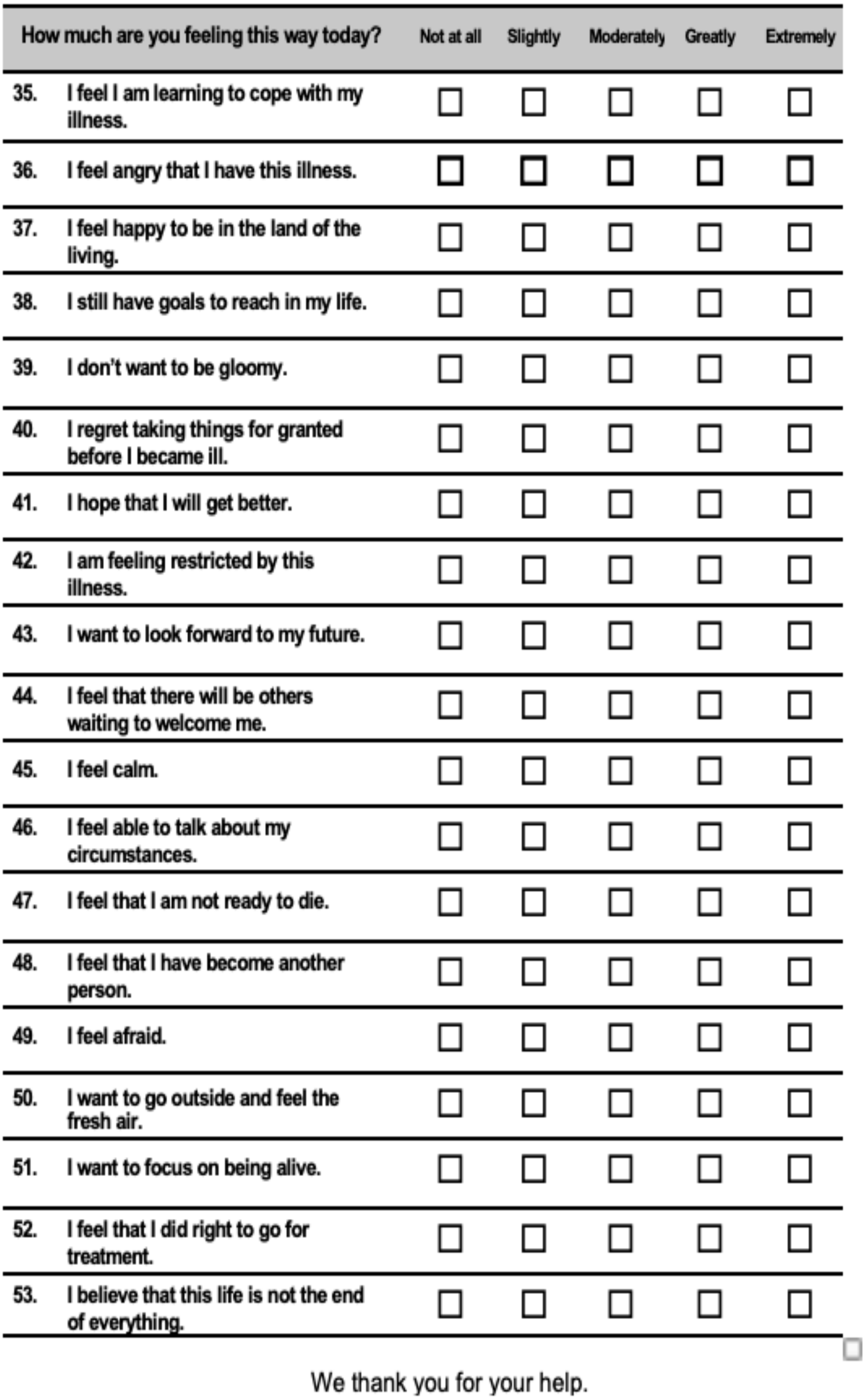
Self-Report Questionnaire
Approval: REC 19/SS/0120; UEC 19/25

Date _________ Client ID_________

Please read each statement below and decide which of the statements are the most important to you and your everyday

	How much are you feeling this way today?	Not at all	Slightly	Moderately	Greatly	Extremely
1.	I wish I could get my life back.	☐	☐	☐	☐	☐
2.	I am trying to be the person I used to be.	☐	☐	☐	☐	☐
3.	I have no energy to do anything.	☐	☐	☐	☐	☐
4.	I feel happy that I have been given another day.	☐	☐	☐	☐	☐
5.	I feel anxious about how it is going to end.	☐	☐	☐	☐	☐
6.	I'm happy I got time to put things right.	☐	☐	☐	☐	☐
7.	I'm taking each day at a time and enjoying it as best I can.	☐	☐	☐	☐	☐
8.	I am not going to take my illness lying down.	☐	☐	☐	☐	☐
9.	I am happy to spend time with my visitors.	☐	☐	☐	☐	☐
10.	I feel that the illness has stopped my life.	☐	☐	☐	☐	☐
11.	I am happy to let the doctors decide about my treatment.	☐	☐	☐	☐	☐
12.	I want to make the most of what I've got.	☐	☐	☐	☐	☐
13.	I feel the pain is too much for me.	☐	☐	☐	☐	☐
14.	I don't want to be reminded of my illness.	☐	☐	☐	☐	☐

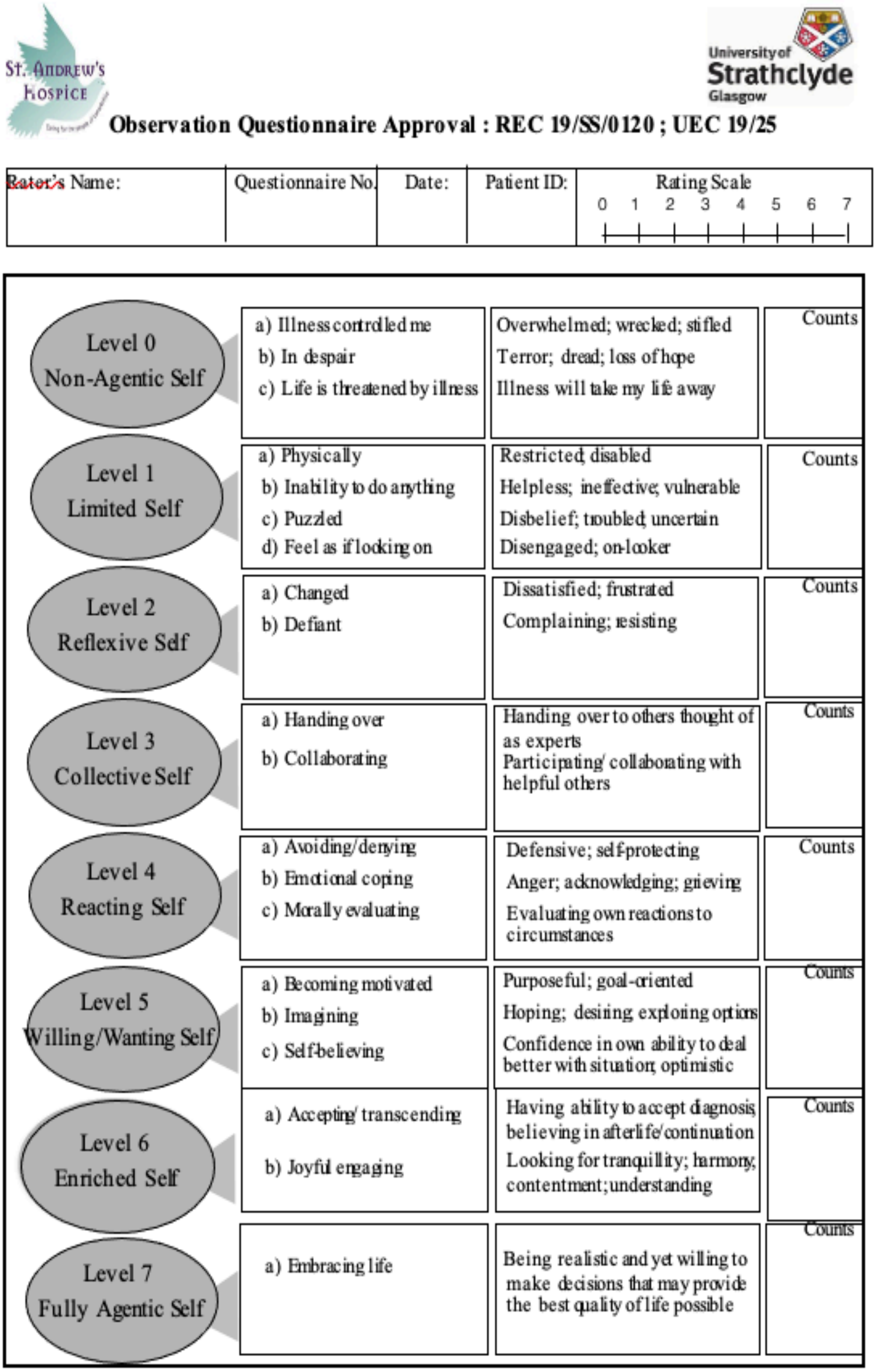
How much are you feeling this way today?		Not at all	Slightly	Moderately	Greatly	Extremely
15.	I feel that I am not in control of my life.	☐	☐	☐	☐	☐
16.	I don't want to be a hospice patient.	☐	☐	☐	☐	☐
17.	I wish I could walk again.	☐	☐	☐	☐	☐
18.	I feel that my fighting spirit is coming back.	☐	☐	☐	☐	☐
19.	I am feeling totally devastated.	☐	☐	☐	☐	☐
20.	I find it hard to believe what the doctors told me.	☐	☐	☐	☐	☐
21.	I have lost a sense of who I am.	☐	☐	☐	☐	☐
22.	I am not going down without a fight.	☐	☐	☐	☐	☐
23.	I feel happy to enjoy the birds and trees.	☐	☐	☐	☐	☐
24.	I want to be normal again.	☐	☐	☐	☐	☐
25.	I am able to ask questions about my treatment.	☐	☐	☐	☐	☐
26.	I can't do anything.	☐	☐	☐	☐	☐
27.	Talking to people is too much for me.	☐	☐	☐	☐	☐
28.	I feel I have a lot more to do with my life.	☐	☐	☐	☐	☐
29.	I find it difficult to understand what's happening to me.	☐	☐	☐	☐	☐
30.	I am aware that I am pushing people away.	☐	☐	☐	☐	☐
31.	I feel like crying.	☐	☐	☐	☐	☐
32.	I feel happy that they are going to give me all the treatments.	☐	☐	☐	☐	☐
33.	I'm trying not to concentrate on my illness.	☐	☐	☐	☐	☐
34.	I long to do the things I used to do.	☐	☐	☐	☐	☐



How much are you feeling this way today?		Not at all	Slightly	Moderately	Greatly	Extremely
35.	I feel I am learning to cope with my illness.	☐	☐	☐	☐	☐
36.	I feel angry that I have this illness.	☐	☐	☐	☐	☐
37.	I feel happy to be in the land of the living.	☐	☐	☐	☐	☐
38.	I still have goals to reach in my life.	☐	☐	☐	☐	☐
39.	I don't want to be gloomy.	☐	☐	☐	☐	☐
40.	I regret taking things for granted before I became ill.	☐	☐	☐	☐	☐
41.	I hope that I will get better.	☐	☐	☐	☐	☐
42.	I am feeling restricted by this illness.	☐	☐	☐	☐	☐
43.	I want to look forward to my future.	☐	☐	☐	☐	☐
44.	I feel that there will be others waiting to welcome me.	☐	☐	☐	☐	☐
45.	I feel calm.	☐	☐	☐	☐	☐
46.	I feel able to talk about my circumstances.	☐	☐	☐	☐	☐
47.	I feel that I am not ready to die.	☐	☐	☐	☐	☐
48.	I feel that I have become another person.	☐	☐	☐	☐	☐
49.	I feel afraid.	☐	☐	☐	☐	☐
50.	I want to go outside and feel the fresh air.	☐	☐	☐	☐	☐
51.	I want to focus on being alive.	☐	☐	☐	☐	☐
52.	I feel that I did right to go for treatment.	☐	☐	☐	☐	☐
53.	I believe that this life is not the end of everything.	☐	☐	☐	☐	☐

We thank you for your help.

Appendix N: Observation Measure, Pilot Study, Study 2

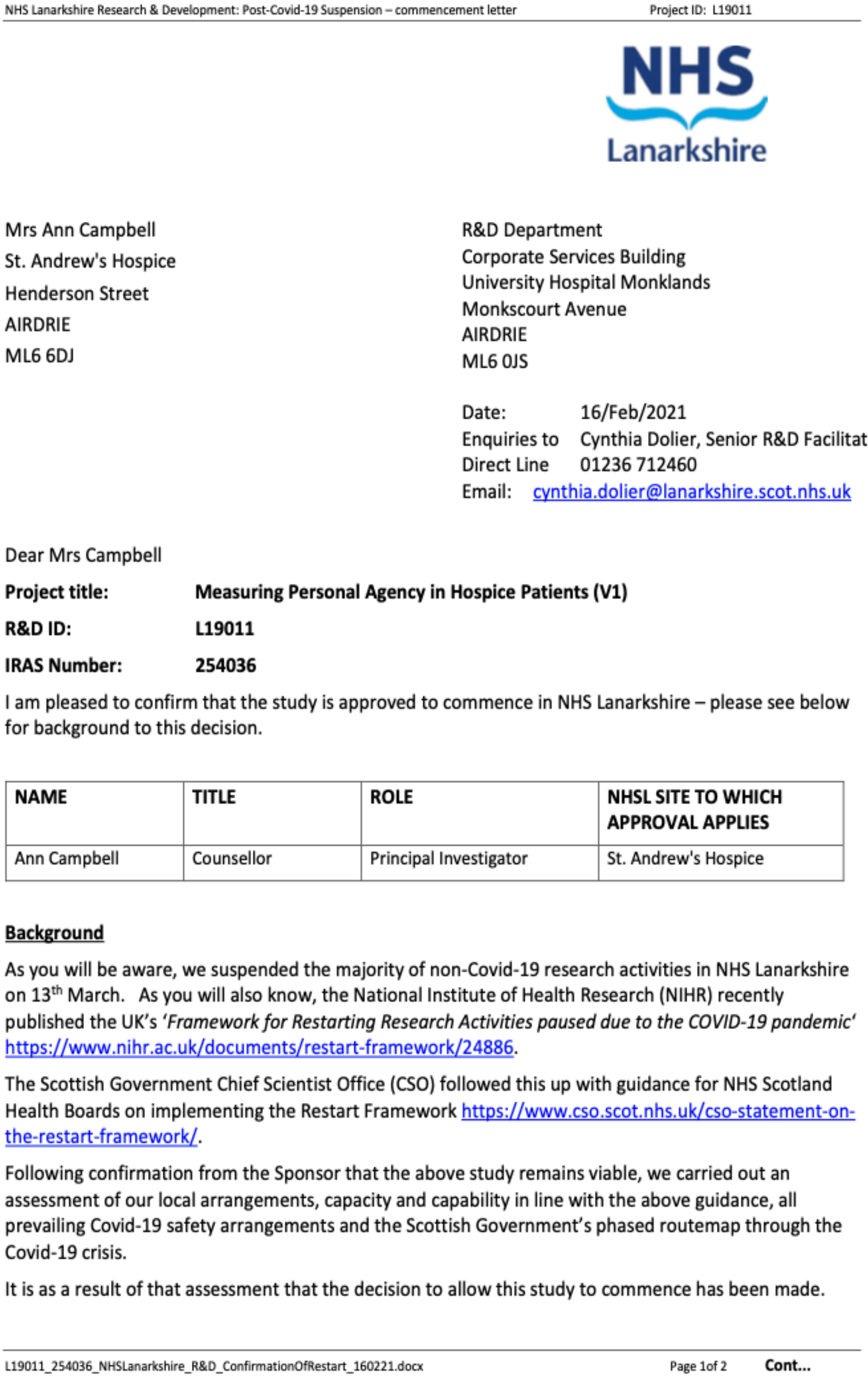


Observation Questionnaire Approval : REC 19/SS/0120 ; UEC 19/25

Rater's Name:	Questionnaire No.	Date:	Patient ID:	Rating Scale 0 1 2 3 4 5 6 7

Level 0 Non-Agentic Self	a) Illness controlled me b) In despair c) Life is threatened by illness	Overwhelmed; wrecked; stifled Terror; dread; loss of hope Illness will take my life away	Counts
Level 1 Limited Self	a) Physically b) Inability to do anything c) Puzzled d) Feel as if looking on	Restricted; disabled Helpless; ineffective; vulnerable Disbelief; troubled; uncertain Disengaged; on-looker	Counts
Level 2 Reflexive Self	a) Changed b) Defiant	Dissatisfied; frustrated Complaining; resisting	Counts
Level 3 Collective Self	a) Handing over b) Collaborating	Handing over to others thought of as experts Participating/ collaborating with helpful others	Counts
Level 4 Reacting Self	a) Avoiding/denying b) Emotional coping c) Morally evaluating	Defensive; self-protecting Anger; acknowledging; grieving Evaluating own reactions to circumstances	Counts
Level 5 Willing/Wanting Self	a) Becoming motivated b) Imagining c) Self-believing	Purposeful; goal-oriented Hoping; desiring; exploring options Confidence in own ability to deal better with situation; optimistic	Counts
Level 6 Enriched Self	a) Accepting/ transcending b) Joyful engaging	Having ability to accept diagnosis; believing in afterlife/continuation Looking for tranquillity; harmony; contentment; understanding	Counts
Level 7 Fully Agentic Self	a) Embracing life	Being realistic and yet willing to make decisions that may provide the best quality of life possible	Counts

Appendix O: Ethical Approval of Research from NHS Research Ethics Committee Letter for Re-start of Research after COVID-19



NHS Lanarkshire Research & Development: Post-Covid-19 Suspension – commencement letter Project ID: L19011

NHS
Lanarkshire

Mrs Ann Campbell
St. Andrew's Hospice
Henderson Street
AIRDRIE
ML6 6DJ

R&D Department
Corporate Services Building
University Hospital Monklands
Monkscourt Avenue
AIRDRIE
ML6 0JS

Date: 16/Feb/2021
Enquiries to Cynthia Dolier, Senior R&D Facilitator
Direct Line 01236 712460
Email: cynthia.dolier@lanarkshire.scot.nhs.uk

Dear Mrs Campbell

Project title: **Measuring Personal Agency in Hospice Patients (V1)**

R&D ID: **L19011**

IRAS Number: **254036**

I am pleased to confirm that the study is approved to commence in NHS Lanarkshire – please see below for background to this decision.

NAME	TITLE	ROLE	NHSL SITE TO WHICH APPROVAL APPLIES
Ann Campbell	Counsellor	Principal Investigator	St. Andrew's Hospice

Background

As you will be aware, we suspended the majority of non-Covid-19 research activities in NHS Lanarkshire on 13th March. As you will also know, the National Institute of Health Research (NIHR) recently published the UK's '*Framework for Restarting Research Activities paused due to the COVID-19 pandemic*' https://www.nihr.ac.uk/documents/restart-framework/24886.

The Scottish Government Chief Scientist Office (CSO) followed this up with guidance for NHS Scotland Health Boards on implementing the Restart Framework https://www.cso.scot.nhs.uk/cso-statement-on-the-restart-framework/.

Following confirmation from the Sponsor that the above study remains viable, we carried out an assessment of our local arrangements, capacity and capability in line with the above guidance, all prevailing Covid-19 safety arrangements and the Scottish Government's phased routemap through the Covid-19 crisis.

It is as a result of that assessment that the decision to allow this study to commence has been made.

L19011_254036_NHSLanarkshire_R&D_ConfirmationOfRestart_160221.docx Page 1of 2 **Cont...**

The conditions outlined in your original approval letter continue to apply.

Finally, while the Coronavirus remains in the UK, I am sure you will appreciate that this decision may be reviewed should the prevailing circumstances change.

Yours sincerely,

Raymond

Raymond Hamill
Senior R&D Manager

cc.

NAME	TITLE	CONTACT ADDRESS	ROLE
Professor Robert Elliott	Professor of Counselling	Robert.Elliott@strath.ac.uk	Sponsor Contact
Mrs Louise McKean	Legal Counsel	ethics@strath.ac.uk	Sponsor Contact

Appendix P: Participant Information Sheet: Pilot Study, COVID-19, Study 2

Participant Information Sheet
Approval: REC 19/SS/0120; UEC 19/25

Title of Study: Measuring Personal Agency in Hospice Patients. (V2)

Pilot Study: Day Hospice Patients

Chief Investigator: Ann Campbell, B.Sc. (Hons) Psych., M.Sc. Counselling, PG Dip. Counselling, MBACP (ann.campbell.100@strath.ac.uk)

Academic Supervisor: Professor Robert Elliott, Ph.D. (0141 548 3703; Robert.Elliott@ strath.ac.uk)

Invitation to take part
We'd like to invite you to take part in our research study. Joining the study is entirely up to you. Before you decide we would like you to understand why the research is being done and what it would involve for you. The Chief Investigator will go through this information sheet with you, to help you decide whether or not you would like to take part and answer any questions you may have. Please feel free to talk to others about the study if you wish.

What is the purpose of the study?
In this study we are trying to learn to measure how hospice patients feel they can help themselves in their everyday living through their own feelings, thoughts and actions. An earlier study was carried out at St. Andrew's Hospice. We found that when patients were able to influence their own feelings, thoughts and actions, they better dealt with their circumstances. For example, they were able to decide what was important for them and make choices. This allowed them to live the best they could, for as long as they could and in ways that felt right to them. Also, we want to test the usability of the self-report and observation measures that will be used in this study.

The study will take place by way of screen or telephone from St. Andrew's Hospice and you can choose which is best-suited to you. The study is sponsored by the University of Strathclyde. The direct care team from St. Andrew's Hospice will identify ten patients from Out Patients. A letter of invitation and PIS will be given to patients at the same time by the care team.

We will work with you respectfully and ask you to fill out a self-report form with questions on it six times, either by yourself or with assistance of the researcher.

Each self-report will take about 10 minutes to fill out. On the same day, or on a day that you take part in an Out Patients' activity, the researcher or a member of the direct care team will fill out a different form that will try to evaluate your sense of control, based on the same topic, by observing you. Each observation session will last 15 minutes. We will ask you to do this once a week when you attend an activity by Near Me/Zoom. The researchers will be in (Day Hospice) Out-patients and the study will last for 6 weeks.

We will ask for your permission to keep your self-report and observation forms for the purpose of this research. We will also ask you to give permission for publication/conference presenting of results.

Why have I been invited?

We are inviting you to take part in this study because you have been diagnosed with an illness that cannot be cured. This means that you live every day with an illness that is life limiting. The purpose of the study is to develop useful measures that can show how much hospice patients experience themselves as having a sense of influence over their feelings, thoughts and actions. We invite you to take part to help us to find out whether we can measure your experience of this ability and how we can improve how we do so.

Do I have to take part?

The answer is "No". Taking part is entirely up to you. Also, you are free to withdraw at any time during the study without giving a reason and without your care, or legal rights being affected.

What should I do if I am interested in taking part?

There will be a box entitled "Ann's Study" in Out Patients. If you are interested in the study and want to be contacted to learn more about it, write your name on the invitation letter and place in the box. If you are not able to do this by yourself, you can ask a member of the direct care team to do this on your behalf. This will give permission for you to be contacted by the researcher for discussion of the study and taking consent.

What does taking part in the study involve?

- Having a discussion, either by video screen or telephone, with the researcher to go over the information about the study, including your involvement in it and giving your consent. We will welcome and answer any questions about the study so that you will feel adequately informed and able to decide whether or not you want to take part. Also, we welcome you to share the information given to you with others important to you (e.g. family, friends, GP). This meeting should last 15 minutes.

- We will check back with you one week later. We will ask if you understand the information. Also, we will answer any further questions you may have about the study. If you decide to take part, we will ask you to sign the Consent Form (Appendix III). If you are unable to sign the Consent Form in person or digitally, you can give your consent for a member of the research team to contact you to confirm your intent to sign the Form. This meeting should last 10 minutes. Taking part will be entirely up to you.

- You will be asked to fill out a simple self-report form at a total of six occasions, either by yourself or with assistance of the researcher, using pen and paper. Each self-report will take 10 minutes to fill out. On the same day or on the day you take part in an out-patients' activity, the researcher or member of the direct care team in Out Patients' will also fill out a different version of the form by observing you, using pen and paper. Each observation session will last 15 minutes. Both of the forms will be filled out in Out Patients. We will ask you to do this once a week when you are taking part in an activity. It is important for you to know choosing to take part or not will in no way affect the care you receive.

- During the observation it is OK for you to talk with the observer but there is no requirement that you do so.

- At the end of each session, there will be time for debriefing when you will be given the opportunity to reflect on your experience of filling out the self-report form and being observed.

Are there any possible disadvantages or risks from taking part?

- The first main risk in this study is emotional distress from filling out the self-report form due to you facing the reality of your circumstances rather than avoiding them. If you feel that you might get too upset as a result of filling out the self-report form, then the researcher will encourage you to not take part in the study. If you agree to take part and find yourself more upset than you thought you would be, then you may be encouraged to stop taking part. The researcher will work with you, helping you to comfort yourself by pausing, relaxing and taking a breath. After filling out the self-report form, the researcher will discuss with you any concerns you may have about your illness or taking part. If, later, you experience any emotional distress, the direct care team will contact the researcher who will contact you to provide the help needed. If the researcher is not available, the direct care team will ask another member of the counselling team to provide the necessary help. Members of the direct care team will be on site to provide the necessary care that you may require. The researcher will support your withdrawal from the study, validating that the choice you have made is right for you.

- The second main risk associated with filling out a self-report form is feeling pressurized to take part. However, you are allowed to withdraw from the study at any time.

- A third risk of filling out self-report forms is that of fatigue due to illness. If you tell us that you are experiencing fatigue, then the giving of forms will be stopped and put off to another time, as appropriate. Members of the direct care team will be on site during the study.

- With respect to the observation form, we will be open about the observation, but you may experience a feeling of uneasiness/self-consciousness through being observed. However, you will be familiar with those collecting the data as it will be either the researcher who administered the self-report or a member of the direct care team from Out Patients. You will be asked for verbal consent before starting each individual observation so that the observer will know whether or not that particular time is suitable and appropriate for you.

- We welcome questions and will be happy to address any concerns about the study at any time.

How will information about me be kept confidential?

- The original copy of your Consent Form will be placed in your medical records. A second copy will be given to yourself. A third copy, with your “Patient Identification Number”, will be stored within the secure cloud storage system, in the University of Strathclyde.

- Codes instead of names will be used to identify both your self-report and observation forms. The forms will be stored within the secure cloud storage system, in the University of Strathclyde. Only the researcher and her academic supervisor will have access to your forms. They will be retained for the purpose of this research, publication and the writing of the academic thesis.

- Only the researcher and her academic supervisor will have access to your study data (self-report/observation forms and analysis. Your study data will be retained securely for 5 years to allow later checking of the forms while the study is still in progress. After 5 years data will be securely deleted.

- Responsible members of the University of Strathclyde or the NHS organization or other authorities may be given access to your data for monitoring and/or audit of the study to ensure that the research is complying with applicable regulations.

- In order to identify you, members of the direct care team St. Andrew’s Hospice will have access to your medical records. Only members of the direct care team will have access to your medical records. The researcher and the academic supervisor will not have access.

- The researcher will request that you provide your demographic information: gender, age in years, occupation, ethnicity, status (single or otherwise), diagnosis and prognosis directly to her. Only the minimum amount of information required will be collected.

What are the possible benefits of taking part?

We do not know what the outcome of the study will be and this is why we are conducting the research. However:

- You will be given the time and opportunity to create space for self-reflection.

Some previous participants have reported that this was useful for them.

- By taking part in the study, you may help others by contributing more knowledge and understanding about a life-limiting illness.

- During or at the end of the study you may discover that you may want to engage in counselling. You can discuss this with the researcher.

Will my General Practitioner/family doctor be informed of my taking part?

We will send a letter to your GP to let him or her know that you have agreed to take part in this study. We will respect your confidentiality.

What will happen if I don't want to carry on with the study?

- Your taking part in the study is entirely voluntary and you can change your mind at a later stage.

- Any decision you make to withdraw (or to decline to be involved in the first place) will not affect the care you receive from any relevant service.

- If you withdraw, all your identifiable personal information will be destroyed. Your data collected up to your withdrawal will be used for the purpose of research for which your consent has already been given.

What will happen to the results of this study?

This study is a part of PhD research. We will write up the results as a thesis and hopefully, present at conference, appear in peer reviewed scientific journals and make available through the University library system and the library within St. Andrew's Hospice. When publishing the results, we will anonymize all of your written data. We will also use pseudonyms to further lessen your identification.

You may want to know the results of the study in which you have taken part. If you request to know them. we will discuss this with you at the end of your participation. This will provide you with feedback on the research to which you have contributed. Emerging findings may also show relevance to future care. We will provide you with a link to a website from which you can get information about the study.

What happens if something goes wrong?

If you have a concern about any aspect of this study, you should ask to speak to the researcher who will do her best to answer your questions (Telephone 0141 548 4971) or Academic Supervisor (Telephone 0141 548 3703). If you remain unhappy and wish to complain formally, you can do this by contacting your local NHS Lanarkshire Complaints' Officer.
http://www.nhslanarkshire.org.uk/ContactUs/Pages/default.aspx.
Health Rights Information Scotland (HRIS) will provide you with accurate and up-to-date information about your health rights. http://www.hris.org.uk/patient-information/.

Independent Contact: Angelique Laverty, Secretary to the University Ethics Committee Research and Knowledge Exchange Services, University of Strathclyde, Graham Hills Building, 50 George Street, Glasgow, G1 1QE. (Tel 0141 548 3707)
Sponsor: The University of Strathclyde has appropriate insurance in place in the unlikely event that you suffer any harm as a direct consequence of your participation in this study.
Site of Research: St Andrew's Hospice, where the research will be conducted, is the employer of the researcher, and is covered by a Certificate of Employers' Liability Insurance.
Researcher: Is covered by a Personal Certificate of Professional Liability Insurance.

How have patients and the public been involved in this study?
The items used in both forms were derived from a previous patient interview study; thus, the previous participants contributed to the design of the research. In addition, participants who will take part in the pilot study will be involved by helping to revise both self-report and observational forms, to be used in the main part of this study. However, participants will not be involved in the management of the research.

Who has reviewed the study?
All research studies are looked at by an independent group of people, called a Research Ethics Committee, to protect your safety, rights, wellbeing and dignity. The South East Scotland Research Committee 01 has granted approval for this study.

Thank-you for considering taking part.

Appendix Q: Consent Form: Pilot Study, COVID-19, Study 2

St. Andrew's Hospice

University of Strathclyde Glasgow

CONSENT FORM
Approval: REC 19/SS/0120; UEC 19/25

Patient's Identification Number for this study: ☐

Title of Study: Measuring Personal Agency in Hospice Patients (V2)

Pilot Study: Day Hospice Patients

Name of Chief Investigator: Ann Campbell

If you agree, please initial box

1. I confirm that I have read and understand the Participant Information Sheet (Appendix II, V4, 22/11/2019) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐

2 I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care, access to counselling or legal rights being affected. ☐

3. I understand that only the direct care team will have access to my medical notes. I give permission for the Chief Investigator to request relevant demographic information directly from me. Only the minimum amount of information required will be collected and shared with the Chief Investigator and her Academic Supervisor at the University of Strathclyde. ☐

4. I understand that this study may be externally monitored by individuals (not the researchers) from the Sponsor (University of Strathclyde) or from the NHS organisation or other authorities. This might involve looking at relevant sections of my medical notes and data collected during the study, to make sure that the study is being conducted properly and that my rights are being protected. I give permission for these individuals to have access to my records. ☐

5. I understand that the Chief Investigator and the Academic Supervisor at the University of Strathclyde may use relevant data collected during the study. ☐

6. I agree to my GP being informed of my participation in the study while I am a patient at St. Andrew's Hospice. ☐

7. I agree to take part in the above study. ☐

8. In the case that I am unable to sign this Consent Form in person or digitally, I give my consent for a member of the research team to contact me to confirm my intent to sign this Form. ☐

Name of Participant	Date	Signature
Name of Confirmer	Date	Signature
Chief Investigator	Date	Signature

Reason for Confirmation: Confirming your intent to sign this Form is important as it means that you are validating your decision to take part in the study and that the choice you have made is right for you. Taking part is entirely up to you and you have the right to withdraw at any point during the study.

Appendix R: Participant Information Sheet: Out-patients and In-patients, Main Study, Study 2

Participant Information Sheet
Approval: REC 19/SS/0120; UEC 19/25

Title of Study: Measuring Personal Agency in Hospice Patients. (V2)

New Sample Test Study: Day Hospice Patients and In-Patients

Chief Investigator: Ann Campbell, B.Sc. (Hons) Psych., M.Sc. Counselling, PG Dip. Counselling, MBACP (ann.campbell.100@strath.ac.uk)

Academic Supervisor: Professor Robert Elliott, Ph.D. (0141 548 3703; Robert.Elliott@ strath.ac.uk)

Invitation to take part

We'd like to invite you to take part in our research study. Joining the study is entirely up to you. Before you decide we would like you to understand why the research is being done and what it would involve for you. The Chief Investigator will go through this information sheet with you, to help you decide whether or not you would like to take part and answer any questions you may have. Please feel free to talk to others about the study if you wish.

What is the purpose of the study?

In this study we are trying to learn to measure how hospice patients feel they can help themselves in their everyday living through their own feelings, thoughts and actions. An earlier study was carried out at St. Andrew's Hospice. We found that when patients were able to influence their own feelings, thoughts and actions, they better dealt with their circumstances. For example, they were able to decide what was important for them and make choices. This allowed them to live the best they could, for as long as they could and in ways that felt right to them. Also, we want to test the usability of the self-report and observation measures that will be used in this study.

The study will take place in St. Andrew's Hospice and is sponsored by the University of Strathclyde. The direct care team from St. Andrew's Hospice will identify twenty patients from Day Hospice and twenty from the In-Unit. A letter of invitation and PIS will be given to patients at the same time by the care team.

We will work with you respectfully and ask you to fill out a self-report form with questions on it six times, either by yourself or with assistance of the researcher.

Each self-report will take about 10 minutes to fill out. On the same day, the researcher or a member of the direct care team will fill out a different form that will try to evaluate your sense of control, based on the same topic, by observing you. Each observation session will last 12 minutes. If you are a day hospice patient, we will ask you to do this once a week for 6 weeks and on the day you attend. The study will last for 6 weeks. If you are an in-patient, we will ask you to do this 6 times over a period of 1 to 2 weeks.

We will ask for your permission to keep your self-report and observation forms for the purpose of this research. We will also ask you to give permission for publication/conference presenting of results.

Why have I been invited?

We are inviting you to take part in this study because you have been diagnosed with an illness that cannot be cured. This means that you live every day with an illness that is life limiting. The purpose of the study is to develop useful measures that can show how much hospice patients experience themselves as having a sense of influence over their feelings, thoughts and actions. We invite you to take part to help us to find out whether we can measure your experience of this ability and how we can improve how we do so.

Do I have to take part?

The answer is “No”. Taking part is entirely up to you. Also, you are free to withdraw at any time during the study without giving a reason and without your care, or legal rights being affected.

What should I do if I am interested in taking part?

There will be a box entitled “Ann’s Study” in both Day Hospice and In-ward Unit. If you are interested in the study and want to be contacted to learn more about it, write your name on the Letter of Invitation and place in the box in either Day Hospice or In-patient Unit. If you are not able to do this by yourself, you can ask a member of the direct care team in Day Hospice or In-ward to do this on your behalf This will give permission for you to be contacted by the researcher for discussion of the study and taking consent.

What does taking part in the study involve?

- Having a face-to-face discussion with the researcher to go over the information about the study, including your involvement in it and giving your consent. We will welcome and answer any questions about the study so that you will feel adequately informed and able to decide whether or not you want to take part. Also, we welcome you to share the information given to you with others important to you (e.g. family, friends, GP). This meeting should last 15 minutes.

- If you are in Day Hospice, we will check back with you one week later; if you are an in-patient, we will check back with you 2 days later. We will ask if you understand the information. Also, we will answer any further questions you may

- have about the study. If you decide to take part, we will ask you to sign the Consent Form (Appendix V). This meeting should last 10 minutes. Taking part will be completely up to you.

- You will be asked to fill out a simple self-report form at a total of six occasions, either by yourself or with assistance of the researcher, using pen and paper. Each self-report will take 10 minutes to fill out. On the same day, the researcher or member of the direct care team in either Day Hospice or in-unit will also fill out a different version of the form by observing you, using pen and paper. Each observation session will last 12 minutes. Both forms will be filled out either in Day Hospice or in the In-unit. If you are in Day Hospice, we will ask you to do this once a week when you attend; if you are an in-patient, we will ask you to do this 6 times over a 1 to 2-week period. It is important for you to know that choosing to take part or not will in no way affect the care you receive.

- During the observation it is OK for you to talk with the observer but there is no requirement that you do so.

- At the end of each session, there will be time for debriefing when you will be given the opportunity to reflect on your experience of filling out the self-report form and being observed.

Are there any possible disadvantages or risks from taking part?

- The first main risk in this study is emotional distress from filling out the self-report form due to you facing the reality of your circumstances rather than avoiding them. If you feel that you might get too upset as a result of filling out the self-report form then the researcher will encourage you to not take part in the study. If you agree to take part and find yourself more upset than you thought you would be, then you may be encouraged to stop taking part. The researcher will work with you, helping you to comfort yourself by pausing, relaxing and taking a breath. After filling out the self-report form, the researcher will discuss with you any concerns you may have about your illness or taking part. If, later, you experience any emotional distress, the direct care team of Day Hospice/In-unit will contact the researcher who will meet with you to provide the help needed. If the researcher is not available, the direct care team of Day Hospice/In-Unit will ask another member of the counselling team to provide the necessary help. The direct care team of Day Hospice/In-Unit will be on site to provide the necessary care that you may require. The researcher will support your withdrawal from the study, validating that the choice you have made is right for you.

- The second main risk associated with filling out a self-report form is feeling pressurized to take part. However, you are allowed to withdraw from the study at any time.

- A third risk of filling out self-report forms is that of fatigue due to illness. If you tell us that you are experiencing fatigue, then the giving of forms will be stopped and put off to another time, as appropriate. The direct care team will be on site if assistance is needed during the study.

- With respect to the observation form we will be open about the observation, but you may experience a feeling of uneasiness/self-consciousness through being observed. However, you will be familiar with those collecting the data as it will be either the researcher who administered the self-report or a member of the direct care team from Day Hospice or the In-unit. You will be asked for verbal consent before starting each individual observation so that the observer will know whether or not that particular time is suitable and appropriate for you.

- We welcome questions and will be happy to address any concerns about the study at any time.

How will information about me be kept confidential?

- The original copy of your Consent Form will be placed in your medical records. A second copy will be given to yourself. A third copy, with your "Patient Identification Number", will be held in the academic supervisor's office in a locked filing cabinet, in a locked room in the University of Strathclyde, to which only the researcher and the academic supervisor will have access.

- Codes instead of names will be used to identify both your self-report and observation forms. The forms will be transported in a securely locked container from St. Andrew's Hospice and stored securely in a locked filling in the academic supervisor's locked room in the University of Strathclyde. Only the researcher and her academic supervisor will have access to your forms. They will be retained for the purpose of this research, publication and the writing of the academic thesis.

- Only the researcher and her academic supervisor will have access to your study data (self-report/observation forms and analysis). Your study data will be retained securely for 5 years to allow later checking of the forms while the study is still in progress. After 5 years data will be securely deleted.

- Responsible members of the University of Strathclyde or the NHS organization or other authorities may be given access to your data for monitoring and/or audit of the study to ensure that the research is complying with applicable regulations.

- In order to identify you, members of the direct care team of St. Andrew's Hospice will have access to your medical records. Only members of the direct care team will have access to your medical records. The researcher and the academic supervisor will not have access.

- The researcher will request that you provide your demographic information: gender, age in years, occupation, ethnicity, status (single or otherwise), diagnosis and prognosis directly to her. Only the minimum amount of information required will be collected.

What are the possible benefits of taking part?

We do not know what the outcome of the study will be and this is why we are conducting the research. However:

- You will be given the time and opportunity to create space for self-reflection. Some previous participants have reported that this was useful for them.

- By taking part in the study, you may help others by contributing more knowledge and understanding about a life-limiting illness.

- During or at the end of the study you may discover that you may want to engage in counselling. You can discuss this with the researcher.

Will my General Practitioner/family doctor be informed of my taking part?

We will send a letter to your GP to let him or her know that you have agreed to take part in this study. We will respect your confidentiality.

What will happen if I don't want to carry on with the study?

- Your taking part in the study is entirely voluntary and you can change your mind at a later stage.

- Any decision you make to withdraw (or to decline to be involved in the first place) will not affect the care you receive from any relevant service.

If you withdraw, all your identifiable personal information will be destroyed. Your data collected up to your withdrawal will be used for the purpose of research for which your consent has already been given.

What will happen to the results of this study?

This study is a part of PhD research. We will write up the results as a thesis and hopefully, present at conference, appear in peer reviewed scientific journals and make available through the University library system and the library within St. Andrew's Hospice. When publishing the results, we will anonymize all of your written data. We will also use pseudonyms to further lessen your identification.

You may want to know the results of the study in which you have taken part. If you request to know them. we will discuss this with you at the end of your participation. This will provide you with feedback on the research to which you have contributed. Emerging findings may also show relevance to future care. We will provide you with a link to a website from which you can get information about the study.

What happens if something goes wrong?

If you have a concern about any aspect of this study, you should ask to speak to the researcher who will do her best to answer your questions (Telephone 0141 548 4971) or Academic Supervisor (Telephone 0141 548 3703). If you remain unhappy and wish to complain formally, you can do this by contacting your local NHS Lanarkshire Complaints' Officer.
http://www.nhslanarkshire.org.uk/ContactUs/Pages/default.aspx.
Health Rights Information Scotland (HRIS) will provide you with accurate and up-to-date information about your health rights. http://www.hris.org.uk/patient-information/.

Independent Contact: Angelique Laverty, Secretary to the University Ethics Committee Research and Knowledge Exchange Services, University of Strathclyde, Graham Hills Building, 50 George Street, Glasgow, G1 1QE. (Tel 0141 548 3707)
Sponsor: The University of Strathclyde has appropriate insurance in place in the unlikely event that you suffer any harm as a direct consequence of your participation in this study.
Site of Research: St Andrew's Hospice, where the research will be conducted, is the employer of the researcher, and is covered by a Certificate of Employers' Liability Insurance.
Researcher: Is covered by a Personal Certificate of Professional Liability Insurance.

How have patients and the public been involved in this study?

The items used in both forms were derived from a previous patient interview study; thus, the previous participants contributed to the design of the research. In addition, participants who will take part in the pilot study will be involved by helping to revise both self-report and observational forms, to be used in the main part of this study. However, participants will not be involved in the management of the research.

Who has reviewed the study?

All research studies are looked at by an independent group of people, called a Research Ethics Committee, to protect your safety, rights, wellbeing and dignity.

Thank-you for considering taking part.

Appendix S: Invitation to Take Part in a Research Study: Out-patients, Main Study, Study 2

Main Study

Invitation to Take Part in a Research Study
Approval: REC 19/SS/0120; UEC 19/25

Having a life-limiting illness can be scary and leave people feeling powerless and out of control. We would like to invite you to take part in a research study, in St. Andrew's Hospice, on coping with this sense of powerlessness. We are trying to understand more about hospice patients' sense of personal control, that is, the sense you have of yourself as having control over your thoughts and actions so that they can help you in your everyday living with a life-limiting illness. In an earlier study, also carried out at St. Andrew's Hospice, we found that having this control helped patients to better deal with their circumstances so that they were able to decide what was important for them and make changes that helped them to live to the best of their ability and for as long as they could in the ways that felt right to them.

This study, called "Measuring Personal Agency in Hospice Patients", seeks to build on the earlier research. This study has been developed in collaboration between St. Andrew's Hospice and the University of Strathclyde and will be carried out by Ann Campbell (a counsellor at St. Andrew's and a PhD student at University of Strathclyde) and with assistance from members of the direct care team of St. Andrew's. The study will be supervised by Professor Robert Elliott of University of Strathclyde and monitored by Margaret Wilkie, Deputy Chief Executive/Head of Clinical Services at St. Andrew's Hospice.

Taking part in the study will be entirely your decision. The researcher, Ann, will ask you to fill out a simple self-report measure, each measure taking 10 minutes to fill out. On the same day, you will be asked to be observed by the researcher or member of the direct care team in Day Hospice, with each observation lasting 15 minutes. We will ask you to do this, 6 times over 6 weeks. If you choose to take part, you will have the right to withdraw from the study at any point and without any part of your care being affected.

If you would like to take part, we would like you to write your name in the box provided.

The Out-Patients' team of St. Andrew's Hospice will identify you and Ann will meet with you to explain, clearly, the purpose of the study and what you would be asked to do. Ann will be very happy to answer any questions or concerns you may have about the study.

Appendix T: Invitation to Take Part in a Research Study: In-patients, Main Study, Study 2

Main Study
Invitation to Take Part in a Research Study
Approval: REC 19/SS/0120; UEC 19/25

Having a life-limiting illness can be scary and leave people feeling powerless and out of control. We would like to invite you to take part in a research study, in St. Andrew's Hospice, on coping with this sense of powerlessness. We are trying to understand more about hospice patients' sense of personal control, that is, the sense you have of yourself as having control over your thoughts and actions so that they can help you in your everyday living with a life-limiting illness. In an earlier study, also carried out at St. Andrew's Hospice, we found that having this control helped patients to better deal with their circumstances so that they were able to decide what was important for them and make changes that helped them to live to the best of their ability and for as long as they could in the ways that felt right to them.

This study, called "Measuring Personal Agency in Hospice Patients", seeks to build on the earlier research. This study has been developed in collaboration between St. Andrew's Hospice and the University of Strathclyde and will be carried out by Ann Campbell (a counsellor at St. Andrew's and a PhD student at University of Strathclyde) and with assistance from members of the direct care team of St. Andrew's. The study will be supervised by Professor Robert Elliott of University of Strathclyde and monitored by Margaret Wilkie, Deputy Chief Executive/Head of Clinical Services at St. Andrew's Hospice.

Taking part in the study will be entirely your decision. The researcher, Ann, will ask you to fill out a simple self-report measure, each measure taking 10 minutes to fill out. You will also be asked to be observed by the researcher or member of the inpatient unit team, with each observation lasting 12 minutes. If you are an inpatient, we will ask you to do this, 6 times over 6 weeks. If you choose to take part, you will have the right to withdraw from the study at any point and without any part of your care being affected.

If you would like to take part, we would like you to write your name in the box provided.

The IPU team of St. Andrew's Hospice will identify you and Ann will meet with you to explain, clearly, the purpose of the study and what you would be asked to do. Ann will be very happy to answer any questions or concerns you may have about the study.

Appendix U: Consent Form: Out-patients and In-patients, Main Study, Study 2

CONSENT FORM

Approval: REC 19/SS/0120; UEC 19/25

Patient's Identification Number for this study: ☐

Title of Study: Measuring Personal Agency in Hospice Patients (V2)

New Sample Study: Day Hospice and In-Patients

Name of Chief Investigator: Ann Campbell

If you agree, please initial box

1. I confirm that I have read and understand the Participant Information Sheet (Appendix IV, V3, 22/11/2019) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐

2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care, access to counselling or legal rights being affected. ☐

3. I understand that only the direct care team will have access to my medical notes. I give permission for the Chief Investigator to request relevant demographic information directly from me. Only the minimum amount of information required will be collected and shared with the Chief Investigator and her Academic Supervisor at the University of Strathclyde. ☐

4. I understand that this study may be externally monitored by individuals (not the researchers) from the Sponsor (University of Strathclyde) or from the NHS organisation or other authorities. This might involve looking at relevant sections of my medical notes and data collected during the study, to make sure that the study is being conducted properly and that my rights are being protected. I give permission for these individuals to have access to my records. ☐

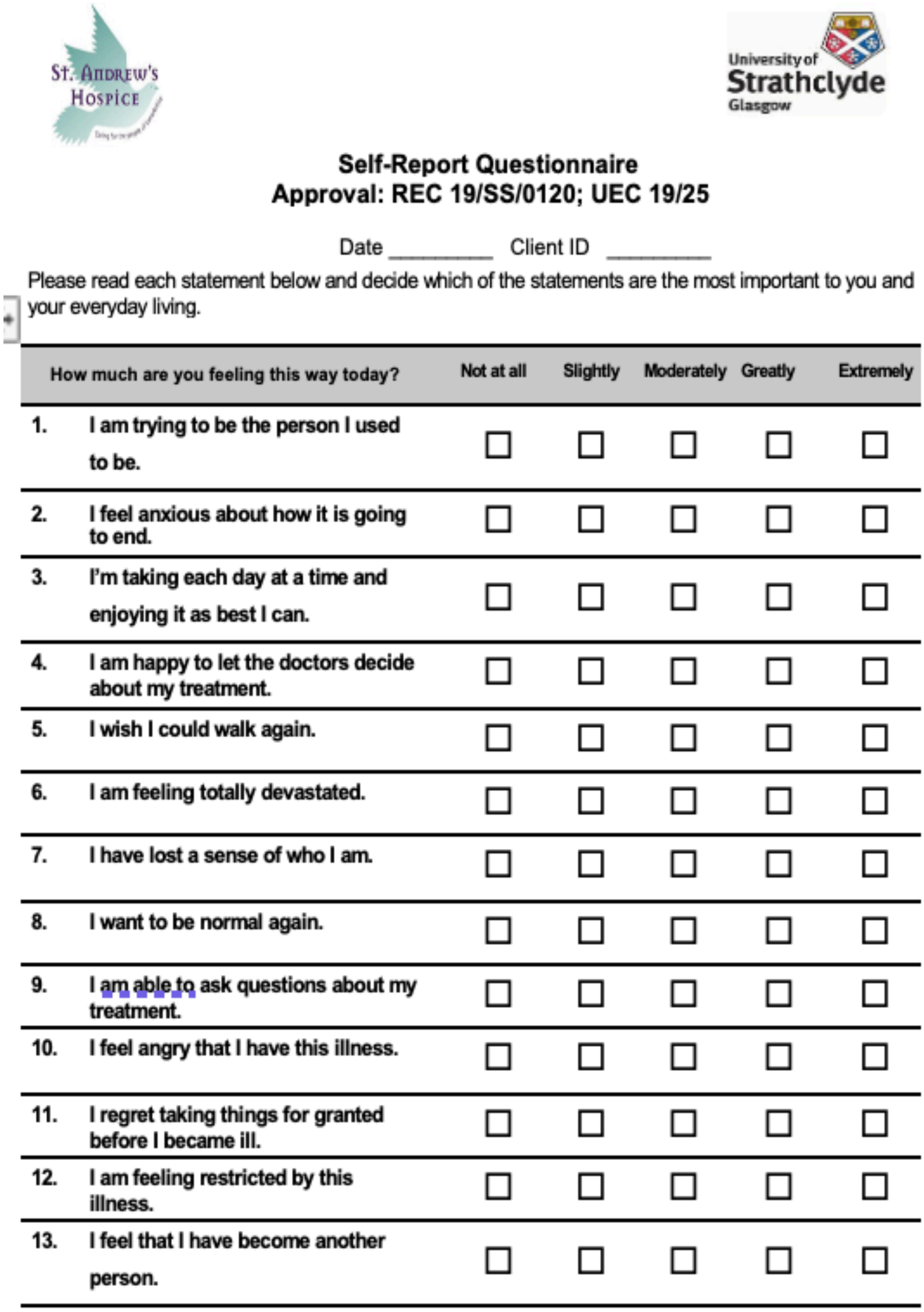
5. I understand that the Chief Investigator and the Academic Supervisor at the University of Strathclyde may use relevant data collected during the study. ☐

6. I agree to my GP being informed of my participation in the study while I am a patient at St. Andrew’s Hospice. ☐

7. I agree to take part in the above study. ☐

Name of Participant	Date	Signature
Chief Investigator	Date	Signature

Appendix V: Self-Report Questionnaire: Revised Version 16-Item, Study 2



St. Andrew's Hospice

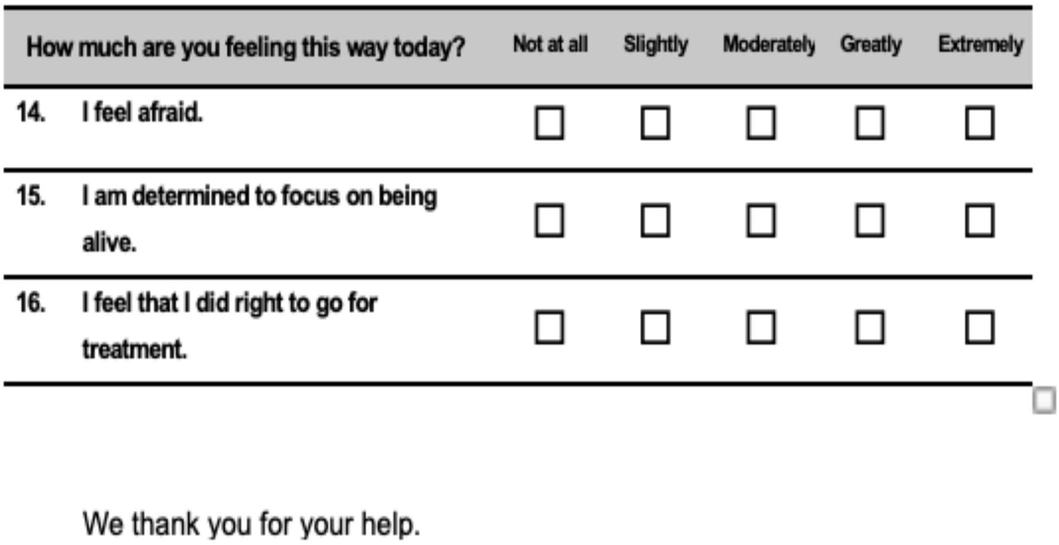
University of Strathclyde Glasgow

Self-Report Questionnaire
Approval: REC 19/SS/0120; UEC 19/25

Date _________ Client ID _________

Please read each statement below and decide which of the statements are the most important to you and your everyday living.

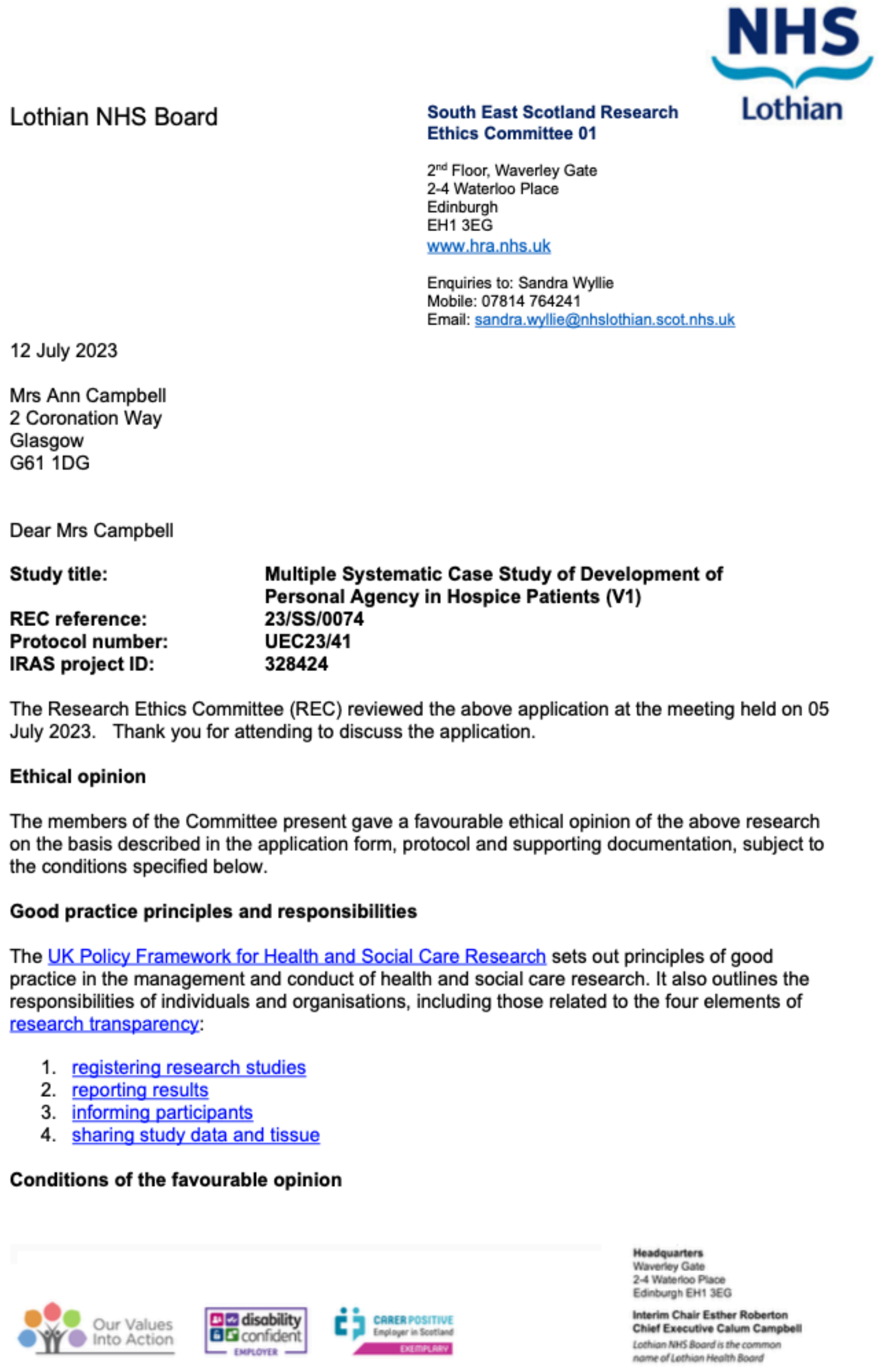
	How much are you feeling this way today?	Not at all	Slightly	Moderately	Greatly	Extremely
1.	I am trying to be the person I used to be.	☐	☐	☐	☐	☐
2.	I feel anxious about how it is going to end.	☐	☐	☐	☐	☐
3.	I'm taking each day at a time and enjoying it as best I can.	☐	☐	☐	☐	☐
4.	I am happy to let the doctors decide about my treatment.	☐	☐	☐	☐	☐
5.	I wish I could walk again.	☐	☐	☐	☐	☐
6.	I am feeling totally devastated.	☐	☐	☐	☐	☐
7.	I have lost a sense of who I am.	☐	☐	☐	☐	☐
8.	I want to be normal again.	☐	☐	☐	☐	☐
9.	I am able to ask questions about my treatment.	☐	☐	☐	☐	☐
10.	I feel angry that I have this illness.	☐	☐	☐	☐	☐
11.	I regret taking things for granted before I became ill.	☐	☐	☐	☐	☐
12.	I am feeling restricted by this illness.	☐	☐	☐	☐	☐
13.	I feel that I have become another person.	☐	☐	☐	☐	☐



How much are you feeling this way today?		Not at all	Slightly	Moderately	Greatly	Extremely
14.	I feel afraid.	☐	☐	☐	☐	☐
15.	I am determined to focus on being alive.	☐	☐	☐	☐	☐
16.	I feel that I did right to go for treatment.	☐	☐	☐	☐	☐

We thank you for your help.

Appendix W: Ethical Approval of Research from NHS Research Ethics Committee, Study 3



Lothian NHS Board

NHS
Lothian

South East Scotland Research Ethics Committee 01

2nd Floor, Waverley Gate
2-4 Waterloo Place
Edinburgh
EH1 3EG
www.hra.nhs.uk

Enquiries to: Sandra Wyllie
Mobile: 07814 764241
Email: sandra.wyllie@nhslothian.scot.nhs.uk

12 July 2023

Mrs Ann Campbell
2 Coronation Way
Glasgow
G61 1DG

Dear Mrs Campbell

Study title:	**Multiple Systematic Case Study of Development of Personal Agency in Hospice Patients (V1)**
REC reference:	**23/SS/0074**
Protocol number:	**UEC23/41**
IRAS project ID:	**328424**

The Research Ethics Committee (REC) reviewed the above application at the meeting held on 05 July 2023. Thank you for attending to discuss the application.

Ethical opinion

The members of the Committee present gave a favourable ethical opinion of the above research on the basis described in the application form, protocol and supporting documentation, subject to the conditions specified below.

Good practice principles and responsibilities

The UK Policy Framework for Health and Social Care Research sets out principles of good practice in the management and conduct of health and social care research. It also outlines the responsibilities of individuals and organisations, including those related to the four elements of research transparency:

1. registering research studies
2. reporting results
3. informing participants
4. sharing study data and tissue

Conditions of the favourable opinion

Our Values Into Action

disability confident EMPLOYER

CARER POSITIVE Employer in Scotland EXEMPLARY

The REC favourable opinion is subject to the following conditions being met prior to the start of the study.

Number	Conditions	Researcher Response
1.	The Committee requested the following changes to the PIS:- Review, proof read and simplify text. Typos should be corrected, (e.g. "what is the purpose of this study?" section, line 8 "a ltter") Please remove/amend text not directed at the participant (e.g. "A Ltter of Invitation and a Participant Information Sheet will be given to the identified patients at the same time by the care team.") The Committee considered that the wording in the section "What are the possible benefits of taking part?" to be quite strongly worded e.g. "you may find an increase in your self-esteem through helping yourself and others" – please soften the language used. Clarify and detail when the patients will be observed, and that permission will be obtained to observe. Remove the section titled "Study:Mixed Methods Design" as this information is not necessary and would not make sense to a non-researcher. In the PIS, ensure that the appropriate standard GDPR wording from your sponsor is included or use the HRA link to wording: https://www.hra.nhs.uk/planning-and-improving-research/policies-standards-legislation/data-protection-and-information-governance/gdpr-guidance/templates/transparency-wording-for-all-sponsors/ . Please note that this should include all three sub-headings: How will we use information about you? What are your choices about how your information is used? and Where can you find out more about how your information is used? When the standard wording has been added, please ensure that the PIS does not include any duplicate, previous or contradicting information. Separate out more clearly the study processes that apply to the inpatient and out-patient groups.	
2.	The letters of invitation currently contain too much detail and information. Please simplify the text and include basic information only.	
3.	In discussion prior to the researcher attending the meeting, the Committee noted that an updated insurance certificate is required. Please submit.	

	Additional Comments	
	The Committee agreed to request that the researcher is reminded that the IRAS form should be as brief as possible and not contain repetitions and unnecessary text. The Committee noted that no academic supervisor attended the meeting and strongly agreed that the PhD student would have befitted from being better supported.	

You should notify the REC once all conditions have been met (except for site approvals from host organisations) and provide copies of any revised documentation with updated version numbers. Revised documents should be submitted to the REC electronically from IRAS. The REC will acknowledge receipt and provide a final list of the approved documentation for the study, which you can make available to host organisations to facilitate their permission for the study. Failure to provide the final versions to the REC may cause delay in obtaining permissions.

Confirmation of Capacity and Capability (in England, Northern Ireland and Wales) or NHS management permission (in Scotland) should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements. Each NHS organisation must confirm through the signing of agreements and/or other documents that it has given permission for the research to proceed (except where explicitly specified otherwise).

Guidance on applying for HRA and HCRW Approval (England and Wales)/ NHS permission for research is available in the Integrated Research Application System.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of management permissions from host organisations.

Registration of Clinical Trials

All research should be registered in a publicly accessible database and we expect all researchers, research sponsors and others to meet this fundamental best practice standard.

It is a condition of the REC favourable opinion that **all clinical trials are registered** on a publicly accessible database within six weeks of recruiting the first research participant. For this purpose, 'clinical trials' are defined as:

- clinical trial of an investigational medicinal product
- clinical investigation or other study of a medical device
- combined trial of an investigational medicinal product and an investigational medical device
- other clinical trial to study a novel intervention or randomised clinical trial to compare interventions in clinical practice.

Failure to register a clinical trial is a breach of these approval conditions, unless a deferral has been agreed by the HRA (for more information on registration and requesting a deferral see: Research registration and research project identifiers).

If you have not already included registration details in your IRAS application form you should notify the REC of the registration details as soon as possible.

Publication of Your Research Summary

We will publish your research summary for the above study on the research summaries section of our website, together with your contact details, no earlier than three months from the date of this favourable opinion letter.

Should you wish to provide a substitute contact point, make a request to defer, or require further information, please visit: https://www.hra.nhs.uk/planning-and-improving-research/application-summaries/research-summaries/

N.B. If your study is related to COVID-19 we will aim to publish your research summary within 3 days rather than three months.

During this public health emergency, it is vital that everyone can promptly identify all relevant research related to COVID-19 that is taking place globally. If you haven't already done so, please register your study on a public registry as soon as possible and provide the REC with the registration detail, which will be posted alongside other information relating to your project. We are also asking sponsors not to request deferral of publication of research summary for any projects relating to COVID-19. In addition, to facilitate finding and extracting studies related to COVID-19 from public databases, please enter the WHO official acronym for the coronavirus disease (COVID-19) in the full title of your study. Approved COVID-19 studies can be found at: https://www.hra.nhs.uk/covid-19-research/approved-covid-19-research/

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

After ethical review: Reporting requirements

The attached document "After ethical review – guidance for researchers" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study, including early termination of the study
- Final report
- Reporting results

The latest guidance on these topics can be found at https://www.hra.nhs.uk/approvals-amendments/managing-your-approval/.

Ethical review of research sites

NHS/HSC Sites

The favourable opinion applies to all NHS sites taking part in the study, subject to confirmation of Capacity and Capability (in England, Northern Ireland and Wales) or NHS management permission (in Scotland)being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Non-NHS/HSC sites

I am pleased to confirm that the favourable opinion applies to any non-NHS/HSC sites listed in the application, subject to site management permission being obtained prior to the start of the study at the site.

Approved documents

The documents reviewed and approved at the meeting were:

Document	*Version*	*Date*
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [Professional Indemnity, University of Strathclyde]		31 July 2023
GP/consultant information sheets or letters [Letter to GP]	Version 1	05 May 2023
IRAS Application Form [IRAS_Form_12062023]		12 June 2023
Letter from statistician [Statistician Report]	Version 1	10 May 2023
Letters of invitation to participant [Invitation to Take Part in a Research Study In-patients]	Version 1	04 May 2023
Letters of invitation to participant [Invitation to Take Part in a Research Study Out-patients]	Version 1	04 May 2023
Non-validated questionnaire [Non-validated Self-report Questionnaire]	Version 1	20 May 2023
Non-validated questionnaire [Non-validated Observation Questionnaire]	Version 1	20 May 2023
Other [Detailed Description of Method]	Version 1	25 April 2023
Other [Employers Liability, St. Andrew's Hospice]		04 March 2024
Other [Employers' Liability, University of Strathclyde]		31 July 2023
Other [Insurance Questionnaire, University of Strathclyde]	Version 1	10 May 2023
Other [Risk Assessment Form]		14 May 2023
Other [Covering Letter]		
Participant consent form [Participant Consent form]	Version 1	17 April 2023
Participant information sheet (PIS) [Participant Information Sheet]	Version 1	16 April 2023
Research protocol or project proposal [PhD Proposal]	Version 2	20 May 2023
Summary CV for Chief Investigator (CI) [CV of Chief Investigator]		24 May 2023
Summary CV for supervisor (student research) [CV of academic Supervisor 2]		03 May 2023
Summary CV for supervisor (student research) [CV of Academic Supervisor 1]		02 May 2023
Summary, synopsis or diagram (flowchart) of protocol in non technical language [Summary of Research]	Version 1	25 May 2023

Membership of the Committee

The members of the Ethics Committee who were present at the meeting are listed on the attached sheet.

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

User Feedback

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website: http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance/

HRA Learning

We are pleased to welcome researchers and research staff to our HRA Learning Events and online learning opportunities– see details at: https://www.hra.nhs.uk/planning-and-improving-research/learning/

IRAS project ID: 328424 **Please quote this number on all correspondence**

With the Committee's best wishes for the success of this project.

Yours sincerely

Lucy Kershaw

Dr Lucy Kershaw
Chair

E-mail: sandra.wyllie@nhslothian.scot.nhs.uk

Enclosures:	List of names and professions of members who were present at the meeting and those who submitted written comments
	"After ethical review – guidance for researchers"
	After ethical review guidance for sponsors and investigators – Non CTIMP Standard Conditions of Approval]
Copy to:	Angelique Laverty

South East Scotland REC 01

Attendance at Committee meeting on 05 July 2023

Committee Members:

Name	*Profession*	*Present*	*Notes*
Dr Balkishan Agrawal	Retired General Practitioner	No	
Dr Emily Ball	Research Fellow, The University of Edinburgh	Yes	
Dr John (Jack) Cafferkey	Doctor - Core Trainee	No	
Mrs Anna Foster	Trials Management Support Officer	Yes	
Dr Jess Gurney	Lecturer and Doctor	Yes	
Dr Lucy Kershaw	Senior Research Fellow	Yes	Chair
Dr Grace Lindsay	Professor in Nursing (Medical Surgical)	Yes	
Mrs Rachel Locherty	Clinical Trial Manager (ECTU)	Yes	
Dr Susan Morrow	Senior Lecturer	No	
Mrs Amy Shepherd	Senior Research Nurse - Regional Infectious Diseases Unit	No	
Mrs Jennyfer Stuart	Student - LLM in Medical law & Ethics	No	
Dr Isla Wallace	Senior Policy Advisor, Mental Health	Yes	

Also in attendance:

Name	*Position (or reason for attending)*
Mrs Ann Campbell	Counsellor
Dr Helen Newbery	Ethics Scientific Officer
Mrs Sandra Wyllie	REC Manager
Miss Eilidh Clifford	REC Assistant
Gillian Merrett	Retired Diabetes Specialist Podiatrist (observer)
Isobel Grundy	Student at University of Edinburgh (observer)
Dr Zoe Fyffe	(observer)

Appendix X- Participant Information Sheet: Out-patients and In-patients, Study 3

Participant Information Sheet

Approval: REC 23/SS/0074; UEC 23/41

Title of Study
"To Measure the Development of Personal Agency in Hospice Patients"

Chief Investigator: Ann Campbell, B.Sc. (Hons) Psych., M.Sc. Counselling, PG Dip. Counselling, MBACP (ann.campbell.100@strath.ac.uk)

Academic Supervisors:
Dr Susan Rasmussen, Ph.D. (s.a.rasmussen@strath.ac.uk)
Professor Robert Elliott, Ph.D. (Robert.Elliott@ strath.ac.uk)

Invitation to take part.
We'd like to invite you to take part in our research study. Joining the study is entirely up to you. Before you decide we would like you to understand why the research is being done and what it would involve for you. The Chief Investigator will go through this information sheet with you, to help you decide whether or not you would like to take part and answer any questions you may have. Please feel free to talk to others about the study if you wish.

What is the purpose of this study?
In this study we are trying to find out if two questionnaires, a self-report, and an observation, developed in an earlier study, can be used to measure the sense that you, as a hospice patient, have of yourself as being able to influence your feelings, thoughts, and actions to deal with your circumstances. In addition, we are trying to discover if the kind of counselling offered, called Emotion-Focused Therapy, can be associated with an increased sense of influence. The study will take place in St. Andrew's Hospice and is sponsored by the University of Strathclyde. The direct care teams from both the out-patient and in-patient units of St. Andrew's Hospice will identify you as a potential participant and you will be given a Letter of Invitation and a Participant Information Sheet at the same time by the care team.

We will ask you to fill out a self-report form, either by yourself or with assistance of the researcher. On the same day, the researcher and a member of the direct care teams will fill out a different form that will try to assess your sense of control by observing you. Also, you will be offered six sessions of counselling. We will ask you to give permission for your counselling sessions to be audio-recorded and for your recordings to be transcribed for analysis. Also, we will ask for your permission to keep the recordings of these sessions and your self-report and observation forms for the purpose of research.

Why have I been invited?

We are inviting you to take part in this study because you have been diagnosed with an illness that cannot be cured. This means that you live every day with an illness that is life-limiting. Prior to the earlier studies, we could not find information about how hospice patients deal with a life-limiting illness. You may help us to find out if the recently developed self-report and observation forms can measure your sense of control in your every-day living and if Emotion-Focused Therapy can help you to have an increased sense of control in dealing with your circumstances.

Do I have to take part?

The answer is "No". Taking part is entirely up to you.

What should I do if I am interested in taking part?

If you are an out-patient, there will be a box entitled "Ann's Study" in the out-patients' unit. If you are interested in the study and want to be contacted to learn more about it, write your name on the Letter of Invitation and place in the box in out-patients' unit. If you are not able to do this by yourself, you can ask a member of out-patients' to do this on your behalf.

If you are an in-patient, and wish to be contacted, write your name in the space on the Letter of Invitation and give it to a member of the in-patient unit. You can ask a member of the in-patient unit to help you if you are not able to do this by yourself.

This will give permission for you, as an out-patient or in-patient, to be contacted by the researcher for discussion of the study and taking consent.

What does taking part in the study involve?

- Having a face-to-face discussion with the researcher to go over the information about the study, including your involvement in it and giving your consent. The researcher will welcome and answer any questions about the study so that you will feel adequately informed and able to decide whether or not you want to take part. Also, we welcome you to share information given to you with others important to you (e.g., family, friends, GP). This meeting should last 15 minutes.

  If you are an out-patient, the researcher will check back with you one week later.
  If you are an in-patient, the researcher will check back with you two days later.

She will ask if you understand the information. The researcher will answer any further questions you may have about the study. If you decide to take part, the researcher will ask you to sign the Consent Form. This meeting should last 10 minutes.

The researcher will return one week later for out-patients and two days later for in-patients to start the study.

- We will work respectfully with you. Whether you are an out-patient or an in-patient you will be asked to fill out a simple self-report form a total of six occasions, either by yourself or with assistance of the researcher, using pen and paper. Each self-report will take 10 minutes to fill out.
  On the same day, the researcher and member of both the out-patients' and in-patients' unit will also, independently, fill out a different version of the form by observing you, using pen and paper. Each observation will last 12 minutes. Both forms will be filled out in either the outpatients or in-patients' unit.

  If you are an out-patient, you will be asked to do this once a week for six weeks on the day you attend out-patients'.

  If you are an in-patient, you will be asked to do this on six occasions over a one-to- two-week period.

- Taking part in counselling sessions: You will be offered six sessions of counselling with the researcher who is also a counsellor.

  If you are an out-patient, you will be offered six sessions (each lasting no longer than 30 minutes) over six weeks, in a room in the out-patient unit and on the day, you attend out-patients'.

  If you are an in-patient, you will be offered six counselling sessions (each lasting no longer than 15 minutes) over a period of one-to-two weeks, in a room in the in-patient unit, and on the day after you fill out the self-report form or as is appropriate.

  We will audio-record your counselling sessions and your recordings will be transcribed to create written copies called transcripts.
- During the counselling sessions, you will be asked to talk about how you experience your illness and the sense you have of yourself as being able to deal with your circumstances.

- Before each observation session we will ask your permission if it is OK for you to be observed. If it is not suitable for you to be observed at that time, observation can take place at another time as appropriate.

  If you are an out-patient you will be observed during an activity such as a quiz, craft work or chatting with other out-patients.

If you are an in-patient, observation will take place while you are having a cup of tea or engaged in a friendly chat with a friend or member of staff.

During the observation it is OK for you to talk with the observer but there is no requirement that you do so.

- At the end of each session, self-report, observation and counselling, there will be time for debriefing when you will be able to reflect on your experience of filling out the self-report, being observed or taking part in counselling.

Are there any possible disadvantages or risks from taking part?
The first main risk in this study is emotional distress from filling out the self-report form and taking part in counselling sessions due to you facing the reality of your circumstances rather than avoiding them. If you feel that you might get too upset as a result of filling out the self-report or taking part in counselling the researcher will encourage you to not take part in the study. You may find it difficult to talk about deeply personal matters. If you agree to take part and find yourself more upset than you thought you would be, then you may be encouraged to stop taking part. The researcher will work with you, helping you to comfort yourself by pausing, relaxing, and taking a breath. After filling out each self-report form and taking part in each counselling session, the researcher will discuss with you any concerns you may have about your illness or taking part. If, later, you experience any emotional distress, the direct care team for out-patients/in-patients will contact the researcher who will meet with you to provide the necessary help. The direct care team of out-patients and in-patients will be on site to provide the necessary care that you may require. The researcher will support your withdrawal from the study, validating that the choice you have made is right for you.

- The second main risk associated with filling out a self-report or taking part in counselling is that you may feel pressurised to take part.

  If you are an out-patient, you will have two weeks to decide if taking part. is right for you.

  If you are an in-patient, you will have four days to decide if taking part is right for you.

- A third risk associated with taking part is that of fatigue due to illness. If you tell us that you are experiencing fatigue, then the filling out of the forms and/or taking part in counselling will be stopped and put off to another time, as appropriate. The direct care team will be on site if you need assistance during the study.

- We will be open about the observation, but you may experience a feeling of uneasiness/self-consciousness through being observed. However, you will be familiar with those collecting the data as it will be either the researcher who administered the self-report and offered the counselling sessions or a member of the direct care team of either the out-patients or in-patients' unit.
- With respect to being audio-recorded, you may experience a feeling of uneasiness/self-consciousness. However, only the researcher will offer counselling sessions and carry out the audio-recording and she will be known to you.
- We welcome any questions and will be happy to address any concerns you may have about the study at any time.

How will we use information about you?

We will need to use information from you for this research project.

This information will include name and demographics:

- Diagnosis and Prognosis
- Age in years: not date of birth
- Gender
- Ethnicity
- Status (Single or otherwise)

The above information will be held by St. Andrew's Hospice, the site of the research.

People who do not need to know who you are will not be able to see your name. Your data will have a code number instead. This means that the sponsor, the University of Strathclyde, does not need to see your name, but will know your code and the list of identifiers.

The researcher and her academic supervisors will have no access to your medical records; only members of the direct care team will have access.

People (researcher) will use this information to do the research or responsible members of the University of Strathclyde, or the NHS organization will check your records to make sure that the research is being done properly.

We will keep all information about you safe and secure.

Once we have finished the study, we will keep some of the data so we can check the results. We will write our reports in a way that no-one can work out that you took part in the study.

What are your choices about how your information is used?

You can stop being part of the study at any time, without giving a reason, but we will keep information about you that we already have.

We need to manage your records in specific ways for the research to be reliable. This means that we won't be able to let you see or change the data we hold about you.

Where can you find out more about how your information is used?
You can find out more about how we use your information.

- at www.hra.nhs.uk/information-about-patients/
- our leaflet available from Patient Data and Research leaflet
- by asking the researcher, Ann Campbell
- by sending an email to a.laverty@strath.ac.uk/ethics@strath.ac.uk
- by ringing us on 0141 548 3707.

The HRA link**: www.hra.nhs.uk/patientdataandresearch**

How will information about me be kept confidential?

- The original copy of your Consent Form will be placed in your medical records. A second copy will be given to yourself. A third copy, with your 'Patient Identification Number', will be transported, together with your self-report and observation forms and audio-recordings, in a securely locked container from St. Andrew's Hospice to the University of Strathclyde. The forms will be held in a locked filing cabinet, in a locked room in the University of Strathclyde, to which only the researcher and the academic supervisor will have access. Your audio-recordings will also be encrypted within the secure 'OneDrive' cloud storage system, in the University of Strathclyde, with only the researcher and her academic supervisors having access.

What are the possible benefits of taking part?

We do not know what the outcome of the study will be and this is why we are conducting the research. However:

- You will be given time and the opportunity for self-reflection and to talk about things that are important to you. Previous participants reported that this was useful for them.

- By taking part in the study, you may experience yourself as thoughtful and supportive by contributing more knowledge and understanding about a life-limiting illness.

- You may maximise your use of counselling towards your own self-empowerment. During or at the end of the study you may find that you may want to engage in counselling. You can discuss this with the researcher.

Will my General Practitioner/family doctor be informed of my taking part?
We will send a letter to your GP to let them know that you have agreed to take part in this study. We will respect your confidentiality.

What will happen if I don't want to carry on with the study?

- Any decision you make to withdraw (or decline to be involved in the first place) will not affect the care you receive from any relevant service.

What will happen to the results of this study?
This study is a part of PhD research. We will write up the results as a thesis and hopefully, present at conference, appear in peer reviewed scientific journals and make available through the University library system and the library within St. Andrew's Hospice. When publishing the results, we will anonymize all your written data. We will also use pseudonyms to further lessen your identification.

What happens if something goes wrong?
If you have a concern about any aspect of this study, **s**hould ask to speak to the researcher who will do her best to answer your questions (Telephone 0141 548 4971) or Academic Supervisor (Telephone 0141 548 2575). If you remain unhappy and wish to complain formally, you can do this by contacting your local NHS Lanarkshire Complaints' Officer.

http://www.nhslanarkshire.org.uk/ContactUs/Pages/default.aspx. Health Rights Information Scotland (HRIS) will provide you with accurate and up-to- date information about your health rights. http://www.hris.org.uk/patient-information/.
Independent Contact: Angelique Laverty, Secretary to the University Ethics Committee Research and Knowledge Exchange Services, University of Strathclyde, Graham Hills Building, 50 George Street, Glasgow, G1 1QE (Tel. 0141 548 3707) a.laverty@strath.ac.uk/ethics@strath.ac.uk
Sponsor: The University of Strathclyde has appropriate insurance in place in the unlikely event that you suffer any harm as a direct consequence of your participation in this study.
Site of Research: St. Andrew's Hospice, where the research will be conducted, is the employer of the researcher, and is covered by a Certificate of Employers' Liability Insurance.
Researcher is covered by a Personal Certificate of Professional Liability Insurance.

How have patients and the public been involved in this study?
Prior to the earlier studies, we could not find recorded and analysed information about how hospice patients deal with a life-limiting illness. We perceive you as an expert who can provide knowledge and experience. The items used in both forms

were derived from the patient counselling sessions in the previous study; thus, the previous participants contributed to the design of the research. In addition, participants helped to revise both the self-report and observational forms. This study will involve you in the implementation of the revised forms. However, participants will not be involved in the management of the research.

Who has reviewed the study?

All research studies are looked at by an independent group of people, called a Research Ethics Committee, to protect your safety, rights, wellbeing, and dignity. The South East Scotland Research Ethics Committee REC 01 has granted approval for this study.

Thank-you for considering taking part.

Appendix Y: Invitation to Take Part in a Research Study: Out-patients, Study 3

Letter of Invitation to Take Part in a Research Study

Approval: REC 23/SS/0074; UEC 23/41

We would like to invite you to take part in a research study, in St. Andrew's Hospice. We are trying to understand more about your sense of personal control, that is, the sense you have of yourself as having control over your feelings, thoughts, and actions so that they can help you in your everyday living with a life-limiting illness. Also, we want to find out if that sense of control can be measured. In earlier studies, at St. Andrew's Hospice, we found that having this control helped patients to better deal with their circumstances.

This study, called "To Measure the Development of Personal Agency in Hospice Patients", is in collaboration between St. Andrew's Hospice and the University of Strathclyde and will be carried out by Ann Campbell (a counsellor at St. Andrew's and a PhD student at University of Strathclyde) and with assistance from the out-patient unit of St. Andrew's.

Taking part in the study will be entirely your decision. Ann will ask you to fill out a simple self-report form. You will be asked to be observed by the researcher and a member of the out-patient unit. Also, Ann will offer you sessions of counselling and these will be audio-recorded. We will ask you to do these 6 times over 6 weeks.

The direct care team will give you a Participant Information Sheet along with this Letter of Invitation. There will be a box entitled "Ann's Study" in the out-patient unit. If you are interested in the study and want to be contacted to learn more about it, write your name in the space below and place this Letter in the box. If you are not able to do this by yourself, you can ask a member of the out-patient unit to do this on your behalf. This will give permission for you to be contacted by Ann for discussion of the study and taking of consent. If I don't hear from you, I will not contact you.

The direct care team of the out-patient unit will identify you and Ann will meet with you to explain, clearly, the purpose of the study and what you would be asked to do. Ann will be very happy to answer any questions or concerns you may have about the study.

Appendix Z: Invitation to Take Part in a Research Study: In-patients, Study 3

Letter of Invitation to Take Part in a Research Study

Approval: REC 23/SS/0074; UEC 23/41

We would like to invite you to take part in a research study in St. Andrew's Hospice. We are trying to understand more about your sense of personal control, that is, the sense you have of yourself as having control over your feelings, thoughts and actions so that they can help you in your everyday living with a life-limiting illness. Also, we want to find out if that sense of control can be measured. In earlier studies, at St. Andrew's Hospice, we found that having this control helped patients to better deal with their circumstances.

This study, called "To Measure the Development of Personal Agency in Hospice Patients", is in collaboration between St. Andrew's Hospice and the University of Strathclyde and will be carried out by Ann Campbell (a counsellor at St. Andrew's and a PhD student at University of Strathclyde) and with assistance from members of the in-patient unit of St. Andrew's.

Taking part in the study will be entirely your decision. Ann will ask you to fill out a simple self-report form. You will also be asked to be observed by the researcher and a member of the in-patient unit. Also, Ann will offer you brief sessions of counselling, and each session will be audio-recorded. We will ask you to do these, 6 times over 1-to-2-weeks.

The direct care team of the in-patient unit will give you a Participant Information Sheet along with this Letter of Invitation. If you are interested in the study and want to be contacted to learn more about it, write your name in the space below. If you are not able to do this by yourself, you can ask a member of the in-patient unit to do this on your behalf. This will give permission for you to be contacted by Ann for discussion of the study and taking of consent.

The in-patient unit team of St. Andrew's Hospice will identify you and Ann will meet with you to explain, clearly, the purpose of the study and what you would be asked to do. Ann will be very happy to answer any questions or concerns you may have about the study.

Appendix AA: Consent Form: Out-patients and In-patients, Study 3

CONSENT FORM

Approval: REC 23/SS/0074; UEC 23/41

Patient's Identification Number for this study: ☐

Title of Study: Multiple Systematic Case Study of Development of Personal Agency in Hospice Patients

Study: Qualitative: Counselling Sessions
Quantitative: Using recently developed self-report and observation forms
Outpatients and In-patients, St. Andrew's Hospice

Name of Chief Investigator: Ann Campbell

If you agree, please initial box

1. I confirm that I have read and understand the Participant Information Sheet (Appendix, IV, 16/04/2023) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐

2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care, access to counselling or legal rights being affected. ☐

3. I understand that only the direct care team will have access to my medical notes. I give permission for the Chief Investigator to request relevant demographic information directly from me. Only the minimum amount of information required will be collected and shared with the Chief Investigator and her Academic Supervisor at the University of Strathclyde. ☐

4. I understand that this study may be externally monitored by individuals (not the researchers) from the Sponsor (University of Strathclyde) or from the NHS organization or other authorities. This might involve looking at relevant sections of my medical notes and data collected during the study, to make sure that the study is being conducted properly and that my rights are being protected. I give permission for these individuals to have access to my records. ☐

5. I understand that the Chief Investigator and the Academic Supervisor at the University of Strathclyde may use relevant data collected during the study. ☐

6. I agree to my GP being informed of my participation in the study while I am a patient at St. Andrew's Hospice. ☐

7. I agree to take part in the above study. ☐

Name of Participant	Date	Signature
Chief Investigator	Date	Signature

Appendix BB: A Complete Record of the Analysis of Study 3

Title of Study 3: Multiple Systematic Case Study of the Development of Personal Agency in Hospice Patients

Construction of Self as an Active Agent within the Hospice Process: A Cross-Case Analysis
Examples of statements as expressed by four out-patients and three in-patients, respectively.

Notes: Study 3: Out-patients: OP1; OP2; OP3; OP4; In-patients: IP1; IP2; IP3; 'T' represents the therapist; (No data) is used to indicate that a category is not expressed as having been experienced.

Level 0: The Non-Agentic Self

This category, the lowest level of personal control, saw patients experience themselves as having no ability to initiate change through their own actions. Devoid of a sense of personal agency, patients cannot construct their experience in alternative ways that would allow them to self-organise, self-regulate, or self-reflect.

0a: Objectified Self

Both the direct and indirect effects of their incurable illness reduce participants to the status of an object, with objectification preventing them from acting as autonomous individuals. This results in a lack of agency, with patients feeling, even if temporary, that their feelings become unimportant due to a denial of subjectivity. As the *Objectified Self*, patients communicate that their sense of lack of control is due to the effects of their illness, the challenging aspects of their treatment and, the involvement of those who they perceive as having influence with respect to their circumstances.

Oa-1: By the Effects of Illness

Out-patients describe a strong image try to provide an understanding of how their illness has left them unable to exercise any influence over their personal life circumstances. Participants also communicate that the effects of illness have impact on both their physical and psychological well-being.

0a-1.1: Physical Effects of Illness

The physical effect is powerfully described by *“...you can’t stop it,,,”.* The psychological impact of the illness is captured with the image of being brought down with no sense of control. In addition, their use of the word “it” supports the sense of a lack of control imposed on them.

Out-patients

OP1-95: … you can’t stop it… out of my power…
OP2-14: [T. … it (illness) interferes?]… it definitely does… definitely
OP3: (No data)
OP4: (No data)

In-patients: (No data)

0a-1.2: Psychological Effects of Illness

Not all patients revealed a psychological impact of the illness that presented an image of being brought down with no sense of control.

Out-patients

OP1-14: … don’t think I… cried…
OP2: (No data)
OP3: (No data)
OP4: (No data)

In-patients

IP1: (No data)
IP2: (No data)
IP3-1: … what it’s done to my life… turned my life upside down.

0a-2: By the Effects of Treatment

The patients did not communicate that treatment had effect on them, physically or psychologically. No data were collected for this category.

0a-2.1: Physical Effects of Treatment

Patients do not express their experience of the physical effects of treatment. Thus, no data were collected for this category.

Out-patients: (No data)
In-patients: (No data)

0a-2.2: Psychological Effects of Treatment

Patients do not express their experience of the psychological effects of treatment. Thus, no data were collected for this category.

Out-patients: (No data)
In-patients: (No data)

0a-3: By the Involvement of Others

Whilst the involvement of others is intended to benefit patients, patients sometimes feel that, on occasions, they are not given the opportunity to influence their own circumstances. When patients sense that their feelings and experiences are not considered they felt *disempowered*, *ignored, or discarded.* Thus, patients become objectified and lacking in agency, and subjected to actions to which they do not respond or initiate an action in return.

0a-3.1: Feeling Disempowered

Patients feeling deprived of the power to make decisions experience themselves as made weak and having lost the ability to influence their circumstances.

Out-patients
OP1-8: ... you'll need to go to the _____
OP2: (No data)
OP3-47: … felt like a burden and…
OP3-91: … quite angry… I'd been left… batted back and forth… 18 months…
OP3-93: … cry… beg… _____ to have a look… sent to pain clinic _____ … need to go to hospital
OP4: (No data)

In-patients: (No data)

0a-3.2: Feeling Ignored

Patients' reveal that they sometimes feel disregarded, and not acknowledged.

Out-patients

OP1-87: … if my daughter was there… chatting to me about it… son doesn't want to talk… doesn't ask about feelings… other son … as if he was five…

OP2: (No data)

OP3-90: … some days when you feel… low…missed… talk to anybody on their system.

OP4: (No data)

In-patients: (No data)

0a-3.3: Feeling Discarded

Patients describe how they sometimes feel abandoned, forsaken, with interest in them relatively insignificant.

Out-patients

OP1: (No data)

OP2-57: I could ask questions… I don't know whether I'll get information…

OP2-66: I'd… liked another scan…

OP2-68: I'd rather they… trying something

OP2-70: … but they wouldn't do it…

OP3: (No data)

OP4: (No data)

In-patients: (No data)

0b: Despairing Self

Participants are cast into the unwanted circumstances of a life limiting illness that destroys their sense of agency. With the reality of their new experience, they become unhappy and disheartened with their world. Patients cannot make their lives personally manageable and so they experience horror, awfulness, and despair. Within the sub-category of the *Despairing Self*, participants communicate that their experience of despair is due to 1) the effects of their illness 2) the harshness of their treatment.

0b-1: Despair due to Illness

Deprived of hope and zest for life, patients must live with the truth about their physicality. Experiencing themselves as dispirited, participants have a deep sense of emotional suffering.

0b-1.1: Physical Effects of Despairing about the Illness

Patients are aware that they can neither remedy nor even improve their physical circumstances.

Out-patients

OP1-48: [T. Is death the end?] … that's what I'd love to know … I am a _____ I question it… I don't know.

OP2: (No data)

OP3-96: … cried my heart out every day… every day…

OP4: (No data)

In-patients: (No data)

0b-1.2: Psychological Effects of Despairing about the Illness

Patients experience themselves as dispirited, stuck and with impending doom due to emotional suffering.

Out-patients

OP1-45: … I just feel like jumping in front of a bus…

OP1-46: … the actual thought of death… that's my fright… my fear…

OP1-50: … wish … faith would come back… don't know if it will… scary… if nothing out there… what was all that life for?... if you just get buried… that's it.

OP2-64: … there is a darkness there…

OP2-65: It's frustrating…

OP2-74: … they went on… 48 hours to live… it's thrown everything…

OP3-45: … were dark days for me…

OP3-124: Yep, I get scared when it gets too sore, and I try and get up off my seat… using my sticks to get myself up. I think this is dreadful… when is this going to end.

OP4: (No data)

In-patients

IP1: (No data)

IP2: (No data)

IP3-7: I've not worked for about fifteen years…that was hard to take… devastating.

0b-2: Despair due to Treatment

Patients do not communicate whether treatment sees them in despair.

0b-2.1*:* Physical Effects of Despairing about the Treatment

Patients do not communicate that they experience despair due to physical effects with respect to treatment.

Out-patients: (No data)

In-patients: (No data)

0b-2.2*:* Psychological Effects of Despairing about the Treatment

Patients do not communicate that they experience despair due to psychological effects with respect to treatment.

Out-patients: (No data)

In-patients: (No data)

0c: Disappearing Self

Participants face the reality of an incurable illness and sense that it is threatening their existence. They experience fragility as their body is disrupted by illness. Whilst they are becoming more aware of their circumstances, participants are aware that they lack control over their circumstances and so cannot avoid the inevitable. Within this sub-category, participants communicate a) how the illness affects their physical existence and b) how that threat to their existence affects them from a psychological perspective.

0c-1: The Sense of Disappearing due to the Effects of Illness

As their bodies are disrupted with illness, patients experience interruption in their normal functioning that acts like a warning of threat to their fragile lives.

0c-1.1: Physical Effects of Disappearing due to Illness.

The reality of participants is that their illness cannot be stopped, with the result that they, as individuals, will disappear by no longer existing.

Out-patients

OP1-15: … in the back of my mind… think this is ____ two nodules ____ thought so…

OP1-67: … the one (blood clot) in my _____ has spread down _____ leg ____ tumour aggressive… growing fast… told me size…

OP2-42: I know this thing's gonny (going to) grow… grow till… it bursts.

OP2-45: … this… gonny (going to) kill me.

OP3: (No data)

OP4: (No data)

In-patients

IP1-37: … just it's (life) no going to last as long as it might have been.

IP1-38: … no lifestyle changes… life--style slowly get shorter… that'll be it.

IP2: (No data)

IP3: (No data)

0c-1.2: Psychological Effects of Disappearing due to Illness.

With increasing awareness, patients sense a lack of personal control needed to change their circumstances and so cannot not prevent the shortening of their lives.

Out-patients

OP1-28: … all I'm scared about is the actual dying part… when I'm going to...

OP1-38: … doctor did say it's time to make your will… I knew what he was telling me… refer you to palliative care… that's you.

OP1-108: … just feeling there's no future…

OP2: (No data)

OP3: (No data)

OP4: (No data)

In-patients

IP1-6: … when I started getting the same I said that's me on my way out…

IP2: (No data)

IP3: (No data)

Level 1: Limited Self

Participants take stock of their own personal sense of control and as they cannot escape from their diagnosis of a life-limiting illness, their unwanted limitations interfere with and diminish the quality of their every-day living. Participants express their experience of limitations regarding their a) physical body, b) capacity to be effective, c) lack of ability to make sense about what is happening to them and d) emotional disconnect from their circumstances.

1a: Bodily-Limited Self

Patients are aware that their bodies provide the means for active exploration of their environment. However, their bodies, are defenceless against the harm caused by illness, and so their physicality becomes not resistant to disease and pain, giving rise to giving rise to limitations. Participants try to judge the limitations of their personal agency within their circumstances.

1a-1: Physical Effects of Illness

Patients communicate that the physical effects such as pain, tiredness, and mobility issues, limiting their ability to move about freely and easily.

1a-1.1: Physical Pain

Out-patients

OP1-2: … had a burning sensation in my… hip

OP2: (No data)

OP3-6: … every day is hard… dealing with… pain… still… lot of pain

OP3 -85: … (pain) once it's built up… horrible… need to sit for a while

OP3-94: … I was… angry… really angry… getting bigger…

OP3-95: … pain was unbearable…

OP3-110: … every day you're reminded of it (cancer)… pain'll remind you…

OP4: (No data)

In-patients

IP1-66: I'll lie down… my legs are getting a bit sore

IP1-68: … because of where the cancer is … in the various spaces… if I sit too long… pain… down my legs

IP2: (No data)

IP3: (No data)

1a-1.2: Physical Tiredness

Out-patients: (No data)

In-patients

IP1-59: … now that I'm here… I'm too tired to do much else… just lie in bed

IP1-60: I lay on the bed… dosed… not so much sleeping…

IP2: (No data)

IP3-9: … I'm very tired…

IP3-11: … it's just exhaustion…

1a-1.3: Mobility

Out-patients

OP1: (No data)

OP2: (No data)

OP3-97: … could hardly walk for… lump

OP4: (No data)

In-patients

IP1-28: … when I'm in hospital… can't get up… wander about… put the kettle on if I want…

FP1-83: I'm stiff again (leg).

IP2: (No data)

IP3: (No data)

1a-1.4 Body Temperature

Out-patients: (No data)

In-patients: (No data)

1a-1.5: Other Physical Effects

Out-patients

OP1-9: They thought it was in my lungs as well …

OP1-107: … now… can't … eat the way I did… appetite is going… meal got left…

OP2-46: … but it's the lungs that give more problems.

OP2-47: … that's where my strength went… breathless…

OP3: (No data)

OP4: (No data)

In-patients

IP1: (No data)

IP2-20: … one (appointment)… have… toenails cut…

IP3: (No data)

IP4: (No data)

1a-2: Physical Effects of Treatment

Participants communicate that treatment can bring constant, unpleasant side-effects like sickness, headaches and hair loss. Unwanted as these side-effects are, participants are not able to stop them occurring or even diminish them "*constant sick; hair fell out.*"

1a-2.1: Sickness/Headaches/Diarrhoea

Out-patients: (No data)

In-patients:

IP1: (No data)

IP2: (No data)

IP3-22: … and I'm covered… floor's covered… that's the toilet

1a-2.2: Loss: Hair/ Toenails/ Appetite

Out-patients: (No data)

In-patients

IP1-13: … the hair… cover it… scarves… hats… wouldn't go out of my way to avoid crowds… what ever is going on.

IP2: (No data)

IP3: (No data)

1b: Non-Functional Self

Participants are deprived of strength and power due to both their illness and their treatment and discover that their resourcefulness is wanting and so see themselves as a) helpless b) vulnerable and c) ineffective, with no ability to act or react. Within this sub-category, participants describe how the feeling of being non-functional affects both their physical and psychological well-being.

1b-1: Patients Experiencing Themselves as Helpless

As participants do not experience a sense of being in control, they are unable to do anything to help themselves.

1b-1.1: Due to Physical Effects of Illness

Out-patients

OP1: (No data)

OP2-34: I couldn’t go out walking the hills or…

OP3-81: … getting out depends on… other people to help

OP4: (No data)

In-patients: (No data)

1b-2: Patients Experiencing Themselves as Vulnerable

Participants do not communicate that they feel exposed to harm and so do not experience themselves as safe, physically, or emotionally.

1b-2.1: Physical Effects of Vulnerability due to Illness

Patients do not express that they feel vulnerable due to physical effects of illness.

Out-patients: (No data)

In-patients: (No data)

1b-2.2: Psychological Effects of Vulnerability due to Illness

One out-patient experiences apprehension and anxiety as they are aware that, because of their illness, they are open to attack and unable to not protect themselves.

Out-patients

OP1: (No data)

OP2-76: … but what can you do… if they refuse…

OP3: (No data)

OP4: (No data)

In-patients: (No data)

1b-3: Patients Experiencing Themselves as Ineffective

One outpatient Participants express that they experience themselves as inefficacious, inadequate.

1b-3.1: Physical Effects of Feeling Ineffective due to Illness.

Patients perceive themselves as inefficacious, and inadequate.

Out-patients

OP1: (No data)

OP2-28: … it's (illness) left me weak about doing anything… physical… things.

OP2-29: I'm no as much a help around… the house.

OP3-58: … simple things… dish washer… I canny (cannot) lift the plates… all together…

OP3-87: … want to get up… do stuff… that's when it hits me… canny (cannot) do sometimes

OP4: (No data)

In-patients

IP1: (No data)

IP2: (No data)

IP3-4: I can't drive anymore… killing me… I love driving

IP3-5: Can't play with the grandkids… can't go… back garden… play with them…

1b-3.2: Psychological Effects of Feeling Ineffective due to Illness.

Out-patients communicate that they cannot bring about any significant or desired change as they have no effect on their circumstances.

Out-patients

OP1-102: … I couldn't do what I would have liked to have done…

OP2-33: … it canny (cannot) be too physical.

OP2-71: … nothing I can do.

OP2-72: Where do I turn… mixed messages… looking at scan…

OP2-87: … nothing you can do… you feel helpless at times.

OP3-39: I get annoyed… all the things… I used to do… I need help with

OP3-46: I felt inadequate… like a child

OP3-82: You don't wasn't to be a burden

OP4: (No data)

In-patients: (No data)

1c: Strongly Puzzled Self

Participants perceive themselves as not knowing or understanding what is happening to them and so they feel puzzled, troubled, and uncertain in the world in face of missing personal resources. They experience that they function differently and that life circumstances have changed and so find it difficult to form judgements that provides them with clarity of their experiences.

1c-1: Patients Experiencing Themselves as Troubled

Due to their illness and treatment, participants experience themselves as troubled, at a loss, as they are beset with problems.

1c-1.1: Troubled by Physical Effects of Illness

1b-3.2: Psychological Effects of Feeling Ineffective due to Illness.

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Due to their illness and treatment, participants experience themselves as troubled, at a loss, as they are beset with problems.

1c-1.1: Troubled by Physical Effects of Illness

Patients experience new, visible signs and/or unpleasant physical sensations, and express that they are unable to control the occurrence of these signs or symptoms.

Out-patients

OP1-6: … got a letter… scan… told me… you've got ________
OP2-49: I feel that's (breathing) got worse.
OP2-60: … is it bleeding… getting bigger
OP3-64: Left such a hole… take muscle from my leg… though I had… heart attack… took muscle from my stomach… put in my back… no bone at ____... no pelvis… no structure… shouldn't… be walking
OP3-89: … when I'm feeling rubbish like that I… can't… do… much… hands… shaking… kicks off… cycle of pain…
OP3-92: … lump… size of a grape… size I was holding in my hand…
OP4: (No data)

In-patients: (No data)

1c-1.2: Troubled by Psychological Effects of Illness

Whilst out-patients express that their new circumstances disrupt their normal functioning, they cannot understand their dilemma and so are perturbed, unsettled, and a loss of mental calmness.

Out-patients

OP1-1: …had the cancer for quite a while without anyone knowing...

OP1-7: …knowing nothing about it ____ they didn't ____ know ____ doctors didn't know.

OP1-30: … I'm worried… I drop dead at their (grandchildren) feet…

OP1-32: … it terrifies me… if I was to drop dead when they're (grandchildren) there…

OP1-51: … friends don't believe you … because I seem OK and I… still go to things…

OP1-82: … I'll miss them (grandsons)… that's my feelings… my biggest worry.

OP1-90: … often lie and think I can feel… lump… blood clot… twinges… think it's ready to burst… oh my God…

OP1-109: … I find it hard to know if there's a God… struggle with it… all the time… question it… what happens when I die…

OP1-121: Sometimes I broach the subject… he (husband) "forget about it" … but he'll have to…

OP1-123: The leaving I'm upset about… because I love these grandchildren…

OP2-52: … went about a year and a half… without them doing anything.

OP3-64: Left such a hole… take muscle from my leg… though I had… heart attack… took muscle from my stomach… put in my back… no bone at ____... no pelvis… no structure… shouldn't… be walking

OP3-89: … when I'm feeling rubbish like that I… can't… do… much… hands… shaking… kicks off… cycle of pain…

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OP1-123: The leaving I'm upset about… because I love these grandchildren…

OP2-52: … went about a year and a half… without them doing anything.

OP2-53: … probably… would have been done then… they might have realised…

OP2-58: I could phone… find out… need to see how it goes.

OP2-59: … it's no going to happen… get a… scan… see… situation

OP2-61: …known for a few years…

OP3-107: … some things I can do… hard to get yourself to think to do that (accept).

OP3-111: … one time I couldn't even look at my self…. devastated

OP4: (No data)

In-patients: (No data)

1c-1.3: Troubled by Lack of Effectiveness of Treatment on Physical Body

One out-patient is aware that treatment is intended to relieve symptoms but is also treatment does not always provide the outcome they expect.

Out-patients

OP1: (No data)
OP2: (No data)
OP3-3: I'm unsure… the doctors… whether it's the right treatment sometimes
OP4: (No data)

In-patients: (No data)

1c-1.4: Troubled by Lack of Effectiveness or Inappropriateness of Treatment on Psychological Well-being

No data was provided for this category.

Out-patients: (No data)

In-patients: (No data)

1c-2: Patients Experiencing Themselves as Puzzled and Confused by their Current Status of Illness and Treatment

Patients are muddled and so find difficulty in understanding their new-found circumstances.

1c-2.1: Puzzled and Confused by the Current Status of Illness, from a Physical Perspective

As patients are unable to make sense of the information given to them about their illness, they want an appropriate professional to explain what was happening to their bodies.

Out-patients

OP1-11: … doctor… I can't operate on you… too far gone… can give you chemotherapy.
OP2-63: Somebody… say… bleeding… somebody else… cannot see… bleeding …

OP3: (No data)

OP4-19: … it's something that's moved somewhere else your cancer… that's how it's been left.

In-patients

IP1: (No data)

IP2: (No data)

IP3-8: (crying) surgeon said we'll fix it in six months… you'll be back up…

IP3-20: I… lost the plot… shouldn't have… knew what stages were…

IP3-21: … was my fault… I didn't put anything over my ____ bag…

1c-2.2: Puzzled and Confused by the Current Status of Illness, from a Psychological Perspective

Patients communicate that they have difficulty with the assimilation of information about their illness, experiencing themselves as baffled and unable to give reasoned judgements that were logical and well-thought.

Out-patients

OP1-12: … will it extend my life… they said no.

OP1-105: … I… went down… pinning all my hopes on Christmas… don't really care after that… got a… bit deflated… feeling down in the dumps.

OP2-48: … that upsets me more… strangely

OP3-65: … cancer comes back… don't think… ever away… always be… in my mind… don't think that's going to change… think sometime… future… it'll be back

OP4: (No data)

In-patients

IP1: (No data)

IP2: (No data)

IP3-32: [T. Taking things for granted?] Yeah I didn't know if I was or not in myself… yeah.

1c-2.3: Puzzled and Confused by the Physical Effects of Treatment on the Current Status of Illness

Patients did not provide data for this category.

Out-patients: (No data)
In-patients: (No data)

1c-2.4: Puzzled and Confused by the Psychological Effects of Treatment on the Current Status of Illness

Patients did not provide data for this category.

Out-patients: (No data)

In-patients: (No data)

1c-3: Effects of the Unexpected

Participants find difficulty in absorbing what has become reality, the unplanned diagnosis of a life limiting illness and effect of treatment.

1c-3.1: Physical Effects of the Unexpected due to Illness

With no knowledge or indication prior to its happening, patients communicate that they are faced with an incurable illness, with its impact manifesting itself in ways that they could not forecast.

Out-patients

OP1-1: … had … without anyone knowing
OP2: (No data)
OP3: (No data)
OP1-4: … but had to go to hospital … scan… found two nodules on my lungs… secondaries… didn't know where the primary was.

In-patients

IP1-35: Given the disease… it can play up… for me it's (waiting) the most sensible solution.
IP2: (No data)
IP3: (No data)

1c-3.2: Psychological Effects of the Unexpected due to Illness

Patients communicate that they do not have the ability to understand why their circumstances has left them unready to deal with their situation.

Out-patients

OP1-24: I don't think I'll be at… whatever occasion they're talking about.
OP1-36: … I didn't think I'd get to this stage… thought I'd be away by now.
OP1-71: … I'm going to put you on palliative care…wee bit of a shock…
OP2-50: … don't know why they continue but… got an appointment… hospital.
OP2-51: … to me only interest… how worse it's got…
OP3: (No data)
OP4: (No data)

In-patients: (No data)

1c-3.3: Psychological Effects of the Unexpected due to Treatment

Out-patients

OP1: (No data)
OP2: (No data)
OP3-88: … pills… I said to GP… they're making me… sometimes stutter if I get anxious… never done that before… drugs…
OP4: (No data)

In-patients: (No data)

1c-4: Patients Experiencing the Effects of Uncertainty

Participants do not have sure knowledge about what is going to happen to them and so they are unclear with respect to their future. Illness and treatment both give rise to uncertainty and their effect is both physical and psychological.

1c-4.1: Physical Effects of Uncertainty due to Illness

One out-patient reveals that they engage in internal dialogues to arrive at a conclusion about their physical situation from partially known or assumed information.

Out-patients

OP1-68: I just want to know… kill me next week… growing two centimetres… not very big… but maybe three centimetres kills you… don't want to know that…

OP2: (No data)

OP3: (No data)

OP4: (No data)

In-patients: (No data)

1c-4.2: Psychological Effects of Uncertainty due to Illness

As patients experience their world as less stable, they are no longer confident about how to relate to it. They experience a lack of surety, with no clear ideas of what they want to do or achieve.

Out-patients

OP1-5: … they said (health care) it's maybe not that… don't worry about it.

OP2-62: They changed their minds… said… couldn't find the source.

OP3: (No data)

OP4: (No data)

In-patients

IP1-77: … no point in saying… good bad or indifferent… not doing that until… final confirmation.

IP1-78: … I am inverted commas… looking forward to … black and white… you can go… everything is fine… no last problems

IP2: (No data)

IP3: (No data)

1c-4.3: Psychological Effects of Uncertainty due to Treatment

No data were provided for this category.

Out-patients: (No data)

In-patients: (No data)

1d: Detached Self

As participants receive information about what is happening to them, they appear to have some degree of awareness of experiencing themselves as emotionally detached from their unwanted circumstances. They refer to what is happening to them but, at the same time, the happening appears independent of them and not part of their lived experience.

1d-1: Detached due to Psychological Effects of Illness

One in-patient hears what they were told about their diagnosis but, at the same time, information appears independent of them.

> **Out-patients:** (No data)
>
> **In-patients**
>
> IP1-65: I don't think I react to anything happy… sad
>
> IP1-76: … I'm not reconnecting with anything until I've got it in black and white… .
>
> IP1-81: … district nurses… carers… care package in place…
>
> IP2: (No data)
>
> IP3: (No data)

Level 2: Reflexive Self

Participants are becoming more self-aware and experience an internal sense of agency that sees them strive for self-preservation, despite their incurable illness. Participants feel dissatisfied that their identity before their diagnosis has become different or even replaced by another identity, bringing with them the feelings of loss and lack of personal control.

2a: Changed Self

As the *Changed Self,* participants communicate a halt to their usual selves, with their identity prior to their illness becoming transformed during their illness.

2a-1: Participants Experience Themselves as having Become Different

Patients feel that they are recast in a new identity that does not represent their self-image, self-esteem, or individuality. The change in identity is perceived as troublesome and disruptive.

Out-patients

OP1-103: … normally I was the one did all the… for everyone…

OP2-7: … don't make plans like I used to.

OP2-30 … probably as I could be…

OP3-28: I was always a chatty person before

OP3-106: I… see changes… accepting… I canny (cannot) go as fast… I used...

OP4: (No data)

In-patients

IP1-55: It's (now) quite enjoyable… till… this year… never had a day's serious illness in my life… nothing serious…

IP2: (No data)

IP3: (No data)

2a-2: Participants Experience Themselves as having Become Replaced

No data was collected for this category.

Out-patients: (No data)

In-patients: (No data)

2b: Defiant Self

Even if illness results in dramatic changes in their living, all patients do not experience themselves as defeated, resisting to accept or comply with their illness and self-defeating ways of feeling and thinking about their circumstances.

2b-1: Participants Resist to Accept/Comply with their Illness.

Some patients are non-defeatist, experiencing themselves with increased self-determination, aiming to maintain independence and continuity by standing up to illness and death.

Out-patients

OP1: (No data)

OP2: (No data)

OP3-4: I look in the mirror… it's still me

OP3-48: I don't need you to be quiet… feeling sorry for me… I'm here… I'm still alive… don't make me feel conscious of my illness

OP3-75: …I'm no such a burden that I canny (cannot) get in their car… I can

OP4: (No data)

In-patients

1P1-39: [T. … something… protects you?] Don't know if it protects me… could be being a realist a pragmatist … protective shield against

IP2: (No data)

IP3: (No data)

2b-2: Participants Resist to Accept/Comply with Self-defeating Attitudes.

As patients experience a greater sense of control, albeit an internal sense of control, they avoid emotional disengagement and face their distressing thoughts and feelings.

Out-patients

OP1: (No data)

OP2: (No data)

OP3: (No data)

OP4-26: … I think they're all getting fed up with me (standing up for self).

In-patients

IP1-40: …I'm not an introvert that goes… deep searching for meaning… I am me… full stop.

IP2: (No data)

IP3: (No data)

Level 3: Collective Self

Patients' experiences of their incurable illness limit or even prevent them from making their own decisions about their circumstances; as a result, they may seek what they need through collaboration with others.

3a: Relinquishing Self

Participants, as the *Relinquishing Self*, are not actively engaged in decision-making but, rather, allow themselves to pass their autonomy to appropriate others who they expect will respond prudently to their needs.

3a-1: Handing Over of Autonomy with respect to Illness

Participants are confident that the relevant others, who have knowledge, expertise, and experience, will respond with wise and well-judged decision-making.

Out-patients

OP1: (No data)

OP2-43: … I'm told that's… medical fact… I canny (cannot) dispute that.

OP3: (No data)

OP4: (No data)

In-patients

IP1-3: … he took one feel… sent me to ______ … general… local… scan

IP1-31: I'm not thinking about going home… a lot can happen… now and T __

IP1-32: It was an indifferent feeling… I got told at _____ but… this disease… kidney… develop other symptoms… could develop this… that… until… you're free to go… I'm here

IP1-34: … there's no point in saying… suddenly… sorry can't… something happened… way I've been… get the green light.

IP1-62: Pain-killers doing job at the minute… they've got it under control.

IP1-74: … guessing… get list… times… district nurses… carers coming in… all the various bits and pieces.

IP2-21: I leave that to… podiatrist…

IP3: (No data)

3a-2: Handing Over of Autonomy with respect to Treatment

One out-patient communicates that they are confident that the relevant professionals will choose the treatment that best meets their needs.

Out-patients

OP1: (No data)

OP2: (No data)

OP3-100: … got a phone call… get a biopsy…

OP4: (No data)

In-patients: (No data)

3b: Active Collaborating Self

The experience of a significant life event like a life-limiting illness prevents the participants from living their lives in individual autonomy and so they choose to l co-operate with others, including helpful professionals, family, and friends.

3b-1: Collective Agency/Efficacy with Helpful Others

Patients willingly engage in collaboration with others, who they believe, can help them in their decision-making, regarding their circumstances.

3b-1.1: Healthcare Professionals

Patients actively engage in collective decision-making with healthcare professionals, expressing a sense of motivation, indicating increased personal agency.

Out-patients

OP1-39: … nurse at _____ have anything to ask I phone him…
OP1-40: … he tells me… I said… what's likely to happen…
OP1-65: … spoke to ____ scans… better than expected…
OP1-69: … he's (nurse) very nice to me… and the doctor took my hand… time … your affairs in order…
OP2: (No data)
OP3: (No data)
OP4-31: … (doctor) we'll need to have a talk… stay in your own house… hospital… I said hospice.

In-patients

IP1: (No data)
IP2-18: … always in total charge… except… go on medical supervision… or…. appointment
IP3: (No data)

3b-2: Therapist

Patients use socially appropriate expressions to communicate mild and polite appreciation.

3b-2.1: Therapist: Mild Appreciation

Out-patients

OP1-100: … that was fine.

OP1-153: Aye… your welcome… your welcome.

OP2: (No data)

OP3-61: This is good… never spoken to anyone about my illness…

OP3-84: [T. … OK for today?] Uh hu… that's grand

OP4-21: … that was good… good to do that…

In-patients

IP1-30: That's fine.

IP1-54: You're welcome.

IP1-69: If you want to come then… [T. That would be lovely.] Yep… you can do that.

IP1-70: … any time after… breakfast… morning medications… so any time after… best time to come.

IP2: (No data)

IP3: (No data)

3b-2.2: Therapist: More Heart-felt Appreciation

Patients express sincere, stronger, more heart-felt appreciation.

Out-patients

OP1-86: … I'm glad to have this … chat today…

OP1-146: … it's good to get a … chat here… and… anonymous… I don't need to think… don't… need to tell things to people I don't want them to know…

OP1-147: … good… great… how many more?... that's good… so I'll be back next week hopefully… as long as that's OK [T. Yes… I look forward to it.]

OP2-88: I enjoyed it (counselling sessions) … it's nice to look into yourself… thank you.

OP3-29: I know you're listening… it's a privilege to have in life someone to talk to… somebody to hear… you're there

OP3-115: [T…. place to finish…] Most definitely… on a very positive note this week… tell you next week. [T. Looking forward to it…]

OP4: (No data)

In-patients

IP1: (No data)

IP2-33: It's nice talking to you [T. thank you… sharing that.]… it's nice to share that with you… [T. … yes it is.]

IP3: (No data)

3b-3: Family Members

Patients work jointly with particular family members in order to make decisions about their illness and its impact on their living.

Out-patients

OP1: (No data)

OP2-19: We'll need to I suppose…

OP2-20: I'd just dropped my granddaughter… watching her… couple of days…

OP2-21: … she (granddaughter) was in the car… saying cheerio to her…

OP2-23: [T. … you talk about it with… ?] Oh… aye… aye… the family… daughters… son…

OP3: (No data)

OP4: (No data)

In-patients

IP1-48: … she'll (cousin) have the list of what I want to do…

IP2: (No data)

IP3-3: We have to work out what the morning's going to be like… arrange… with my daughters… sons-in-law…

IP3-6: … older two (grandkids)… chat with me…

IP3-31: …it's up to them (mums and dads)… (to tell grandchildren)… they know I've got a sore stomach… want's to know when will I get better…

3b-4: God/ Friends/Clergy

One out-patient expresses that they perceive God and friends as helpful others.

Out-patients

OP1: (No data)

OP2: (No data)

OP3-72: I'm no ungrateful that they're coming to see me… happy to see them

OP4: (No data)

In-patients: (No data)

Level 4: Reacting Self

Participants, through an increasing sense of awareness, internally respond to their individual circumstances, and carefully appraise their illness.

4a: Avoiding Self

Participants react to their circumstances in ways to help them better control their anxiety in the face of what is happening to them and so try to mentally distance themselves through psychological strategies brought into play by the unconscious mind.

4a-1: Patients try to Escape form their Stressor

Patients try to escape from their diagnosis/prognosis by mentally removing themselves from their difficult situation.

Out-patients

OP1-20: … six weeks… as long as that… I can't remember …

OP1-22: … I joke about it… only way to deal with it…

OP1-93: … I do get… mad thoughts now and again… suppose everybody does… if you know you've got something wrong…

OP2-4: … no got round to it yet.

OP2-5: No too keen in making long term plans.

OP3-31: … come to… hospice… don't have time to reflect… when I'm here… everybody's accepting… just get on with it… we don't mention it

OP3-32: … it's a day away from thinking about it constantly… so… good

OP4: (No data)

In-patients

IP1: (No data)

IP2-13: … when I was diagnosed… don't want… think about that… I think you'd run away…

IP3-29: … if I talk about normal things that's great.

4a-2: Patients Playing Down their Stressor

Patients use defence mechanisms, such as minimising, rationalising and distracting, to protect themselves from psychological damage arising from the reality of the diagnosis of a life-limiting illness.

Out-patients

OP1-77: … I'll maybe kid him on... don't you try and jump in front of me (in the queue… (for dying)

OP2-75: I felt they were talking about someone else… my scan…

OP3-34: …I'm feeling no too bad today… yesterday… sore… it is what it is… moan

OP4-4: … sitting here… not as breathless… so … don't believe… got cancer

In-patients

IP1-18: … the way I am now… have lunch… sleep… get up… kids… come round… see me… blether with them… play with them…

IP2: (No data)

IP3-16: At the moment… everything is tickety-boo…

IP3-27: …I say I feel fine… let's get on with it… what are we doing now?

4b: Coping Self

Patients consciously take stock of their physical, psychological, and social resources, in relation to their circumstances. Whilst their coping remains an intra-personal process, from the perspective of selves to their circumstances, they selectively affirm those aspects of their illness they perceive as positive, whilst complain and protest about those they identify as negative.

4b-1: Patients as Complaining /Protesting

Patients experience a drastic change in their every-day living and so feel aggrieved, expressing angry irritation through complaining and protesting.

4b-1.1: Patients Complaining/Protesting about Aspects of their Illness that they see as Negative.

With full awareness, patients react by expressing their feelings of dissatisfaction and annoyance due to the physical effects of their illness.

Out-patients

OP1: (No data)

OP2: (No data)

OP3-35: … I try different things… realise I canny (cannot)… sit down… get sore

OP4-2: … at times… feel rough… during the night… breathlessness.

In-patients

IP1-68: I mean… doing nothing… killing time until… transport ready.

IP2-22: … lying here… want a new set of teeth… lost four and a half stone… my teeth… new… tried… dentist to come in…

IP3-2: I had a nice family relationship… still have… but… could do things with… family… now… strenuous on me… family

4b-1.2: Patients Complaining/Protesting about the Impact of Negative Aspects of their Illness on their Psychological Well-being

Patients, with full awareness, come to understand that what has negative impact on their physical being also has a negative effect on their psychological well-being.

Out-patients

OP1-25: … tend to wake up at 3 o'clock in the morning… lie awake… thinking about a funeral… what's going to happen …

OP1-27: … always seems to be in the middle of the night it comes…

OP1-60: … other peoples' opinions about how I should be dealing with it can affect me… they'll say "There's nothing wrong with you … you'll see us out."

OP1-63: … don't like to hear anybody dying… upsets me… I think… I'm getting nearer the end of the queue…

OP1-106: … I've hardly been out… maybe a fortnight or three weeks…

OP1-114: … felt God cheated me… not for me but for children… feel sorry for them… but I suppose everybody gets crosses to bear… have to accept it…

OP2-67: … told me they couldn't operate… I'd rather they did… and I died on the table…

OP3-13: I don't think I would have (liked to have talked)… I don't think it (diagnosis) is a weight on my chest… just angry

OP3-14: … when I got my diagnosis… was God's fault… I didn't go to church… He (God) should have known better… I've never done anything to deserve it… never… hurt anybody

OP3-19: You lose your independence

OP3-23: I'd rather they (people)… treat me the same… I've no… said… don't fuss… I did say to my husband… he went look you need to be careful

OP3-24: I miss the independence… no getting out… depend on someone else… take me

OP3-30: … feels like better days… bit happier… pain subsides… never away… always there

OP3-33: If they're (friends) are dwindling… start to think about yourself… worry… scared to ask

OP3-36: … frustrating when you can't do it or do you accept? I can't do that just now… angry with myself

OP3-37: Angry with my self… on my sticks… was very house proud… now I feel as though everything has went to the dogs

OP3-38: I don't like it when they tell me you can't… don't touch that… makes me angry

OP3-42: … sitting doing exercises… strange… takes a lot of acceptance… takes a long time

OP3-51: … lot of people… see you in it (trolley) I try to avoid them because it's the saddest thing… like… don't want them to feel sorry for you… doesn't help you

OP3-54: … it's like I was the cancer… constantly and it was me me me… I'm still here it's still me… why treat me as… different person

OP3-68: … sometimes… go out… before… now… if I have no got my sticks… got my… stroller… people… no respectful… bump into you… move you… horrible… I feel angry inside

OP3-76: … sometimes you're scared of response… are they going to say "Do you not want me to visit… or…"

OP3-86: … I canny (cannot) sit it (pain) out… frustrating…

OP3-116: … maybe my week didn't pan out… as well as I expected…

OP3-123: I feel that I can control it a wee bit better definitely… em… it's just pain… if the pain's really bad then I get kind of veered in another direction…

OP3-126: … when I've got the pain… feel a bit sorry for myself… when I'm getting down…

OP4-15: … I think that…. would put me down… having to get carers… come… do what they had to do… gone away… and I'd have gone back to bed… till time for them to come back…

In-patients

IP1: (No data)

IP2-23: … you could get to look at the other side of the pond.

IP3-23: … frustrating… especially when… close to the toilet…

4b-1.3: Patients Complaining/Protesting about Aspects of their Treatment that they see as Negative.

With full awareness, patients react by protesting about the physical effects of their treatment.

Out-patients

OP1-17: … what would be the point… make myself ill… I'm going to die … rather have a good year.

OP1-18: I don't see the point… my daughter had been all through it…

OP2: (No data)

OP3: (No data)

OP4-7: … they did stop it on 15 weeks…rather than 17… was beginning to get a reaction… I collapsed… stopped it…

OP4-8: … I don't know if I'd go for it (treatment) again… I couldn't do anything.

OP4-11: … it (treatment)… stays in your system for… while… maybe where tiredness is coming from…

OP4-18: I've been drained three times… not… again because… infection.

In-patients: (No data)

4b-1.4: Patients Complaining/Protesting about the Impact of Negative Aspects of their Treatment on their Psychological Well-being

One out-patient, with full awareness, communicates that what they perceive as negative aspects of their treatment has also impacted negatively on their psychological well-being.

Out-patients

OP1: (No data)

OP2-73: I knew all along… getting worse… was going to… the end…

OP3: (No data)

OP4: (No data)

In-patients: (No data)

4b-2: Patients as Acknowledging/Accepting

Patients react, with full awareness, by no longer turn away from their feelings but to be open and choose to face the truth.

4b-2.1: Acknowledging/Accepting Physical Aspects of Illness Perceived as Positive

Patients acknowledge their life-limiting illness, actively affirming those perceptions that activate constructive, helpful experiences of themselves in the context of their illness.

Out-patients

OP1-13: I think I expected the news.

OP1-52: … some days I… stay in bed… if I've not had a good night… lie quietly… maybe read a book…

OP1-53: If I'm not in pain… can put… emotional side away… think about that tomorrow… tomorrow's worries

OP1-89: … going back lying in bed… couple of hours… when I got up I was OK… not even pain… kind of a downer… come out of it again…

OP1-92: … I go to sleep… wake up… fine again

OP1-94: You worry that's going to… thing that'll carry me away… but… I'm still eating… everybody says… you've no lost weight… everybody in the situation has.

OP1-149: … I was just lying in bed most of the day… could sleep… 16 hours without getting up… other than toilet… going back to sleep…

OP2: (No data)

OP3-17: … it canny (cannot) all be about me… why do I complain… about my pain… I can get up… shower

OP4-3: … breathlessness… took me to the doctors… discovered… fluid around lung… and ______ cancer.

OP4-5: I think they're just telling me that… because… no pain…

In-patients

IP1-4: … I was kind of expecting it at the time… was relieved… thought that's what I had… now got official medical diagnosis…

IP1-5: …they thought it would be curable… it wasn't… aggressive… I knew the symptoms my grandmother had…

IP1-8: … 'cause I was half expecting it… what I knew about my grandmother…

IP1-36: Nothing's changed it's the same… nothing's really changed… I wouldn't say life has changed… not an emotional person… difficult to say… life is still the same…

IP1-57: … both my paternal grandparents… paternal great grandfather… great great grandmother… died from _____ so I got it… wasn't surprised… genetics… was relief… medical diagnosis

IP1-71: … one thing… cancer and treatment never took away my appetite.

IP1-84: … I never bother with visitors coming here… two hour trip… have half hour conversation… bit of a waste of time for me. [T. … missed conversation?] No.

IP2-3: cancer give me a new lease of life.

IP3: (No data)

4b-2.2*:* Acknowledging/Accepting: Psychological Impact on Physical Being

Patients come to understand that what has impact on their physical being also affects them psychologically.

Out-patients

OP1-16: … went to ____ to see consultant… she said could do chemo.. but I said only if ____ gives me time …

OP1-23: I'm not pessimistic… just factual…

OP1-26: … then I have to say enough… put it in the box and get to sleep.

OP1-31: … when one of them (blood clots) goes… I'll just go… no way of telling when or how.

OP1-35: … don't really make plans… go with the flow…

OP1-37: … they gave me 12 to 18 months… 2 years 3 months ago… over my time… longer than I though I would have got…

OP1-41: … you need to go into palliative care… wasn't particularly shocked… I must be due to go.

OP1-61: … I'll say I'm just a wee bit ahead of you in the queue… I've jumped the queue… you're behind me…

OP1-70: …I says… knew it was terminal... you're not shocking me…

OP1-105: … I think I sat down… can't do any more… done enough… would be a quick decline…

OP1-131: I'm no going to buy tickets… I'll definitely no be here… quite sure… leave it nearer the time… if… felling all right…

OP1-132: … don't really make plans for the future..

OP1-133: …I think I'll no be here then… so it (future) doesn't mean anything…

OP1-138: …it's (life) quite grey…

OP2-1: [T. … making plans?] I don't make them too … much in the future.

OP2-25: Getting used to it (illness) is the wrong word.

OP2-31: I've gotten used to it (illness)…

OP2-38: [T. So it's accepting…?] Aye… definitely aye.

OP2-41: [T. Is that a hope?] Naw (no)… I don't think… there's any chance of it.

OP2-44: … just got to live with it.

OP2-54: … it's all water under the bridge now…

OP2-55: I just have to accept…

OP3-67: Don't make plans too far ahead… make some plans

OP4: (No data)

In-patients

IP1-1: [T. …diagnosis a surprise…?] Not really … felt a lump… my grandmother died from ______ when I felt the lump… thought that's no right…

IP1-7: … they said… terminal diagnosis… didn't come as a surprise

IP1-9: … I went on doing what I was doing until it got changed… and in hospital… infections…

IP1-10: … I'm not an emotional person… pragmatist… got this disease… it's going to kill me…

IP1-16: [T. Does uncertainty bother you?] No!

IP1-24: I never… get upset about… much.

IP1-33: … I'm a pragmatist… until there's a paper saying… go home… not going home.

IP1-43: [T. … feels like… helpful?] Yea… suppose… never thought about it that way.

IP1-56: … not exactly (a shock)… when I felt the lump I thought… probably ____ went to GP… sent me down… came back as _____ wasn't a shock… more confirmation…

IP1-58: …they thought… try to cure the tumour… get it off… aggressive… got rid of the old tumour… new tumour more aggressive… less susceptible to… drugs… they came in… I ended up terminal.

IP1-86: Change is inevitable if… gradual… cancer from big lump… all through…

IP1-89: … part of my personality… realist… pragmatist… don’t sit down… oh woe is me… got cancer… I’m dying.

IP1-91: I’ll just lie here and dose… whatever’s coming.

IP2-2: No… being angry doesn’t solve anything.

IP2-8: … got to go sometime I suppose I don’t worry about it all… not afraid…

IP2-9: (life)… very precious… what have you got… take away all the material things… left with… nothing.

IP3: (No data)

4b-2.3*:* Acknowledging/Accepting the Impact of the Positive Aspects of Treatment /Surgery

Patients communicate their experience of treatment /surgery as positive, with both aiming to keep them alive.

Out-patients

OP1-19: ...the doctor … could offer… radiation… to kill pain… did six weeks.

OP1-21: … it (radiation) got rid of it (pain)… over a year… I didn’t have pain.

OP1-148: …doctors putting me on these… tablets… given… strength back…

OP2: (No data)

OP3-18: … first got out of hospital… couldn’t do anything… now I can… go to the …myself… shower myself… got… bit of something (control) that I’ve lost

OP4: (No data)

In-patients

IP1-27: … I’ve got it (pain) reasonably under control.

IP1-80: … pain’s under control… can sleep… all through… so doing not too bad that way.

IP2: (No data)

IP3-10: … slept… better yesterday… got a sleeping tablet… relaxed… next thing I knew… was six in the morning…

4b-2.4*:* Acknowledging/Accepting the Psychological Impact of Positive Aspects of Treatment

Patients acknowledge that what they perceive as positive aspects of their treatment have positive impact on their psychological well-being.

Out-patients

OP1-42: … controlling the pain… they would fix it… here… given me a great deal of comfort…

OP1-54: … if my pain's bad… take pain killers… they do work… couple of hours… settle down…

OP2: (No data)

OP3: (No data)

OP4-6: … never had sickness during (treatment)

In-patients: (No data)

4c: Morally Evaluating Self

Patients hold standards of right and wrong that serve as counsel. Hence, they consciously engage in the process of self-regulation and monitor how they react to their circumstances to judge what they feel is appropriate within their circumstances. Moreover, they express how they conduct themselves by translating their moral thoughts into moral conduct.

4c-1: Patients Showing Consideration for Others

Patients show kindness by considering the feelings, thoughts and needs of others.

Out-patients

OP1-34: … frightened it (death) happens up there… I don't want a fuss… don't want them (grand children) to get upset…

OP1-44: … wouldn't like my husband left with the memory… he gets… upset

OP1-73: … I've spoke to them… don't … crying… don't want them upset…

OP1-76: …husband doesn't want to talk… bursts out crying… I'll say… "don't get upset"… now I don't talk about it…

OP1-79: … worrying about him (husband) and the boys… if… boys… would accept it quickly…

OP1-91: … I'll be in my bed…. be over and done with… the boys aren't here

OP1-120: … worries me how he'll (husband) manage…

OP1-122: … I've told him (husband),,, keep going… your social life… talking to men… nights out… don't sit in house… TV seven days a week…

OP1-130: … I hope it doesn't affect them in later life…

OP2-6: … it's only going to disappoint everybody if I say…

OP2-22: I don't know if she knows… told them it's a hospital…

OP3-15: … unfair… thought about it… it's me… would you rather… your husband… one of your sons… better me

OP3-83: I suppose everything's new for them as well… if I don't ask… they think I don't need them

OP4-30: … I'm going into… hospice… would be easier for my family…

In-patients

IP1-21: … if I ever get discharged… go back home… arrange my funeral… so my cousin… doesn't have so much to worry about…

IP1-51: … saves a lot of hassle for them once I've gone…

IP1-91: … probably that's why I'm more accepting… the practical side… had to work out what he (elderly father) wanted for his funeral… sort… financials affairs… solicitors… I knew I was going the same way… so I said 'no'… get practical stuff out of the way… my cousin doesn't have to sort out… when time comes… funerals… rest of it.

IP2: (No data)

IP3-26: … when they(family) see I'm on a downer…."Are you all right dad"… "Are you sure"… they know I'm no…

4c-2: Patients Showing Gratitude/Appreciation/Respect

Patients communicate that they are thankful for the help and support received from others and hold these others in high regard. Also, patients are grateful for the positive effects of their care/treatment, communicating that they experience a sense of enhanced personal well-being.

Out-patients

OP1-55: … been very fortunate… I've got this long… didn't think I'd get this long.

OP1-62: … quite comforting… in a queue…

OP1-75: [T. What's it like talking this way?] … absolutely fine … getting out what's in my head…

OP1-134: … got Christmas with the boys… enjoyed it… main thing to have

OP1-143: … they're (friends) supportive… if you need anything… shopping…

OP1-144: … I'm fortunate… got family… brother's good… doing things for me…

OP2-78: [T. … it (life) … important?] Oh yeah… definitely…

OP2-80: I'm old… had a good life… canny (cannot) complain… lucky.

OP2-81: … been fortunate… 13 years I survived… bonus…

OP2-82: … they (health care) done wonders for me…

OP2-83: Nobody wants… but… nicest experiences I've had… they (health care)… caring… giving a big donation

OP2-84: … you're glad you get another chance…

OP3-27: … this (hospice) is not only a family… a life line… if I didn't have this… I don't know what I'd do… I would be sitting at home

OP3-117: I was thankful… I was there to help him (son)… even if I didn't get to do… I wanted… null and void…

OP3-129: … they'll (family)… I'll give you a … hand and I'll let them help me… get up when pain is bad

OP3-131: I think independence plays a big part in it. If I didn't have my independence I don't know how I would be feeling.

OP3-133: I don't take life for granted at all… like I did before

OP4-2: I'm a very positive person… a bit down… but feel lucky… at my age… diagnosed… felt grateful…

OP4-14: … I'm in palliative care…don't need carers… my daughter comes… day… son for a while before I go down at night… got a daughter comes … stays the weekend with me…

OP4-17: … went down to the hospital… were waiting for me… got an X-ray… bloods taken… within half an hour I knew my results.

OP4-23: (daughter) with me all day… get dinner come lunch before she goes… son… comes… gives me a snack…

In-patients

IP1: (No data)

IP2-4: Without the (clergy) support I wouldn't be here… greatest inspiration to me… turned my whole life greatest inspiration…

IP2-5: … not once do I regret what happened… support I've had… coughs…

IP2-6: … support from church… 8 or 9 different (clergy)… oils of… sacraments… in here…

IP2-10: [T. … illness do to independence?] Don't think about it a lot… don't think about it… support from church… family sustained me.

IP2-15: … thanks… family… church.

IP2-27: Feel terribly blessed… family… up here in loads at a time… a man couldn't ask… better family…

IP2-28: … church… spirituality… get communion every day… appreciate it… it's a big thing… tonight… talking about eternity… only here for a wee… while.

IP3: (No data)

4c-3: Patients Showing Regret

Patients express that they experience themselves as sad, repentant, and disappointed as a result of feeling 'sorry about' something that they have either done or not succeeded in doing.

Out-patients

OP1-29: The leaving I'm upset about… because I love these grandchildren…

OP2-77: It (life) is not as enjoyable…

OP3-101: … don't even look at alcohol anymore… even… in pain… been there… wouldn't do it again…

OP4: (No data)

In-patients: (No data)

Level 5: Willing/Wanting Self

Dissatisfied with their circumstances, patients become proactive and purposeful, experiencing the desire or need to initiate action. They know and want what is good for them and experience themselves as goal oriented. Patients do not implement action but experience their agency in the form of action tendencies that organise them toward internal actions and move them toward their goals.

5a: Motivated Self

Participants, from the perspective of wanting to continue their identity and activities and reduce uncertainty about themselves, communicate their drive to strengthen their own efficacy through the expression of their own personal needs and wishes. As *Motivated Selves,* patients are goal-oriented, with the active process of wanting, providing a channel for intrinsic motivation and a greater sense of well- being and fulfilment. Also, patients indicate that the *Need / Reason*, *Willingness* and *Enthusiasm* are key components in the drive to achieve their goals.

5a-1: Need/Reason

Patients engage in a process of self-evaluation that results in better understanding of themselves, providing them with the motivation to reinforce their personal effectiveness and efficacy in order to resist changes in their perceived self-concept.

Out-patients

OP1-3: I did phone the doctor… said it was… took pain killers… did help.

OP2-56: … be interesting… to know how bad… or…

OP3-25: … need to be out… for my mental health… it can get dark… no sure if I want to go out…might meet somebody… I know… just stay in

OP3-113: … like you're saying now you've come this far… there's days you feel look what I've done… not a person… said to me [T. … affirming what you've done… you're here?] I have… aye.

OP3-119: … I'm glad I got out… for a wee while… great… out the door… this is my time…

OP4: (No data)

In-patients

IP1-72: … waiting for confirmation (go home)… when that comes… start thinking about what happens next.

IP2: (No data)

IP3-19: … chances are I'll struggle on…

5a-2: Willingness

Patients are prepared to persevere and remain resilient in the face of their adversity, and they recognise willingness as a resource, crucial for their desire to continue their identity.

Out-patients

OP1: (No data)

OP2-37: [T. … concentrate on… things you can do?] Yeah… aye… aye… definitely aye.

OP3-63: I gave them permission to take… tumour… do research

OP4-22: … I slid… silly mistake… I'll stay out of the kitchen

In-patients

IP1-2: … … go to the doctor…

IP1-14: … pragmatic bit… had an appointment… overnight… blood tests for kidney function… were not good kept me in… or in here… keep the pain under control…

IP1-20: [T. … you can control certain areas of your life?] Well… be able to eat and drink when I wanted… things I like to do…

IP1-45: … I think I told you last time… you either laugh or you cry… I'm not a crier.

IP2: (No data)

IP3: (No data)

5a-3: Enthusiasm

Patients are goal-oriented, eagerly wanting to embrace life, and with an expectancy that something especially good will happen because of their own efficacy.

Out-patients

OP1: (No data)

OP2-2: … we're going to…

OP2-3: … other thing to book up in _____

OP2-8: I want to do things.

OP2-9: … looking forward to going to A.

OP2-10: … looking forward to going to S.

OP2-11: … looking forward to coming here (Hospice).

OP2-32: … be interesting… to know how bad… or…

OP2-55: … I've still got the enthusiasm…

OP3-114: … it's nice to think… tomorrow will be a good day… I could try W____ … could give it a go…

OP4-33: You need goals… goals… I'm off to M

In-patients

IP1-29: … food brought… straight to your bed… don't… washing up (laughs)… don't have beds to make up… look at it that way… perks… outweigh these.

IP2: (No data)

IP3-33: … I'll go for… donner (short walk)… bits (of hospice) I've not seen… I'll go… have a look.

5b: Imagining Self

Participants communicate specific future goals that they want to achieve and express these through imagination. Imagination and fantasy see patients create images in their minds and they reflect on these images and associated feelings. Through *wishing*, *hoping*, *wanting,* and *constructing mental pictures,* patients are able to think of themselves in the future.

5b-1: Wishing

Patients express their desires, however, what they desire cannot or probably will not happen as what they wish for is not realistic. However, wishing allows patients to muse on what could happen, what could be, thereby giving rise to a degree of excitement, even if temporary.

Out-patients

OP1: ((No data)

OP2-69: … if I'd got the opportunity…

OP3: (No data)

OP4: (No data)

In-patients

IP1-87: I like to be in control of everything… but… times you can't be…

IP2: (No data)

IP3: (No data)

5b-2: Hoping

By hoping, patients consider what can be, with reasonable confidence that they can realise what they desire. Patient motivation is stronger and so they continue working toward a future in the face of adversity.

Out-patients

OP1-47: … if I knew… would go to sleep… not wake up… be content…

OP1-58: … I hope… feeling the way I am … It'll be fine.

OP1-66: … got blood clot _____ it could move… still sitting… a number of months… so hopefully…

OP1-83: …I'm hoping when… on the other side you can see them (grandchildren)… find out how they are doing in life…

OP1-84: … drugs… operating theatre (laughs) makes them hallucinate… but… people… got into the light… and it was beautiful… I hope that is right… .

OP1-99: … maybe one day I'll wake up and it's all been a nightmare…

OP1-113: … I'm hoping he (clergy) can talk me into… after (daughter) died… began to doubt my faith.

OP1-117: … I hope… comes the day… I feel up to it…

OP1-126: I'm hoping… (clergy)… can't work miracles… if he can reassure me… there's a future for me… next life…

OP1-128: …hopefully nurses will keep me comfortable… why I wanted to come here… daughter died peacefully.

OP1-150: … hoping to get… energy back…

OP2-79: I'd love to be here… see how they (grandchildren) progress in life.

OP3-52: … want to meet people… look at you… talk to you… how are you doing… don't need anything else…

OP3-77: … that would be such a boost… for me… aw well… such is life

OP4: (No data)

In-patients: (No data)

5b-3: Wanting

Patients want to take action in order to achieve their goals and, as the *Imagining Selves,* the act of imagining provides a new direction for thinking. Through their increasing capacity as agents, patients choose to initiate change by generating alternative ways of constructing their experience through imagining, "*I want 40 years... if I get 39 1/2... I've won... 2 years; I don't want to feel like this... don't want this.*"

Out-patients

OP1-43: I don't want to die at home... don't want to die… street… want to die in the hospice…

OP1-56: If I get Christmas… with my boys at Christmas… great.

OP1-72: …I could get a while… Christmas with the kids… be happy if I get that…

OP1-85: …I'd love to know… definite… go there (Heaven)… see… daughter… be with daughter… Mum and Dad… love to meet somebody… that know for certain…

OP1-115: … would be a big relief to me… get a bit… faith back… believe… something in…

OP1-123: I would like to talk… he's (husband) not for it… my son talks… he'll (son) deal with everything…

OP1-129: … that's the way (peaceful) I would like to go for… family… wouldn't want them to see me suffering… don't want to see that.

OP1-151: It would be nice to see spring time… would be nice.

OP2: (No data)

OP3-53: … I don't need… poor soul… going through the mill… oh no… that doesn't help

OP3-59: I would like a… bit of freedom… somewhere… on my own… no for long

OP3-60: … leave me for a day… because you don't get time to think when they're in the house…

OP3-70: … electric scooter… I… look at it… don't want to meet people… they go… last time… you had your sticks… you in that now… escalate the pity… no wanting that

OP3-71: … people think they're being kind… visit you… why can't they come… pick me up… take me to their's

OP3-98: I wanted everything to be as normal…

OP3-99: I didn't want to lose anything I was still doing…

OP4-28: … the very end… I want… go into… the hospice.

In-patients

IP1: (No data)

IP2: (No data)

IP3-14: When my friends come… family… don't want to be spending… time in bed… want to be up.

IP3-15: I want to be up talking… great to see them (friends)… brilliant…

5b-4: Fully Imagining

As patients can to some degree direct and control what they experience, they deliberately choose to focus on a particular script that is under the control of their will. With a shift from the abstract to the more concrete, the construction of mental imagery is more than exploring options and is want seen to anticipate possible desired future experiences.

Out-patients

OP1-74: If I get up there (Heaven) and she (daughter) no there… I'll be raging…

OP1-98: I dream a lot… whether… because I take _____ … at night… vivid dreams… with daughter, mum and dad… comforting… sometimes I don’t want to get out of bed…dreams too good…

OP2-40: I imagine (laughs) it would be great if… a cure.

OP3-10: Life is my family… me being part of that… them being there without me would be heart breaking

OP3-74: … why can’t they come… say… get yourself ready… take you out…

OP4: (No data)

In-patients: (No data)

5c: Fighting Self

With a strong sense of self-efficacy, patients remain goal-oriented in the face of their demanding circumstances. They approach their situation with the assurance that they can exercise control and so they set themselves challenging goals and try to maintain commitment to them. In addition, patients communicate that their fighting self appears more evident at this particularly significant phase in their life.

5c-1: Believing in Self-Ability to Influence/Succeed

Participants experience a strong sense of confidence in their own ability to influence the circumstances that affect their life.

Out-patients

OP1-57: I would hate to loose… be away before Christmas… I’ve told them I’ll be there…

OP1-136: … I’ll take my time I’ll be fine.

OP1-145: … go along for years without thinking about anything like that…think everything’s… fine… hear about a family… tragedy… cope with that… you just have to…

OP2-36: I’m determined not to lie down to any… illness… moping about….

OP2-86: I believed I would get through it.

OP3-7: … but I don’t give up… if I… give up… don’t think I would have long

OP3-8: … I’ve always had determination… keep moving along regardless… always done

OP3-9: … you’ve got to grab it and hold it

OP3-22: … do some things… no suppose to do… others don't know… because… they're mollycoddling me at times… I appreciated… back then… don't… now sometimes… you need to do it for me

OP3-40: How things have changed… it doesn't stop me… still try… get down… back up

OP3-44: … get helped out of bed… put you on your ____ … I thought… can't live like this… quicker I try… find my feet the better

OP3-55: … (life) I will strive… make it better

OP3-57: … I've had to say to him (son)… you can watch me if you want… but I'm doing it

OP3-62: … between stage 2 and stage 3… I'm not going anywhere

OP3-66: … if it comes back… I'm going to hold on to it (life)

OP3-69: I thought no I'm going to do what I like

OP3-104: … got to have … feeling inside that you need to get up… get on with it

OP3-109: I think I look for a good day… it turns out no too bad… a bit of control… the best days…

OP3-127: … I still try… get up… get stuff done

OP3-130: I accept help but… where it's manageable… get up myself

OP4-20: It (cancer) gets in the way of other people… doesn't get in my way… in my house it's my rules

OP4-25: … she (carer) says I'll phone the paramedics… no… no… I did mean no.

OP4-34: … I'm getting more determined as I get old… helps me…

In-patients

IP1-17: I'm not a spontaneous person that likes going on mysteries… rest of it

IP1-19: If you're used to doing something… suddenly… you can't… you have to change…

IP1-41: … if I get out on… practical side of me start organising funeral arrangements… so partly in place… in case I get carted back here… hospital…

IP1-49: If I didn't get round to doing it … I've still got what I want there ready…

IP1-50: I'd get the right coffin … things… everything… I've got all the instructions there…

IP1-64: I mean I still like living… still like living…

IP1-90: … I'm dying of _____ … need to get funeral arrangements organised… sort out… stuff… so nice pile for the solicitors… not hunting the house for all my stuff.

IP2-14. … but you've always to come back… always… face it… my view…

IP2-19: … nobody tells me what to do… I'm my own man.

IP3-13: I'm getting there… after three weeks I'm getting there…

5c-2: Dealing with Circumstances

Patients do not avoid difficult challenges but, instead, communicate that their belief in their self-efficacy enables them to deal with their testing situation by giving it attention and making decisions that can enhance their personal well-being.

Out-patients

OP1-10: … so I went into G …

OP1-59: … I make sure I get up every day… do things… if I lie down… no get up again…

OP1-81: … I keep telling him (grandson) I'll be watching down on you… keep going… for your goals…

OP1-96: … worrying… not going to make a difference… not going to make me miserable… get it out of your head just get on with it…

OP1-111: … hoping he (clergy)… give me something to read… talk… get beliefs back…

OP1-127: … not afraid of dying… not frightened of dying… I'm frightened if it's painful

OP2: (No data)

OP3-11: I need to let my boys understand… no matter what life throws at you… chin up… keep marching on… get through

OP3-21: I always make sure I try something new… in an area where I've got stuff I can hold on… I do the risks…

OP3-50: It was another person they were talking to… I could hear… but… thought… I'm not listening… I don't want to hear

OP3-102: … good days and bad… got to take… good with the bad.

OP3-120: … these… talks have learned me… I need my time too… had time… think about what we've talked about… need my time…

OP3-128: … it (pain) still there… tried to work my way through the pain

OP4-27: I think the "home's" getting nearer… they'll have to catch me… hold me down.

In-patients

IP1-11: … I'll live with it… until it does kill me.

IP1-18: … I'm not someone who has everything ready to me… things can change.

IP1-22: … been my philosophy from the start… I'm a practical person…

IP1-23: …I'm a pragmatist… would rather know about things…same all my life… I've been a practical person… never been emotional… some things need tackled head on… likes of this (illness) and all the rest of it…

IP1-26: …it's better than having whoever untangle… details of… estate… everything.

IP1-42: … never been anxious about what's going on… I can't change what's happened… the fact I'll be dead in few weeks/months… deal with it as it's going along.

IP1-63: I don't look at it negatively or positively… I deal with it the way I look at things… no point… saying… cancer… going to get worse… need stronger pain killers… force myself to live I just take it… need stronger pain killers… when it comes.

IP1-79: … my stuffs all ready… just need to get out of this into going away clothes… you can't

IP1-88: … basically practical … deal with practical problems… solving them… gives… acceptance of… you can't change it … you can't whatever.

IP2: (No data)

IP3-17: [T. … when things change?] I just want to go…

5c-3: Accomplishing a Challenge

Patients communicate their personal achievement of successfully accomplishing challenges that need great mental and/or physical effort. An increase in self-belief in their own efficacy sees patients less beset with self-doubts. This allows them to set goals for themselves and plan courses of action designed to attain their aims and aspirations.

Out-patients

OP1-88: I don't say too much… just say… no doing that… don't feel up to it… he (son) accepted that…

OP1-97: … go and watch telly (TV)… read a book… sleep for hours… really sleep… felt great when I got up…

OP1-110: … I decided to phone (clergy)… he was very nice… come over and see you… have a talk… took pressure off me… I feel I've dealt with it a bit…

OP1-124: …I've got that under control… a big weight off me…

OP1-125: … lifted the (clergy) phone… dozen times… managed to… conversation… taken a load off me…

OP1-135: … determined to go here… out… speak to people… determined in going to my meeting… glad I've made it.

OP2-15: It's no always there… no always.

OP2-27: … just doing the things I can do…

OP3-12: … sit and cry… important… get it out…

OP3-20: … been times… tried to do things… had… slips… fell… lying there… need to get yourself back… feeling sorry… find a way… get back up

OP3-49: I had to stop it… anybody that came to visit…

OP3-112: … now… this is my war wounds (laughs)… was a big fight… got through it.

OP3-125: : Some days when the pain is really bad it's like oooof… was it worth all that surgery… was it worth this… but I know in my heart that it was worth it… it was worth…

OP4-13: … panicked during the night… I couldn't get a breath… managed to get my inhaler… managed with all my fingers… got a couple of puffs… went back to sleep…

In-patients

IP1-25: … I'm not one… put off till tomorrow… like making a will… 'cause that brings up your mortality… I'll face that…

IP1-46: … for me … gets it done and dusted… then once that's done… doesn't matter how I get on after that.

IP1-47: … always been a pessimistic optimist… glass is half full or half empty… I'd sit there and say no… wait to see what happens… pouring stuff into… out of… I will look on the negative side… you're not disappointed… prepared for it.

IP2: (No data)

IP3: (No data)

Level 6: Enriched Self

Patients engage in a dialectical process, confronting the difference between the partial restoration of their normal or historic, past self, and the accepting/transcending future self. As *"Enriched Selves",* patients also experience enhanced value and significance in their present living.

6a: Historic Self

With patients experiencing an incongruence between their past self and their present self-concept, they want to return to their self before their diagnosis. They recognise that their new present self gives rise to different understandings of themselves, and so they reconnect with their past self through recalling past events, influenced by their personal schemas.

6a-1 Incongruence Between Patients' Past and Present Selves

One out-patient makes comparisons between their past and present selves, with the self in the present experienced as less efficacious. This causes disequilibrium and is experienced by the patient as frustration and so they may reminisce or try to restore to their former selves. Their need to reduce the incongruence between their normal and transformed self-concepts is the motivation towards change and maintenance.

Out-Patients

OP1: (No data)

OP2: (No data)

OP3-1: I've got to understand… some things now I can't do… I would have done before

OP3-5: … what goes on in my head is different… used to be before

OP3-43: … came out of hospital… thought… no the person I used to be… made me sad

OP3-73: I used to drive… can't anymore

OP4: (No data)

In-patients: (No data)

6a-2: Rosy Retrospection

Patients remember their past selves with a "rosy retrospection", perceiving their past selves as more positive than they judge their present being. Nostalgia makes them feel happier, more self-confident, and closer to people around them.

Out-patients

OP1-118: … we used to always go out… every month… evening… four of us… but since they know how I'm feeling…

OP2: (No data)

OP3: (No data)

OP4: (No data)

In-patients

IP1-85: I take things as they come… lucky… over past 40 plus years… achieved… done everything I wanted to do… terminal cancer… not a big panic… this isn't a depressive comment… nothing left for me to go for… lucky… other people… I was lucky… took it (opportunity)…

IP2: (No data)

IP3: (No data)

6a-3: Restoring to Past Self

No data were collected from this category.

Out-patients: (No data)

In-patients: (No data)

6b: Accepting/Transcending Self

Patients accept that they are finite beings, acknowledging that their physical bodies will cease to exist. Some patients choose to transcend that finiteness through belief in a form of afterlife, freed from the limitations inherent in matter and having an existence outside the created world.

6b-1: Accepting Life as Finite

By accepting that the human being is finite, the individual acknowledges that they have a time-limited existence. Although the human individual does not represent a deterministic organism, devoid of goals and plans, they accept that they do not have the ability to avoid death which may be perceived as a means of escaping from their pain, physical and emotional.

Out-patients

OP1-80: I have spoken to them… said I'll be with Mum in heaven…

OP2: (No data)

OP3: (No data)

OP4: (No data)

In-patients

IP1-44: … I've got cancer… treatment… didn't work… now dying… the practical the medical decisions the practical bits… now in final stages… what am I going to do?... bla bla… got it… nothing I can do… deal with.

IP1-52: … this (death) to me is another journey… I might lie here… brain stopped… spirit comes out go somewhere… up.. down… sideways… going on holiday… somewhere you've never been…

IP2-53: … never thought about it… it doesn't bother me one way or the other… think this all we've got..

IP3: (No data)

6b-2: Believing in the Power of a Higher Being/After Life

Patients communicate their belief that there must be something, undefined and beyond this earthly world, that has a power greater than themselves. In addition, patients express that there may be an after-death existence that may see the reuniting of people separated by death.

Out-patients

OP1-49: … I would like to believe… that God will come and get me… to be with my daughter… when I go.

OP1-112: … there will be someone there (Heaven) when you go… if… nothing… what's the point of living… if… you're dead… that's it…

OP2: (No data)

OP3-16: … I've turned back to my faith again… it's pulled me through… never miss praying… before I shut my eyes at night

OP3-103: … God I can't do this… can't get this done anymore… last a day… feel… horrible… go to bed…God please don't let tomorrow be like today…

OP4-29: … when I say my prayers… I'll say… whenever you're ready to take me I'm ready to go… doesn't frighten me.

In-patients

IP1: (No data)

IP2-1: No fear…. My religion… gave me strength and support

IP2-7: … there's an afterlife… just leave all that to God…

IP2-12: … I don't worry… family… church… Lord should come before… even family.

IP2-29: Eternally? … means forever… going to be here for ever… ever… no end.

IP2-30: … we'll make that journey through the help of God… through my spirit… faith.

IP2-31: … two things concern me… my family… faith and spirituality and… where I'm going somewhere else… eternal life.

IP3: (No data)

6c: Joyfully Engaged Self

As patients become fully aware of their finiteness, they purposefully engage in living, enhancing the quality of life in the time they have left. Patients are provided with the opportunity to live true to themselves and recognise what is important to them. Hence, they choose to turn their attention towards internal satisfaction.

6c-1: Patients Experiencing Joy

Patients experience a sense of being one with the world. Their joy is constructed form their own accomplishments or progress towards their goals.

Out-patients

OP1-78: …we'll go a run down to _____ sit and look at the water…

OP1-139: …grandchildren coming down… cheers me up tremendously… love their company…

OP1-140: … they'll (grandchildren) have a chat… phones me nearly night… chat…

OP2-39: [T. … do they present joy… ?] Oh yes… aye… uhhu… definitely.

OP3-2: … every day is precious… no getting away from that

OP3-56: … things that were… important… now… no… my family… spending time with them

OP3-79: … you look up… birds… trees… never took time to look before… see so much more now… sit in the garden… look at the sky… never… stopped to look now… be all and end all

OP3-108: Life is still good… if I can get up in the morning… carry on… doesn't get any better… some days are really good.

OP3-134: There's so much that is important to me now. I see the sky. I hear the birds. I see the trees.

OP4: (No data)

In-patients

IP1-61: Enjoying the nice blue sky out the window

IP1-73: … it's getting milder (outside)… allow me to do things.

IP2-24: … every moment is precious…

IP3-25: … C____ and E____ K____ (family) funny… annihilated with their jokes… I love it…

IP3-30: My grandkids I love them to bits… they're great… keep me going…

6c-2: Patients Experiencing Enjoyment

Patients communicate great pleasure and happiness brought on by the satisfaction because of taking part in an activity that provides interest and enjoyment. By participating in activities, patients experience a greater a sense of achievement and self-fulfilment.

Out-patients

OP1-33: … going to spend Christmas with them (grandchildren) … they're coming… stay… for a few days…

OP1-101: … got my Christmas… lovely… had a great time…

OP1-104: … I… sat with the boys… had a good time…

OP1-116: … I go to things… friends… afternoon tea for me…

OP1-152: … got snowdrops in… garden… all blooming… love to see snowdrops… didn't think I would see them this year…

OP2-17: [T. … enjoy engaging in activities?] I do… I do…F

OP3-26: …it's another family I look forward coming here

OP3-41: I enjoy the exercises… stuff… in here… some I can do

OP3-78: I'll need to… son's birthday on ____ I'm going to go… make him happy… me happy

OP3-118: … was good we had pancakes (laughs)… we made them

OP3-131: It's me… like I've achieved something on my own out with the family but look at me. Look at what I'm doing. I'm away I'm enjoying myself. I've got arts and crafts whatever… I take my stuff home and it's like look at what I made and …

OP4-9: … now I've stopped… got a way of life… getting out… every fortnight… group of friends… meet up…

OP4-10: … my daughter takes me over… see my friends every fortnight

OP4-16: … I thoroughly enjoy coming… definitely… great… coming here…

In-patients

IP1-75: [T. … something you'll look forward to… the house?] Yes… a glass of lemonade… that's the one thing I'm thinking of if I get confirmation, I'm going home…

IP1-82: A glass of lemonade… or … with diluting juice… that's as far as… I've got… after that… other things.

IP2-11: Church is important…wife all the rest of it… love life to the full… enjoy your family.

IP2-17: … that's how I feel… elated… good day… every day's a good day.

IP3-24: …it (humour) does for me… I've got these two here and they'll make a joke about anything… I start laughing… I'll carry on…

6c-3: Patients Experiencing Excitement for Life

Within this level, patients experience themselves as pro-active, generating novel ways of constructing their experience, indicating an increased power of agency. As active initiators, patients engage in their every-day living with a sense of excitement.

Out-patients

OP1-119: … be nice to see friends… chat… tell them things…

OP1-137: I like to see people… how everybody's doing… nice to chat… takes you out yourself…

OP1-141: It's good (talking)… don't get anybody else to talk to… even… friends…

OP1-142: … four of us… talking about _____ family with… usually me that'll say… "talk about something nice… forget about _____ "

OP2-12: … getting out of the house and doing things.

OP2-16: [T. … it (illness) stops zest for life?] Oh no … no.

OP2-18: Talking about… looking forward to that… very much.

OP3-80: … open your eyes in the morning… well that's me… made it… another day

OP3-121: … I'm here a person… might be a wife… whatever… I'm also me

OP4-24: … went to see my granddaughter… every fortnight my son takes me to her… lovely day…

OP4-32: … I've… booked my holiday with ____ ____ … my daughter's going with me… two of us…

OP4-35: … I'm looking forward to my week (holiday)…

In-patients

IP1: (No data)

IP2-16: … amount of visitors… lot of visitors… staff… music… party time…

IP2-25: … before… didn't appreciate things… didn't take it for granted… now… all I live for is being happy…

IP2-26: Life is so precious every minute… everyday counts… I love life.

IP3-18: The way I am now…have lunch…sleep…get up… kids… come round… see me… blether with them… play with them

IP3-28: … (football) the only thing I do watch… I hope… we'll see them pick up the cup and championship…

Level 7: The Fully Agentic Self

Faced with the diagnosis of an incurable illness, patients are aware of themselves as vulnerable and experience events within their physical body that limit their sense of control. They are aware of their *givens but* optimistically and realistically choose to engage in life to their best ability. Determined not to be the victim of their *limit situation*, patients decide to live authentically by accepting their freedom to make choices whilst owning their personal decisions and actions. As "*Fully Agentic Selves*", patients experience themselves as optimistic, realistic, goal-oriented, contented, autonomous individuals.

Out-patients

OP1-64: I'm quite philosophical … know it's going to happen… put it to the side… live each day the best I can.

OP2-85: … told me sixty forty… knew it was bad… lost six and a half stone… some hair… serious… never…thought I was going to die… chemo… jags… I was determined… get through it.

OP3-122: I need to do things… I want to do… Keep that thought with me… take every day as it comes… hope for the best… I can control it better… definitely.

OP4: (No data)

In-patients

IP1-12: I'm… doing it that way for me… I can live… not exactly the same… close as possible… to the same as I did before… the disease and everything else.

IP1-15: … future… day at a time… never know… disease… kill you… complications with drugs… infections… viruses… how long I've got... could be tomorrow… I take a day at a time… just keep going that way.

IP2-32: … I don't want to leave here (earth)… I'm quite content the way I am… when it comes to the end… I'll have no regrets… done the best… family… worked hard… never cheated… means a lot.

IP3: (No data)