

‘Adaptation and self-management after stroke: exploring the
application of the Selection, Optimisation and Compensation
model’

Thesis submitted for the Degree of Doctor of Philosophy

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Index of terms

CHSS – Chest Heart & Stroke Scotland

DCV – Discriminant Content Validation

ICF – International Classification of Functioning, Disability and Health

PRISMA – Preferred Reporting Items for Systematic Reviews and Meta-Analyses

R&D – Research and Development

RCT – Randomised Controlled Trial

REC – Research Ethics Committee

SOC- Selection, Optimisation and Compensation

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Abstract

Background: Stroke can have long-term consequences for survivors, and recovery can be a complex process. Unfortunately, there is a lack of theory-based evidence as to how stroke survivors can be aided in coping or adjusting to their new circumstances. The Selection, Optimisation and Compensation (SOC) model describes three processes of selection, optimisation and compensation, which are suggested to allow older adults to maintain activity in areas of life that are important to them, despite loss of functional or cognitive capacity. This thesis explored the Selection, Optimisation and Compensation (SOC) model as a model for post-stroke adaptation.

Method: A mixed method approach consisted of systematically reviewing previous applications of the SOC model; conducting qualitative interviews with 30 stroke survivors to determine if SOC processes could be identified within coping strategies; and using Discriminant Content Validation (DCV) methodology to further analyse stroke-specific SOC strategies. Finally, the model was operationalised in the context of stroke through the development of a SOC self-management intervention, which was piloted with five stroke survivors.

Findings: One hundred and forty nine stroke-specific SOC strategies were elicited from the interviews; 78% of which were significantly classified as at least one of the theoretical constructs of SOC using DCV analysis. Such findings were used to develop a SOC self-management intervention, which included descriptions of the SOC processes and examples of stroke-specific SOC strategies.

Discussion: Overall, this thesis provided strength to the argument that the SOC model is indeed appropriate for the aim of helping stroke survivors come to terms with living with the long-term consequences of stroke. Further refinements are, however, necessary in the operationalisation of the SOC model into a post-stroke intervention. Future research should build upon these findings in order to increase the effective use of SOC strategies; with the ultimate aim of improving adaptation in stroke survivors.

1 Introduction

1.1 Background

Stroke statistics and outcomes

Cardiovascular Disease is an overarching term for diseases relating to the heart and blood vessels, whilst Cerebrovascular Disease describes a sub-classification of diseases affecting the blood vessels supplying the brain (British Heart Foundation, 2015). A stroke is one of the most common types of Cerebrovascular Disease and occurs when blood supply to the brain is interrupted, causing brain cells to be deprived of oxygen and therefore damaged (NHS, 2014; World Health Organisation, 2006). There are two main types of stroke: ischaemic, resulting from a blockage of blood supply to the brain and haemorrhagic, resulting from bleeding in the brain (Lincoln, Kneebone, Macniven, & Morris, 2011; Stroke Association, 2017). There are around 8900 first-time strokes in Scotland each year and over 100,000 per year in the UK overall, equating to an incidence rate in Scotland of 178 per 100,000 of the population (ISD Scotland, 2017; Stroke Association, 2017). A stroke is a major health event and is the third single leading cause of death in Scotland and fourth leading cause in the UK (British Heart Foundation, 2015; Stroke Association, 2017; The Scottish Government, 2014).

Stroke survival rates are, however, improving and there are more than 1.2 million stroke survivors currently living in the UK (Stroke Association, 2017). In Scotland there has been a 38% reduction in stroke mortality over the past decade, with mortality rates decreasing from 75 to 47 per 100,000 of the population between 2006 and 2015 (ISD Scotland, 2017). Overall, stroke mortality rates in the UK have fallen by 78% over the past 40 years (British Heart Foundation, 2015). Around 85% of those admitted to hospital in Scotland as a stroke emergency are now surviving 30 days or more, a measure that is suggested to reflect a combination of disease severity and quality of care (ISD Scotland, 2017). For example, achieving a stroke care bundle consisting of timely stroke unit admission, a swallow screen, brain scan and use of aspirin has been found to be associated with reduced mortality and increased chance of discharge to home (Turner et al., 2015). In Scotland, the percentage of people receiving the appropriate stroke care bundle has increased from 43% to 64% since 2011 (NHS National Services Scotland, 2016).

An increasing number of stroke survivors are therefore surviving and living with the long-term consequences of stroke. Those that survive a stroke are typically left with difficulties, the range and severity of which will vary depending on the area of the brain affected and the size of the damage (Lincoln et al., 2011). Stroke is a heterogeneous condition and common post-stroke impairments can include reduced mobility and motor functions, limb weakness, aphasia, dysphagia, incontinence, impaired cognitive abilities, visual difficulties, mood problems, emotionalism, and fatigue (Arnold et al., 2016; Lawrence et al., 2001; Lincoln et al., 2011; NHS Scotland, 2009; Royal College of Physicians, 2016; Stroke Association, 2017). In a survey of stroke survivors in the UK, 20% reported difficulties with reading; 30-40% reported difficulties with sight, speech, emotions, pain and incontinence; and 40-60% reported difficulties with mobility, falls, fatigue, concentration and memory (McKevitt et al., 2011). Around one third of stroke survivors experience communication impairment in the form of aphasia (Royal College of Physicians, 2016). 'Hidden' post-stroke impairments can include mental fatigability, concentration and memory difficulties, irritability, emotional instability and sensitivity to stress (Carlsson, Moller, & Blomstrand, 2004, 2009). Furthermore, stroke is associated with a wider range of impairments in comparison to other conditions. A study by Adamson, Beswick, and Ebrahim (2004) compared stroke impairments to those experienced by individuals with heart, digestive, musculoskeletal, respiratory, sensory and mental conditions. The authors concluded that stroke was the only condition that was significantly associated with impairment in all of the studied domains, including locomotion, reaching/stretching, dexterity, sight, hearing, incontinence, communication and behaviour. Stroke was also associated with higher odds of reporting severe disability than any of the aforementioned conditions (Adamson et al., 2004).

Experiencing a stroke is likely to result in changes to the activities of daily living and social activities that people are able to perform, and have a considerable psychological and social impact. For example, approximately 24-33% of stroke survivors experience depression (De Wit et al., 2008; Hackett, Yapa, Parag, & Anderson, 2005) and around 25% experience anxiety (De Wit et al., 2008). Bays (2001) reviewed 39 studies that focused on stroke survivor quality of life, ranging from one week to six years post-stroke. Quality of life was found to be lower in stroke survivors than healthy adults, with stroke survivors experiencing greater impairment in activities of daily living, less social activity and higher

depression. Lincoln et al. (2011) examined a number of qualitative studies and biographical accounts of stroke to provide an overview of psychological aspects of the post-stroke journey. Some of the common experiences include difficulties after discharge from hospital, when activity limitations and participation restrictions become apparent, and changes to relationships and roles as assistance is required and restrictions prevent participation in previous social activities (Lincoln et al., 2011). A qualitative meta-synthesis examining the experience of living with stroke identified social isolation as a recurrent theme across studies, with stroke survivors withdrawing from social situations and experiencing changed relationships with family and friends (Salter, Hellings, Foley, & Teasell, 2008). Restrictions preventing participation in social circumstances can be complex in nature and range from physical difficulties to feelings of embarrassment and not wishing to burden others with post-stroke symptoms (Dowswell et al., 2000).

Even those for whom the stroke was initially categorised as mild can experience lasting effects. Mild stroke is categorised in the following studies using measures such as the Barthel Index (Mahoney & Barthel, 1965) and the National Institute of Health Stroke Scale (Brott et al., 1989; Goldstein, Bertels, & Davis, 1989). Carlsson, Moller, and Blomstrand (2003) examined post-stroke difficulties in stroke survivors who experienced little or no impairments in motor function or cognition. One year after stroke, 75% of stroke survivors reported that stroke had an impact on their everyday lives and 50% reported that their lifestyle was significantly restricted due to stroke. Similarly, stroke survivors who had experienced a mild stroke had lower health-related quality of life in the domains of general and mental health, emotional and physical roles, social and physical function, and vitality, but not body pain, when compared to healthy controls (Duncan et al., 1997). In survivors of mild stroke, 87% reported stroke-related symptoms at six months post-stroke, with the most common being difficulties with community mobility, attention, concentration, and decreased interest and participation in social activities (Edwards, Hahn, Baum, & Dromerick, 2006). Sixty-two percent reported decreased ability in the domains of employment and volunteering and 22% reported irritable mood. The authors suggest that negative outcomes may be due to mild, undetected cognitive impairment or alternatively, may be manifestations of the emotional response to suddenly and unexpectedly experiencing a stroke (Edwards et al., 2006).

The results of stroke can also be long-lasting; research with 490 stroke survivors in England determined that after three years, 26% were moderately or severely disabled according to Barthel Index scores, 51% were inactive in extended activities of daily living and physical health-related quality of life was low (Patel et al., 2006). Qualitative studies examining the long-term impact and experience of living with stroke found that the theme of loss was frequent, ranging from loss of activities, abilities and independence, to personal characteristics, social and emotional losses and changes in identity (McKevitt, Redfern, Mold, & Wolfe, 2004; Pearce et al., 2015; Salter et al., 2008). The recurrent theme of change has also been identified in qualitative studies, with stroke survivors perceiving that stroke had permanently changed and had a considerable impact on their lives (Pearce et al., 2015; Salter et al., 2008). It is typical for stroke survivors to perceive that their stroke has impacted on almost every aspect of everyday life (Burton, 2000; Dowswell et al., 2000; Salter et al., 2008). Burton (2000), for example, interviewed stroke survivors monthly for one year post-stroke and found that not only were all new life experiences influenced by their stroke, but that stroke survivors felt the impact of stroke would permeate through their entire future. Similarly, Dowswell et al. (2000) found that stroke survivors perceived stroke to have made a considerable impact on their lives, even when the initial stroke event was categorised as mild. A range of emotions including anger, frustration and vulnerability were also experienced, particularly when stroke survivors discussed the suddenness of stroke and made comparisons to life before the stroke (Burton, 2000; Dowswell et al., 2000; Pearce et al., 2015).

Uncertainty occurs frequently in the narrative of life post-stroke, with stroke survivors indicating they were uncertain about the path of recovery and how this would influence life in the future (McKevitt et al., 2004; Pearce et al., 2015; Salter et al., 2008). For example, Carlsson et al. (2009) found that despite being categorised as experiencing a mild stroke, 'striving to manage an everyday life of uncertainty' was a key theme in the coping processes of stroke survivors in the study, who felt uncertain about the recovery process and how their post-stroke symptoms would affect everyday situations. Bendz (2003) also found that despite experiencing a wide range of post-stroke difficulties, all stroke survivors in the study had a common uncertainty about participating in activities and felt a loss of control that stemmed from body difficulties, cognitive difficulties, fatigue and fear of stroke recurrence. Similarly, after completing monthly interviews for one year post-stroke, Burton

(2000) identified that stroke survivors felt uncertain, unable to anticipate and plan, and perceived they had lost control over their bodies, circumstances and the future.

In addition, stroke survivors are also faced with the worry and potential of a subsequent stroke (Pearce et al., 2015). Risk of stroke recurrence within five years of the initial stroke is around 25% (Mohan et al., 2011). There are several known risk factors for stroke including age, sex, socioeconomic status, health conditions and health behaviours. Stroke risk increases with age; for example, incidence rates in Scotland are 84 per 100,000 of the population for those aged under 75, rising to 1134 per 100,000 in those aged over 75 (ISD Scotland, 2017). Stroke is more common in males compared to females, with respective incidence rates of 198 versus 159 per 100,000 of the population in Scotland (ISD Scotland, 2017). Stroke is also more common and has poorer outcomes in low- and middle-income countries and in areas of lower socioeconomic status (Marshall et al., 2015). A review by Marshall et al. (2015) found good to high quality evidence that low socioeconomic status was associated with increased risk of stroke, mortality from stroke, more severe stroke and poorer functional outcomes. There was, however, no clear relationship between socioeconomic status and mortality for countries which have universal healthcare systems, such as the UK and Canada. The links between socioeconomic status, stroke incidence and outcomes may, in-part, be due to the presence of other stroke risk factors, although the evidence for this remains unclear (Marshall et al., 2015). Such additional high risk factors for stroke include health conditions and health behaviours, such as hypertension, diabetes, depression, psychosocial stress, smoking, waist-to-hip ratio, poor diet, lack of physical activity and high alcohol intake (O'Donnell et al., 2010). It has been estimated that hypertension is a causal factor in 50% of strokes, whilst health behaviours such as smoking double the risk of death due to a stroke (Stroke Association, 2017). Lack of physical activity and obesity increase stroke risk by 50-64% (Stroke Association, 2017). Within their recovery, stroke survivors may also, therefore, be faced with making changes to their health behaviours in order to combat future stroke risk. Health promotion was a category identified within the coping processes of stroke survivors interviewed by Carlsson et al. (2009). Stroke survivors sought to make health and lifestyle changes in accordance with their perceived thoughts about the cause of their stroke, ranging from changes to work circumstances to modifying health behaviours such as diet and exercise. Fear of stroke recurrence has been found to be a common response to stroke, in turn having

consequences for the everyday lives of stroke survivors (Bendz, 2003; Carlsson et al., 2009; Pearce et al., 2015; Salter et al., 2008). Bendz (2003), for example, found that stroke survivors were keen to gain awareness about the cause of their specific stroke, such that they could try to prevent another. Stroke survivors therefore avoided situations where they perceived (correctly, or not) that there might be an increased risk of stroke recurrence.

Stroke recovery, rehabilitation and long-term management

Given the potential range and severity of post-stroke difficulties, coupled with the experience of making lifestyle changes and dealing with stroke recurrence fears, it is not surprising that stroke can have long-term physical, emotional, social and psychological consequences for survivors. Indeed, stroke has been described as a “complex coping situation”, where stroke survivors not only have to deal with adapting to the impairments, activity limitations and participation restrictions described above, but also cope with having experienced a serious, life-threatening health event and the potential of a subsequent stroke (Carlsson et al., 2009). The recovery from stroke is therefore equally complex; a multidimensional process specific to each individual, their post-stroke difficulties, and how they perceive these within their lives (Burton, 2000; Dowswell et al., 2000; McKeivitt et al., 2004).

Prevention, treatment and rehabilitation of stroke in the UK and Scotland are currently targeted through a number of guidelines, action plans and policies. Improvements in identification, prevention and early treatment are essential priorities for stroke care and as such remain the focus of many of these guidelines. The Better Heart Disease and Stroke Care Action Plan, for example, describes aims to prevent cardiovascular disease, improve experience of services and ensure that high quality services are delivered efficiently and effectively, embedded within communities where appropriate (NHS Scotland, 2009). With regards to the longer-term care of stroke, the action plan states that stroke survivors should have access to information, rehabilitation, psychological support in the community, secondary prevention support, exercise, social care and self-management support. The majority of the action points relating to these aims are discussed in terms of specific rehabilitation therapies such as physiotherapy, speech and language therapy and occupational therapy and there is limited discussion outside of these regarding helping stroke survivors come to terms with the long-term consequences of stroke. An exception within this specific action plan is the recommendation that NHS boards should encourage

the use of a stroke workbook with stroke survivors, although the description and justification for this is brief. The Stroke Improvement Plan continues the work of the Better Heart Disease and Stroke Care Action Plan, identifying eight priority areas in the prevention, detection, treatment and longer term care of stroke and stroke survivors (The Scottish Government, 2014). Only one of the eight priorities, 'supported self-management and living with stroke' relates to helping stroke survivors come to terms with the long-term consequences of their stroke. The plan identifies three actions relating to the above priority:

- 1) Stroke teams should offer self-management support, including signposting to self-management tools and websites and to other services such as communication, exercise and peer groups, and professional help lines.
- 2) Stroke survivors should have access to appropriate exercise services and advice.
- 3) Stroke survivors should be signposted to vocational rehabilitation services when requested and as appropriate (The Scottish Government, 2014).

A summary of progress within the Scottish Health Boards is provided for action one, with three of the 13 health boards achieving complete implementation status by having evidence of facilitated self-management options available and in use by stroke survivors (NHS National Services Scotland, 2016). Five health boards had non-facilitated versions of the above available to stroke survivors. Four health boards had only written or online resources available, whilst one was currently planning to develop self-management approaches (NHS National Services Scotland, 2016).

The Scottish Intercollegiate Guidelines Network has produced guidelines for the management of stroke prevention, discharge planning and rehabilitation (SIGN 118, The Scottish Intercollegiate Guidelines Network (SIGN) (2010)). The guidelines contain a brief discussion of longer term stroke rehabilitation in the community, suggesting that NHS boards should consider self-referral to stroke therapy services, and make references to voluntary organisations that can provide support services such as peer support and communication groups. In addition, the guidelines suggest that there is limited evidence to suggest the most effective method of helping stroke survivors' emotional adjustment post-stroke. Only one recommendation is provided, focusing on the use of stroke workbook

approaches to assist emotional adjustment in the form of improving confidence in recovery.

The National Clinical Guideline for Stroke also provides a range of recommendations regarding the management of stroke care and rehabilitation, but acknowledges that stroke research and services focus on the acute and early recovery stages (Royal College of Physicians, 2016). Similar to the action plans detailed above, the guideline provides rationale for recommendations relating to therapy rehabilitation. These are discussed in relation to individual impairments and not in relation to longer term adaptation as a whole. Social participation is also discussed, with the statement that whilst therapy rehabilitation focuses on the ability to perform activities, social participation occurs due to the work of the stroke survivor and their family. It is therefore recommended that self-management plans are used to help stroke survivors identify barriers and solutions to participation and that stroke survivors are signposted to relevant organisations that can support participation. With regards to further long-term rehabilitation, the guideline suggests that services should be commissioned that enable annual follow-ups for stroke survivors, in order for them to receive appropriate support living with long-term impairments, activity limitations and participation restrictions. Such services should also ensure that stroke survivors are able to participate in social and leisure activities, and access interventions and services that will improve or maintain their wellbeing and health. The guideline does suggest that stroke survivors who wish to continue with rehabilitation may be prevented from doing so due to a lack of resources, perceptions around a recovery plateau and a lack of evidence about the efficacy of interventions. They further suggest that rehabilitation should continue, despite shifts in the longer term, from recovery to compensation and adaptation. Unfortunately, however, individual therapy rehabilitation interventions and self-management plans appear to be the only recommendations within the guideline relating to long-term adjustment to stroke.

In summary, whilst current policies and guidelines appear to provide comprehensive and evidence based recommendations for prevention and acute care of stroke, there is less evidence and therefore fewer recommendations regarding best practice for longer-term care. The recommendations that do exist centre around further therapy rehabilitation, exercise, and self-management in the form of online resources, communication and peer support groups and professional advice lines (NHS Scotland, 2009; Royal College of

Physicians, 2016; The Scottish Government, 2014; The Scottish Intercollegiate Guidelines Network (SIGN), 2010). Indeed, a review of stroke services in England found that whilst most areas had well-established pathways of care for the acute phase of stroke, only half had established pathways of care provision for the longer term (Care Quality Commission., 2011). Further, satisfaction with stroke care within UK hospitals is high, however satisfaction with post-discharge care is poorer (Commission for Healthcare Audit and Inspection, 2006). In a UK survey of stroke survivors, 49% reported having unmet needs (McKevitt et al., 2011). Common unmet needs following discharge from hospital include requests for further support with memory and concentration problems, fatigue and emotional difficulties (Commission for Healthcare Audit and Inspection, 2005; McKevitt et al., 2011).

Qualitative accounts of stroke survivors' experiences support the suggestion that long-term provision for stroke survivors is lacking, with indications that the long-term adjustment process often coincides with a plateau in physical recovery and a reduction in input from healthcare professionals, leading to stroke survivors feeling abandoned by services (Lincoln et al., 2011; Pearce et al., 2015). A meta-review of qualitative systematic reviews found that this period of recovery also coincides with the stroke survivor's realisation that they are typically not going to be able to recover to their pre-stroke levels of functioning (Pearce et al., 2015). For example, a study of post-stroke challenges and coping behaviours found that despite reduction and cessation of rehabilitation, stroke survivors expressed concern that they had not fully recovered (Ch'ng, French, & McLean, 2008). Psychological, emotional and social needs were often not supported at this stage and stroke survivors wished further information on the longer-term stroke experience, what to expect at different stages of recovery, how to accept changes and how to self-manage (Pearce et al., 2015).

Adaptation, coping and psychosocial interventions after stroke

The lived experience of stroke has been extensively researched, with typical post-stroke experiences described above. A recent qualitative systematic meta-review of stroke self-management suggests that data saturation in this area has been achieved and that research needs to move beyond examining the experience of stroke survivors, to developing new ways to help individuals manage after stroke (Pearce et al., 2015). Furthermore, through the establishment of a Priority Setting Partnership, Pollock, St George, Fenton, and Firkins

(2014) conducted a rigorous evaluation of treatment uncertainties in stroke, from the viewpoints of stroke survivors, carers and healthcare professionals. Treatment uncertainties relate to interventions for which the evidence base is currently unclear or under-researched. Determining the best ways of helping people come to terms with the long-term consequences of stroke was subsequently identified as a top research priority (James Lind Alliance, 2016; Pollock et al., 2014).

Qualitative accounts of how and whether stroke survivors adapt to the impact of stroke vary, with accounts of some stroke survivors perceiving recovery of their pre-stroke lives as their primary goal, and others seeking to adapt and restructure their lives around their new circumstances and difficulties (Lincoln et al., 2011). There is a paucity of theory-based research into the latter post-stroke adjustment. Studies have aimed to identify how stroke survivors develop their own ways of adapting to life after stroke (Ch'ng et al., 2008; Pound, Gompertz, & Ebrahim, 1999). These often, however, lack a theoretical underpinning, which limits their ability to inform interventions to support stroke survivors in the longer term, and research in this field falls behind that of other health conditions (Pound et al., 1999). For example, findings suggest that stroke survivors can implement creative and resourceful coping strategies to help them adjust to the long-term consequences of living with stroke (Ch'ng et al., 2008; Pound et al., 1999). Ch'ng et al. (2008) examined the challenges faced by stroke survivors in the long-term and the behaviours they used to cope with their post-stroke difficulties. The aim of the study was to identify the factors that stroke survivors perceived had aided them in adjusting to stroke. The authors found that coping strategies centred around three themes: social support from friends, family and stroke support groups; active strategies, such as information seeking, problem solving, engagement in activities and practical strategies; and cognitive strategies such as reaching a sense of acceptance and accepting help from others. Some reported a range of positive outcomes from their stroke such as increased patience and a changed outlook on life. However, some continued to experience feelings of anger and frustration and were unable to identify any positive aspects of their stroke experience (Ch'ng et al., 2008). Pound et al. (1999) sought to identify the practical and social strategies employed by stroke survivors and suggested that stroke survivors were active participants in the reorganisation and renegotiation that takes place when they have to adapt to life post-stroke. Common strategies included accessing social support, creating new ways of doing things, pacing, relearning and

exercising. Ch'ng et al. (2008) therefore suggest that interventions targeting adaptive coping may be beneficial, particularly if they address such skills as acceptance, relaxation, humour and positive reinterpretation. The optimal methods of translating these suggestions into practice and the efficacy of doing so are unclear, particularly as the concept of coping has been inconsistently applied and related interventions have resulted in relatively few positive findings within stroke recovery. A review of coping following stroke, for example, found that out of 14 studies, only four referenced a coping theory or model (Donnellan, Hevey, Hickey, & O'Neill, 2006). Ways of measuring coping were not consistent across the literature. Ten out of 14 studies examined used different coping measures, which suffered from poor reliability and validity (Donnellan et al., 2006). Donnellan et al. (2006) therefore concluded that it was not possible to determine a typical coping response to stroke using quantitative methods, nor which coping strategies were used most effectively by stroke survivors.

There are various theoretical approaches to coping within the wider literature. Lazarus and Folkman (1984) proposed two categories of coping strategies within the Transactional Theory of Stress and Coping: problem-focused coping and emotion-focused coping. Problem-focused strategies relate to efforts to address the problem, whereas emotion-focused coping relates to efforts to alleviate the emotional distress associated with the problem. Problem-focused strategies can include implementing alternative solutions, learning new skills, taking action or reappraising the meaning of the situation. Emotion-focused coping strategies can include distancing, avoiding, wishful thinking and seeking social support (Lazarus & Folkman, 1984; Lyon, 2002). Transactional theory was employed in three studies identified in the above systematic review, although one focused on acquired brain injury rather than stroke specifically (Boynton De Sepulveda & Chang, 1994; Finset & Andersson, 2000; Gillespie, 1997). The theory was also described as a potential framework for post-stroke rehabilitation by Lyon (2002), who drew upon it to identify ways which stroke survivors and healthcare professionals could improve or encourage use of coping strategies. These ranged from providing information and reassurance that accepting help can be positive, to the use of comics to invoke humour, however these were not actively implemented or evaluated. Furthermore, despite the use of transactional theory to develop stroke caregiver interventions (see Cheng, Chair, and Chau (2014) for a systematic

review and meta-analysis), no studies could be identified that utilised the model to develop an intervention for stroke survivors.

Self-management is one further type of psychosocial intervention common in the stroke literature. Self-management refers to individuals taking an active role in managing their chronic health condition, ranging from making decisions about their medical care to dealing with symptoms and treatment, making adaptations to roles and behaviours in order to cope with impairments, and dealing with the emotional consequences of living with their condition (Corbin & Strauss, 1988; Lorig & Holman, 2003). As previously discussed, a number of policies suggest that self-management support should be provided to stroke survivors (NHS Scotland, 2009; Royal College of Physicians, 2016; The Scottish Government, 2014; The Scottish Intercollegiate Guidelines Network (SIGN), 2010). A wide range of self-management interventions have been examined in stroke survivors, however research in the stroke population is still very much behind that of other chronic health conditions (Jones, Riazi, & Norris, 2013; Parke et al., 2015). Stroke-specific self-management programmes do exist, albeit they have not been subjected to large-scale randomised controlled trials and their efficacy is still unclear. A Cochrane review of self-management programmes for stroke survivors (Fryer, Luker, McDonnell, & Hillier, 2016) was able to pool the data on self-efficacy outcomes from four interventions (Hoffmann, Ownsworth, Eames, & Shum, 2015; Jones et al., 2016; Kendall et al., 2007; McKenna, Jones, Glenfield, & Lennon, 2015) and the data on quality of life outcomes from six interventions (Harwood et al., 2012; Jones et al., 2016; Kendall et al., 2007; A. Lund, Michelet, Sandvik, Wyller, & Sveen, 2012; McKenna et al., 2015; Tielemans et al., 2015). The authors concluded that self-management programmes resulted in significant improvements in self-efficacy, compared to standard care or an active control, although the quality of the evidence was low (Fryer et al., 2016). The authors also concluded that there was moderate quality evidence of self-management programmes resulting in significant improvements in quality of life in stroke survivors, despite no individual study providing evidence for such beneficial effects (Fryer et al., 2016). There was no evidence that self-management programmes improved activity limitations (based on the Barthel Index) or anxiety and depression (based on the Hospital Anxiety and Depression Scale) in stroke survivors.

The Cochrane review described above would suggest that there is some merit in larger trials of self-management interventions, particularly as few have progressed past the

piloting and feasibility stages. However, there was quite considerable variation in the development, content and delivery of each of the interventions. Quality of life data, for example, was pooled through combining the effects of a 90 minute self-directed task to set rehabilitation goals in activities of daily living (Harwood et al., 2012), a proactive planning intervention over 10 weeks (Tielemans et al., 2015) and a lifestyle intervention based on the Canadian Occupational Performance Measure delivered over 10 months (A. Lund et al., 2012). Fryer et al. (2016) included studies within the review if they contained at least one of the following components: problem solving, goal-setting, decision making, self-monitoring, coping with the condition, or 'alternative method designed to facilitate behaviour change and improvements in physical and psychological functioning'. Grouping the effects from such a range of components fails to provide us with the necessary information about which are effective in achieving outcomes. Indeed, the included studies are so varied that the review does not really provide us with additional insight other than that some form of post-stroke support containing at least one of the above components is beneficial. The findings from stroke-specific self-management interventions and the limitations of such an approach will be discussed in more detail in chapter five.

Lifespan models and successful ageing

It is clear that further research is required to determine the optimal method of helping stroke survivors come to terms with the long-term consequences of stroke. Currently, the long-term adjustment period coincides with a reduction in health professional input, and there is a paucity of knowledge surrounding how to continue meeting psychological, emotional and social needs. In particular, there is a lack of theory-based evidence as to how stroke survivors can be aided in coping or adjusting to their new circumstances.

A lifespan approach to such adjustment may have utility in describing the efforts stroke survivors make to adapt post-stroke, inform an intervention to aid post-stroke adaptation, and may have the ability to provide a common language between healthcare professionals at various stages of stroke recovery. Lifespan theories refer to the study of human development across the lifespan, and often therefore make specific references to ageing. The work of gerontologists and their study of the psychological, cognitive and biological aspects of ageing are becoming increasingly important as the effects of an ageing population emerge; in Scotland, for example, there are now more people aged over 65 than aged under 15 years (Ellis, 2014). An increase in older adults will result in an increase in

chronic health conditions and is it not surprising that research in ageing has been traditionally centred around disability, disease and loss (M. Baltes & Carstensen, 1996; Rowe & Kahn, 1997). Over the past two decades, however, there has been a shift in the perspective of ageing research (Depp, Glatt, & Jeste, 2007). A field that typically focused on ill health began to re-examine the concept of 'successful ageing', largely following Rowe & Kahn's (1987) proposal to distinguish between usual ageing and those who are managing to age 'successfully'. Rowe and Kahn (1987) define 'successful agers' as those who are at low risk of disease and related disability, and who maintain high cognitive and physical functioning (Rowe & Kahn, 1987, 1997). This primarily biological stance on successful ageing also later incorporated active engagement in the form of good interpersonal relationships and involvement in meaningful activity (Rowe & Kahn, 1987, 1997).

Since its inception, however, the definition and measurement of successful ageing have been debated (P. Baltes & Baltes, 1990; Bowling, 2006; Bowling & Iliffe, 2006; Depp et al., 2007; Depp & Jeste, 2006). Critics of the Rowe and Kahn (1987) model suggest that categorising ageing success based solely on physical health is too narrow a definition. Doing so neglects, for example, those with chronic health conditions who may have high cognitive functioning and high life satisfaction (Depp & Jeste, 2006; Minkler & Fadem, 2002). A review by Depp and Jeste (2006) found that out of 28 studies, 29 different definitions of successful ageing were used. While most included some aspect of physical health, others examined social functioning, life satisfaction and well-being. Other psychological aspects of successful ageing have included variables such as self-efficacy, optimism, and adaptation to life's challenges (P. Baltes & Baltes, 1990; Bowling & Iliffe, 2011; Ryff, 1982). When older adults themselves were asked to define successful ageing, they often mentioned more than one aspect; 66% discussed health and disability and 47% mentioned satisfaction and enjoyment in life (Bowling, 2006). A multi-criteria definition may be necessary, defining adults as having aged successfully based on a combination of various outcomes.

According to lifespan theorists, however, focusing on categorising adults according to set outcomes significantly limits our understanding of successful ageing (M. Baltes & Carstensen, 1996; P. Baltes & Baltes, 1990; Schulz & Heckhausen, 1996). Firstly, this outcomes approach only provides a broad set of measureable domains and fails to address the processes that people go through as they age (Schulz & Heckhausen, 1996). Secondly,

it is unlikely that a consensus on which outcomes constitute successful ageing could be reached and applied to all individuals, given the heterogeneity in ageing that exists both within people and across cultures (M. Baltes & Carstensen, 1996; P. Baltes & Baltes, 1990). As M. Baltes and Carstensen (1996) state, perhaps we need to move away from attempting to define *what* successful ageing is and shift towards examining *how* people age successfully. By focusing on the processes through which people achieve their personal goals, the criteria for successful ageing are shifted from a set of standard ideals to personal goal achievement. Crucially it also allows for investigation of the actual strategies used by older adults to achieve specific goals in the face of loss.

The Dual-process model of accommodative and assimilative coping is one lifespan-based theory that has had some application within the context of stroke (Brandtstadter & Renner, 1990b). The Dual-process model of accommodative and assimilative coping consists of two distinct but inter-related strategies that can be employed to reduce discrepancies between experienced and desired life circumstances, therefore maintaining satisfaction in situations that are typically perceived as negative (Brandtstadter & Renner, 1990b). The Dual-process is suggested to begin with an appraisal of the individual's current life situation in contrast to their plans and goals. Where this appraisal is negative, and where sufficient resources for change are available, the individual will adopt assimilative coping strategies. Assimilative coping tendencies, also referred to as Tenacious Goal Pursuit, involve adjusting personal and life circumstances so that there is consistency between what the individual experiences and what they wish to experience. Alternatively, where such changes are unsuccessful or where sufficient resources are lacking, an individual may adopt accommodative coping strategies. Also referred to as Flexible Goal Adjustment, accommodative coping strategies involve adjusting goals and preferences in line with the existing circumstances and constraints (Brandtstadter & Renner, 1990b).

The application of the Dual-process model within stroke has, however, been limited. A recent review focusing on the association between coping strategies and health-related quality of life in stroke identified three studies that employed the model (Lo Buono, Corallo, Bramanti, & Marino, 2015). As an aside, however, it should be noted that this review was not systematic, only searched two databases and failed to provide information such as reasons for study exclusion. Within the review, Darlington et al. (2007) conducted a longitudinal study of assimilative and accommodative coping and quality of life in stroke

survivors at less than six months post-stroke until 12 months post-discharge. Prior to discharge, general functioning predicted quality of life, and there was no relationship between coping and quality of life. This pattern, however, changed over time. Five months post-discharge, both general functioning and assimilative coping predicted quality of life. Nine-twelve months post-discharge, general functioning and both assimilative and accommodative coping predicted quality of life. The authors concluded that both forms of coping were essential for good quality of life, providing a mixture of pursuing important goals and adjusting goals when necessary. Visser, Aben, Heijenbrok-Kal, Busschbach, and Ribbers (2014) also conducted a cross-sectional study measuring accommodative and assimilative coping, depression and health-related quality of life in stroke survivors over 18 months post-stroke. Accommodative coping emerged as a significant predictor of the psychological health domain within health-related quality of life, but not the domains of physical health, social relationships or environment. Both authors concluded that interventions targeting coping strategies may be beneficial to health-related quality of life in stroke survivors. No interventions could be identified, however, that targeted coping in stroke survivors using the Dual-process model.

The Selection, Optimisation and Compensation (SOC) model: research and evidence

The Selection, Optimisation and Compensation (SOC) model is a lifespan model that has potential utility in its application to stroke (P. Baltes & Baltes, 1990). The model was developed based on a framework of seven propositions. In summary the propositions state that there are differences between normal, pathological and optimal ageing, acknowledging that the path of an individual experiencing ageing without major illness will differ to that of an individual ageing with a major, potentially age-related illness. This leads to a great deal of variability in the ageing process. There is also evidence of reserve and plasticity, where interventions such as exercise, training or learning can allow older adults to maintain functioning and acquire new skills or knowledge under optimal conditions. There are indeed limits to this reserve; loss of cognitive capacity will occur, and cannot be fully compensated for by training. Such reserve limits may not, however, affect day to day life and may only be relevant when capacity is particularly reduced. In addition, knowledge and technology may compensate for such declines. Finally, although the balance of gains and losses becomes increasingly negative over time, older adults can demonstrate

resiliency and experience similar levels of satisfaction than younger adults (P. Baltes & Baltes, 1990). Following on from this framework, P. Baltes and Baltes (1990) developed a “prototypical strategy of mastery”, whereby three processes can be utilised for successful adaptation. The processes are necessary because biological, psychological and socio-economical resources are not limitless, and such resources decline with age (Freund & Baltes, 2000). The first process, selection, involves concentrating on areas in life or activities that are of high priority, so that attention is narrowed to the most important goals (M. Baltes & Carstensen, 1996; P. Baltes & Baltes, 1990). This can involve reducing or eliminating, or introducing new or altered goals, activities or areas of life (P. Baltes & Baltes, 1990). Two types of selection have since been identified: elective selection and loss-based selection. Elective selection occurs when one proactively selects goals or activities from a variety of available choices, often in anticipation of future change. Alternatively, loss-based selection can be described as reactive, occurring when a sudden or unpredictable loss in function or ability is experienced (Freund & Baltes, 1998). The aim of this process can be, therefore, to alter expectations, such that life satisfaction and control can be maintained despite losses (P. Baltes & Baltes, 1990). The second process, optimisation, involves strategies to enrich, expand, and make the greatest use of current resources and means by which selected goals can be achieved (M. Baltes & Carstensen, 1996; P. Baltes & Baltes, 1990). The exact form of optimisation will vary greatly depending on the final goal. Ways in which an older adult can help improve their memory, for example, will differ significantly from those that can help improve their walking. There may be several optimisation strategies available which allow the individual to strive to reach the same goal. The third process, compensation, comes into play when an individual loses the inherent resources, skills or capacity to continue functioning to a desired level (M. Baltes & Carstensen, 1996; P. Baltes & Baltes, 1990). Rather than selecting an alternative goal, the individual uses alternative means to reach their goal. Compensation strategies can include psychological, technological or human assistance methods, for example, walking aids or gadgets.

Overall, therefore, the model identifies the processes that allow older adults to maintain activity in areas of life that are important to them, despite loss of functional or cognitive capacity (P. Baltes & Baltes, 1990). P. Baltes and Baltes (1990) provide the example of a marathon runner who wishes to continue running marathons as they age; investing more

time and energy is a requirement if they wish to maintain performance, therefore they must utilise *selection* to reduce or eliminate other activities. In addition they must improve training and knowledge to ensure *optimisation* of their existing resources. Finally, they must use techniques to *compensate* for loss of functioning, e.g. identify and use particular shoes. Outside of this example, further specific manifestations of SOC strategy use can be extremely varied and dependent on individual circumstances, preferences and the application of the model. Indeed, the model is described as a 'meta-theory', suggesting that it requires incorporation within a specific theoretical framework before it is applied to a specific stage of development (P. Baltes, 1997; P. Baltes & Baltes, 1990; Freund & Baltes, 2000). As such, the general model of SOC refers to the general process that can be used to deal with gains and losses across the lifespan and does not specify the content of selection, optimisation and compensation (P. Baltes, 1997). Whilst the SOC strategy descriptions and examples provided above are discussed at an individual level, the model can also be applied at a societal level, within various domains of life, and within various life developmental stages (P. Baltes, 1997; Freund & Baltes, 2000). For example, the model has been applied to the design and use of nursing home environments, infant and child development, and intellectual development across the lifespan (P. Baltes, 1997; P. Baltes & Baltes, 1990). In addition, the application of SOC is not restricted to the active choices made by individuals. SOC strategies may exist along a continuum of active-passive, internal-external and conscious-non-conscious choices (P. Baltes, 1997; Freund & Baltes, 2000). Whilst all of these considerations should be taken into account when discussing the SOC model, the most common application of the model is a focus on active and conscious SOC strategy use within an action-theoretical framework (P. Baltes, 1997; Freund & Baltes, 2000). Such an action-theoretical framework refers to the field of personal goals, within which selection refers to goal or outcomes, optimisation to the means used to achieve such outcomes, and compensation to the strategies used to maintain outcomes despite a loss in resources (P. Baltes, 1997; Freund & Baltes, 2000). Suggested examples of SOC within an action-theoretical framework are presented in Figure 1.1.

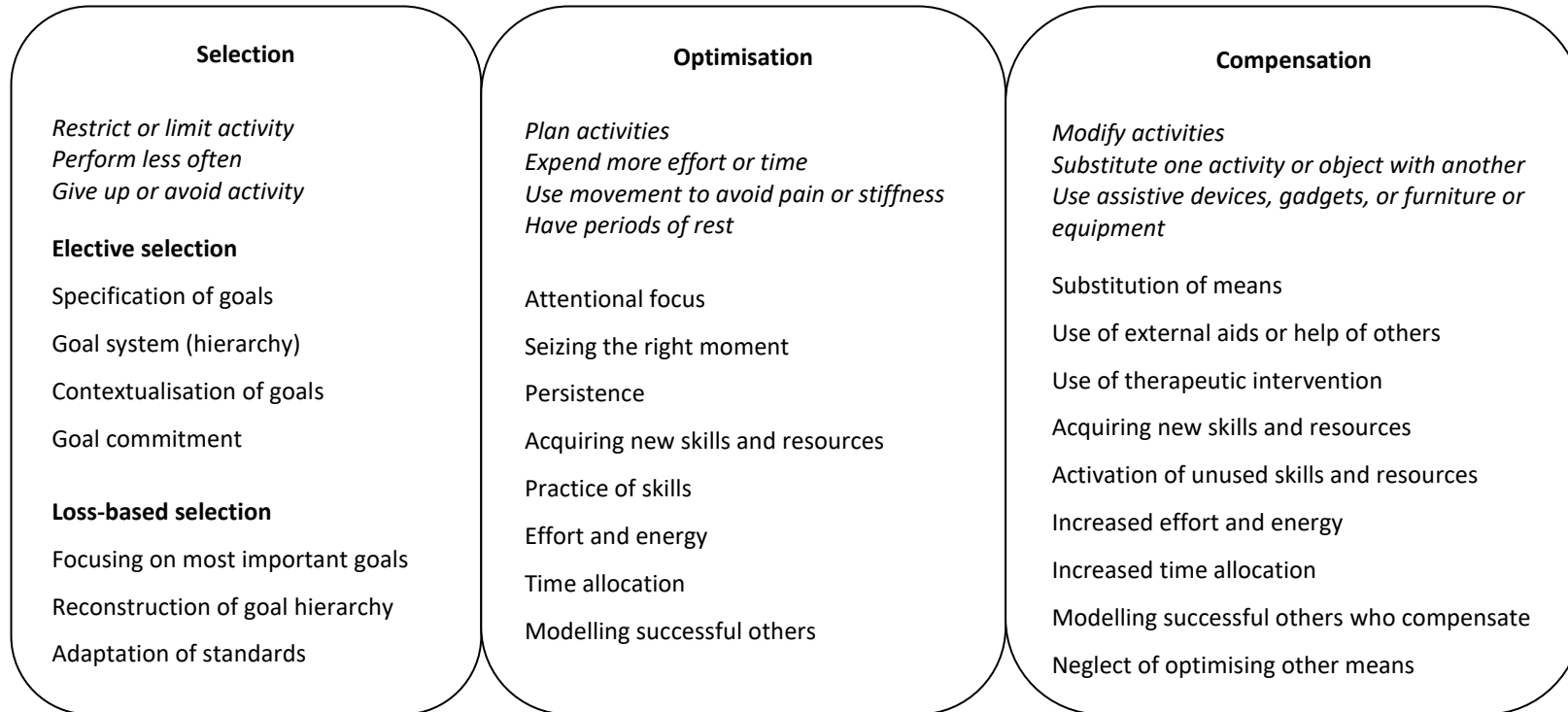


Figure 1.1: Suggested instances of SOC within an action-theoretical perspective

Note. Examples in italics taken from Gignac, Cott, and Badley (2002), all other examples taken from Freund and Baltes (2002b).

The SOC model may be more suitable within the context of stroke than the previously discussed Dual-process model. Specifically, the SOC model has a goal-oriented focus when it is applied within the action-theoretical framework described above, with goal-setting being the primary aim of the selection process (Freund & Baltes, 2002b). Goal-setting is an integral part of stroke rehabilitation, and should be included within clinical practice, according to rehabilitation guidelines (Royal College of Physicians, 2016; The Scottish Intercollegiate Guidelines Network (SIGN), 2010). According to the Royal College of Physicians (2016), goal-setting is the “process by which the person with stroke (and their family or carers if they wish) and member of the stroke team identify individual treatment goals that are meaningful, challenging and have personal value” (p23). Such goal-setting should be collaborative and involve the stroke survivor and members of the multidisciplinary stroke team, with stroke survivors being aided in both understanding the goal-setting process and identifying appropriate goals (The Scottish Intercollegiate Guidelines Network (SIGN), 2010). There is some evidence that goal-setting has positive effects on patient experience and recovery. For example, systematic reviews suggest that goal-setting helps patients become involved in the rehabilitation process, improves motivation and adherence to rehabilitation regimes, and has subsequent positive effects on performance, satisfaction and goal attainment (Levack et al., 2006; Rosewilliam, Roskell, & Pandyan, 2011; Sugavanam, Mead, Bulley, Donaghy, & van Wijck, 2013). It seems evident therefore that for a model to have utility within post-stroke adaptation and rehabilitation, it should contain a specific focus on goal-setting. Whilst Flexible Goal Adjustment within the Dual-process model also refers to goal-setting, Freund and Baltes (2002b) argue that this primarily refers to cognitive restructuring of the goal hierarchy in response to a discrepancy between perceived and actual circumstances. In contrast, goal-setting processes within the SOC model are more explicit and can involve the setting of goals without this discrepancy, i.e. where there has been no loss of resources (Boerner & Jopp, 2007; Freund & Baltes, 2002b). Indeed, correlations between self-reported SOC selection and self-reported Dual-process flexible goal adjustment were weak to modest, suggesting that whilst the two processes share some similarities they are primarily different (Boerner & Jopp, 2007; Freund & Baltes, 2002b). Furthermore the use of the SOC strategies has been found to be adaptive and related to a range of positive outcomes, even when tenacious goal pursuit and flexible goal adjustment were controlled (Freund & Baltes, 2002b). Overall, self-reported SOC strategy use correlated with outcomes of psychological

wellbeing and positive emotions (Freund & Baltes, 2002b), satisfaction with ageing (Jopp & Smith, 2006), self-esteem, and life satisfaction (Chou & Chi, 2002b).

In addition to ageing, the SOC model may have utility in the context of chronic health conditions. For example, SOC strategy use was found to mediate the relationship between coping planning and exercise goal attainment following discharge from an orthopaedic rehabilitation programme (Ziegelmann & Lippke, 2007a). Qualitative studies have also utilised the SOC model to explore how individuals adapt to ageing and health changes and cope with their circumstances (Hutchinson & Nimrod, 2012; Janke, Jones, Payne, & Son, 2012; Kelly, Fausset, Rogers, & Fisk, 2014; Rozario, Kidahashi, & Derienzis, 2011; Rush, Watts, & Stanbury, 2011; Ryan, Anas, Beamer, & Bajorek, 2003; Wilhite, Keller, Hodges, & Caldwell, 2004). For example, the model has been used effectively to categorise the coping behaviours of individuals living with osteoarthritis (Gignac, Cott, & Badley, 2000; Gignac et al., 2002). Furthermore, Boerner and Jopp (2007) suggest that the fact the SOC model recognises the adaptive nature of the orchestrated use of selection, optimisation and compensation makes it particularly appropriate in the context of chronic health. They provide the example of an individual with chronic health difficulties who is required to pursue goals that are relevant to their health, but adjust the goals that they no longer have the capacity to pursue, an interplay that is in accordance with the SOC processes. Indeed, qualitative research within the context of stroke suggests that both goal pursuit and goal disengagement is important. For example, Burton (2000) found that stroke survivors had to progress towards goals, adapt to new challenges and also make adjustments to their social roles.

Within the specific context of stroke, the SOC model has had limited application. One study utilised a generic self-report measure of SOC strategy use, finding that SOC use one month post-stroke did not predict functional ability, health-related quality of life or depression in stroke survivors one year after stroke (Donnellan, Hevey, Hickey, & O'Neill, 2012). There were however limitations with regards to the generic SOC self-report measure employed, and stroke survivors were initially interviewed prior to discharge from hospital, meaning they may not have had the opportunity to adopt SOC strategies. Furthermore, despite the lack of relationships with outcomes, SOC strategies were used at least once by 73% of stroke survivors, with loss-based selection and compensation the most common at one month, and loss-based selection and optimisation the most common at 12 months.

Given the range of post-stroke difficulties faced by survivors, and the finding that helping stroke survivors come to terms with the long-term consequences of stroke has emerged as a vital research priority, theory-based research and subsequent interventions are greatly required. The SOC model may provide an ideal model through which to explore post-stroke adaptation and potentially inform an intervention designed to aid stroke survivors in this process. Firstly, the model consists of processes that allow individuals experiencing functional or cognitive loss to maintain activity in areas of life that are important to them, and the interplay of such processes is suggested to be particularly important. Secondly, the use of SOC strategies appears to be related to positive outcomes within other contexts. Thirdly, the model has a goal-oriented focus, which supports the important process of goal-setting within the context of stroke. Finally, the SOC model has been previously applied successfully to explore how individuals adapt to ageing and health challenges. Further research is therefore required into the application of the SOC model in the context of stroke.

1.2 Overview of thesis

This thesis will explore the potential of the Selection, Optimisation and Compensation (SOC) model as a model of post-stroke adaptation. *Chapter one* has discussed the prevalence of stroke and common post-stroke impairments, activity limitations and participation restrictions. In addition, chapter one has reviewed stroke rehabilitation policies, psychosocial interventions, and introduced the SOC model. *Chapter two* will present a systematic review of the application of the SOC model within the contexts of ageing and health. Subsequently, *chapter three* will present qualitative theory-based interviews to explore how stroke survivors have adapted to life after stroke. The SOC model will be used to guide the analysis of such interviews. *Chapter four* will present further analysis of the qualitative interviews, discussing a Discriminant Content Validation study conducted in order to provide a reliable and replicable method of identifying the SOC strategies used by stroke survivors. *Chapter five* will present the acceptability and feasibility study of a stroke-specific SOC intervention, developing using findings from the above analysis and systematic review. Finally *chapter six* will conclude with final discussions about the use of the SOC model within the context of stroke, exploring the implications of the thesis research and suggesting future research directions.

2 The Selection, Optimisation and Compensation model in the contexts of ageing and health: A systematic review

Abstract

Background: The regulatory processes that allow individuals to adapt well as they cope with changes throughout life have been the focus of several lifespan theories. The Selection, Optimisation and Compensation (SOC) model is a lifespan model describing three processes used by people to achieve their goals as they age and experience both gains and losses. Whether adults use the processes of selection, optimisation and compensation as they age, and the relationships between their use and positive outcomes, has been examined using a range of approaches. The aim of this study was to conduct a systematic review of studies examining the SOC model in the contexts of ageing and health.

Method: A systematic review of studies utilising the SOC model in adults was conducted, using a systematic database search and hand-searching of eligible studies.

Findings: The full text of 456 articles was reviewed, with 54 meeting the criteria for inclusion in the review. Cross-sectional and longitudinal studies were the most common SOC study designs. The relationship between SOC and outcomes was examined in a number of populations including older adults and those with chronic health conditions such as arthritis, stroke and those undergoing orthopaedic rehabilitation. Use of SOC strategies was measured using a range of methods, from a standardised questionnaire to interpretation of adaptations as selection, optimisation or compensation; however the reliability of several methods was unclear. In general, the studies found positive relationships between the use of SOC strategies and positive outcomes, particularly when resources, e.g. good health, were low.

Discussion: There were generally positive relationships between SOC strategy use and outcomes. However, the review revealed a range of methodological limitations within the existing evidence base. There is a particular need for population and/or situation specific measures of SOC, and for further discussions regarding how the model can be translated into an intervention in the context of health conditions such as stroke. Interventions based on SOC are beginning to emerge, however their efficacy and optimal method of delivery has yet to be established.

2.1 Background and rationale

The Selection, Optimisation and Compensation model

It is inevitable that individuals experience change and loss as they progress through life. The regulatory processes that allow individuals to develop and adapt well as they cope with physical, social and psychological changes have been the focus of several lifespan theories (Boerner & Jopp, 2007; Riediger & Ebner, 2007). The Selection, Optimisation and Compensation model describes three processes that can be used by people to achieve their goals as they experience both gains and losses throughout the lifespan. This is suggested to be particularly relevant in old age, as older adults experience losses in the form of reductions in cognitive and functional capacities (M. Baltes & Carstensen, 1996). The model describes how individuals can master adaptation to such changes in life using three processes; selection, optimisation and compensation. These have been described in detail in chapter one. Further evidence on the application of the SOC model is presented below.

SOC model research and evidence

Whether individuals use the processes of selection, optimisation and compensation, and the relationships between their use and positive outcomes have primarily been examined in older adults, using a range of methodological approaches from self-report measures to examining patterns of behaviour. For example, using a SOC self-report measure developed by Baltes and colleagues (1999; 2002) studies have found that older adults who report more use of selection, optimisation and compensation also reported more satisfaction with ageing (Jopp & Smith, 2006), positive emotions and subjective wellbeing (Freund & Baltes, 2002b). This generic self-report measure, the SOC-48 and its shortened SOC-12 version, has demonstrated psychometric validity (P. Baltes, Baltes, Freund, & Lang, 1999; Freund & Baltes, 2002b) and is typically used in studies with older adults. The measures contain examples of elective selection, loss-based selection, optimisation and compensation, in a forced choice 'person A-person B' format. Respondents must select whether they would behave most like 'person A' the prototypical SOC example, or 'person B' the non-SOC example. The SOC-48 and SOC-12 ask respondents to think about their lives overall, including things they want to improve and things they are satisfied with and want to maintain, rather than thinking about a particular goal or area of their life. Measure instructions and examples of the SOC strategies and the non-SOC examples included in the measure are presented in Figures 2.1 and 2.2.

Domain–general instruction: Life-management

We are very interested in learning about how you decide which things in life are important for you and how you go about accomplishing what you want in life.

In the following, we present examples of two different ways people might behave. Imagine there are two people talking about what they would do in a particular situation. We would like you to decide which person is most similar to you – in other words, which one behaves most like the way you probably would.

Now, think about your life overall, including how things are going, think about your goals – that is, both things you want to improve and things that you are satisfied with and want to maintain.

Figure 2.1: Domain-general SOC instructions (P. Baltes et al., 1999), used with permission

	Target	Distractor
Elective Selection		
S1	I concentrate all my energy on few things.	I divide my energy among many things.
S2	I always focus on the one most important goal at a given time.	I am always working on several goals at once.
S3	When I think about what I want in life, I commit myself to one or two important goals.	Even when I really consider what I want in life, I wait and see what happens instead of committing myself to just one or two particular goals.
Loss-based Selection		
LBS1	When things don't go as well as before, I choose one or two important goals.	When things don't go as well as before, I still try to keep all my goals.
LBS2	When I can't do something important the way I did before, I look for a new goal.	When I can't do something important the way I did before, I distribute my time and energy among many other things.
LBS3	When I can't do something as well as I used to, I think about what exactly is important to me.	When I can't do something as well as I used to, I wait and see what comes.
Optimisation		
O1	I keep working on what I have planned until I succeed.	When I do not succeed right away at what I want to do, I don't try other possibilities for very long.
O2	I make every effort to achieve a given goal.	I prefer to wait for a while and see if things will work out by themselves.
O3	If something matters to me, I devote myself fully and completely to it.	Even when something matters to me, I still have a hard time devoting myself fully and completely to it.
Compensation		
C1	When things don't go as well as they used to, I keep trying other ways until I can achieve the same result I used to.	When things don't go as well as they used to, I accept it.
C2	When something in my life isn't working as well as it used to, I ask others for advice or help.	When something in my life isn't working as well as it used to, I decide what to do about it myself, without involving other people.
C3	When it becomes harder for me to get the same results, I keep trying harder until I can do it as well as before.	When it comes harder for me to get the same results as I used to, it is time to let go of that expectation.

Figure 2.2: Items within domain-general SOC-12 self-report measure (P. Baltes et al., 1999), used with permission

Patterns of behaviour have also been used to examine SOC use (Lang, Rieckmann, & Baltes, 2002; Li, Lindenberger, Freund, & Baltes, 2001). Li et al. (2001) asked younger and older adults to perform a dual task activity of walking while memorising. The authors suggest that older adults exhibited behavioural patterns which indicated the SOC processes of loss-based selection and compensation, by prioritising walking over memorising and compensating for their declining abilities through the use of a walking aid. Lang et al. (2002) categorised behaviour as selection, optimisation or compensation based on activities undertaken in various areas of life. Behaviour such as spending more time with family, reducing their range of activities and sleeping more during the day were suggested to be examples of selection, optimisation and compensation respectively. Lang et al. (2002) found that older adults who were rich in sensorimotor, cognitive and social resources were more likely to display behavioural patterns indicative of SOC than those who lacked such resources.

Although the SOC model is a general model of successful development and mastery, it has most commonly been applied within the field of ageing (P. Baltes & Baltes, 1990; Freund & Baltes, 2002b). The model may also, however, be useful in describing how adults overcome challenges due to chronic health conditions. A number of studies have therefore explored the utility of the model in examining adaptation in adults who have experienced a health condition such as stroke (Donnellan et al., 2012), osteoarthritis (Gignac et al., 2000, 2002) and musculoskeletal conditions requiring orthopaedic rehabilitation (Ziegelmann & Lippke, 2007a, 2007b; Ziegelmann, Lippke, & Schwarzer, 2006).

There have been mixed findings, however, surrounding the relationship between SOC use and positive outcomes in health studies. Similar to studies with older adults, Ziegelmann and Lippke (2007b) found that SOC use predicted subjective wellbeing in individuals undergoing orthopaedic rehabilitation. The authors also found that SOC use predicted physical outcomes such as exercise, flexibility, strength, endurance and balance. Donnellan et al. (2012), on the other hand, found that SOC strategy use was not related to objective or subjective outcomes including functional ability, depression or health-related quality of life, in stroke survivors. Finally, Janke, Son, and Payne (2009) found that elective selection, loss-based selection, optimisation and compensation were differentially related to outcomes in adults with arthritis. Elective selection, optimisation and compensation were related to

more positive outcomes such as less pain and fewer difficulties with activities of daily living whereas loss-based selection was related to more pain and anxiety.

There are a number of potential explanations for these contradictory findings, including the possibility that SOC use influences subjective wellbeing but not physical outcomes. The different methods used to measure and examine SOC use also merits further investigation, as SOC studies within the context of chronic illness adopted a range of methodological approaches, from self-report measures to examining patterns of behaviour. Whether the previously discussed generic self-report measure is suitable for examining the relationships between SOC use and positive outcomes in adults with chronic health conditions requires further examination. Such studies often focus on specific physical outcomes, and it may be that these are better predicted by outcome specific strategies rather than the very general approach to strategy measurement evident in the SOC 48/12.

To-date there has been no systematic review of the use of the SOC model to understand outcomes in older adults and people with chronic health conditions. By collating and appraising the current evidence we might identify future directions for the SOC model. For example, it may be possible to intervene to teach individuals to use selection, optimisation and compensation strategies to optimise wellbeing and quality of life for people who are ageing and living with chronic health conditions; a review of the evidence may help inform such a SOC intervention.

Research questions

This systematic review has the following research questions:

- 1) How are selection, optimisation and compensation measured in older adults and those with chronic health conditions?
- 2) Are the use of selection, optimisation and compensation strategies related to outcomes in older adults and those with chronic health conditions?
- 3) What are the limitations of the current evidence base and what are the possible future directions for the Selection, Optimisation and Compensation model within the contexts of ageing and health?

2.2 Method

Eligibility criteria

Details of the protocol were registered on PROSPERO (CRD42016038426) (Dryden, Dixon, & Grealy, 2015). The primary inclusion criterion was the application of the Selection, Optimisation and Compensation model in the fields of ageing or chronic health. Whilst those over 65 years of age are typically described as older adults, it was decided that a broader criterion would be adopted for this review in order to allow for the inclusion of studies with mixed-aged samples that were still applying the SOC model to the process of ageing. Studies were therefore included if their participant sample had a mean age of 50 years or older, if the study analyses involved a subgroup of older adults, or if participants had a chronic health condition.

While the review was being conducted, the decision was taken to apply one additional exclusion criterion, excluding all studies applying the SOC model to the context of work. This decision was undertaken in order to avoid a fragmented discussion of the SOC model in work environments; less than 50% of studies in this domain met the age inclusion criteria discussed above. Rather, these studies included a wide range of participants at work, often with a mean age that just fell below 50 years. It was felt, therefore, that a clear picture of SOC in the workplace could not be provided within the scope of this review. Furthermore a systematic review and meta-analysis of the SOC model within the context of work was published in early 2016 and provides a detailed overview of the work outcomes associated with SOC use and limitations of the evidence base in this field (Moghimi, Zacher, Scheibe, & Van Yperen, 2016).

Papers that were solely theoretical were excluded. Studies that did not include the model in the design, rationale or analysis of their study were excluded, i.e. those that only mentioned the model in their discussion as a response to their findings. In addition, dissertations, theses, book chapters, conference abstracts and non-English studies were excluded.

Search strategy and information sources

The search strategy was applied to the following databases: PsychInfo, Cinahl, ISI Web of Science, Embase, Medline and the Cochrane Central Register. The search was initially carried out from the beginning of the databases to May 2013. An updated search was then

carried out from the beginning of 2013 until the end of 2015. The following search terms were used to identify all studies utilising the Selection, Optimisation and Compensation model: (select* AND optim* AND compensation) OR “successful ageing” or “successful aging”.

Reference lists of all included papers were searched for potentially eligible studies. In addition, in response to a large number of relevant conference abstracts in *The Gerontologist*, published conference abstracts from 1990-2013 were manually searched. Authors of relevant abstracts were contacted to enquire if they had subsequently published this information in peer-reviewed journals.

No limits were placed on the search in terms of date, place or language; however studies that were not available in English were subsequently excluded.

Study selection

All titles and abstracts were screened for inclusion/exclusion by author JD. The full text of identified studies was read by author JD and the inclusion/exclusion criteria applied to determine the final studies for inclusion in the review. At both stages, a second reviewer independently screened 25% of the studies.

Data collection and quality assessment process

A data extraction sheet was developed and piloted independently by JD and a second reviewer on 10% of included studies. The data extraction sheet was deemed to be adequate and subsequently used for all remaining studies. Data extracted were as follows: health condition, aim and hypotheses of study, population characteristics, study design, SOC measurement, other outcome measures, and outcomes.

The review had three broad research questions and the inclusion of a range of study designs was therefore anticipated, particularly as the Selection, Optimisation and Compensation model has been examined in a range of settings using a number of methodologies. In addition, no studies were excluded on the basis of methodological quality. These were deemed to be important features of the review as it aimed to provide an overview of the SOC literature, including limitations of existing SOC research and future directions for the model. An overall picture of SOC research was sought and thought to be beneficial to the research contained within this thesis as a whole.

The range of study designs and lack of exclusion criteria relating to methodological quality do, however, present some issues that require consideration. Firstly, it is important to provide some discussion around the method of assessing methodological quality and how this influenced the quality 'scores' of studies. Secondly, it is important to consider how these influence the conclusions provided within the review.

As noted by authors of other systematic reviews, there are a lack of quality assessment tools which are suitable for examining methodological quality across varying study designs (Boger et al., 2015). The Effective Public Health Practice Project (EPHPP) Quality Assessment tool (appendices 2.1 and 2.2) (Thomas, Ciliska, Dobbins, & Micucci, 2004) was therefore employed as a tool to explore the methodological quality of key areas of bias for quantitative data. The EPHPP consists of six sections assessing selection bias, study design, data collection methods, and where appropriate, confounders, blinding and withdrawals and dropouts. Each section is rated as strong, moderate or weak using the EPHPP tool dictionary as a guide (appendix 2.2). Intervention integrity and analysis can also be assessed but are not provided with a rating. For example, with regard to selection bias, questions are asked about whether study participants are representative of the target population and what percentage of selected individuals agreed to participate in the study. The EPHPP tool dictionary provides guidance on how to score these questions and states what constitutes a rating of strong, moderate or weak for selection bias overall. For example, a rating of strong is given when study participants are very likely to be representative of the target population (question one) and study participation is greater than 80% (question two). An overall rating of strong, moderate or weak is calculated from the individual section ratings as follows: strong (no weak ratings in individual section ratings), moderate (one weak rating in individual section ratings) and weak (two or more weak ratings in individual section ratings).

However, comparing the overall methodological quality rating of studies may not be the most appropriate way of exploring methodological quality of studies with varying designs. For example, the EPHPP tool states that only randomised controlled trials and controlled clinical trials are of strong methodological quality. Studies with cross-sectional or longitudinal designs are rated as having weak study designs due to their cross-sectional and longitudinal natures. When calculating the overall quality assessment, the number of weak individual ratings was taken into account. As a consequence, cross-sectional and

longitudinal studies would never be rated as of overall strong methodological quality. Furthermore studies only had to be rated as weak in one other area to be assessed as weak overall. The review also therefore considered and discussed the individual components of the EPHPP tool. Where appropriate, the quality of these individual components was used to guide the conclusions that were drawn from the results of each study.

Methodological quality of qualitative studies was assessed using the Critical Review Form – Qualitative Studies (Version 2.0) (Letts et al., 2007a). Similar to quantitative studies, issues such as sampling, data collection and data analyses can also be assessed in qualitative studies. The Critical Review Form – Qualitative Studies (Version 2.0) (Letts et al., 2007a) states that sampling in qualitative studies should be purposeful, the sample should be adequately described, and that sampling should continue until data saturation is reached. The Critical Review Form also states that the role of the researcher and their relationship with participants, including any assumptions and biases of said researcher, should be described in order to ensure that data collection has descriptive clarity. In addition, the data collection strategies should be clearly described. Finally, regarding the methodological quality of the data analyses, the Critical Review Form states that data analyses should be inductive and consistent with the data, the process of analysing the data should be clearly described and auditable, and should result in a meaningful picture emerging.

Unlike the EPHPP, the qualitative critical review form does not provide an overall rating of methodological quality; instead overall rigour is assessed through examining whether the study showed evidence of trustworthiness, specifically the components of credibility, transferability, dependability and confirmability. As in other systematic reviews, studies were judged as having provided sufficient evidence for each component if they met the majority of the ideal study characteristics described in the Critical Review Form Guidelines (Letts et al., 2007b; Sugavanam et al., 2013).

Data synthesis

Data synthesis was conducted using a systematic narrative review approach, with information presented in the text and in tables. The narrative synthesis describes the characteristics of the included studies, with a particular focus on two key areas: how selection, optimisation and compensation were measured within each study, and the

relationships between the use of selection, optimisation and compensation strategies and outcomes.

2.3 Results

Study selection

The initial database search yielded 8527 results. Once duplicates, books, theses and patents were removed 3840 articles remained. After screening the titles and abstracts, 300 articles remained. The full text of the 300 articles was reviewed, with 40 selected for inclusion in the study. The updated search yielded 5219 results. Once duplicates, books, theses and patents were removed 4297 articles remained. After screening the titles and abstracts, 154 articles remained. Many studies could not be excluded on the basis of their titles and abstracts due to poor quality abstracts with missing information, resulting in a high number of studies selected for full text review. The full text of the 154 articles was reviewed, with 14 selected for inclusion in the study. This resulted in a review of 54 studies.

Of the 54 studies, 33 focused on SOC in the context of ageing or older adults, whereas 21 examined SOC within adults with chronic health conditions. Search results and reasons for exclusion from the review are displayed in Figure 2.3. A summary of the included studies is presented in Table 2.1.

A second reviewer independently screened the abstracts and titles of 26% (1001) of the articles in the initial search. The second reviewer also independently screened 25% (72) of the 300 articles selected for full text review in the initial search. Reliability at both stages was excellent, with Cohen's Kappas of .99 and .96 respectively.

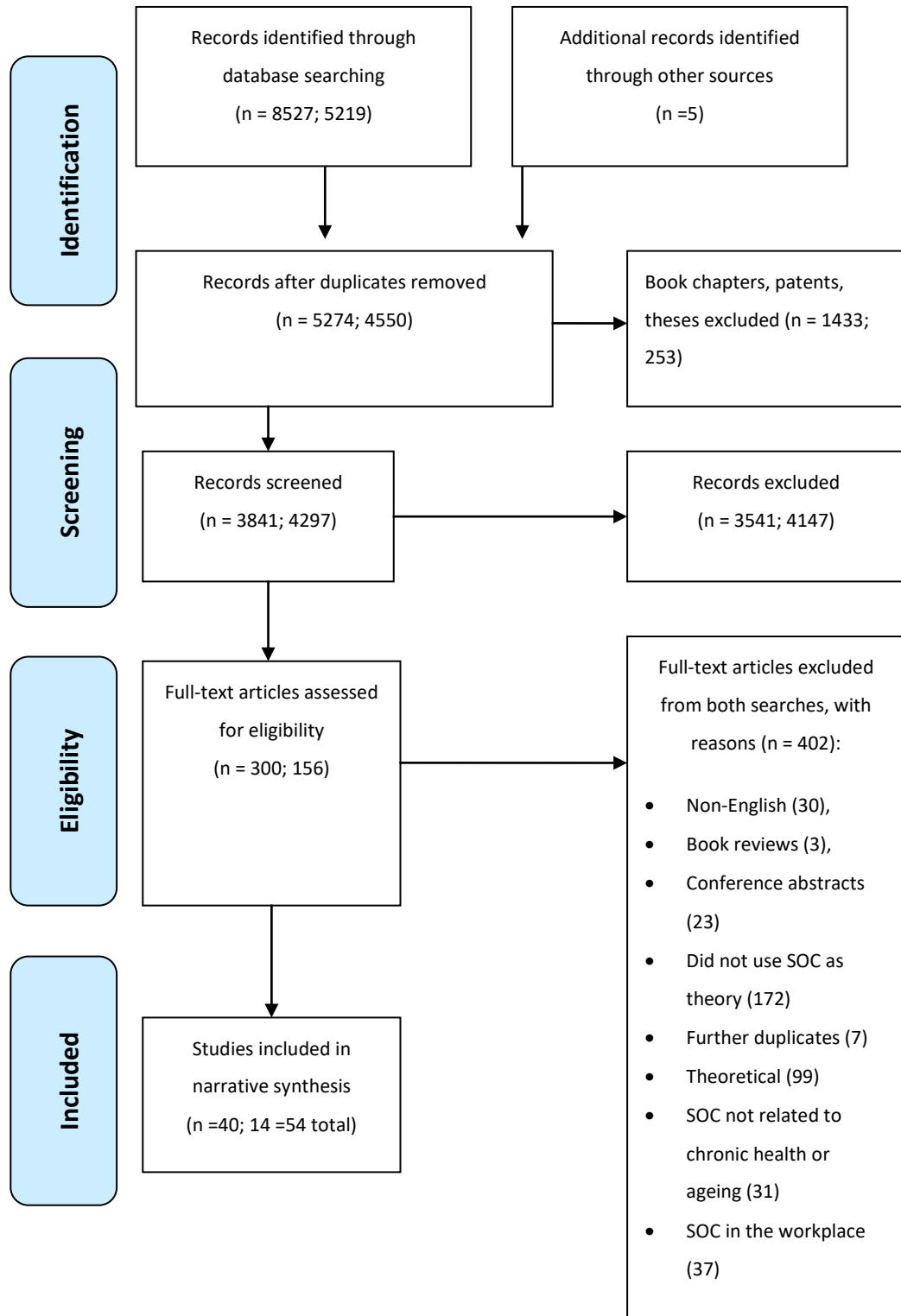


Figure 2.3: PRISMA (Moher, Liberati, Tetzlaff, Altman, & Group, 2009) Flow Diagram of search including initial and updated search details, (n=initial search; updated search).

Study characteristics

As can be seen in Table 2.1, evidence for the Selection, Optimisation and Compensation model and its utility in describing adaptation to loss was examined in a range of situations. Many of the studies focused on ageing, examining the evidence for SOC within older adults in general and in specific circumstances such as driving and physical activity environments. Of the 54 studies included in the review, 33 examined SOC within the context of ageing. The SOC model was also used to examine adaptation in those with chronic health conditions. Of the 54 studies included in the review, 21 examined SOC use by individuals with chronic health conditions such as arthritis, depression and stroke.

Overall, cross-sectional and longitudinal studies were the most common SOC study designs, with 30 out of the 54 studies utilising these designs. One study examined SOC using a prospective cohort design. Three studies examined SOC experimentally and seven randomised control trials/interventions were identified. Thirteen studies examined SOC qualitatively within ageing and across a range of health conditions

Ageing

Within the context of ageing, 25 studies examined SOC use within older adults generally (Carmichael, Reis, & Duberstein, 2015; Chou & Chi, 2002a, 2002b; Freund, 2006; Freund & Baltes, 1998, 2002a, 2002b; Haase, Heckhausen, & Wrosch, 2013; Hahn & Lachman, 2015; Janke & Davey, 2006; Jopp & Smith, 2006; Kelly et al., 2014; Kleiber & Nimrod, 2009; Lang et al., 2002; Li et al., 2001; Lien, Steggell, & Iwarsson, 2015; Okabayashi, 2014; Opitz, Lee, Gross, & Urry, 2014; Penningroth & Scott, 2012; Rush et al., 2011; Scheibner & Leathem, 2012; Tovel & Carmel, 2013; van der Goot, Beentjes, & van Selm, 2015; Viglund et al., 2013; Wurm, Warner, Ziegelmann, Wolff, & Schuz, 2013). Also within the context of ageing, three studies examined older adults and driving, quantitatively (Bieri, Nef, Müri, & Mosimann, 2015; Pickard, Tan, Morrow-Howell, & Jung, 2009) and qualitatively (Nasvadi & Vavrik, 2007). Four studies also examined SOC in relation to ageing and physical activity (Evers, Klusmann, Ziegelmann, Schwarzer, & Heuser, 2012; Gellert, Ziegelmann, Krupka, Knoll, & Schwarzer, 2013; Reuter et al., 2010; Son, Kerstetter, Mowen, & Payne, 2009). Finally, one study spanned the contexts of both health and ageing (John & Lang, 2012). The authors examined how young, middle-aged and older adults dealt with unavoidable loss, using a video depicting a multiple sclerosis diagnosis. The study sought to examine thinking about

coping strategies in response to a simulated health-loss, and the age differential effects of thinking about such strategies on well-being.

Health

The SOC model was examined within individuals with a range of health conditions including arthritis (Gignac et al., 2000, 2002; Janke et al., 2012; Janke et al., 2009; Son & Janke, 2015), cancer (Janse, Ranchor, Smink, Sprangers, & Fleer, 2015; Rose, Radziewicz, Bowman, & O'Toole, 2008), general chronic illness (Hutchinson & Nimrod, 2012; Rozario et al., 2011), chronic pain (Alonso-Fernández, López-López, Losada, González, & Wetherell, 2015; Alonso, Lopez, Losada, & Luis Gonzalez, 2013), depression (Weiland, Dammermann, & Stoppe, 2011), multiple sclerosis (Wilhite et al., 2004), in those undergoing orthopaedic rehabilitation (Ziegelmann & Lippke, 2007a, 2007b; Ziegelmann et al., 2006), stroke (Donnellan et al., 2012) and vision loss (Ryan et al., 2003). Three studies also used SOC within the context of those caring for family members who were older or had chronic health conditions such as dementia or stroke (DiLauro, Pereira, Carr, Chiu, & Wesson, 2015; Greenwood, MacKenzie, Cloud, & Wilson, 2010; D. Lund et al., 2014).

Methodological quality

Quantitative studies

Overall methodological quality was assessed as moderate for 16 studies and weak for 24 studies (Table 2.1; appendix 2.3). However, as has been previously discussed, there are a lack of suitable tools which can provide an accurate overall quality 'score' across various study designs. It is particularly important therefore, to discuss the individual components of the EPHPP tool, particularly with regards to study design, selection bias and data collection methods, as there were commonalities in these three sections between the various studies.

Regarding study design, the EPHPP tool states that only randomised controlled trials and controlled clinical trials are of strong methodological quality. As a result, the majority of studies were assessed as having weak study designs due to their cross-sectional and longitudinal natures.

Studies which utilised the validated SOC self-report measures, validated outcome measures, and reported psychometric properties such as reliability were typically assessed

as having strong data collection methods. A number of studies modified the validated SOC measures, made no comment on their validity or reliability, and were therefore assessed as weak in this respect. Furthermore the use of validated outcome measure varied between the studies. Several authors utilised their own measures, which often consisted of one or two items, and did not report on the validity or reliability of these measures.

Finally, with regards to participant sampling and recruitment, several of the studies either lacked specificity with regards to participant recruitment, or had poor participation; these were assessed as methodologically weak in this respect. Others recruited participants through referral from health professionals and were assessed as moderate quality.

How the methodological quality of the studies influenced the conclusions that can be drawn regarding SOC research is discussed in further detail within the narrative synthesis of each research question and within the overall review discussion.

Qualitative studies

Methodological quality of the qualitative studies was assessed using the Critical Review Form – Qualitative Studies (Version 2.0) (Letts et al., 2007a) and is displayed in Table 2.1 (see also appendix 2.4). The overall rigour was examined, in particular whether sufficient evidence was provided for credibility, transferability, dependability and confirmability. The majority of the studies did not provide sufficient evidence to demonstrate credibility of their results. Letts et al. (2007b) suggest that credibility can be ensured through actions such as using a range of participants, gathering data using a variety of methods, keeping a reflective journal, triangulation of data, and having participants verify data and interpretations. Only five of the thirteen studies employed more than two of these methods, with three studies utilising no methods to ensure credibility of findings. In contrast, all of the studies adequately described the study participants and their context, helping to determine whether the findings could be transferred to other contexts. Eight studies did not demonstrate rigour in the dependability of their data; whilst data collection methods were well-described, descriptions of analyses were typically poor and evidence of audit trails were lacking. Finally, nine studies did not employ more than two of the following strategies suggested by Letts et al. (2007b) to limit research biases: reflective journals, peer review of the data analysis and findings, participant verification of findings, and utilising a team of researchers.

Table 2.1: Characteristics of included studies

Authors (country)	Area	Design	Methodological quality^a	Measurement of SOC
Alonso et al. (2013) (Spain)	Health - Chronic pain	RCT	Weak	SOC-48.
Alonso-Fernández et al. (2015) (Spain)	Health - Chronic pain	RCT	Moderate	SOC-12
Bieri et al. (2015) (Switzerland)	Ageing	Cross-sectional	Weak	Driving Behaviour Adaptations Questionnaire (38 item measure consisting of strategic (advanced) and tactical (whilst driving) SOC items.
Carmichael et al. (2015) (USA)	Ageing	Prospective cohort	Moderate	SOC not measured however differential relationships between quantity and quality of social activity at ages 20 and 20, and wellbeing at aged 50 suggested to be consistent with SOC model and indicate selection and optimisation.
Chou and Chi (2002b) (China)	Ageing*	Cross-sectional	Moderate	SOC 36 (Chinese version)
Chou and Chi (2002a) (China)	Ageing	Cross-sectional	Moderate	SOC 36 (Chinese version)
DiLauro et al. (2015) (Canada)	Health- Dementia	Qualitative	Credibility ✘ Transferability ✓ Dependability ✘ Confirmability ✓	Thematic content analysis
Donnellan et al. (2012) (Ireland)	Health – Stroke*	Longitudinal	Moderate	Reduced SOC-48 (SOC-15).
Evers et al. (2012) (Germany)	Ageing and physical activity*	RCT	Moderate	Modified SOC-12 (Ziegelmann & Lippke, 2007a, 2007b), with differing Likert scale.
Freund (2006) (Germany)	Ageing	Experimental	Weak	Induced optimisation and compensation experimentally, instructing participants in a sensorimotor computerised task.

Authors (country)	Area	Design	Methodological quality ^a	Measurement of SOC
Freund and Baltes (1998) (Germany)	Ageing	Cross-sectional	Moderate	SOC-12
Freund and Baltes (2002b) (Germany)	Ageing	Longitudinal	Moderate	Study 1. SOC-36. Study 2. SOC-48.
Freund and Baltes (2002a)(Germany)	Ageing	Cross-sectional	Weak	SOC not measured but proverbs deemed to reflect SOC life management skills examined.
Gellert et al. (2013) (Germany)	Ageing and physical activity*	RCT	Moderate	Intervention designed to foster SOC strategies however SOC not measured.
Gignac et al. (2000) (Canada)	Health – Musculoskeletal*	Qualitative and cross-sectional	Weak	Strategies and modifications used to deal with difficulties explored and coded as SOC.
Gignac et al. (2002) (Canada)	Health – Musculoskeletal*	Qualitative and cross-sectional	Weak	Strategies and modifications used to deal with difficulties explored and coded as SOC.
Greenwood et al. (2010) (UK)	Health - Stroke	Qualitative	Credibility ✓ Transferability ✓ Dependability ✗ Confirmability ✗	Identification of themes, including SOC strategies
Haase et al. (2013) (USA/Germany)	Ageing	Cross-sectional	Moderate	SOC-36
Hahn and Lachman (2015) (USA)	Ageing	Longitudinal	Weak	SOC-12
Hutchinson and Nimrod (2012) (Canada)	Health - Chronic illness	Qualitative	Credibility ✗ Transferability ✓ Dependability ✗ Confirmability ✗	Identification of themes & consideration of whether categories were consistent with SOC strategies
Janke and Davey (2006) (USA)	Ageing	Longitudinal	Weak	Relationships between variables used to determine the presence of selection, optimisation and compensation.

Authors (country)	Area	Design	Methodological quality ^a	Measurement of SOC
Janke et al. (2012) (USA)	Health - Musculoskeletal	Qualitative	Credibility ✓ Transferability ✓ Dependability ✓ Confirmability ✓	Content analysis, identifying themes of elective selection, loss-based selection, optimisation and compensation in the text.
Janke et al. (2009) (USA)	Health - Musculoskeletal	Cross-sectional	Weak	Reduced SOC-48 (SOC-21) modified to include the words 'leisure activities' in each item.
Janse et al. (2015) (Netherlands)	Health – Cancer	Longitudinal	Weak	SOC not measured, however used to inform the hypothesis that those with cancer will decrease their goals over time.
John and Lang (2012) (Germany)	Ageing	Cross-sectional	Weak	SOC-48
Jopp and Smith (2006) (Germany)	Ageing	Cross-sectional & longitudinal	Weak	SOC-48
Kelly et al. (2014) (USA)	Ageing	Qualitative	Credibility ✗ Transferability ✓ Dependability ✓ Confirmability ✗	Strategies coded as elective selection with optimisation; elective selection with compensation; loss-based selection with compensation; or loss-based selection.
Kleiber and Nimrod (2009) (USA)	Ageing	Qualitative	Credibility ✓ Transferability ✓ Dependability ✗ Confirmability ✗	SOC categories used as 'sensitising concepts' within grounded theory analysis.
Lang et al. (2002) (Germany)	Ageing	Longitudinal	Weak	Indicators of everyday functioning generated relating to SOC, e.g. Selection = % of time spend with family members or other relatives.

Authors (country)	Area	Design	Methodological quality ^a	Measurement of SOC
Li et al. (2001) (Germany)	Ageing*	Experimental	Moderate	SOC assessed experimentally, using a dual-task procedure involving walking and memorizing.
Lien et al. (2015) (USA)	Ageing	Qualitative	Credibility ✘ Transferability ✔ Dependability ✘ Confirmability ✘	Content analysis, with codes based on theoretical SOC categories
D. Lund et al. (2014) (USA)	Health – Caregiving	Intervention description/development	Weak	Intervention designed to foster SOC strategies however SOC not measured.
Nasvadi and Vavrik (2007) (Canada)	Ageing	Qualitative	Credibility ✘ Transferability ✔ Dependability ✘ Confirmability ✘	Focus group analysed with respect to SOC but method of analysis not stated.
Okabayashi (2014) (Japan)	Ageing	Cross-sectional	Moderate	SOC-26 (Japanese version)
Opitz et al. (2014) (USA)	Ageing	Experimental	Weak	SOC not measured however relationships between cognitive ability and cognitive reinterpretation suggested to support the idea that use of SOC strategies requires resources.
Penningroth and Scott (2012) (USA)	Ageing	Cross-sectional	Weak	SOC not measured but differences between goal characteristics of younger and older adults suggested to support selection.
Pickard et al. (2009) (USA)	Ageing	Cross-sectional	Weak	SOC not measured but model used to examine differences between groups of older drivers.
Reuter et al. (2010) (Germany)	Ageing and physical activity	Longitudinal	Weak	Modified SOC-12 (Ziegelmann & Lippke, 2007a, 2007b), with different domain of healthy lifestyle.

Authors (country)	Area	Design	Methodological quality ^a	Measurement of SOC
Rose et al. (2008) (USA)	Health - Cancer	RCT description/development	Moderate	Intervention designed to foster SOC strategies however SOC not measured.
Rozario et al. (2011) (USA)	Health - Chronic illness	Qualitative	Credibility ✘ Transferability ✔ Dependability ✘ Confirmability ✘	Identification of theme, using SOC model.
Rush et al. (2011) (Canada)	Ageing	Qualitative	Credibility ✘ Transferability ✔ Dependability ✔ Confirmability ✘	Interviews coded as selection, optimisation and compensation
Ryan et al. (2003) (Canada)	Health - Vision loss	Qualitative	Credibility ✘ Transferability ✔ Dependability ✘ Confirmability ✘	Identification of SOC strategies from interview text
Scheibner and Leathem (2012) (New Zealand)	Ageing	Cross-sectional	Weak	SOC-12 with added Likert scale.
Son et al. (2009) (USA)	Ageing and physical activity	Cross-sectional	Weak	SOC-12, with 3 items omitted.
Son and Janke (2015) (USA)	Health - Musculoskeletal	Cross-sectional	Moderate	Reduced SOC-48 (SOC-34, excluding elective selection) modified to reflect leisure activities in relation to arthritis, with person A-person-B format changed to yes/no
Tovel and Carmel (2013) (Israel)	Ageing	Longitudinal	Weak	SOC-36 including loss-based selection, optimisation and compensation

Authors (country)	Area	Design	Methodological quality ^a	Measurement of SOC
van der Goot et al. (2015)	Ageing	Qualitative	Credibility ✓ Transferability ✓ Dependability ✓ Confirmability ✓	Definitions of selection and compensation used as sensitising concepts, with which to interpret responses.
Viglund et al. (2013) (Sweden)	Ageing	Cross-sectional	Weak	SOC-10 (Swedish version)
Weiland et al. (2011) (Germany)	Health - Depression	Longitudinal	Moderate	SOC-48.
Wilhite et al. (2004) (Germany)	Health - Multiple Sclerosis	Qualitative	Credibility ✓ Transferability ✓ Dependability ✓ Confirmability ✓	Content analysis, with responses grouped into strategies for optimising health and wellbeing and the discovery and development of such strategies.
Wurm et al. (2013) (Germany)	Ageing	Longitudinal	Moderate	Reuter et al. (2010) adapted SOC -48.
Ziegelmann and Lippke (2007a) (Germany)	Health - Musculoskeletal	Longitudinal	Weak	Modified SOC-12, forced choice replaced by Likert scale. Strategies reflected physical activity retrospectively.
Ziegelmann and Lippke (2007b) (Germany)	Health - Musculoskeletal	Longitudinal	Weak	Modified SOC-12, forced choice replaced by Likert scale. Strategies reflected physical activity retrospectively.
Ziegelmann et al. (2006) (Germany)	Health - Musculoskeletal	RCT, with longitudinal analysis of SOC	Weak	Coping plans coded for presence of loss-based selection and compensation.

^a ✓ indicates criteria met, ✗ indicates criteria not met or issue not addressed.

Narrative Synthesis

1) How are selection, optimisation and compensation measured in older adults and those with chronic health conditions?

Measurement of selection, optimisation and compensation by self-report (questionnaire)

The majority of the quantitative studies measured SOC using a self-report measure. Within the context of ageing, six studies used the validated SOC-48, SOC-36 or SOC-12 (Freund & Baltes, 1998, 2002b; Haase et al., 2013; Hahn & Lachman, 2015; John & Lang, 2012; Jopp & Smith, 2006; Tovel & Carmel, 2013). Non-English language versions, including Chinese, Japanese and Swedish were also developed and used in subsequent studies (Chou & Chi, 2002a, 2002b; Okabayashi, 2014; Viglund et al., 2013). Within the context of health, the validated SOC-48 measure was only used in three studies, in the health domains of chronic pain and depression (Alonso-Fernández et al., 2015; Alonso et al., 2013; Weiland et al., 2011).

Several studies in both the ageing and health domains modified the generic SOC measure to varying degrees, although this was more common in the contexts of health. Modifications ranged from simply reducing the number of items or measuring responses using a Likert scale rather than the usual forced choice format (Donnellan et al., 2012; Scheibner & Leathem, 2012; Son et al., 2009), to modifying the measure to reflect specific domains such as leisure activities, physical activity or health living (Evers et al., 2012; Janke et al., 2009; Reuter et al., 2010; Son & Janke, 2015; Wurm et al., 2013; Ziegelmann & Lippke, 2007a, 2007b). Domain-specific measures were created by the inclusion of additional words such as 'leisure activities' to give each item a specific behaviour focus, or asking individuals to think about specific situations rather than their lives in general.

Going beyond domain-specific versions of the original SOC questionnaire, a new SOC questionnaire was developed for the specific context of driving, consisting of SOC strategies to reduce risk whilst driving (Bieri et al., 2015).

Selection, optimisation and compensation measurement by self-report (non-questionnaire)

Three studies involved the authors rating whether participants' self-reported adaptation and coping strategies were indicative of selection, optimisation and compensation (Gignac et al., 2000, 2002; Ziegelmann et al., 2006). Ziegelmann et al. (2006) asked participants to devise coping plans to overcome anticipated barriers that would prevent them taking part in physical activity after rehabilitation. The authors assessed the coping plans and coded them as loss-based selection or compensation. Specifically, strategies such as adaptation of standards, searching for new goals, focusing on the most important goals and reconstructing the goal hierarchy were deemed to indicate loss-based selection. Substituting means, using aids, skills, other persons or participating in a therapeutic intervention, increasing effort or modelling the performance of a successful other were taken as indicative of compensation. Gignac et al. (2000, 2002) opted for a mixed method approach to SOC measurement. Firstly, participants were asked to rate their difficulty with up to 30 activities from five different domains such as personal care, in-home mobility, community mobility, household tasks and valued activities. Participants who reported difficulty with a task were asked whether they had changed the way they performed this activity, or whether they required assistance/gadgets/equipment in order to this activity. Responses were content analysed and self-reported behavioural efforts coded as selection, optimisation or compensation.

Two studies measured selection, optimisation and compensation through the assessment of changes in the relationships between self-reported behaviours (Janke & Davey, 2006; Lang et al., 2002). Lang et al. (2002) asked participants to recall their daily activities on two occasions and suggested that particular changes in behaviour indicated selection, optimisation and compensation. An increase in the percentage of time spent with relatives and a decrease in the diversity of leisure activities were suggested to indicate selection whilst an increase in regenerative activities such as daytime sleeping was taken to indicate compensation. The authors suggested that participants optimised when they spent differential amounts of time on activities, therefore investing more time and effort in specific tasks compared to others. Janke and Davey (2006) also looked at behaviour that indicated SOC. Correlations between functional impairment and involvement in formal, informal and physical leisure activities were suggested to indicate selection. Specifically, as functional health decreased, involvement in the three types of leisure activities decreased

at differing rates; the authors suggested that selection was demonstrated by the steep decline in physical activity compared to the gradual decline in informal leisure participation. The authors classified participants as optimisers if they experienced functional impairment throughout the study but maintained or increased their leisure participation.

Other quantitative measures of selection, optimisation and compensation

Two studies conducted experiments designed to assess selection, optimisation and compensation (Freund, 2006; Li et al., 2001). Li et al. (2001) assessed SOC using a dual-task procedure involving walking and memorizing. The authors wished to determine if older adults would use selection, prioritising the walking task over memorising due to the higher physical costs associated with a fall. Individuals were deemed to use compensation when they utilised a compensatory memory or walking aid. Freund (2006) also sought to induce optimisation and compensation experimentally, instructing participants in a sensorimotor computerised task. An optimisation condition was induced through instructing participants to 'become as good as possible' in the task. A compensation condition was induced by making the task more difficult while instructing participants to try to perform as accurately as before. Length of time spent in each condition was suggested to indicate preference for optimisation or compensation.

Finally, Freund and Baltes (2002a) were interested in whether older and younger adults would differ in their choice of proverbs reflecting SOC life management skills or non-SOC alternatives. Participants were asked to determine which proverbs gave better advice. Examples included 'jack of all trades, master of none' to reflect selection, 'practice makes perfect' to reflect optimisation and 'those without a horse walk' to reflect compensation. A non-SOC alternative example was 'good things come to those who wait'.

Qualitative measurement and analysis of SOC

Thirteen studies examined SOC qualitatively within the contexts of ageing and chronic health conditions, and as such their measurement of SOC consisted of analysis of their qualitative data (DiLauro et al., 2015; Greenwood et al., 2010; Hutchinson & Nimrod, 2012; Janke et al., 2012; Kelly et al., 2014; Kleiber & Nimrod, 2009; Lien et al., 2015; Nasvadi & Vavrik, 2007; Rozario et al., 2011; Rush et al., 2011; Ryan et al., 2003; van der Goot et al., 2015; Wilhite et al., 2004). The extent to which SOC was applied to the analysis of these studies varied and ranged from the model as a 'sensitising concept' in the analysis, to SOC strategy examples being used to code behavioural adaptations in a range of contexts.

Four studies stated that they employed content analysis to their interview data but varied in how the SOC model was applied (DiLauro et al., 2015; Janke et al., 2012; Lien et al., 2015; Wilhite et al., 2004). DiLauro et al. (2015), for example, state that qualitative interviews with those caring for spouses with dementia were conducted and analysed to identify categories and themes; however the authors did not explicitly state what role SOC played in this process. Similarly, Lien et al. (2015) simply stated that themes were identified then compared to the theoretical categories during their content analysis. Wilhite et al. (2004) provided a more detailed description of their content analysis of interviews with persons living with multiple sclerosis. In this study, responses from all of the participants were grouped according to the main interview questions, which included asking about strategies for optimising health and wellbeing, and about the processes that preceded the discovery and development of such strategies. The authors state that the strategies could be grouped according to the SOC model, however, they do not describe how this conclusion was reached. In contrast, the content analysis employed by Janke et al. (2012) used the SOC model at all three stages of coding and analysis. Broad themes relating to loss-based selection, elective selection, optimisation and compensation were identified from the qualitative interviews. These themes, alongside the examples of SOC strategies described by Freund and Baltes (2002b), were used to create a codebook which was subsequently applied to the data in order to identify SOC themes relating to arthritis and leisure activities.

Grounded theory was the only other specific type of qualitative data analysis described, with the authors stating that selection, optimisation and compensation were used as sensitising concepts when coding and categorising the adaptive processes used by older adults to participate in leisure activities (Kleiber & Nimrod, 2009). Use of the SOC model as a sensitising concept was, however, described in another study, when television viewing behaviours of older adults were interpreted according to the definitions of selection and compensation (van der Goot et al., 2015).

The remaining studies did not specify a particular type of qualitative analysis, instead they either identified themes within the studies, or coded participant responses according to the SOC model. Three studies stated that they identified themes within interviews with stroke carers and those living with chronic health conditions (Greenwood et al., 2010; Hutchinson & Nimrod, 2012; Rozario et al., 2011). Greenwood et al. (2010), for example explored

changes in autonomy and control in carers of those who had experienced a stroke, however, they did not describe the role of SOC in this analysis. Rozario et al. (2011) used the SOC model as a guide to identify themes surrounding the strategies employed by individuals with chronic illness to achieve their goals. Hutchinson and Nimrod (2012) also identified themes related to general coping strategies and leisure activity participation in those living with chronic health conditions. Once themes were identified they were collated, for example, all of the strategies used to compensate for activity limitations were grouped together. The authors then considered whether such categories of strategies were consistent with SOC.

Two studies coded adaptation strategies according to the SOC model (Kelly et al., 2014; Rush et al., 2011). Exploring how older adults would overcome difficulties in managing their homes when faced with hypothetical losses of a perceptual, cognitive, limited mobility or physical nature, Kelly et al. (2014) categorised the adaptations as either elective selection with compensation, elective selection with optimisation, loss-based selection with compensation or loss-based selection. Similarly, Rush et al. (2011) categorised mobility adaptations of older adults as either selection, optimisation or compensation.

Finally, two studies provided no description of the qualitative analysis they used to identify SOC strategies in those experiencing reading-related difficulties due to visual problems or in driving-related behaviours of older adults (Nasvadi & Vavrik, 2007; Ryan et al., 2003). Ryan et al. (2003) state that definitions provided by Gignac et al. (2000) and P. Baltes and Baltes (1990) were used, however, they did not describe how they applied these definitions to reach their conclusions. Nasvadi and Vavrik (2007) provided no description of the role SOC played in the analysis of their findings.

2) Are the use of selection, optimisation and compensation strategies related to outcomes in older adults and those with chronic health conditions?

As part of the narrative synthesis relating to the above research question, the methodological quality of the participant selection and data collection methods of each study presented below was reviewed. Participant selection and data collection methods were chosen as two individual sections of the EPHPP tool that were of particular relevance to, and could be compared across, cross-sectional and longitudinal designs (the most

common study designs in this section). Unless stated otherwise, the conclusions stated below were drawn from 'good quality' evidence consisting of either moderate or strong participant selection and/or data collection methods. Whilst findings from poorer quality studies were also discussed in order to provide an overview of existing SOC research, a clear indication was provided when studies were rated as methodologically weak.

Selection, optimisation and compensation and indicators of well-being in older adults

Overall, positive correlational relationships were found between those who reported using selection, optimisation and compensation and most measured indicators of subjective wellbeing (Table 2.2). These included satisfaction with ageing (Freund & Baltes, 1998; Jopp & Smith, 2006), lack of agitation and personal life investment (Freund & Baltes, 1998), life satisfaction (Chou & Chi, 2002b; Okabayashi, 2014; Wurm et al., 2013) and self-esteem (Chou & Chi, 2002b). Composite SOC use substantially correlated with wellbeing and positive emotions (Freund & Baltes, 2002b). Individually, selection, optimisation and compensation significantly correlated with most of the measured indicators of wellbeing, including autonomy, environmental mastery, personal growth, positive relations, purpose in life and self-acceptance (Freund & Baltes, 2002b). In another study, optimisation and compensation, but not loss-based selection, positively correlated with a composite measure of successful ageing, which included individual measures of life satisfaction, happiness and will to live (elective selection was not measured in this study) (Tovel & Carmel, 2013).

With regards to the methodological quality of the above studies, all except the final study discussed were assessed as having strong data collection methods and either moderate or strong participant selection, indicating that the studies lack bias in these two key areas. This suggests that there is good quality evidence regarding the positive relationships between self-reported SOC use and the above indicators of subjective wellbeing.

In addition, Chou and Chi (2002b) and Okabayashi (2014) found that selection, optimisation and compensation negatively correlated with depression, with participant selection rated as moderate and data collection methods rated as strong for both of these studies. Overall, therefore, there is some good quality evidence regarding the negative relationship between SOC use and depression. Janke and Davey (2006) also examined the relationship between

leisure optimisation and depression in older adults. The authors suggest that their interpretation of optimisation in the domain of formal leisure was related to lower depression, however, their data collection method was rated as weak due to an interpretation of optimisation that lacked validity. One study found no significant correlation between the use of SOC and depression during the development of the Swedish version of the SOC questionnaire (Viglund et al., 2013). Again, however, there were issues with the data collection method in this study. Low reliability of the subscales within the measure, however, resulted in the removal of some elective selection items and the authors suggest that further testing of this measure is likely required.

Several studies also indicated that the use of selection, optimisation and compensation may have a protective effect, having a positive influence on outcomes particularly when resources such as health and finances are low (Chou & Chi, 2002a; Hahn & Lachman, 2015; Jopp & Smith, 2006). Jopp and Smith (2006) for example found that for a group of older adults aged 80-90, use of selection, optimisation and compensation only predicted satisfaction with ageing when resources were low. In a second study, Jopp and Smith (2006) found that higher use of SOC was related to more positive and less negative changes in satisfaction with ageing when resources were limited. Chou and Chi (2002a) also found that the impact of financial strain on life satisfaction was lower when individuals reported higher selection or optimisation. For both of these studies, selection and data collection methods were rated as moderate or strong, indicating good quality evidence. In a study of memory decline, Hahn and Lachman (2015) found a similar protective effect, with the use of SOC strategies buffering the relationship between low perceived control and everyday memory problems. Among those who had experienced the greatest memory decline over 10 years, individuals reported more memory problems during the weeks that they also reported low perceived control and less SOC strategy use. However, for this study both selection and data collection were rated as weak and the results should therefore be interpreted with caution.

There was also some evidence that the use of SOC strategies was found to mediate the relationship between negative perceptions of ageing and subjective outcomes (Scheibner & Leathem, 2012; Wurm et al., 2013). In older adults who had experienced a serious health event, the use of SOC strategies to maintain a healthy lifestyle differed depending on the older adults' perceptions of their ageing (Wurm et al., 2013). Older adults who perceived

that ageing was associated with physical losses used fewer SOC strategies to maintain a healthy lifestyle, which was subsequently associated with poorer life satisfaction and self-rated health, but not with physical functioning. This study was rated as moderate and strong for participant selection and data collection methods respectively. Similarly, in adults aged 18-81, beliefs about memory significantly predicted perceptions of everyday forgetfulness (Scheibner & Leathem, 2012). Such memory beliefs included perceptions of current memory ability, confidence in strategies to improve memory, beliefs about the ability to control memory by investing effort, and beliefs that memory decline is uncontrollable and age-related. Optimisation was found to partially mediate this relationship, with those with less positive memory beliefs reporting the use of fewer optimisation strategies and subsequently perceiving themselves as more forgetful. This study however, was of poorer quality, with weak participant selection alongside moderate data collection.

Two studies did not measure the relationships between SOC use and indicators of wellbeing directly, instead using the SOC strategies to develop new models (Haase et al., 2013; John & Lang, 2012). Haase et al. (2013) integrated the SOC model, Dual-process model of assimilative and accommodative coping (Brandtstadter, 1989; Brandtstadter & Renner, 1990a) and motivational theory of life-span development (J. Heckhausen & Schulz, 1993; Schulz & Heckhausen, 1996). The authors suggested that the 11 different strategy types proposed by the three theories centred around three processes: goal engagement, goal disengagement and meta-regulation. Elective selection, optimisation and compensation are goal engagement strategies whilst aspects of loss-based selection relate to goal disengagement. Using data from Freund and Baltes (2002b), higher goal engagement was found to predict higher wellbeing, specifically purpose in life and positive relations. In addition, goal engagement strategies were positively associated with environmental mastery and purpose of life in middle aged adults. Goal engagement strategies were not associated with environmental mastery and were less closely associated with purpose of life in young or older adults, suggesting that goal engagement was predominantly adaptive during middle age (Haase et al., 2013). This study was assessed as being of good quality, with strong data collection and participant selection methods.

Finally, John and Lang (2012) based their four types of strategies for dealing with unavoidable loss on the SOC model, and suggested that these strategies would be

associated with self-reported selection, optimisation and compensation. Optimisation correlated with the strategy maintenance, compensation with improvement and elective selection with disengagement, however, no SOC strategy correlated with reorientation. These unavoidable loss strategies did not therefore map onto the SOC model entirely as hypothesised. Subsequently authors hypothesised that thinking about these strategies after watching a video-vignette depicting a multiple sclerosis diagnosis would have differential effects on wellbeing depending on the age of the participant. Indeed for older adults, thinking about improvement strategies when faced with this situation was associated with higher negative affect but not so for younger adults. There was no relationship between SOC and reorientation, and unfortunately the authors do not report any interaction effects for the strategies of maintenance or disengagement. It is not surprising therefore that this study was assessed as weaker quality, with weak data collection methods.

Table 2.2: Selection, optimisation and compensation and indicators of well-being in older adults

Authors	Main outcome measures	Main outcomes ^a
Chou and Chi (2002b)	<ul style="list-style-type: none"> Centre for Epidemiological studies of depression (Chinese version) (Chi & Boey, 1993; Radloff, 1977) Satisfaction Index-A (Chinese version) (Chou & Chi, 1999; Neugarten, Havighurst, & Tobin, 1961) Rosenberg self-esteem inventory (Rosenberg, 1979) 	<ul style="list-style-type: none"> S, O and C positively correlated with life satisfaction ($r = 0.24, 0.13, 0.13$ respectively, all $p < 0.01$) and self-esteem ($r = 0.30, 0.35, 0.28$, respectively, all $p < 0.01$). S, O and C negatively correlated with depression ($r = -0.19, -0.22, -0.21$, respectively, all $p < 0.01$).
Chou and Chi (2002a)	<ul style="list-style-type: none"> Life Satisfaction Index-A (Chinese version) (Chou & Chi, 1999; Neugarten et al., 1961) 3-item Financial strain measure (Mendes De Leon, Rapp, & Kasl, 1994) 	<ul style="list-style-type: none"> S, O and C negatively correlated with financial strain ($r = -0.20, -0.19, -0.18$, respectively, all $p < 0.01$). S, O and C positively correlated with life satisfaction ($r = 0.24, 0.13, 0.13$, respectively, all $p < 0.01$). Significant interaction between financial strain and selection ($b = -.086, \beta = -.13, p < .001$) and financial strain and optimisation ($b = -1.56, \beta = -.22, p < .001$) on life satisfaction. Impact of financial strain on life satisfaction lower when respondents had higher selection or optimisation scores.
Freund and Baltes (1998)	<ul style="list-style-type: none"> Philadelphia Center Morale Scale (subscales satisfaction with aging, lack of agitation and satisfaction with life) (Lawton, 1975) Positive and negative affect scale (subscale positive affect) (Watson, Clark, & Tellegen, 1988) 	<ul style="list-style-type: none"> SOC positively correlated with personal life investment ($r = 0.28, p \leq .01$). SOC positively correlated with satisfaction with age ($r = 0.24, p \leq .01$), lack of agitation ($r = 0.16, p \leq .05$) but not with life-satisfaction ($r = 0.07, p = n.s.$), absence of emotional loneliness ($r = 0.25, p \leq .01$), absence of social loneliness ($r = 0.25, p \leq .01$), positive emotions ($r = 0.29, p \leq .01$). Optimisation and compensation accounted for 8.2% of the variance in satisfaction with age. Optimisation and compensation accounted for 13.9%, 8.6% and 7.7% of the variance in positive emotions, absence of emotional loneliness and absence of social loneliness respectively. Elective selection and loss-based selection were significantly related to lack of agitation (n.b. no data provided).
Freund and Baltes (2002b)	<ul style="list-style-type: none"> Positive and negative affect scale (Watson et al., 1988) Ryff Inventory of Psychological Wellbeing (Ryff, 1989) 	<ul style="list-style-type: none"> SOC positively correlated with positive emotions ($r = 0.28, p < .01$), autonomy ($r = 0.39, p < .01$), environmental mastery ($r = 0.45, p < .01$), personal growth ($r = 0.42, p < .01$), positive relations ($r = 0.29, p < .01$), purpose in life ($r = 0.47, p < .01$), self-acceptance ($r = 0.31, p < .01$). Positive canonical correlation of SOC with positive emotions and Ryff inventory subscales listed above ($r = 0.36, p < .05$) when rival predictor variables were controlled for (Tenacious goal pursuit, flexible goal adjustment, state orientation, personality variables).

Authors	Main outcome measures	Main outcomes ^a
Haase et al. (2013)	<ul style="list-style-type: none"> Ryff Inventory of Psychological Wellbeing (Ryff, 1989) 	<ul style="list-style-type: none"> Goal engagement (ES, O and C) positively predicted positive relations ($\beta = .31, p < .01$) and purpose in life ($\beta = .46, p < .001$). Goal engagement (ES, O and C) was positively associated with environmental mastery in the middle-aged group ($\beta = .47, p < .01$) but not in the young ($\beta = .13, p = n.s$) or older age group ($\beta = .27, p = n.s$). Goal engagement (ES, O and C) was more closely associated with purpose of life in the middle-aged group ($\beta = .65, p < .001$) than the younger ($\beta = .41, p < .01$) or older adults ($\beta = .34, p < .05$).
Hahn and Lachman (2015)	<ul style="list-style-type: none"> Working memory- decline in backwards and forwards digit span and serial sevens over 10 years Memory problems – Number of days per week experienced any of 11 everyday memory problems Weekly perceived control- 1 item (authors' own measure) 	<ul style="list-style-type: none"> SOC strategy use was not a predictor of memory problems. Three way interaction effect of weekly perceived control, SOC and memory decline significant. (Est -0.28, SE 0.13, $p = 0.036$). Participants who experienced greater declines in memory reported greater memory problems on weeks with low perceived control if they used fewer SOC strategies, and fewer memory problems if they used more SOC strategies.
Janke and Davey (2006)	<ul style="list-style-type: none"> Centre for Epidemiological studies of depression (Radloff, 1977) 	<ul style="list-style-type: none"> 'Optimising' in domain of formal leisure was significant predictor for decrease in depression ($b = -.06, p < 0.05$). 'Optimising' in domain of informal leisure was not a significant predictor for decrease in depression ($b = -.001, p = n.s$). 'Optimising' in domain of physical leisure was not a significant predictor for decrease in depression ($b = -.039, p = n.s$).
John and Lang (2012)	<ul style="list-style-type: none"> Affective wellbeing questionnaire (Abele-Brehm & Brehm, 1986) 	<ul style="list-style-type: none"> Thinking about improvement positively correlated with compensation ($r = .26, p < .01$). Thinking about maintenance positively correlated with optimisation ($r = .27, p < .01$). Thinking about disengagement negatively correlated with elective selection ($r = -.20, p < .05$). Thinking about disengagement or reorientation did not correlate with loss-based selection.

Authors	Main outcome measures	Main outcomes ^a
Jopp and Smith (2006)	<ul style="list-style-type: none"> Philadelphia Geriatric Centre Moral Scale (subscale satisfaction with ageing) (Lawton, 1975) 	<ul style="list-style-type: none"> SOC positively correlated with ageing satisfaction ($r = .20, p < .05$). Interaction between age, SOC strategy use and resources on ageing satisfaction was not significant ($b = -0.43, SE = 0.24, \beta = -.44, p = 0.8$). Age-group specific analyses showed interaction between resources and SOC use on ageing satisfaction was not significant for young-old (aged 70-80 years) ($b = 0.4, SE = 0.16, \beta = .03, p = n.s$) but was significant for old-old (aged 80-90 years) ($b = -0.39, SE = 0.18, \beta = -.24, p < .05$). In the old-old group, SOC predicted ageing satisfaction when resources were reduced ($\beta = .41, p < .05$). SOC strategy use predicted change in ageing satisfaction over time ($F(1, 36) = 4.43, p < .05$). Interaction between resource group and SOC use predicted change in ageing satisfaction over time ($F(1, 36) = 4.62, p < .05$). Resource poor individuals who used SOC strategies benefited more in terms of ageing satisfaction than resource rich individuals.
Okabayashi	<ul style="list-style-type: none"> Centre for Epidemiological studies of depression (Radloff, 1977) Life Satisfaction Index-A (Neugarten et al., 1961; Okabayashi, Liang, Krause, Akiyama, & Sugisawa, 2004) (short version) Locus of control (short version) (Kamahara, Higuchi, & Shimizu, 1985) 	<ul style="list-style-type: none"> ES, LBS, O and C positively correlated with life satisfaction ($r = 0.20, 0.12, 0.22$ and 0.22, both $p > 0.001$, respectively). ES, LBS, O and C negatively correlated with depression ($r = -0.24^{***}, -0.28^{***}, -0.28^{***}$, and -0.31^{***}, respectively, all $p < 0.001$).
Scheibner and Leathem (2012)	<ul style="list-style-type: none"> Memory Controllability Inventory (Lachman, Bandura, Weaver, & Elliot, 1995) Cognitive Failures Questionnaire (subscales memory and memory for names) (Broadbent, Cooper, FitzGerald, & Parkes, 1982) 	<ul style="list-style-type: none"> Optimisation was a significant predictor of everyday forgetfulness ($\beta = -.22, p < .001$), but not elective selection, loss-based selection or compensation. Optimisation mediated the relationship between memory control beliefs and everyday forgetfulness facets: preset ability beliefs ($b = -0.45, SE = 0.16, \beta = -.13, p < .01$), potential for improvement beliefs ($b = -0.59, SE = 0.17, \beta = -.18, p < .01$) and inevitable decrement beliefs ($b = -0.64, SE = 0.17, \beta = -.19, p < .01$).

Authors	Main outcome measures	Main outcomes ^a
Tovel and Carmel (2013)	<ul style="list-style-type: none"> Mean score of following scales used as a successful ageing measure: Philadelphia Center Morale Scale (Lawton, 1975), Life Satisfaction Index-A (Neugarten et al., 1961), Satisfaction with life scale (Carmel & Mutran, 1997), Happiness Scale (Lyubomirsky & Lepper, 1999) & Carmel's Will to Live (Carmel, 2011) 	<ul style="list-style-type: none"> Optimisation positively correlated with successful ageing ($r = 0.23, p < .01$). Compensation positively correlated with successful ageing ($r = 0.18, p < 0.5$). No correlation between loss-based selection and successful ageing ($r = -.06, p = n.s.$). Model including gender, decline in health/function, resources and coping patterns accounted for 48.7% of the variance in successful ageing but neither loss-based selection, optimisation or compensation were significant predictors.
Viglund et al. (2013)	<ul style="list-style-type: none"> Rosenberg self-esteem inventory (Rosenberg, 1979) Ways of coping questionnaire (Folkman & Lazarus, 1988; Lundqvist & Ahlstrom, 2006) Geriatric Depression Scale (Yesavage et al., 1982) 	<ul style="list-style-type: none"> Translated Swedish version of SOC-12 had poor reliability (Cronbach's Alpha = 0.50, ranging from 0.14 to 0.63 in the subscales). Two elective selection items were removed, improving the reliability (Cronbach's Alpha = 0.68). 10-item version subsequently used for correlational analysis. SOC did not significantly correlate with ways of coping, self-esteem or geriatric depression. SOC significantly positively correlated with ways of coping subscale 'planful problem-solving' ($r = .27, p < .001$).
Wurm et al. (2013)	<ul style="list-style-type: none"> Negative Self-Perceptions of Ageing (Steinerink, Westerhof, Bode, & Dittmann-Kohli, 2001) Satisfaction With Life Scale (Diener, Emmons, Larsen, & Griffin, 1985) 	<ul style="list-style-type: none"> SOC positively correlated with life satisfaction ($r = .38, p < .01$). Significant interaction between serious health event and negative self-perceptions of ageing (SPA) on SOC strategy use ($b = -0.43, SE = 0.15, p < .01$), those with less negative SPA increased their SOC strategy use more than those with stronger negative SPA after a serious health event. Negative SPA after a serious health event was associated, via SOC strategy use, with lower self-rated health ($b = 0.24, SE = 0.15, 95\% CI [0.031, 0.681]$) and life satisfaction ($b = 0.25, SE = 0.06, 95\% CI [0.045, 0.651]$) but not with physical functioning ($b = 0.86, SE = 1.52, p = n.s.$).

^a S = selection, ES = elective selection, LBS = loss-based selection, O = optimisation, C = compensation; SOC = composite score; n.s = not significant.

Selection, optimisation and compensation and physical activity outcomes in older adults

A number of studies have researched the relationships between SOC strategy use in older adults and outcomes other than subjective wellbeing, in particular physical activity (Table 2.3) (Evers et al., 2012; Reuter et al., 2010; Son et al., 2009). In two studies with strong data collection methods, SOC use significantly predicted adherence to physical activity goals and exercise regimes (Evers et al., 2012; Reuter et al., 2010). When examined individually for women over 70 who were taking part in a 26-week exercise programme, the strategies of optimisation and compensation were found to positively predict adherence, whilst loss-based selection negatively predicted adherence to the programme (Evers et al., 2012). Overall SOC use also predicted physical activity in individuals ranging in age from 19-64 years old (Reuter et al., 2010). Both studies used a SOC measure which was modified to reflect SOC use in relation to either physical activity or healthy living (Evers et al., 2012; Reuter et al., 2010).

SOC was found to play both mediating and moderating roles in the relationship between planning and adhering to physical activity goals (Evers et al., 2012; Reuter et al., 2010). As a moderator, optimisation and compensation together interacted with coping plans to influence adherence (Evers et al., 2012). When optimisation and compensation use were lower, the effect of coping plans on adherence was stronger, suggesting that coping plans are particularly beneficial when individuals are not able to use such goal pursuit strategies. As a mediator, SOC was partially responsible for planning being particularly effective in improving physical activity for older compared to younger adults (Reuter et al., 2010). The authors stated that older adults were more successful in using SOC strategies to follow through with their plans and achieve their physical activity goals.

One study found that generic SOC strategy use did not influence overall leisure-time physical activity but that it did predict activity duration depending on the individual's expectations (Son et al., 2009). For those with high expectations that participating in the activity would give them immediate enjoyment, pleasure, or would be good for their health, the use of SOC strategies was related to longer activity duration during the past seven days. For those with low to moderate expectations, the use of SOC strategies was related to shorter activity duration. The use of individual strategies was, however, not

examined; it may be that individuals with low expectations are experiencing life circumstances which require them to utilise selection strategies and reduce their leisure-time physical activity. It should also be noted that both participant selection and data collection methods were rated as weak for this study, indicating poorer quality evidence.

Table 2.3: Selection, optimisation and compensation and physical activity outcomes in older adults

Authors	Main outcome measures	Main outcomes ^a
Evers et al. (2012)	Adherence to physical activity programme: <ul style="list-style-type: none"> Percentage ratio of sessions attended to exercise sessions offered. 	<ul style="list-style-type: none"> Goal-pursuit strategies positively predicted adherence ($\beta = .39, p < .01$) and loss-based selection negatively predicted adherence ($\beta = -.26, p < .05$). Coping plans, goal-pursuit strategies (optimisation and compensation), loss-based selection and interaction between coping plans and goal-pursuit strategies explained 34% of variance in adherence. Significant interaction between coping plans and goal pursuit strategies on adherence ($b = -0.22, SE = 0.10, t = -2.20, p < .05$). Coping plans predicted adherence when goal pursuit strategies were mean ($t = 2.93, p = 0.005$) or low ($-1 SD; t = 3.49, p < .001$).
Reuter et al. (2010)	Physical activity: <ul style="list-style-type: none"> Godin Leisure-Time Exercise Questionnaire (one item) (Godin & Shephard, 1985) "I have performed physical activity and sports for at least 30 minutes per week in my leisure time (e.g. gym and playing soccer) with an increased heart rate and sweating" (one item) "I was physically active due to locomotion (e.g. going to work by bike instead of taking the bus)" (one item) 	<ul style="list-style-type: none"> SOC positively correlated with physical activity ($r = 0.38, p < .01$). Significant interaction between age and planning ($\beta = .15, p < .01$) for physical activity. Physical activity was lower in older adults than younger adults, but only for those with low planning. For those with high planning, physical activity was higher in older adults compared to younger adults. Age by planning interaction was associated with SOC strategy use ($\beta = .21, p < .001$) and in turn SOC strategy use was associated with physical activity ($\beta = .17, p < .05$). Age by planning interaction on physical partially mediated by SOC.
Son et al. (2009)	Physical activity: <ul style="list-style-type: none"> Physical Activity Scale for the Elderly (leisure time activity subscale) (modified) (New England Research Institutes, 1991). 	<ul style="list-style-type: none"> SOC did not predict overall physical activity but predicted activity duration ($b = -1.22, SE = 0.55, \beta = -.39, p < .05$). Significant interaction between SOC and outcome expectations on physical activity duration ($b = 0.14, SE = 0.07, \beta = .44, p < .05$). For those with high expectations that physical activity would give them immediate enjoyment, please or would be good for their health, use of SOC strategies positively related to activity duration. For those with low expectations, use of SOC strategies negatively related to exercise duration.

^a S = selection, ES = elective selection, LBS = loss-based selection, O = optimisation, C = compensation; SOC = composite score.

Relationships between SOC strategies and various outcomes within health conditions

A number of studies examined SOC strategy use within adults with musculoskeletal conditions, although the quality of the evidence was mixed, particularly in comparison to the previous sections reviewing subjective wellbeing and physical activity in older adults (Table 2.4) (Gignac et al., 2000, 2002; Janke et al., 2009; Son & Janke, 2015; Ziegelmann & Lippke, 2007a, 2007b; Ziegelmann et al., 2006). Three studies were in orthopaedic rehabilitation, where patients are encouraged to continue exercising after outpatient rehabilitation programmes (Ziegelmann & Lippke, 2007a, 2007b; Ziegelmann et al., 2006). A further three studies examined how adults with arthritis used SOC processes to adapt to their disabilities (Gignac et al., 2000, 2002; Janke et al., 2009) and one study examined the relationships between SOC use, leisure, and health outcomes (Son & Janke, 2015).

There were positive relationships between the use of SOC strategies and outcomes such as exercise and attainment of exercise goals (Ziegelmann & Lippke, 2007a, 2007b; Ziegelmann et al., 2006) and orthopaedic outcomes as measured by self-reported flexibility, strength, endurance and balance (Ziegelmann & Lippke, 2007b). In one study, for example, SOC strategy use predicted exercise and orthopaedic outcomes, with optimisation and elective selection also predicting subjective wellbeing (Ziegelmann & Lippke, 2007b). The relationship between SOC strategy use and both orthopaedic outcomes and subjective wellbeing was fully mediated by exercise, indicating that the use of SOC strategies increased physical activity, which in turn improved other outcomes.

The interplay between coping planning, SOC strategy use and physical activity was also studied (Ziegelmann & Lippke, 2007a; Ziegelmann et al., 2006). Following discharge from an orthopaedic rehabilitation programme, SOC strategy use was found to mediate the relationship between coping planning and exercise goal attainment (Ziegelmann & Lippke, 2007a). Ziegelmann et al. (2006) examined which components of an action planning and coping planning intervention contributed towards physical activity plans. Participants were asked to select up to three physical activities to take part in following rehabilitation and prepare an action plan for each. Participants also anticipated up to three barriers to performing each activity and developed coping plans to combat these barriers. Participants completed this process either with the assistance of an interviewer or by themselves. The coping plans were coded as to the presence of loss-based selection and compensation

strategies. Only loss-based selection coping plans predicted exercise six months after the intervention. Interestingly, participants who were assisted in developing plans developed significantly more action plans than those without assistance but overall did not develop more coping plans. Instead older adults generated more loss-based selection and compensation coping plans in the interviewer assisted condition whereas younger adults generated more in the self-administered condition. Taking such age differential effects into consideration may be important when developing interventions designed to increase the use of SOC processes. Whilst two of the Ziegelmann et al. studies were rated as having strong data collection methods, the data collection in this final study was rated as weak. The method of assessing SOC consisted of coding coping plans, and was therefore not a validated measure.

There were also positive relationships between the use of SOC strategies and outcomes relating to the impact of arthritis on everyday living (Janke et al., 2009). Those who reported more elective selection and optimisation reported fewer difficulties in activities of daily living while those who reported more compensation had less pain and fewer difficulties with their overall health.

There was some weak quality evidence that cross-sectional relationships existed between the use of SOC strategies and negative outcomes in individuals with arthritis, osteoarthritis and osteoporosis. Gignac et al. (2000, 2002) examined the use of SOC strategies and their relationship with feelings of independence, dependence, helplessness, coping efficacy and perceptions of changed capacity within the areas of mobility, household tasks, personal care and valued activities. Across most of these areas, selection and compensation positively correlated with perceptions about loss of independence, dependence and helplessness. Optimisation positively correlated with perceptions about loss of independence, dependence and helplessness for only two areas: personal care and mobility (Gignac et al., 2000). When further analyses were carried out, excluding the osteoporosis participants, selection and compensation were also associated with perceptions of changed capacity and goals however SOC was no longer related to helplessness (Gignac et al., 2002). Selection, optimisation and compensation were also associated with difficulties in areas of everyday living including personal care and mobility. In addition, Janke et al. (2009) found that those who reported more loss-based selection reported more pain, anxiety and poorer overall health. Son and Janke (2015) reported that SOC use was negatively associated with

arthritis-related health. The authors state that loss-based selection was responsible for this negative relationship and that using such strategies may result in cessation of activities that are required to improve or maintain health.

However, it should be emphasised that these were not all strong quality studies. Indeed, with the exception of Son and Janke (2015), all of the studies were assessed as having weak participant selection and data collection methods. The overall evidence for cross-sectional relationships between SOC strategy use and negative outcomes in those with arthritis, osteoarthritis and osteoporosis can therefore be concluded as poor.

Participants with osteoarthritis and osteoporosis did, however, appear to use a range of SOC processes to manage their health condition, with the authors stating that participants were proactive and flexible in their self-managing (Gignac et al., 2000, 2002). Son and Janke (2015) reported that every adult with arthritis in their study used at least three SOC strategies in relation to their leisure activities.

Finally, SOC use one month post-stroke did not predict functional ability, health-related quality of life or depression in stroke survivors one year after stroke (Donnellan et al., 2012). The data collection method utilised within this study was assessed as moderate, however the authors state it may not have been appropriate or reliable for use within the stroke population. SOC strategies were, however, used at least once by 73% of stroke survivors, with loss-based selection and compensation the most common at one month, and loss-based selection and optimisation the most common at 12 months.

Table 2.4: Relationships between SOC strategies and various outcomes within health conditions

Authors	Chronic illness	Main outcome measures	Main results ^a
Donnellan et al. (2012)	Stroke	<ul style="list-style-type: none"> Health-Related Quality of Life (Stroke-Specific Quality of Life Scale) (Williams, Weinberger, Harris, Clark, & Biller, 1999) Functional Ability (Nottingham Extended Activities of Daily Living Scale) (Nouri & Lincoln, 1987) Depression (Hospital Anxiety Depression Scale) (depression subscale) (Zigmond & Snaith, 1983) 	<ul style="list-style-type: none"> 73% of participants used at least one strategy one month and one year post-stroke. SOC didn't predict Health-Related Quality of Life ($b = -0.005$, $SE = 0.02$, $\beta = -.0.02$, $p=n.s$), functional ability ($b = -0.001$, $SE = 0.21$, $\beta = 0.001$, $p=n.s$) or depression ($b = 0.08$, $SE = 0.12$, $\beta = 0.06$, $p=n.s$) at 1 year.
64 Gignac et al. (2000)	Musculoskeletal – osteoarthritis/ osteoporosis	<ul style="list-style-type: none"> Degree of disability: activities drawn from measures of functional disability and divided into five domains (personal care, in-home mobility, community mobility, household activities and valued activities. Independence and feelings of dependence (two items) (authors' own measure) Arthritis Helplessness (DeVellis & Callahan, 1993) 	<ul style="list-style-type: none"> Participants reported an average of 17.2 behavioural efforts. Selection comprised 21% of all behavioural efforts; optimisation 29.3%; and compensation 41.6%. Selection was positively correlated with perceptions of loss of independence and feelings of dependence in most of the following areas of personal care, in-home mobility, community mobility, household activities & valued activities ($r = .21$ to $r = .35$, $p<.001$), and with helplessness in areas of in-home mobility, community mobility and household activities ($r = .16$ to $r = .27$, $p<.001$). Optimisation was positively correlated with perceptions of independence, dependence and helplessness in the areas of personal care ($r = .22$, $p<.001$) and in-home mobility ($r = .28$, $p<.001$). Compensation was positively correlated with perceptions of independence, dependence and helplessness in all of the assessed areas except valued activities ($r = .24$ to $r = .46$, $p<.001$).
Gignac et al. (2002)	Musculoskeletal – osteoarthritis	<ul style="list-style-type: none"> Social network (Lubben, 1988) Arthritis Helplessness (DeVellis & Callahan, 1993) Changed capacity and goals (seven items) (authors' own measure) Degree of disability (as above (Gignac et al., 2000)) 	<ul style="list-style-type: none"> At least one instance of selection was reported by 83.3% of adults, optimisation by 93.1% and compensation by 96.7 %. Selection was associated with greater perceptions of changed capacity ($b = 0.17$, $\beta = 0.28$ $p<.001$) and difficulties in personal care disability ($b = 1.40$, $\beta = 0.23$ $p<.01$). Optimisation was associated with mobility disabilities ($b = 2.98$, $\beta = 0.39$, $p<.001$). Compensation was associated with greater perceptions of changed capacity ($b = 0.20$, $\beta = 0.20$, $p<.01$), personal care disabilities ($b = 2.80$, $\beta = 0.28$, $p<.001$) and mobility disabilities ($b = 4.19$, $\beta = 0.42$, $p<.001$).

Authors	Chronic illness	Main outcome measures	Main results ^a
Janke et al. (2009)	Musculoskeletal – arthritis	<ul style="list-style-type: none"> Arthritis Impact Measurement Scale (subscales of activities of daily living, pain, depression, anxiety and total health) (Meenan, Gertman, & Mason, 1980) 	<ul style="list-style-type: none"> Elective selection ($b = -.05$, $SE = .02$, $\beta = -.20$, $p < .05$) and Optimisation ($b = -.07$, $SE = .02$, $\beta = -.33$, $p < .01$) were significant predictors of difficulty performing ADLs. Loss-based selection was a significant predictor of pain ($b = 1.07$, $SE = 0.27$, $\beta = .34$, $p < .001$), anxiety ($b = .92$, $SE = 0.29$, $\beta = .24$, $p < .01$) and greater difficulties with overall health ($b = 2.17$, $SE = 0.68$, $\beta = .31$, $p < .01$). Compensation was a significant predictor of less pain ($b = -.45$, $SE = 0.20$, $\beta = -.19$, $p < .05$) and fewer difficulties with overall health ($b = -1.10$, $SE = 0.50$, $\beta = -.21$, $p < .05$).
Son and Janke (2015)	Musculoskeletal – arthritis	<ul style="list-style-type: none"> Health: Arthritis Impact Measurement Scale (Meenan et al., 1980) Leisure activity expenditure – sum of energy expenditure from leisure activities in one week. Physically active leisure – computed through weekly frequency x duration x intensity. Arthritis severity (1 item, authors own measure, “how does arthritis affect your daily life?”) Health satisfaction (1 item, authors own measure) 	<ul style="list-style-type: none"> Every participant used at least 3 SOC strategies. SOC significantly correlated with leisure activity expenditure ($r = .17$, $p < .05$). SOC negatively associated with health ($b = -1.01$, $SE = 0.44$, $\beta = -.16$, $p < .05$). SOC was not associated with physically active leisure.

Authors	Chronic illness	Main outcome measures	Main results ^a
Ziegelmann et al. (2006)	Musculoskeletal	<ul style="list-style-type: none"> Perceived exercise self-efficacy and (three items) and Intention (three items, T1) adapted from Fuchs (1997) Subjective physical health (SF-12) (German) (Bullinger, 1998; Ware, Kosinski, & Keller, 1996) Exercise (total duration of physical activity and strenuous exercise) adapted from Bernstein (1998) 	<ul style="list-style-type: none"> Compensation coping planning positively correlated with exercise duration per week at four weeks ($r = .21, p < 0.01$) and six ($r = .14, p < 0.01$) after rehabilitation. Loss-based selection coping planning positively correlated with exercise duration per week at two weeks ($r = .15, p < 0.01$), four weeks ($r = .16, p < 0.01$) and six months ($r = .20, p < 0.01$) after rehabilitation. Age ($\beta = -.14, p < .05$) and interaction between age and condition ($\beta = .11, p < .05$) were significant predictors of loss-based selection and compensation coping planning. Older and middle-aged adults generated more LBS and compensation coping plans in the interviewer assisted condition whilst younger adults generated more in the self-administered condition. Compensation coping planning predicted strenuous exercise four weeks after rehabilitation ($\beta = .13, p < .05$). Loss-based selection coping planning predicted strenuous exercise four weeks ($\beta = .10, p < .05$) and six months after rehabilitation ($\beta = .12, p < .05$).
Ziegelmann and Lippke (2007a)	Musculoskeletal	<ul style="list-style-type: none"> Risk perception, Task self-efficacy, Recovery self-efficacy, Positive outcome expectancies, Exercise intentions, Action plans, Coping plans, all adapted from (Fuchs, 1996) Physical exercise goal attainment (two items) (authors' own measure) Subjective physical and mental health (SF-12) (Ware et al., 1996) 	<ul style="list-style-type: none"> SOC positively correlated with exercise goal attainment ($r = .54, p < .01$) Including SOC in a model predicting exercise goal attainment increased amount of variance explained from 27% to 54% among younger adults and 30% to 49% among older adults. SOC predicted exercise goal attainment in the above model, among both younger adults ($\beta = .70, p < .001$) and older adults ($\beta = .59, p < .001$). SOC mediated the relationship between coping planning and exercise goal attainment; when SOC was included in the above model, coping planning was no longer a significant predictor of exercise goal attainment in younger adults ($\beta = .05, p = n.s$) or older adults ($\beta = .15, p = n.s$).

Authors	Chronic illness	Main outcome measures	Main results ^a
Ziegelmann and Lippke (2007b)	Musculoskeletal	<ul style="list-style-type: none"> • Exercise intentions, Action plans, Coping plans, all adapted from (Fuchs, 1996) • Maintenance self-efficacy (Scholz, Sniehotta, & Schwarzer, 2005) • Perceived resource loss (three items) (authors' own measure) • Exercise (total duration of physical activity and strenuous exercise) adapted from Bernstein (1998) • Orthopaedic outcome (Stones & Kozma, 1996; Wyman, 2001) • Subjective wellbeing (Philadelphia Center Morale Scale) (subscales satisfaction with aging, lack of agitation and satisfaction with life) (Lawton, 1975) 	<ul style="list-style-type: none"> • SOC positively correlated with exercise ($r = .42$, $p < .01$). • SOC predicted exercise ($\beta = .47$, $p < .01$) and orthopaedic outcome ($\beta = .12$, $p < .05$). • Exercise mediated the relationship between SOC and orthopaedic outcome; when exercise was included in the above model, SOC was no longer a significant predictor of orthopaedic outcome ($\beta = .03$, $p = n.s.$). • Optimisation and elective selection predicted exercise ($\beta = .48$, $p < .001$) and subjective wellbeing ($\beta = .08$, $p < .05$). • Exercise mediated the relationship between SOC and subjective wellbeing; when exercise was included in the above model, SOC was no longer a significant predictor of subjective wellbeing ($\beta = .01$, $p = n.s.$).

^a S = selection, ES = elective selection, LBS = loss-based selection, O = optimisation, C = compensation; SOC = composite score; n.s = not significant.

Other studies applying the Selection, Optimisation and Compensation model in the contexts of ageing or health

Due to the wide inclusion criteria of this review, studies were included even if they did not examine the relationships between SOC use and outcome. There were therefore a number of other strands of SOC research, including: use of the SOC model as rationale for studies and to guide hypotheses and analyses; examining patterns of SOC use; use of the SOC model to develop interventions; and qualitative studies.

Use of the SOC model as rationale for hypotheses and analyses

The model was also used as rationale for the hypotheses and analyses of three studies (Table 2.5) (Carmichael et al., 2015; Janse et al., 2015; Opitz et al., 2014). Two such studies suggested that their findings could be attributed to, and provided support for the model (Carmichael et al., 2015; Opitz et al., 2014). In one study this involved the relationships between quantity and quality of social activities for participants aged 20 and 30, and wellbeing at aged 50 (Carmichael et al., 2015). The authors found that both higher quantity of social activity at age 20 and better quality of social activity at age 30 predicted friendship quality and psychological outcomes during middle-age. Such findings were suggested to indicate age-related SOC use; 20 year olds selected and optimised social information seeking whilst 30 year olds sought quality social experiences. Such social activities were suggested to provide the maximum benefits to participants' social goals at each developmental stage.

The SOC model was also applied to the domain of emotion regulation, with Opitz et al. (2014) examining the relationship between the resource of cognitive ability and the emotion regulation strategy of cognitive reinterpretation. The authors suggested that a positive relationship between cognitive ability and cognitive reinterpretation would support the idea that the use of SOC strategies for emotion regulation requires resources. Higher fluid cognitive ability was associated with better cognitive reappraisal, although there was no significant difference in cognitive reappraisal between younger and older adults.

One study briefly utilised the SOC model to develop one of their hypotheses for goal adjustment in colorectal cancer patients, suggesting that patients would reduce the number of goals they reported over six months due to decreasing resources (Janse et al.,

2015). This hypothesis was supported; however SOC was not examined further in the study.

Table 2.5: Use of the SOC model as rationale for hypotheses and analyses

Authors	Context	Aim	Main results ^a
Carmichael et al. (2015)	Ageing	To examine the relationships between quantity and quality of early adult social activity (aged 20 and 30), and social connectedness and psychological outcomes in middle-age (aged 50)	<ul style="list-style-type: none"> Quantity of social activity at aged 20 predicted social integration, friendship quality and psychological outcomes at aged 50 ($\beta = .23, p < .01$; $\beta = .26, p < .01$; $\beta = .34, p < .01$, respectively), with relationship remaining when outcome variables at aged 30 were controlled. Quality of social activity at aged 20 or aged 30 was not associated with social integration ($\beta = .07$; $\beta = -.10$). Quality of social activity at aged 20 predicted friendship quality and psychological outcomes at aged 30 ($\beta = .29, p < .01$; $\beta = .31, p < .01$), which in turn predicted friendship quality and psychological outcomes at aged 50 ($\beta = .38, p < .01$; $\beta = .23, p < .05$). Quality of social activity at aged 20 did not predict friendship quality and psychological outcomes at aged 50 when social activity quality at aged 30 was controlled.
Janse et al. (2015)	Health – Cancer	To examine goal adjustment in cancer patients over time.	<ul style="list-style-type: none"> SOC used to inform hypothesis that participants would reduce number of goals over 6 months. Patients reported significantly fewer goals after 6 months ($t = 3.64, p < .01$).
Opitz et al. (2014)	Ageing	To examine the relationship between successful emotional regulation (e.g. cognitive reappraisal) and resources (e.g. cognitive ability)	<ul style="list-style-type: none"> Higher fluid cognitive ability was associated with better cognitive reappraisal, both for decreasing ($b = -0.37, p < 0.001$) and increasing emotional response ($b = 0.42, p = 0.001$) No age differences in cognitive reappraisal.

^a S = selection, ES = elective selection, LBS = loss-based selection, O = optimisation, C = compensation; SOC = composite score.

Patterns of SOC use between younger and older adults

A range of approaches were used to examine the differences between younger and older adults in their preference for SOC use, with the model hypothesising that younger and middle-aged adults will seek out growth and maintenance opportunities whilst older adults will report a preference for compensatory activities (P. Baltes, 1997) (Table 2.6).

Approaches included a self-report questionnaire (Bieri et al., 2015); inducing optimisation and compensation conditions experimentally during a sensorimotor task (Freund, 2006); using performance in a dual-task experiment to examine loss-based selection and compensation (Li et al., 2001); assessing preferences for proverbs that matched SOC strategies (Freund & Baltes, 2002a); and examining differences in goal characteristics (Penningroth & Scott, 2012).

Optimisation and compensation conditions were induced in a sensorimotor task by asking participants to first become as good as possible at the task, and then to achieve the same level of performance when the difficulty of the task was increased (Freund, 2006). Across three studies, younger adults demonstrated more motivation to persist in the optimisation condition than in the compensation condition, whereas the opposite was true for older adults. Loss-based selection and compensation were also examined experimentally using dual-task walking and memorising (Li et al., 2001). In contrast to younger adults, older adults had poorer memory performances when asked to perform both the memory and walking tasks together. Both younger and older adults had a reduction in walking speed when the difficulty of the walking task was increased. For older adults, however, this reduction did not decrease any further when the memory task was also made more difficult. The authors suggested that these findings indicated older adults used selection to prioritise the walking task over memorising, due to the higher costs associated with a fall. In addition, older adults used the walking aid more effectively to improve walking performance, compared to younger adults who used the memory aid more effectively to improve memory performance. The authors suggested that this indicates compensation in the selected tasks (Li et al., 2001).

Patterns of SOC use were also examined through identifying SOC strategies within proverbs (Freund & Baltes, 2002a). The authors suggested that proverbs often reflected the life management strategies of selection, optimisation and compensation, and 18 SOC proverbs

were selected to examine age-differential SOC preferences. Participants were asked to choose which of two proverbs (SOC versus non-SOC alternative) better matched the phrases “when things don’t go as well as they used to”, “when one needs to make a decision” and “to make one’s plans come true”. SOC proverbs were chosen more quickly than non-SOC alternatives. Older adults in particular chose compensation proverbs more quickly than the non-SOC alternative, whereas this difference was not found in younger adults. Younger adults were found to choose selection more often and compensation less often than older adults. These findings were partially replicated in a second study, where vignettes were used to depict either a resource loss or a healthy life. Despite no age-differential effects in this study, overall SOC proverbs were again chosen more quickly than non-SOC alternatives.

One study explored differences in goal characteristics between younger and older adults, in order to test predictions from the SOC model (Penningroth & Scott, 2012). As expected, older adults indicated a smaller percentage of goals that were centred on achieving gains, than younger adults. Unexpectedly, older adults had a greater variation of goals than younger adults, and whilst older adults reported fewer goals than younger adults, this difference was not significant.

Finally, Bieri et al. (2015) developed the Driving Behaviour Adaptations Questionnaire, based on SOC strategies drawn from literature into the differences in driving-related behaviour between younger and older adults. Older adults used such behavioural adaptations more than younger drivers however the development and psychometric properties of the questionnaire require further exploration.

Patterns of SOC use between other groups

Differences in SOC use between various groups and over time were also examined (Table 2.6) (Lang et al., 2002; Pickard et al., 2009; Weiland et al., 2011). Difference in patterns of behaviour between groups of individuals with differing resource levels were examined by Lang et al. (2002), identifying four indicators of SOC measured over a four year time period. Two resource factors (a sensorimotor-cognitive factor and a personality-social factor) were determined through assessing constructs such as cognitive ability, balance and social support. The initial behaviour of those who didn’t survive the four year period indicated less selection and optimisation but more compensation in the form of longer and more

frequent passive phases, compared to those who did survive. Those who were categorised as poor in resources also exhibited more compensation, again in the form of longer and more frequent passive phases, compared to those rich in resources. The authors noted, however, that there were discrepancies between their multiple indicators of compensation. For example, resource rich individuals had fewer passive phases but more frequent and longer phases of sleeping during the day. Such regenerative activities were proposed to indicate compensation; however in this instance the resource rich individuals were using both more and less compensation.

The SOC model was also used to examine differences between groups of drivers, namely those who had given up driving, drove less than previously, or continued to drive. Each group were interviewed about their transport needs and participation in other activities (Pickard et al., 2009). The authors suggested that those who had given up driving were receiving adequate help with transport, which they suggested indicated compensation. The authors also indicated that selection was supported by the finding that those who had given up driving gave up a lower proportion of high physical demand leisure activities than those who drove to a lesser extent than previously. Unfortunately the application of the model in this study was limited, group sizes were too small to conduct statistical analyses and both of the other groups also had a high number of people reporting receiving enough assistance with transportation.

Finally, Weiland et al. (2011) investigated changes in SOC use over time in inpatient psychiatric patients with depression and found that SOC strategy use increased following discharge and during remission. The authors suggested, therefore that SOC strategy use is changeable and mood dependent.

Table 2.6: Patterns of SOC use

Authors	Context	Aim	Main results ^a
Bieri et al. (2015)	Ageing	To create a questionnaire to assess driving-related behavioural adaptations aimed at reducing the risk while driving	<ul style="list-style-type: none"> Factor analysis of DBAQ revealed 2 factors: 1 with 24 items of risk reducing behaviour and 1 with 13 items where behavioural adaptation did not occur. Adaptations included passenger support, taking breaks, planning, not overtaking slow car, giving right of way, wearing sunglasses, checking settings on mirror, removing ice/condensation from windows. Higher scores for older drivers than younger drivers on risk reducing factors ($t(84.5) = 2.21, p=0.013$). Older drivers reported being overtaken more (indicating slower driving) ($F(1, 89) = 6.73, p=0.011$), planned in advance more when to take breaks on a longer trip ($U(31, 61) = 1,267.5, p=0.002$), took sunglasses more often to combat glare ($U(31, 61) = 1,247.5, p=0.009$) and cleared condensation/ice from car windows ($F(1, 89) = 7.62, p=0.007$).
Freund (2006)	Ageing	To experimentally induce optimisation and compensation conditions in a sensorimotor task and examine age-related differences in motivation to persist in each condition.	<ul style="list-style-type: none"> Interaction between condition and age ($F(1, 59) = 7.17, p=.01$). Younger adults demonstrated more motivation to persist in the optimisation condition (to become as good as they could be) ($M = 31.74$ minutes) than in the compensation condition (to try to achieve same levels of performance despite reduction in accuracy) ($M = 24.46$ minutes). Older adults demonstrated more motivation to persist in the compensation condition ($M = 49.04$ minutes) compared to the optimisation condition ($M = 45.35$ minutes). Findings replicated in study 2 (independent sample), with interaction between condition and age ($F(1, 36) = 7.61, p=.009$) and similar findings to study 1. Study 3 labelled optimisation condition 'difficult' and compensation condition 'easy' to determine if older adults perceived compensation condition as easier and so spent more time on it. Interaction between condition and age ($F(1, 57) = 9.74, p=.003$) and similar findings to studies 1 and 2. Study 4 removed optimisation and compensation inducing conditions, replacing with a goal mean standard of comparison and labelling the sessions as 'easy' or difficult'. There was no significant interaction between condition, age and sequence of sessions ($F(1, 109) = 0.53, p=n.s$) and no effect of task condition ($F(1, 109) = 2.11, p=n.s$).

Authors	Context	Aim	Main results ^a
Freund and Baltes (2002a)	Ageing	To examine age-differential preferences for selection, optimisation and compensation based on proverbs deemed to reflect SOC strategies	<ul style="list-style-type: none"> • Study 1 found an interaction between age group and SOC strategy preference ($F(2, 61) = 6.87, p=.002$). Younger adults chose selection proverbs more often ($t(62) = 2.65, p=.01$) and compensation less often ($t(62) = -1.99, p=.05$) than older adults. • When SOC proverbs were chosen they were selected more quickly than when non-SOC alternatives were chosen ($F(2, 61) = 12.3, p=.001$). • Older adults chose compensation proverbs quicker than non-SOC alternatives ($t(32) = -2.19, p=.04$) however younger adults did not ($t(30) = -0.78, p=n.s$). • Study 2 used vignettes depicting either a resource loss or healthy life, however no differences in responses were found between these scenarios. • Study 2 replicated finding that SOC proverbs were selected more quickly than non-SOC alternatives ($F(1, 129) = 61.9, p<.001$). • Study 2 found no interaction between age group and SOC strategy preference ($F(2, 128) = 2.18, p=n.s$).
Lang et al. (2002) ^b	Ageing	To examine whether strategies of everyday functioning indicating SOC differ between individuals with differing levels of resources, and examine whether such SOC indicators differ between survivors and non-survivors.	<ul style="list-style-type: none"> • Those who didn't survive after 4 years differed on initial measures compared to those who did survive, having used less selection (indicated by greater diversity of activities) ($M = 50.4$ versus $M = 37, \eta^2 = .067, p<.01$), less optimisation (indicated by less variability of time investments across activities) ($M = 36.7$ versus $M = 44.7, \eta^2 = .028, p<.01$) and more compensation (indicated by more and longer passive phases) (more passive phases: $M = 2.7$ versus $M = 1.4, \eta^2 = .060, p<.01$; longer passive phases: $M = 62$mins versus $M = 38$mins, $\eta^2 = .030, p<.01$). • Resource poor individuals differed on initial measures compared to resource rich individuals, using more compensation (more passive phases: $M = 2.5$ versus $M = 1.5, \eta^2 = .042, p<.05$; longer passive phases: $M = 61$mins versus $M = 38, \eta^2 = .050, p<.05$). • There was an interaction between resource group and survival status, with the RP NS group having less selection ($\eta^2 = .044, p<.001$) and more compensation (passive phases: $\eta^2 = .056, p<.01$) than the RR NS group. • Regarding changes in everyday functioning over four years, RR had increased selection (Percentage social time with family: $+6.6$ versus $-9.2, \eta^2 = .049, p<.05$; diversity of activities: -2.4 versus $+4.2, \eta^2 = .065, p<.05$), optimisation ($+4.5$ versus $-6.6, \eta^2 = .071, p<.05$) and more compensation (less passive phases -0.2 versus $+0.6, \eta^2 = .065, p<.05$ but more $+0.1$ versus $-0.2, \eta^2 = .075, p<.05$) and longer sleeping during the day ($+8.9$ versus $-18.8, \eta^2 = .056, p<.05$).

Authors	Context	Aim	Main results ^a
Li et al. (2001)	Ageing	To investigate task priority during dual-task performance as an indicator of loss-based selection and compensation using cognitive and sensorimotor tasks.	<ul style="list-style-type: none"> • Dual task costs^c in memory were greater across all task difficulty conditions for older adults than younger adults ($F(1, 75) = 22.31, p < .001$). • Younger adults showed dual task costs in memory when memory task difficulty, or memory plus walking task difficulty were increased. Older adults showed dual task costs in memory even when memory task difficulty was not increased in any way. • Dual task costs in walking speed were similar across all conditions for older adults compared to younger adults ($p = n.s.$). • There was an interaction between age and task difficulty ($F(3, 73) = 5.56, p = .002$) for dual task costs in walking speed. Older adults showed similar walking speed dual task costs when walking task difficulty, or memory plus walking task difficulty were increased. • Younger adults showed differences in walking speed dual task costs across all task difficulty conditions. • Correlation between memory performance gain and use of memory aid in younger adults ($r = .52, p < .01$) but not older adults ($r = .14, p = n.s.$). • Correlation between walking accuracy performance gain and use of walking aid in older adults ($r = .68, p < .01$) but not younger adults ($r = .18, p = n.s.$).
Penningroth and Scott (2012)	Ageing	To examine predictions from the SOC model and Socioemotional Selectivity Theory about age-related differences in goals.	<ul style="list-style-type: none"> • Goal restriction: older adults listed fewer goals than young adults, however this was not significant ($p = .075$). • Goal dissimilarity: older adults ($M = .82, SD = .20$) had higher goal dissimilarity than younger adults ($M = .73, SD = .19$) ($t(103) = 2.24, p = .027$). • Goal orientation - older adults ($M = 66.9\%, SD = 30.9$) had lower percentage of goals with a gain orientation than younger adults ($M = 96.3\%, SD = 10.2$) ($t(107) = 7.29, p = .001$).
Pickard et al. (2009)	Ageing & driving	To use the SOC model to compare older drivers who had given up driving, those who still drive and those who drive less.	<ul style="list-style-type: none"> • 8 out of 12 drivers who had given up driving and required transportation reported enough assistance, compared to 4 out of 7 drivers who drove less, and 2 out of 2 drivers who continued to drive^d. Authors suggest this indicates former group are utilising compensation. • Group who drove less had given up the highest proportion of high physical demand leisure activities (0.70), compared to those who had given up driving (0.59) and those who continued to drive (0.45) ($f(16, 04), p < .0001$). Authors suggest this indicates selection in former group.

Authors	Context	Aim	Main results ^a
Weiland et al. (2011)	Health - Depression	To investigate patterns of SOC use in individuals with depressive disorders.	<ul style="list-style-type: none"> Increase in relative mean scores for composite SOC measure (M = 19.9 to M = 30.7) and for four subscales: ES (M = 4.7 to M = 6.9), LBS (M = 5.2 to M = 8.3), O (M = 4.6 to M = 7.4) and C (M = 5.3 to M = 8), all p<.001 (t-test statistics not reported).

^a S = selection, ES = elective selection, LBS = loss-based selection, O = optimisation, C = compensation; SOC = composite score; n.s = not significant.

^b NS (non-survivor), S (survivor), RR (resource rich), RP (resource poor).

^c Dual task costs calculated as differences from task performance during the training phase of the study.

^d Sample sizes were too small for statistical analysis.

SOC interventions

Seven studies detailed the use of SOC in the development or analysis of an intervention (Table 2.7) (Alonso-Fernández et al., 2015; Alonso et al., 2013; Evers et al., 2012; Gellert et al., 2013; D. Lund et al., 2014; Rose et al., 2008; Ziegelmann et al., 2006). In a 'Coping and Communication Support' intervention for patients with advanced cancer, Rose et al. (2008) stated that Coping and Communication Support Practitioners (CCSPs) were trained in using the SOC model to enable coping and adaptation. The main roles of the Advanced Nurse CCSPs were to discuss concerns and symptoms, refer for symptom management and act as a liaison where appropriate. This study is ongoing and this paper reported preliminary data on patient preferences for engagement and communication. Unfortunately no information on the efficacy of the intervention is yet available, and a more detailed explanation of training and how SOC strategies were incorporated into the intervention would have been beneficial.

Alonso et al. (2013) and Alonso-Fernández et al. (2015) report on the efficacy of an Acceptance and Commitment Therapy and SOC training intervention, designed to increase independence and activity in older adults with musculoskeletal chronic pain. The SOC aspect of the intervention involved discussing life goals and coping practices based on selection, optimisation and compensation. The initial pilot study consisted of five adults taking part in twice weekly sessions for five weeks (Alonso et al., 2013). Whilst the small sample and other weaknesses in methodology and analysis meant that limited conclusions could be drawn from the pilot, a larger scale version of this intervention was conducted with 101 participants (Alonso-Fernández et al., 2015). The study included 'minimal support' (control) participants who received a two hour education session including information on different attitudes towards ageing and SOC strategies. The participants receiving the intervention improved more than the controls on pain interference in walking ability, pain anxiety, pain acceptance and use of compensation strategies. Unfortunately only 52% of participants completed the sessions and follow up assessment. Due to the minimal therapist contact received by the control group and the mixture of both ACT and SOC training within the intervention group, it is difficult to attribute the findings directly to selection, optimisation and compensation training. Nevertheless, the study provides an example of the application of SOC in interventions and the overall quality of the latter study was assessed as moderate.

D. Lund et al. (2014) described the use of the SOC model to inform the 'Time for Living and Caring' intervention to increase the effectiveness of respite time for family caregivers. The intervention seeks to guide carers through identifying and prioritising goals during their respite time (selection), considering goal attainment strategies (optimisation) and identifying barriers and limitations in resources (compensation). The authors state that at present this guide is available in a booklet; future research will focus on examining its delivery through individual coaching. The authors present data from a pilot study, however due to a sample size of only 20, no statistical analyses were conducted.

Three studies conducted RCTs involving SOC and physical activity (Evers et al., 2012; Gellert et al., 2013; Ziegelmann et al., 2006). Gellert et al. (2013) was the only study to embed training in SOC strategies within a randomised controlled trial of a planning intervention. Older adults who wished to increase their physical activity levels were randomly allocated to either an age neutral or age tailored physical activity planning intervention. Both conditions involved setting a physical activity goal and generating up to three plans to conduct this activity, alongside coping plans to target up to three potential barriers. The age tailored condition received strategy training, where each of the SOC strategies were introduced and examples used to instruct participants on how to use them to achieve their goals. Participants adapted each strategy to their circumstances and physical activity goal. Those who received the SOC training were more successful in increasing their physical activity 6-12 months later than those who did not receive the training. This RCT was assessed as moderate quality overall.

Findings from the remaining two physical activity RCTs have been described previously, as both studies examined the relationships between SOC use and outcomes within the RCTs (Evers et al., 2012; Ziegelmann et al., 2006).

Table 2.7: SOC interventions

Authors	Context	Aim	Main results ^a
Alonso et al. (2013) ^b	Health - chronic pain	To assess efficacy of treatment programme based on Acceptance and Commitment Therapy and training in SOC strategies to increase functional autonomy and quantity of activities of older people with chronic pain of a musculoskeletal nature.	<ul style="list-style-type: none"> • Both control ($z = -2.03, p=0.04$) and intervention groups ($z = -2.04, p=0.04$) had significant increases in the subscale 'success in living according to one's own values'. • Control group had a significant increase in beliefs about pain disability ($z = -2.03, p=0.04$). • Significant difference in gain scores between groups on beliefs about usefulness of medication to control pain ($u = 3.50, p=0.04$).
Alonso-Fernández et al. (2015)	Health - chronic pain	To assess efficacy of treatment programme based on Acceptance and Commitment Therapy and training in SOC strategies for older people with chronic musculoskeletal pain	<ul style="list-style-type: none"> • Intervention group improved more than the minimal support group on pain interfering with their walking ability ($F(1, 50) = 4.50, p=.05$), anxiety due to pain ($F(1, 51) = 4.05, p=.05$), pain acceptance ($F(1, 51) = 5.42, p=.01$) and use of compensation strategies ($F(1, 48) = 4.06, p=.05$).
Evers et al. (2012)	Ageing & physical activity	To trial an RCT of self-administered versus telephone assisted planning and examine the role that SOC strategy plays on physical activity.	<ul style="list-style-type: none"> • Described in Table 2.3.
Gellert et al. (2013)	Ageing & physical activity	To trial an age-tailored intervention including SOC based coping strategy training to improve physical activity.	<ul style="list-style-type: none"> • Between six months and 12 months post intervention, the intervention group's days per week of physical activity increased ($M=2.26$ to $M=2.74$) whilst the age-neutral (control) group's decreased ($M=2.38$ to $M=2.37$). • Between six months and 12 months post intervention, the intervention group's physical activity distance covered increased ($M=3.73$ to $M=4.19$), as did the age-neutral (control) group's ($M=3.62$ to $M=3.91$). • Those in the intervention group had a larger increase in physical activity between 6 months and 12 months post intervention, compared to the age-neutral (control) group ($b = 0.49, p=.01$).
D. Lund et al. (2014)	Health – caregivers	To describe the intervention 'Time for Living and Caring' (TLC) designed to enhance effectiveness of respite services for family caregivers and present pilot data on feasibility and usefulness of intervention.	<ul style="list-style-type: none"> • Small sample size precluded statistic tests however control group ($n=7$) had no changes in satisfaction with respite time or perceived satisfaction with caring. • Intervention group ($n=14$) has small improvement in satisfaction with respite time and small reduction in burden levels but no change in satisfaction with caregiving • Some positive qualitative responses to intervention reported.

Authors	Context	Aim	Main results^a
Rose et al. (2008)	Health - Cancer	Describe the development of Coping and Communication Support intervention for advanced cancer patients and present preliminary data on patients' problems, preferences and engagement in the intervention.	<ul style="list-style-type: none"> • No age group differences in the intervention strategies used (p=n.s). • The most commonly used strategies were supportive listening, education/handouts and cognitive problem solving.
Ziegelmann et al. (2006)	Health - Orthopaedic rehabilitation and physical activity	To investigate the relationship between SOC strategy use and outcomes in individuals undergoing orthopaedic rehabilitation.	<ul style="list-style-type: none"> • Described in Table 2.4.

^a S = selection, ES = elective selection, LBS = loss-based selection, O = optimisation, C = compensation; SOC = composite score; n.s = not significant.

^b Small sample size of 5 participants per group.

Qualitative application of the SOC model

The SOC model was utilised in thirteen qualitative studies, exploring the changes experienced by older adults and those with chronic health conditions, and the strategies employed in order to cope with such changes (Table 2.8) (DiLauro et al., 2015; Greenwood et al., 2010; Hutchinson & Nimrod, 2012; Janke et al., 2012; Kelly et al., 2014; Kleiber & Nimrod, 2009; Lien et al., 2015; Nasvadi & Vavrik, 2007; Rozario et al., 2011; Rush et al., 2011; Ryan et al., 2003; van der Goot et al., 2015; Wilhite et al., 2004). In contrast to the majority of the quantitative SOC studies, qualitative studies did not focus on the relationships between SOC use and outcomes, but rather utilised the SOC model to explore how individuals adapt to changes and cope with their circumstances. Furthermore, the qualitative studies often identified specific examples of selection, optimisation and compensation, drawn from the participants' own experiences and words.

Seven studies identified the use of SOC strategies to perform and adapt to activities, by older adults and those with chronic health conditions including visual difficulties, arthritis and multiple sclerosis (Hutchinson & Nimrod, 2012; Janke et al., 2012; Kelly et al., 2014; Rozario et al., 2011; Rush et al., 2011; Ryan et al., 2003; Wilhite et al., 2004). These include specific examples of selection, optimisation and compensation behaviour, and categories of behaviour which reflect the SOC processes. There were similarities between the selection, optimisation and compensation strategies identified and adopted by a range of individuals. Common selection examples included selecting appropriate goals based on the life domains and activities that were most important, adopting new goals in the face of losses, and adjusting standards if necessary (Janke et al., 2012; Rozario et al., 2011; Rush et al., 2011; Wilhite et al., 2004). In addition, selection examples also centred around restricting participation in activities, either by performing them less often or for a shorter time, or giving them up altogether (Janke et al., 2012; Rush et al., 2011; Ryan et al., 2003). One study described the substitution of leisure activities that could no longer be performed as a selection strategy (Hutchinson & Nimrod, 2012), however, this was most commonly viewed as a compensatory strategy (Rozario et al., 2011; Wilhite et al., 2004). In further contrast to Rozario et al. (2011) and Wilhite et al. (2004), Ryan et al. (2003) categorised the adjustment of standards as optimisation rather than selection.

Optimisation examples differed more than those of selection, and perhaps varied depending on the context of the individual's behaviour. Common optimisation strategies included pacing and resting, practising, planning and organising, scheduling important activities for when energy was at a maximum, and using exercise and leisure to optimise health, ability and wellbeing (Hutchinson & Nimrod, 2012; Rozario et al., 2011; Rush et al., 2011; Ryan et al., 2003; Wilhite et al., 2004). Optimisation strategies used within the context of leisure included taking on a different role within a previous leisure activity (Hutchinson & Nimrod, 2012) and using personal beliefs and self-talk as a motivation strategy to take part in leisure activities (Hutchinson & Nimrod, 2012; Janke et al., 2012). Additional optimisation strategies included seeking education and knowing about the body, memorising, developing new techniques, seizing opportunities, using the influence of role models and pushing oneself to capacity (Janke et al., 2012; Rush et al., 2011; Ryan et al., 2003; Wilhite et al., 2004). One leisure study also described reducing involvement or intensity of leisure activities as optimisation, however this is classed as selection in a number of other studies (Hutchinson & Nimrod, 2012). In addition, Kelly et al. (2014) focused on the relationships between strategies, therefore identifying 'elective selection with optimisation' strategies that enabled older adults to continue with their essential or desired activities. These included changing behaviour so that an activity could be continued, persevering even if the activity takes more time, developing routines so that activities become more familiar and redesigning the environment.

Examples of compensation strategies included using assistive devices and aids, paying for service or delegating tasks, help from friends and family members, substituting one activity for another, modifying activities and acquiring new skills (Hutchinson & Nimrod, 2012; Janke et al., 2012; Kelly et al., 2014; Rozario et al., 2011; Rush et al., 2011; Ryan et al., 2003; Wilhite et al., 2004). Assistive devices, help from others and home modifications were categorised as 'elective selection with compensation' by Kelly et al. (2014).

Two studies identified behaviours adopted by older adults to adjust to their home environments, and in response to constraints to their leisure activities (Kleiber & Nimrod, 2009; Lien et al., 2015). Whilst both of these studies used the SOC model as an analytical framework and discussed behaviours that were similar to those described as selection,

optimisation and compensation above, they were not explicitly categorised as SOC. Lien et al. (2015) stated that older adults adjusted behaviours or attitudes, increased their support from assistive devices and family/friends, and introduced other modifications and new strategies in order to remain living in their homes. Kleiber and Nimrod (2009) identified five themes of behaviours used by adults to adapt to difficulties with leisure activities: reducing and eliminating activities, persisting with commitment, focusing leisure activities around the limitation, substituting one activity for another and using exploration and self-discovery. The authors did attempt to relate the study themes to the SOC strategies, for example, stating that reducing and eliminating was related to loss-based selection, and that substitution may be selection or compensation. It was also, however, acknowledged that the model may not clearly capture all the study themes, for example exploration and self-discovery.

The SOC model was used as a general model to explore changes in autonomy and control, and changes in shared leisure participation, for carers of stroke survivors and carers of spouses with dementia respectively (DiLauro et al., 2015; Greenwood et al., 2010). Those caring for family members after a stroke were found to experience reduced control and choice, increased unpredictability and helplessness, and a need to plan ahead (Greenwood et al., 2010). Strategies identified to increase autonomy included selection (e.g. giving up activities), optimisation (e.g. making efforts to increase control such as forward planning and ensuring rest is taken), and compensation (e.g. aids in the home and receiving help from others). For those caring for spouses with dementia, an overarching theme was identified; making iterative changes to activities such that the carer and spouse are able to enjoy shared leisure experiences (DiLauro et al., 2015). The authors suggest that this process involves recognising and acknowledging changes, making sense of changes and embracing such change, although few specific examples of SOC strategy use are identified

Finally, two qualitative studies focused on the specific behaviours of driving and television viewing (Nasvadi & Vavrik, 2007; van der Goot et al., 2015). An older driver education course was suggested to represent an optimisation strategy of information seeking, and Nasvadi and Vavrik (2007) explored the strategies employed by groups of older drivers who attended the course, although they did not state the method of qualitative analysis. The authors suggested that those classified as 'crashers' (having at least one crash after attending the course) recalled less information from the course than 'perfects' (no crashes

pre or post-course) and 'pre-crashers' (no crashes post-course). Such drivers also demonstrated reluctance to change their travel goals or give up their activities. In contrast, those who had not experienced an accident reported selection activities such as avoiding specific roads or busy driving times, and compensation strategies such as sharing or stopping driving due to medical difficulties. Television viewing as a SOC strategy was also explored, with the suggestion that the activity was most often classified as compensation due to reduced resources and activities (van der Goot et al., 2015). Older adults were also, however, found to use television viewing as a selection strategy, chosen due to its social function or information/relaxation qualities. Television viewing operated as a compensation strategy less often, used as a substitute for social losses and to replace information or provide stimulation or an alternative activity due to reductions in function and resources.

Table 2.8: Qualitative SOC studies

Authors	Context	Aim	Main results
DiLauro et al. (2015)	Health-Dementia	To identify caregivers' perceptions of their spouses' participation in leisure activities since the onset of dementia.	<ul style="list-style-type: none"> The key theme was that carers make iterative changes to leisure activities in order to create shared experiences and enjoyment with the person with dementia. Three themes identified as part of the key theme: 1) recognising and acknowledging changes, 2) making sense of changes and conflicts, and 3) embracing changes and forging ahead. Little discussion of SOC explicitly, other than the suggestion that optimal functioning can occur if individuals minimise losses and maximise gains by allowing for changes in cognition, function and behaviour.
Greenwood et al. (2010)	Health - Stroke	To explore the experiences of informal carers, caring for stroke survivors, including the strategies adopted over the first three months to overcome changes in autonomy and control.	<ul style="list-style-type: none"> Six themes identified relating to changes in autonomy and control, including reduced control and unpredictability, choice, helplessness, planning ahead, increasing stroke survivor autonomy and its effect on reducing carer autonomy, and dependency on the carer. Strategies for increasing autonomy included selection (e.g. giving up activities), optimisation (e.g. making efforts to increase control such as forward planning and ensuring rest is taken), and compensation (e.g. aids in the home, receiving help from others).
Hutchinson and Nimrod (2012)	Health - Chronic illness	To examine how older adults with chronic illness use leisure to enhance and manage their health and wellbeing, and to identify the strategies they employ to continue with leisure in the face of health-related barriers.	<ul style="list-style-type: none"> Three themes identified relating to how those with chronic illness continue with leisure participation: 1) drawing on existing resources, 2) setting leisure based goals, and 3) using strategies to get more out of life. Practical strategies employed included 1) selection, particularly substituting one activity for another, 2) optimisation (e.g. taking on different roles in leisure activity, reducing involvement and intensity of activities), and 3) compensation (e.g. using adaptive equipment, external aids or support of family members).

Authors	Context	Aim	Main results
Janke et al. (2012)	Health - Musculoskeletal	To examine how older adults with arthritis develop and utilise SOC strategies to self-manage their arthritis through participation in leisure activities.	<ul style="list-style-type: none"> • Themes identified were related to SOC: <ul style="list-style-type: none"> - Focusing on essential activities and restructuring participation in leisure – loss-based selection - Health-promoting aspects of leisure and commitment to leisure for health purposes – elective selection - Influence of role models, seizing opportunities and using personal beliefs as motivators – optimisation - Modification of leisure activities, use of external aids and resources and social support – compensation.
Kelly et al. (2014)	Ageing	To identify strategies that older adults would adopt for managing their homes in the face of hypothetical losses of a perceptual, cognitive, mobility loss and physical nature.	<ul style="list-style-type: none"> • Older adults identified strategies they would use as a response to such losses. Strategies were coded as: <ul style="list-style-type: none"> - Elective selection with compensation – strategy types included tools and technology (e.g. hearing aids, grabbers, magnifying glasses, hand rails), assistance from others (e.g. spouse of friend to help with tasks), and home modifications (e.g. installing ramps). - Elective selection with optimisation – strategy types included overt action (changing behaviour to continue with tasks, e.g. take their time standing up before walking), reliance on familiarity (developing habits and routines that would lessen the cognitive effort required for tasks, e.g. keeping keys and glasses always in the same place), perseverance (continuing with task even if it required more time), and redesign (e.g. taking up rugs for easier walking and to reduce chance of falls). - Loss-based selection with compensation – strategy types included outsourcing and assisted living. These were mentioned more frequently in response to hypothetical cognitive difficulties however few segments were coded as such. - Loss-bases selection consisted of ‘task not done’ and few segments were coded as such.

Authors	Context	Aim	Main results
Kleiber and Nimrod (2009)	Ageing	To examine strategies adopted by older adults in response to barriers to leisure activities.	<ul style="list-style-type: none"> • Older adults faced a range of barriers to leisure activities, including physical limitations, caring responsibilities, time scarcity and finances. • Older adults adopted strategies in response to these barriers, which were categorised into five themes: <ul style="list-style-type: none"> - Reducing and eliminating - eliminating some activities and reducing involvement in others, particularly if they were less meaningful, satisfying or more difficult to do. - Persistence with commitment – commitment to an activity was sometimes strengthened in the face of barriers. - Constraint as 'project' – the barriers faced by older adults sometimes resulted in leisure activities centring on this constraint. - Substitution - substituting one activity for another was the most common strategy employed. - Exploration and self-discovery – barriers and constraints sometimes led to transformative exploration, self-discovery and innovation. • Older adults' emotional response to these barriers and the strategies they utilised included frustration, acceptance & gratitude
Lien et al. (2015)	Ageing	To identify and understand the adaptations older adults make in order to achieve a Person-Environment (PE) fit within their homes.	<ul style="list-style-type: none"> • Three themes were identified that described adaptive behaviours to achieve a Person-Environment fit within the homes of older adults. • Adjusting behaviour or attitudes: <ul style="list-style-type: none"> - In order to remain at home, older adults modified behaviours or attitudes. Modified behaviours included using alternative methods to achieve essential and desired activities, e.g. using planters in the garden when they could no longer reach the ground to garden. Difficulties with the environment in which they live are sometimes used as motivation, e.g. keep using the stairs to benefit health. • Increasing functional or environmental support: <ul style="list-style-type: none"> - Strategies included assistive devices, help from family members, home modifications and seeking more suitable housing, • Counteracting losses in functional or environmental support: <ul style="list-style-type: none"> - Modification to home in response to injury or event. - Increased attention towards acquiring new strategies, e.g. using non-impaired abilities, increasing knowledge of home modifications and other resources.

Authors	Context	Aim	Main results
Nasvadi and Vavrik (2007)	Ageing	To explore an older drivers' education programme as an optimisation strategy of information/knowledge seeking, and to identify which strategies learned via the course were adopted by attendees.	<ul style="list-style-type: none"> • There was no significant difference in post-course crash rates between attendees and controls ($\beta = 0.141, p=.427$) • Optimisation: knowledge gained from the course categorised as optimisation, with those categorised as 'crashers' reporting less learning than those categorised as 'perfects' (no crashes pre or post-course) and 'pre-crashers' (no crashes post-course). • Selection: various selection strategies taught in course; 'crashers' did not want to change their travel goals to incorporate selection strategies, however 'perfects' and 'pre-crashers' made selection style changes including avoiding specific roads and turns. • Compensation: all 'crashers' were primary drivers in the household and expressed determination to continue driving, whereas some 'pre-crashers' and 'perfects' stopped driving due to medical conditions or shared driving.
Rozario et al. (2011)	Health - Chronic illness	To identify the strategies used by adults with chronic illness to maintain, maximise and generate resources for the purpose of achieving their goals, and to identify patterns that might explain the adoption of such strategies.	<ul style="list-style-type: none"> • Strategies identified included: <ul style="list-style-type: none"> - Selection, e.g. selecting appropriate goals and setting appropriate levels for goals such as lowering standards so that goals are achievable. Selection employed due to the experience of competing demands and reduced/limited resources. - Optimisation, e.g. enhancing health and ability through exercise, pacing by taking breaks during activities, practising, and arranging activities for when energy is at a maximum. - Compensation, e.g. using aids such as walking stick or walker, paying for services and support, and substituting one activity for another • Patterns of use identified included the use of selection strategies as a form of maintaining autonomy, i.e. reframing the cessation of activity as a choice rather than a necessity due to loss of ability or resources. • Fewer instances of optimisation were identified and the authors suggest this is due to the requirement of resources necessary for optimisation. • Those with access to a range of resources employed, and had access to more means of compensation.

Authors	Context	Aim	Main results
Rush et al. (2011)	Ageing	To explore the mobility adaptations of older adults.	<ul style="list-style-type: none"> • Older adults used selection, optimisation and compensation strategies alone, and in combination. • Selection (81 types identified) often described as a choice which allows older adults to remain in control and prioritise in response to slowing down, not keeping up, feeling unsafe or losing interest/enjoyment : <ul style="list-style-type: none"> - Reducing activities – performing less often or for shorter duration (often due to limitations or injury), and giving up or avoiding activities (often due to age-related declines). - Changing goals - modification, transformation and redirection of goals due to losses. These can also refer to changing expectations, e.g. allowed to reduce effort or avoid situations and still receive satisfaction and be in control. • Optimisation (115 types identified): included various ways of addressing fatigue such as pushing self to capacity (push to complete difficult but essential mobility tasks), balancing the tensions (taking care not to overdo it) and anticipatory planning (e.g. planning activities by performing essential activities at a time of maximum energy, or spreading activities over the day). Also included changing environments and planning for changes that may be required in the future. • Compensation (83 types identified) - including substituting for alternative modes of mobility, modifying activities (e.g. carrying less when shopping, using shower instead of bath, reducing driving in certain conditions), receiving help (both physical and psychological, e.g. encouragement) and using aids.
Ryan et al. (2003)	Health - Vision loss	To identify and explore the strategies utilised by those with vision loss to manage reading-related difficulties.	<ul style="list-style-type: none"> • Authors identified SOC strategies within reading-related activities of daily living and provided examples for meal preparation, telephone use and finance. • Selection examples included continuing as before, making simpler meals, or giving up the activity in favour of others. • Optimisation examples included memorising, adjusting standards, being more organised, developing new techniques, receiving help from others and practising. • Compensation examples included a range of assistive devices such as magnifiers, high intensity lamps and computers, and receiving help from others.

Authors	Context	Aim	Main results
van der Goot et al. (2015)	Ageing	To identify whether television viewing is a selection or optimisation strategy for older adults.	<ul style="list-style-type: none"> • TV viewing was identified as selection when it was a positive choice from a range of alternative choices, chosen in order to achieve goals in domains that were important and not because of a lack of other activities. Often chosen due to its social function (e.g. sharing TV viewing with a partner) or as company within the home. Also chosen because it offers information or pleasure in relation to domains of everyday life, e.g. information about current affairs, relaxation from shows or relevant to hobbies and professions. • TV viewing was identified as compensation when it was used as a substitute for reduced activities or abilities, e.g. as a way to pass the time. Often chosen as a substitute for social losses, e.g. as company or to help structure the day when lonely. Content of viewing was chosen to replace information and to provide stimulation that was previously provided by other activities. Also used to replace other activities, e.g. watching church services instead of going to church. • Whether the behaviour was selection or compensation could not be ascertained from the duration or content of viewing, nor health status of the individual. For example, older adults who spent the majority of their days at home due to health difficulties did not always increase their TV viewing as a result.
Wilhite et al. (2004)	Health - Multiple Sclerosis	To explore adaptation and health and wellbeing in individuals with multiple sclerosis, in order to further develop the Optimising Lifelong Health and Wellbeing through Therapeutic Recreation (OLH-TR) practice model.	<ul style="list-style-type: none"> • Results grouped according to categories of a) Perceptions of health and wellbeing, b) activities contributing to optimal health and wellbeing, c) strategies for optimising health and wellbeing and d) discovering and developing strategies. • Those with MS used a variety of SOC strategies to optimise their health and wellbeing: <ul style="list-style-type: none"> - Selection – involved focusing resources on life domains and activities most important to their health and wellbeing, and choosing, developing and committing to goals. Also included loss-based selection; adopting new goals or activities in the face of losses and adjusting standards in other areas of life. - Optimisation - included knowing my body, resting, organising, educating myself, and maximising energy used to optimise engagement in chosen activities. - Compensation - included asking for help, delegating tasks, using assistive devices, acquiring new skills, and substituting one activity for another. • Strategies were discovered and developed through determination, trial and error, education, support and encouragement from others, exploration of options, and observation of others. • Strategies could be collaborative or an individual effort.

2.4 Discussion

Relationships between SOC use and outcomes

It is clear from this review that the adaptive nature of SOC strategies within the context of ageing is well documented. Indicators of wellbeing varied extensively in the reviewed studies, and included life satisfaction, satisfaction with ageing, positive emotions and self-esteem. There was good quality evidence that the use of selection, optimisation and compensation strategies was positively associated with a range of indicators of subjective wellbeing and negatively associated with depression in older adults (Chou & Chi, 2002b; Freund & Baltes, 1998, 2002b; Janke & Davey, 2006; Jopp & Smith, 2006; Okabayashi, 2014; Tovel & Carmel, 2013; Wurm et al., 2013). There was also good quality evidence that SOC use was found to predict physical activity outcomes in older adults, including adherence to physical activity goals and exercise programmes (Evers et al., 2012; Reuter et al., 2010). In addition, a range of SOC strategies were identified in older adults adapting to age-related losses (Kelly et al., 2014; Rush et al., 2011).

The findings from this review also indicate that there is a willingness to extend selection, optimisation and compensation research beyond the domain of ageing and to determine whether it has the ability to predict outcomes and describe adaptation in those with chronic health conditions. The SOC model has been applied to a range of health conditions including arthritis (Gignac et al., 2000, 2002; Janke et al., 2012; Janke et al., 2009; Son & Janke, 2015) and other musculoskeletal conditions (Ziegelmann & Lippke, 2007a, 2007b; Ziegelmann et al., 2006), cancer (Janse et al., 2015; Rose et al., 2008), chronic pain (Alonso-Fernández et al., 2015; Alonso et al., 2013), depression (Weiland et al., 2011), general chronic illness (Hutchinson & Nimrod, 2012; Rozario et al., 2011), multiple sclerosis (Wilhite et al., 2004), stroke (Donnellan et al., 2012), vision loss (Ryan et al., 2003) and family caregivers caring for family members with dementia, stroke or other chronic illnesses (DiLauro et al., 2015; Greenwood et al., 2010; D. Lund et al., 2014). The use of selection, optimisation and compensation strategies were related to a wealth of positive physical activity and health outcomes in adults with musculoskeletal conditions, including exercise, attainment of exercise goals, subjective wellbeing, orthopaedic outcome, fewer difficulties with activities of daily living, less pain and fewer difficulties with overall health (Janke et al., 2009; Ziegelmann & Lippke, 2007a, 2007b; Ziegelmann et al., 2006).

Use of SOC strategies was not always, however, related to positive outcomes, and alternative relationships between SOC and outcomes in older adults and those with chronic health conditions were occasionally reported when the SOC strategies were examined individually, or when modified SOC measures or interpretations of SOC strategies were utilised (Evers et al., 2012; Gignac et al., 2000, 2002; Janke et al., 2009; Son & Janke, 2015; Tovel & Carmel, 2013; Viglund et al., 2013). Further research is required to examine whether such relationships between negative outcomes and SOC use are due to poor quality evidence, particularly a lack of understanding as to the optimal ways of measuring SOC use in various situations, or whether it may be that not all of the SOC strategies equally contribute to the adaptive nature of the model.

Selection, optimisation and compensation as a synchronised process

SOC model researchers have proposed that selection, optimisation and compensation operate as three inter-related facets of one process (P. Baltes & Baltes, 1990; Freund & Baltes, 2000). As such, selection, optimisation and compensation should be measured as a synchronized effort rather than individual strategies. The researchers state that whilst this is the most theoretically sound conceptualisation of the SOC model, further research is required. A number of studies have, however, gone on to examine relationships between the individual strategies and outcomes separately, or indeed chose to focus only on certain strategies (e.g. loss-based selection and compensation (Ziegelmann et al., 2006)). This was also noted in a systematic review of the SOC model in the context of work, where the authors suggested that more studies should analyse and discuss the strategies individually in order to further examine the situations where selection, optimisation and compensation may be differentially adaptive (Moghimi et al., 2016).

In their brief review of SOC studies, Ouwehand, de Ridder, and Bensing (2007) suggest that optimisation and compensation appear to be the predominantly relevant strategies for combating losses and achieving successful ageing. Within this review, there is some limited evidence that selection, in particular loss-based selection, may have a differential relationship with outcomes than the other SOC strategies. For example, loss-based selection was not associated with successful ageing in one study, and was negatively associated with adherence to an exercise programme and arthritis-related health, with participants who reported more loss-based selection reporting more pain, anxiety and poorer overall health (Evers et al., 2012; Janke et al., 2009; Son & Janke, 2015; Tovel &

Carmel, 2013). The poor quality of some of these studies, however, means that such results should be interpreted with caution and whilst selection, optimisation and compensation were proposed to operate in a synchronised manner, further research is required to determine the extent to which use of the individual strategies have differing outcomes. Freund and Baltes (2000) agree that SOC strategies can occasionally be maladaptive, and this avenue of research could help to identify occasions where this is so (Moghimi et al., 2016).

Measurement and interpretation of SOC

Some of the contrasting findings and rating of studies as poor quality may be due, in part, to the range of ways in which the SOC model is interpreted and operationalised. In general, when the validated SOC self-report measure was utilised in older adults, the positive relationships between use of SOC strategies and 'good' outcomes were as expected (Chou & Chi, 2002a, 2002b; Freund & Baltes, 1998, 2002b; Jopp & Smith, 2006; Okabayashi, 2014). This was also true when the measure was modified to be specific to the domains of physical activity and living a healthy lifestyle (Reuter et al., 2010; Wurm et al., 2013). Two exceptions to this surround loss-based selection, which has previously been discussed (Evers et al., 2012; Tovel & Carmel, 2013). Using the Swedish version of the SOC questionnaire, however, SOC use was not related to self-esteem or geriatric depression (Viglund et al., 2013). This modified measure suffered from poor reliability, resulting in the removal of some items and requires further testing (Viglund et al., 2013). Future research in older adults should ensure that modified versions are valid and reliable, with even small modifications potentially influencing the validity of the measure (for example, see Freund and Baltes (2002b) for a description of why the forced-choice format was employed in the original measure).

There is also a lack of evidence surrounding the optimal way of measuring SOC strategy use by individuals with chronic health conditions. It is unlikely that we can expect the generic examples of SOC strategies, as measured by the generic self-report measure, to be related to the specific and often physical outcomes commonly examined in studies of individuals with chronic ill-health conditions. In the context of orthopaedic rehabilitation, when studies modified the SOC self-report questionnaire to reflect a certain goal, the use of selection, optimisation and compensation strategies predicted positive outcomes (Ziegelmann & Lippke, 2007a, 2007b). In these instances, SOC processes were examined in

the context of the particular health behaviour of exercise, and a clear link was established between the use of SOC strategies and orthopaedic and subjective wellbeing outcomes, with exercise mediating this relationship (Ziegelmann & Lippke, 2007a, 2007b). General self-reported SOC strategy use did not, however, predict functional ability, health-related quality of life or depression in stroke survivors one year post-stroke (Donnellan et al., 2012). This lack of predictive utility might be explained by a lack of correspondence between the SOC measure and these specific outcomes. The generic self-report measure assesses general mental representations of the SOC processes. Individuals are asked to consider their lives overall rather than their behaviour targeted towards a specific goal and although statistically significant, correlations with subjective wellbeing outcomes are modest (Freund & Baltes, 2002b). This may explain why no relationships were found between the general SOC strategies and specific outcomes such as functional ability in the context of health.

The generic self-report measure may also be inappropriate for use in some groups. Within stroke survivors, it had low internal reliability, potentially contributing to its lack of predictive utility (Donnellan et al., 2012). In addition, within individuals with depression, a high amount of missing data meant that the authors were unable to perform analyses with absolute SOC scores, instead calculating a relative score (Weiland et al., 2011). Freund and Baltes (2002b) warn that using a self-report approach assumes that individuals use and are able to access and report mental representations that reflect the use of SOC processes. The need for further operationalisations of the SOC model, outside of the standard self-report questionnaires, are required (Moghimi et al., 2016; Ouweland et al., 2007).

Asking individuals about their behaviour and then subsequently interpreting it as selection, optimisation and compensation may overcome some of the challenges of questionnaire self-report measures, and was employed as the methodology for both quantitative and qualitative studies. Care should, however, be taken with such subjective interpretations. For example, Lang et al.s' (2002), interpretation of compensation was problematic; an increase in regenerative activities was suggested to indicate compensation, however participants reported *fewer* passive phases at the same time as *more* frequent and longer phases of sleeping during the day. In addition, Janke and Davey (2006) defined optimisation as the maintenance or increase of leisure participation despite an increase in

functional impairment. Such behaviour could, however, result from either selection or effective use of compensatory behaviours.

The issue of identifying strategies as selection, optimisation or compensation is particularly relevant for qualitative studies. A number of the qualitative studies in this review conducted interviews with older adults and those with chronic health conditions, identifying examples of adaptation strategies and classifying these as SOC. Few, however, provided a detailed description of this process, with several studies simply stating that the examples of strategies were compared to the SOC constructs. Some exceptions exist, for example, Janke et al. (2012) clearly describe the use of the SOC strategy examples described by Freund and Baltes (2002b) to create a codebook with which to analyse the interviews. On the whole, however, the interpretations of what constituted selection, optimisation or compensation were, again, subjective and reliability of the methodology was often not described. This was evident in the findings of this systematic review, where similar strategies were coded differently. For example, adjustment of standards was categorised as an example of optimisation in one study (Ryan et al., 2003) and an example of selection in two studies (Rozario et al., 2011; Wilhite et al., 2004).

Distinguishing between optimisation and compensation can also be problematic for researchers. The SOC model is clear in its definition of compensation as in response to a loss in goal-related means and an attempt to continue functioning to a desired level. Optimisation, on the other hand, refers to the means through which individuals attempt to achieve new goals (P. Baltes & Baltes, 1990; Freund & Baltes, 2000). As such, the same behaviour can be either optimisation or compensation depending on whether it is in response to loss. Freund and Baltes (1998), for example, classify time allocation, effort and energy as optimisation strategies whereas *increased* time allocation, effort and energy are compensation strategies. Researchers must ensure that precise and comprehensive theoretical definitions of each strategy are applied reliably when interpreting and categorising elicited strategies in order to avoid confusion between strategies (Freund & Baltes, 2000). Context is important and is therefore required when interpreting behaviour as selection, optimisation or compensation. John and Lang (2012), for example, state that their strategy 'improvement' correlated with compensation and strategy 'maintenance' correlated with optimisation, as the authors expected. Based on the SOC model definitions it could be hypothesised that the opposite would be true; improvement should be related

to optimisation and maintenance to compensation. Gignac et al. (2002) also interpreted behaviour as selection, optimisation and compensation, stating that “optimisation strategies revolve around anticipating and avoiding difficulties before they occur”. This interpretation resulted in behaviours such as planning, using more time and effort, and having periods of rest categorised as optimisation. Care needs to be taken however to distinguish between whether these behaviours are being used to achieve a new goal, or to combat arthritis-related losses and maintain functioning.

Future research should concentrate on valid and robust SOC measures which are sensitive to the challenges of working with particular populations and ask individuals about particular SOC strategies relating to specific health related behaviours or goals in order to further investigate the relationship between SOC use and outcomes. Furthermore SOC measures which rely on interpretation or coding of strategies should employ methodological rigour and state the reliability of their findings. Future research could develop a SOC taxonomy for such purposes, similar to that created to code behaviour change techniques (Michie et al., 2013).

Study designs

Cross-sectional study designs may also have contributed to some of the contradictory findings in the relationships between SOC use and outcomes. For example, perceptions about loss of independence, dependence and helplessness could result in increased use of SOC strategies as people attempt to deal with the effects of arthritis on their daily lives (Gignac et al., 2000, 2002). Similarly, adults with more severe arthritis symptoms may be forced to use loss-based selection strategies due to their pain and health difficulties (Janke et al., 2009; Son & Janke, 2015). Even when positive cross-sectional relationships are found between SOC use and beneficial outcomes, longitudinal studies are required to examine the temporal relationships between SOC strategy use, outcomes and adjustment and to investigate how the use of SOC strategies develops and changes over time (Freund & Baltes, 2002b).

The need for longitudinal designs is particular relevant when we consider whether SOC strategy use is typically considered as a state or trait, dynamic or stable group of behaviours. As a lifespan model, the SOC model and the processes of selection, optimisation and compensation can be utilised across the lifetime to balance gains and

losses. Their use could therefore be considered as dynamic and dependent on states such as cognitive and functional ability, social support, social environment and other resources (Freund & Baltes, 2002b). A number of studies within this review summarised how SOC use differed between various groups of individuals, such as younger and older adults. For example, younger adults preferred the optimisation condition of a sensorimotor task, whilst older adults preferred the compensation condition (Freund, 2006). In addition, in an experimental task, Li et al. (2001) found that older adults used selection and compensation more effectively, whilst younger adults utilised optimisation. Freund and Baltes (1998) and Freund and Baltes (2002b) also found that older adults reported engaging in less SOC-related behaviour overall. This may be because SOC behaviours are effortful and require the use of resources, meaning they can be constrained by resource limitation in old age. However, further longitudinal studies are required to investigate how the use of SOC strategies develops and changes over time and in varying contexts, e.g. changes in resource availability (Freund & Baltes, 2002b).

The lack of longitudinal designs and exploration of changes in SOC use over time is particularly pronounced within the field of SOC and chronic health conditions. Weiland et al. (2011) found that self-reported SOC use increased following treatment for depressive disorders, however Donnellan et al. (2012) found no significant changes at one year post-stroke, compared to immediately post-stroke in stroke survivors. Similarly, Alonso et al. (2013) found no changes in general SOC strategy use as a result of a SOC/ACT intervention. It is evident therefore that further longitudinal SOC research is required, exploring how SOC use changes over time, and the utility of various SOC strategies at different timepoints. It may be that SOC strategy use in those with chronic health conditions develops differently than in those who are experiencing general ageing, particularly following a sudden change such as occurs after a stroke, for example.

Systematic review strengths and limitations

This systematic review provided a comprehensive overview of the SOC evidence base, with wide inclusion criteria that allowed for the discussion of SOC study designs, SOC research contexts, measurement and interpretation of SOC, and the relationships between SOC use and outcomes. In addition, the review included qualitative SOC studies, which had not previously been eligible for inclusion in reviews such as those by Moghimi et al. (2016) and Ouwehand et al. (2007). Reliability at all stages of study selection was excellent.

Furthermore, due to hand searching, multiple database searching, and a systematic review update, it is suggested that the review likely captured all of the relevant SOC literature.

Such a wide focus was essential in order to gather as much information as possible to inform how the SOC model could be applied in the context of stroke, and could be considered a strength of the review. However, the broad search criteria meant that studies were included in the review that were perhaps of somewhat limited relevance to the main three research questions. For example, studies relating to patterns of SOC use and use of the SOC model as rationale for hypotheses and analyses of specific studies provided limited insight into the measurement of SOC, relationship between SOC use and outcomes, and future directions for the model. Future reviews relating to the SOC model, or updates to this systematic review, should ensure that either the search criteria is specific to the research questions, or that a specific exclusion criterion is applied to remove these studies from the review.

Unfortunately, Non-English and non-peer reviewed studies were not eligible for inclusion within the review. However, considering the narrative synthesis focus of the review this is not considered a major study limitation. Future studies wishing to conduct meta-analyses should aim to ensure such studies are included. Regarding the process and reporting of the review, the Preferred Reporting Items for Systematic reviews and Meta-Analyses (PRISMA) statement was followed (Moher, Liberati, Tetzlaff, Altman, & Group, 2009). The systematic review protocol was also registered on PROSPERO (CRD42016038426) (Dryden et al., 2015). This ensures that systematic reviews are both replicable and correctly reported.

Findings from the systematic review may have been limited by the lack of quality assessment tools which are suitable for examining methodological quality across varying quantitative study designs, a limitation which was noted within other systematic reviews (Boger et al., 2015). This prevented studies being excluded due to overall poor methodological quality. For example, the EPHP tool could have resulted in well conducted cross-sectional studies being rated as of lower methodological quality than poorly conducted randomised controlled trials. Future reviews including a range of study designs may wish to split the analysis of methodological quality into groups of differing study designs, using a tool developed for that specific context. Nevertheless, the EPHP tool was able to provide an overview of the quality issues that are present in existing SOC research

studies. In addition, the quality of evidence within sections that were considered relevant to each research question were reviewed.

Future directions

In addition to the aforementioned suggestions, findings from this review can be used to inform and progress SOC intervention research. It is evident from the wealth of research that SOC strategy use is linked to positive outcomes, and interventions based on SOC are emerging. Only three studies have reported findings from SOC training interventions, however planning interventions also increased SOC strategy use and subsequently outcomes (Alonso-Fernández et al., 2015; Alonso et al., 2013; Gellert et al., 2013; Ziegelmann et al., 2006). Further research into the efficacy of SOC interventions should be a priority for future SOC research; identifying situations where SOC interventions would be particularly beneficial, for example, where SOC strategy use can act as a buffer against difficult life events or lack of resources.

In addition to targeting SOC strategy use directly, it may also be possible for interventions to focus on variables influencing SOC use and subsequent outcomes. It is primarily in the context of work that such antecedents, mediators, and moderators, such as job autonomy and burnout, have been examined (Moghimi et al., 2016). Within the contexts of ageing and health, variables such as individuals' perceptions about whether ageing is associated with physical losses were related to less SOC use after a serious health event, and as a consequence, poorer life satisfaction and self-rated health (Wurm et al., 2013). Similarly, when individuals had high expectations that physical activity participation would give them enjoyment, pleasure and health benefits, using SOC strategies was related to longer duration of such activities. On the other hand, for those who had low expectations, using SOC strategies was related to shorter physical activity. It is important, therefore, that additional variables which might mediate or moderate the SOC-outcomes relationships are also addressed.

Conclusion

Despite the methodological problems facing SOC research, the majority of the studies reviewed indicate that SOC use is associated with positive outcomes, and that the SOC model plays a role in describing adaptation and regulation when people are ageing or living with a chronic health condition. Donnellan et al. (2012) for example found that 80% of

participants reported using at least one SOC strategy one month post-stroke. Gignac et al. (2000) found that individuals with osteoarthritis were active in managing their condition, using an average of 17 behavioural efforts to manage their difficulties and that these could be categorised as selection, optimisation and/or compensation strategies. Similarly, the majority of qualitative studies found examples of SOC strategy use in older adults and those living with chronic health conditions. Rush et al. (2011), for example, identified around 80 different types of both selection and compensation, and 115 types of optimisation in older adults adapting to mobility difficulties.

It is evident that there is further scope for applying the selection, optimisation and compensation model in the contexts of ageing and health. Establishing the most appropriate ways of measuring SOC strategy use, determining the factors which link SOC strategy use to outcomes and examining the development and journey of strategy use while individuals adapt and manage their ageing and health conditions is essential. Progressing in these research directions will help inform SOC interventions and determine whether SOC strategy use and adaptation can be improved.

3 Examining adaptation after stroke using the Selection, Optimisation and Compensation model

Abstract

Background: Determining the best ways of helping people come to terms with life after stroke has emerged as an important research priority. Interventions such as self-management programmes have been suggested to be potentially beneficial in helping stroke survivors to adapt, however, they have not been widely implemented in the stroke setting. Outside of formal interventions stroke survivors often develop their own ways of adapting to life after stroke, implementing creative and resourceful strategies to help them adjust to the long-term consequences of their condition. Theoretical models have rarely been employed to examine such post-stroke adaptation however, and little is known about how stroke survivors manage and what strategies that they use to manage.

It is suggested that the Selection, Optimisation and Compensation (SOC) model may provide an ideal model to examine how stroke survivors adapt. The SOC model describes three adaptive processes: selection, optimisation and compensation. These processes can be used by people to master adaptation and achieve their goals as they experience gains and losses throughout life. Further work on exploring the relevance and utility of the SOC model in stroke survivors would be useful. By categorising post-stroke adaptation strategies using the SOC model, we may be able to integrate these strategies into stroke rehabilitation efforts.

The aim of this study was to explore the utility of the Selection, Optimisation and Compensation model in understanding the post-stroke adaptation strategies adopted by stroke survivors.

Method: Thirty stroke survivors (20 male and 10 female), between three and 65 months post-stroke took part in a semi-structured interview. Participants were aged between 23 and 90 years, with a mean age of 61.9 years (SD = 14.4). One Occupational Therapist and one Physiotherapist working in stroke rehabilitation were also interviewed.

Activities and body functions from the International Classification of Functioning, Disability and Health (ICF) Core Measurement Set for Stroke were used to prompt participants to

discuss the strategies they employed to adapt to their post-stroke difficulties. Participants were asked to identify those activities that posed difficult post-stroke. Participants elaborated on how they had addressed the difficulties encountered whilst performing or attempting to perform each problematic activity. Responses were coded against the theoretical definitions of selection, optimisation and compensation strategies, with two researchers independently coding 25% of the interviews.

Findings: Responses could be coded to the definitions of selection, optimisation and compensation strategies. One hundred and forty nine distinct strategies were identified. These 149 strategies were collated into 23 different categories of strategy: seven selection categories, nine optimisation, and seven compensation categories.

Discussion: Consistent with SOC strategy use in other chronic conditions, stroke survivors were found to develop a range of adaptation strategies that could be categorised according to the SOC model. These included focusing on the most important goals and activities, working towards goals and activities using a range of optimisation strategies, and employing compensatory behaviours and aids to continue functioning despite a loss of resources. Study strengths included interviewing a wide range of stroke survivors, including those with language impairments; utilising a semi-structured interview designed to elicit as many SOC strategies as possible; and using a systematic method of analysis. Future research should aim to further explore the discriminant content validity of selection, optimisation and compensation strategies, and develop stroke-specific SOC interventions designed to improve post-stroke rehabilitation.

3.1 Background and rationale

As discussed in detail in chapter one, an increasing number of stroke patients are surviving and living with the long-term consequences of stroke, which can vary depending on the area of the brain affected (Lincoln et al., 2011). Common post-stroke difficulties include reduced mobility and motor functions, impaired communication and cognitive abilities, visual difficulties and mood problems (Lincoln et al., 2011; NHS Scotland, 2009). Half of all stroke survivors live with one or more type of impairment, and stroke is associated with a wider range of impairments and higher odds of severe disability in comparison to other chronic health conditions (Adamson et al., 2004; Mayo et al., 1999; NHS Scotland, 2009). Determining the best ways of helping people come to terms with the long-term consequences of stroke has been identified as an important research priority by stroke survivors, carers and healthcare professionals (James Lind Alliance, 2016; Pollock et al., 2014). Qualitative accounts of stroke survivors' experiences indicate that this long-term adjustment process can be difficult, as stroke survivors cope with change, loss, uncertainty, fear of stroke recurrence, and having to adjust to a condition that they perceive impacts all areas of their lives (Burton, 2000; McKeivitt et al., 2004; Pearce et al., 2015; Salter et al., 2008). In addition, the long-term adjustment process often coincides with a reduction in input from healthcare professionals, which can lead some stroke survivors to feel abandoned by services (Lincoln et al., 2011).

As reviewed in chapter one, a wide range of evidence-based policies have been developed regarding the prevention and acute care of stroke, however, there are fewer recommendations regarding longer-term stroke care (NHS Scotland, 2009; Royal College of Physicians, 2016; The Scottish Government, 2014; The Scottish Intercollegiate Guidelines Network (SIGN), 2010). Outside of the standard therapy rehabilitation disciplines such as, for example, physiotherapy and speech and language therapy, best practice recommendations for long-term support are centred on self-management. For example, the Stroke Improvement Plan contains 'supporting self-management and living with stroke' as a priority that should involve sign-posting to self-management resources, vocational rehabilitation services, communication and peer support groups and exercise services (The Scottish Government, 2014). Self-management refers to tasks that individuals undertake to help them play an active role in managing their chronic health condition, including being able to make decisions about the medical aspects of their health, such as dealing with

symptoms and treatment; adapting their roles and behaviour to cope with impairments; and dealing with the emotional consequences of their condition (Corbin & Strauss, 1988; Lorig & Holman, 2003). Within the context of stroke, this may translate into managing health to prevent a secondary stroke, changing behaviour to adjust to post-stroke impairments, and dealing with the psychological effects of experiencing a stroke (Parke et al., 2015). Lorig and Holman (2003) identified five core self-management skills that they suggested would enable individuals with chronic health conditions to perform such self-management tasks: problem solving, decision making, utilising resources, forming a patient/healthcare provider partnership, and taking action. For stroke survivors, this could involve generating and implementing practical solutions to problems (problem solving); ensuring one has accurate information about stroke recovery and prevention in order to make appropriate care decisions (decision making); being able to locate and utilise stroke and health resources (resource use); having a collaborative relationship with healthcare professionals so that they can provide guidance and information whilst feeling they are able to feedback symptoms and discuss their healthcare decisions (forming patient/professional partnership); and taking action to change their behaviour through strategies such as action planning, coping planning and goal-setting (taking action) (Joice, 2012).

Self-management programmes which incorporate training in these skills have been developed, with both generic and disease-specific programmes implemented and evaluated (Lorig & Holman, 2003). Programmes such as the Arthritis Self-management Programme and Chronic Disease Self-management Program resulted in benefits such as increased exercise time and increased use of symptom management techniques, less pain, fatigue, health distress and improved disability (Lorig & Holman, 2003; Lorig, Ritter, et al., 2001). Disease specific programmes however, have primarily focused on conditions such as arthritis, chronic obstructive pulmonary disease and diabetes (Jones, 2006). Stroke-specific self-management programmes include an adaptation of the Chronic Disease Self-management Programme for stroke survivors and interventions to improve control cognitions such as perceived control and self-efficacy (Johnston, Morrison, MacWalter, & Partridge, 1999; Jones, Mandy, & Partridge, 2009; Kendall et al., 2007). Research into the implementation and effectiveness of such stroke-specific self-management programmes, however, is scarce compared to other chronic conditions (Jones, 2006). Stroke-specific self-management interventions have not been widely implemented or incorporated into

standard practice in the UK. Indeed, in a comprehensive systematic meta-review of self-management in stroke, Parke et al. (2015) highlighted the paucity of stroke-specific self-management research. The authors concluded that there were a lack of randomised-controlled trials explicitly focusing on self-management programmes with stroke survivors and that the term self-management itself was poorly defined. The meta-review took a widely inclusive approach, however, and found that some elements of self-management support were present in the standard rehabilitation therapies offered to stroke survivors. For example, interventions which involved occupational therapy, or rehabilitation for stroke survivors with cognitive impairments included components of goal-setting, action planning and problem solving. Whilst such rehabilitation resulted in improvements in activities of daily living and reductions in poor outcomes (e.g. deterioration in activities of daily living, dependency, the requirement of institutional care, or death), it is not possible to determine whether the self-management support components contributed to these positive outcomes. Self-management support for stroke survivors is addressed in further detail in chapter five.

Research also suggests that, outside of formal interventions, stroke survivors often develop their own ways of adapting to life after stroke, implementing creative and resourceful strategies to help them adjust to the long-term consequences of their condition (Ch'ng et al., 2008; Pound et al., 1999). Social support and information seeking; engagement in activities; practical strategies such as creating new ways of doing things; pacing and relearning; and cognitive strategies such as seeking a sense of acceptance and accepting help from others were identified as efforts utilised by stroke survivors in their quest to reorganise and renegotiate their lives after stroke. Despite such findings, theoretical frameworks are rarely applied to examine post-stroke adaptation and little is known about how stroke survivors manage and the strategies that they use.

The lifespan model of Selection, Optimisation and Compensation (SOC) (P. Baltes & Baltes, 1990) may provide an ideal model to both examine how stroke survivors adapt and inform stroke rehabilitation efforts (Donnellan et al., 2012). The SOC model has been described in some detail in chapters one and two. The systematic review presented in chapter two examined how this SOC model has been applied to older adults and those living with chronic health conditions. The review found that the use of SOC strategies was frequently associated with positive outcomes, however such relationships had been examined less

often in those living with chronic health conditions and such research focused on those with musculoskeletal conditions. The SOC model had, however, also been used to describe adaptation in those living with arthritis, vision loss and a range of other chronic health conditions (Gignac et al., 2000, 2002; Hutchinson & Nimrod, 2012; Janke et al., 2012; Rozario et al., 2011; Ryan et al., 2003). Gignac et al. (2002) interviewed older adults living with osteoarthritis and found that the strategies they used to adapt to their condition could be categorised as selection, optimisation and compensation. The authors also identified categories of strategies within selection, optimisation and compensation.

Other studies also used qualitative approaches, typically conducting interviews and identifying examples of SOC strategies within the adaptation behaviours of older adults and those with chronic health conditions. Examples of selection strategies included efforts to select appropriate goals and activities that were most important, restrict participation in non-essential activities, and adopt new goals or standards if necessary (Janke et al., 2012; Rozario et al., 2011; Rush et al., 2011; Ryan et al., 2003; Wilhite et al., 2004). Optimisation strategies varied to a greater extent, depending on the context of the behaviours. Common examples of optimisation included pacing and resting, practising, planning and organising, scheduling important activities at a time when energy was at a peak, and using activities such as exercise and leisure to optimise health and wellbeing (Hutchinson & Nimrod, 2012; Rozario et al., 2011; Rush et al., 2011; Ryan et al., 2003; Wilhite et al., 2004). Types of compensation strategies did not tend to differ; examples included using devices and aids, paying for services, receiving help from friends or family members, and modifying activities (Hutchinson & Nimrod, 2012; Janke et al., 2012; Kelly et al., 2014; Rozario et al., 2011; Rush et al., 2011; Ryan et al., 2003; Wilhite et al., 2004).

Whilst the qualitative research described above has resulted in a wealth of data, few studies described their analysis procedure in detail, nor applied a systematic approach to identifying SOC strategies. This has led to discrepancies between researchers with regards to classification of behaviours as selection, optimisation or compensation. The adjustment of standards, for example, was classified as optimisation by one author and selection by others (Rozario et al., 2011; Ryan et al., 2003; Wilhite et al., 2004). Difficulty distinguishing between SOC strategies, particularly optimisation and compensation has previously been discussed in chapter two. Such difficulty, when coupled with methodological weaknesses in analysis, limits the reliability of SOC research.

The optimal process of exploring adaptation using the SOC model and identifying examples of selection, optimisation and compensation is therefore unclear, particularly in the context of specific situations such as stroke. To date only one study has examined SOC strategy use in stroke survivors. Donnellan et al. (2012) interviewed stroke survivors using a generic SOC self-report questionnaire. The authors found that stroke survivors used SOC strategies; however these did not predict outcomes such as quality of life, functional ability or depression. Unfortunately, the authors concluded that the generic questionnaire was inappropriate for use in the specific population of stroke. Rather than assessing specific behavioural strategies, the measure required agreement or disagreement with various general personal statements such as “I concentrate all my energy on a few things” or “when something in my life isn’t working as well as it used to, I ask others for advice and help”. Kelly et al. (2014) agreed that a questionnaire approach to SOC research limits the breadth of findings that can be obtained, and alternative approaches are necessary in order to understand SOC within different contexts. Further work is therefore required on both exploring the SOC model in stroke survivors and on ensuring any qualitative approach is coupled with reliable analysis. In doing so we may be able to identify the SOC strategies adopted by stroke survivors and incorporate these into rehabilitation and self-management interventions.

Study aim

The aim of this study is to explore the utility of the Selection, Optimisation and Compensation model in understanding the post-stroke adaptation strategies adopted by stroke survivors.

3.2 Method

Participants and recruitment

Thirty stroke survivors participated in the study. One Occupational Therapist and one Physiotherapist working in stroke rehabilitation were also interviewed. Further participant characteristics are discussed in detail within the results section of this chapter.

Participants were recruited through Greater Glasgow and Clyde Stroke Services clinical teams, Stroke Research Nurses and Chest Heart & Stroke Scotland (CHSS) community communication groups. Stroke Liaison Nurses identified stroke survivors known to their services and posted potential participants an information pack (appendices 3.1 and 3.2). Stroke Research Nurses also identified and approached stroke survivors attending outpatient stroke clinics, providing them with the same information pack as above. In addition to this, participants were recruited from one community communication group run by CHSS. In this instance the group leader provided all members attending the group with an information leaflet (appendix 3.3). Potential participants then contacted the researcher for an information pack (appendices 3.4 and 3.5).

The principal inclusion criteria for participants recruited through the NHS were confirmed diagnosis of stroke (ICD10 codes 160 - 167); minimum three months post-stroke; minimum 18 years of age; able to provide informed consent and spoke English as a first language. The exclusion criteria were standard to any study of assessment in stroke survivors – those with substantial psychiatric or cognitive problems that precluded informed consent were excluded, as were participants with a potentially terminal medical condition. Non-English speakers were also excluded from the study. No additional assessments were performed as part of participant screening, rather the participant's clinical team judged the suitability of the participants based on the inclusion and exclusion criteria. For participants recruited through CHSS community communication groups, a diagnosis of stroke was confirmed by the participant prior to interview and the inclusion/exclusion criteria remained otherwise the same as NHS-recruited participants.

Participants who wished to take part in the study were asked to complete the consent form (appendices 3.2 or 3.5) and post it to the researcher. The consent form confirmed that the participant had fully read the information sheet and understood that their participation was voluntary. The consent form also confirmed that the participant understood their treating

clinical team may share some medical information with the research team. This medical information consisted of scores on the standard stroke assessment measures: the Barthel Index and the Montreal Cognitive Assessment (MoCA). Where these data were not available from the treating clinical team, these assessments were performed by the researcher prior to commencing the interview. No medical record access was requested from CHSS recruited participants. The consent form also asked the participant to indicate if they were willing to be contacted in the future about participating in further research. Upon receiving the consent form, participants were contacted by telephone, given the opportunity to ask questions, confirmed consent and arranged a date for the interview to take place.

Procedure

Ethical approval was obtained from the NHS West of Scotland Research Ethics Committee under the title 'Adaptation to stroke: Examining post-stroke coping strategies using a model of successful ageing' (appendices 3.6-3.9). NHS management approval for the study was obtained from NHS Greater Glasgow and Clyde Research and Development team. The University of Strathclyde was the study sponsor.

Participants were interviewed at home, using one semi-structured interview which lasted between 30 – 90 minutes. Interview length depended on the nature of the post-stroke difficulties, number of adaptation strategies used and self-reported, and participant fatigue. The interview was recorded using a small digital recorder, with interviews transcribed into text.

A stroke-specific, semi-structured SOC interview was developed (appendices 3.10 and 3.11), using items from the International Classification of Functioning, Disability and Health (ICF) Core Set for Stroke (Geyh et al., 2004). The ICF Core Set for Stroke is a framework which describes the spectrum of potential post-stroke outcomes faced by stroke survivors. In a similar method to Gignac et al. (2002), participants were asked to indicate which activities and body functions they experienced difficulty with. For each, participants were asked two questions: 1) *Have you changed the way that you do this since having a stroke?* 2) *Do you need assistance from another person or do you need a special gadget or piece of equipment in order to do this?* Participants who responded yes to these questions were asked to elaborate. The interview continued until all of the potential difficulties from the ICF Core

Set for Stroke had been discussed. It was anticipated that some participants may have aphasia and therefore pictorial messages with large, clear text were included alongside spoken descriptions of the interview items. Examples are provided in appendix 3.12.

The participant was then asked to indicate if they had any other difficulties or ways of coping that they wished to discuss. Finally, the participant was debriefed, with the aims of the study summarised and the participant encouraged to raise any questions they had regarding the study. A participant debrief information sheet was provided (appendix 3.13).

Healthcare professionals who were interviewed (one Physiotherapist and one Occupational Therapist) were shown the same list of post-stroke outcomes discussed with the stroke survivors and asked the following four questions: 1) *In your professional experience and education, how would you recommend a stroke survivor deals with a difficulty in this area?* 2) *Is there anything you would recommend he/she does instead of this activity/body function?* 3) *Is there any way you would recommend he/she should change the way they perform this activity/body function?* 4) *Are there any methods of assistance, aids or devices you would recommend he/she can use to help with this activity/body function?*

Healthcare professionals were provided with an information sheet, consent form and debrief sheet that were modified from the stroke survivor information pack (appendices 3.14-3.16).

Measures

Demographics: demographic information was collected and included age, gender, length of time post-stroke at interview, living arrangements and postcode.

The Barthel Index (Mahoney & Barthel, 1965): The Barthel Index assesses the degree of independence in performing basic activities of daily living (Mahoney & Barthel, 1965; Quinn, Langhorne, & Stott, 2011). Independence in 10 self-care abilities of feeding, bathing, grooming, dressing, continence (bowels and bladder), toilet use, transfers (bed to chair and back), mobility and stairs is rated as 0, 5, 10 or 15, with an overall score of 0-100. The range of scores can vary per item; for example, bathing can be rated as 0 (dependent) or 5 (independent), whereas mobility can be rated as 0 (immobile), 5 (wheelchair independent), 10 (walks with help of one person), or 15 (independent). Higher scores

indicate more independence. The Barthel Index is used to assess outcome in stroke (Quinn, Dawson, Walters, & Lees, 2009; D. T. Wade & Collin, 1988).

Montreal Cognitive Assessment (Nasreddine et al., 2005) (version 7.2_alternative):

Cognitive impairment was measured using the Montreal Cognitive Assessment (MoCA); a score below 26 indicates mild cognitive impairment on the 30-point measure. Eight cognitive domains are covered: short-term memory recall, visuospatial abilities, aspects of executive function, attention, concentration and working memory, language, and orientation to time and place. The measure is suggested to be the most practical tool for screening for mild cognitive impairment in stroke survivors, with excellent sensitivity and an administration time of less than 10 minutes (Blackburn, Bafadhel, Randall, & Harkness, 2013; Lincoln et al., 2011; Nasreddine et al., 2005; Pendlebury, Cuthbertson, Welch, Mehta, & Rothwell, 2010).

Stroke-specific, semi-structured SOC interview (appendices 3.10 – 3.12): A stroke-specific, semi-structured SOC interview was developed to identify the adaptations used by stroke survivors to cope with their post-stroke difficulties. The method was adapted from Gignac et al. (2002), who asked participants with osteoarthritis about the degree of difficulty they faced carrying out 24 specific activities in four domains: personal care, mobility, household tasks and valued activities. In order to elicit as many post-stroke adaptation strategies as possible, it was essential to systematically address the wide spectrum of potential difficulties faced by stroke survivors. Areas of potential post-stroke difficulty were therefore drawn from the ICF Core Set for Stroke (Geyh et al., 2004), which contains 130 body structures and functions, activities, and participation restrictions that can be affected by stroke. Giving consideration to the avoidance of placing too much burden on the stroke survivor, 80 out of the potential 130 items were included in the interview. Items were selected for their ability to be understood by participants, and such that participants would be able to identify the adaptations and behaviours they employed to cope with difficulties relevant to each item. For example, none of the items relating to body structure were selected, as it was felt that it would be confusing to ask participants to identify how they coped with difficulties in areas such as 'structure of the brain' and 'structure of the cardiovascular system'.

Of 80 items, 42 were categorised by the ICF as ‘activities and participation’ and 38 as ‘body functions’. The ‘activities and participation’ category contained six areas where a stroke survivor might face difficulty: mobility (11 items), communication (four items), using your knowledge (six items), at home and in the community (six items), caring for yourself (six items) and working and money (four items). Within ‘body functions’ there were four areas where a stroke survivor might face difficulty: your brain (14 items), your emotions (10 items), your senses (six items) and how your body works (eight items). In instances where a participant experienced difficulties with more than three items in a single area they were asked to indicate the three items of most importance to them; discussions about post-stroke adaptations would then focus on these three items within each area.

During the interview, one area at a time was discussed, beginning with those from ‘activities and participation’ and then moving onto ‘body functions’. Participants were told in advance which area (e.g. mobility) would be discussed, and the following preface was used:

“I’m going to ask you about some different activities/body functions. Some of these things you might find difficult since having a stroke. You may find them so difficult that you are no longer able to do them. I’m going to go through each activity/body function and ask you if you have difficulty with it since having a stroke.”

Each item was stated verbally and displayed on a card alongside a picture of the item (appendix 3.12). Participants were asked whether they had difficulty with, or were unable to do each activity or use each body function. For each item where the participants indicated difficulty, two questions were asked:

- 1) *“Have you changed the way that you do this since having a stroke?”*
- 2) *“Do you need assistance from another person or do you need a special gadget or piece of equipment in order to do this?”*

Participants who responded yes to these questions were asked to elaborate. The interview continued until all of the items from the interview had been discussed.

Data coding and analysis

The interviews were transcribed and then analysed with reference to the Selection, Optimisation and Compensation model. As such, the text was examined to identify the SOC strategies used by stroke survivors.

Data coding

A sample of eight interviews was randomly selected in order to develop the coding scheme and to assess coding reliability. The coding scheme resulted in four stages of coding:

1) Identification of potential SOC strategies

Sections of text describing potential SOC strategies were identified by coding each section of text for the presence or absence of potential SOC strategy. A standard method of identifying theoretically defined self-regulation strategies was used (as described by Abraham and Michie (2008)). Text was divided into short sections and each section coded for the presence or absence of potential SOC strategies.

2) Coding potential strategies as selection, optimisation and compensation

Each potential SOC strategy was coded as a match (or no match) to the theoretical definition of each SOC strategy, i.e. selection, optimisation or compensation. *Selection* involves concentrating on areas in life or activities that are of high priority to the individual, so that attention is narrowed to the most important goals. *Optimisation* involves strategies to enrich, expand, and make the greatest use of current resources and means by which people can achieve their selected goals. *Compensation* comes into play when an individual loses the inherent resources, skills or capacity to continue functioning to a desired level. Rather than selecting an alternative goal, the individual uses alternative means to reach their goal (M. Baltes & Carstensen, 1996; P. Baltes & Baltes, 1990; Freund & Baltes, 1998, 2002b). In a similar procedure to Janke et al. (2012), examples of SOC such as those obtained from Freund and Baltes (2002b) and Gignac et al. (2002) were used to aid in this coding. As per Lang et al. (2002) and Gignac et al. (2002) selection was not further categorised as elective and loss-based, as it was felt the function of selection surrounding goal-setting was of primary importance, rather than focusing on whether a loss preceded such action.

3) Identification of reason for strategy use

Each SOC strategy, as expressed within its section of interview text, was coded as to whether its application was the result of necessity due to post-stroke impairments, or an active decision by the stroke survivor. For example, with selection strategies particular care had to be taken to distinguish between stroke survivors who actively chose to use a particular strategy in response to a loss of ability, and those who were forced to reduce, give up or limit their activities due to their post-stroke limitations.

There is some debate surrounding whether forced abandonment of activities represents selection, depending on how the behaviour is framed by the individual. Rozario et al. (2011) suggested that those living with chronic health conditions often reframed their behaviour as an active choice despite constraints that meant an activity could no longer be performed. The authors discussed behaviours such as driving, where individuals stated that they no longer performed an activity because they felt it was the correct decision, rather than acknowledging that they were forced to do so due to their limitations. In contrast, however, others did not frame their behaviour as being under their control and instead recognised that their limitations forced them to give up activities (Hutchinson & Nimrod, 2012). As the current study did not explore stroke survivors' perceptions about activities they could no longer perform, such instances were not classified as selection.

4) Role of stroke in strategy use

Each SOC strategy, as expressed within its section of interview text, was also coded as to whether its application was due to post-stroke impairments, or whether it was related to other difficulties (for example, age or co-morbidities). This ensured that only stroke-related SOC strategies were selected.

Analysis

The coding resulted in a list of stroke-specific SOC strategies that were expressed by participants idiosyncratically. Following the coding process, the strategies were therefore further analysed in order to translate these from participants' own words and group together similar strategies. This was a three stage process:

1) Collation and labelling of strategies idiosyncratically described by participants

Often, participants described the same underlying strategies but expressed them in their own words. Similar strategies were therefore collated and labelled using standard wording. For example, a quote such as “*well I get help with buttons when I’m dressing. I don’t try to do it by myself anymore and better if he helps me*” would be labelled as ‘assistance with bathing and dressing’.

2) Collation of strategy groups generated in stage one and generation of strategy descriptors

The labelled strategies from stage one were then collated further, such that strategy descriptors were created. For example, labels such as ‘assistance with bathing and dressing’ and ‘getting a chiropodist to cut nails’ could be collated into one strategy descriptor ‘seeking assistance from family, friends or carers with tasks such as dressing, bathing and looking after body parts’.

3) Developing categories of different selection, optimisation and compensation strategies

As seen in previous research, it is possible to identify categories within selection, optimisation and compensation (Freund & Baltes, 1998; Gignac et al., 2002). The final stage of this analysis therefore involved grouping the SOC strategies into categories. This was an iterative process, where judgements were made as to whether each strategy could be collated with a similar strategy and grouped into a single category. For example, selection strategies that included focusing on the most important activities and goals would be grouped together, whereas strategies that centred on choosing and focusing on a new goal or activity would similarly be grouped.

3.3 Results

Participants

Stroke participants were 20 male and 10 female stroke survivors, between three and 65 months post-stroke at time of interview. The mean length of time post-stroke at interview was 12.1 months (SD = 16.6). Stroke participants were aged between 23 and 90 years, with a mean age of 62 (SD = 14.4). Two-thirds of the stroke participants lived with a spouse or partner whilst six lived alone, three lived with their children but no partner, and one lived

with their parents. One Occupational Therapist and one Physiotherapist working in stroke rehabilitation were also interviewed. Stroke participant characteristics are displayed in Table 3.1.

The Scottish Index of Multiple Deprivation quintiles can be calculated from participant postcodes and refer to the area in which they live, in terms of employment, income, health, education, access to services, crime and housing (Scottish Government, 2012). The majority of the participants resided in datazones within the top 20% most deprived or the 20% least deprived.

Twelve participants were able to complete the Montreal Cognitive Assessment (MoCA), however 13 were unable to complete the visuospatial element due to difficulties with their dominant writing hand. Adjusted MoCA scores were calculated by adding the 5 visuospatial points to their final score. Five participants were unable to complete the MoCA due to aphasia. As the MoCA was not used within this study to ascertain capacity to take part in the study, participants who were unable to complete the measure were still able to participate. The participant's clinical team judged the suitability of the participants shortly before inclusion into the study.

Table 3.1: Participant characteristics

	Frequencies	Mean (SD)	Range
Gender	Male – 20 Female - 10	-	-
Age	-	61.03 (15.07)	23-90
Living arrangements	Spouse/partner – 20 Alone – 6 Children (no partner) – 3 Parents - 1	-	-
Length of time post-stroke (months)	-	11.83 (16.41)	3-65
Adjusted Montreal Cognitive Assessment (MoCA)	-	25.76 (3.44)	16-30
Barthel Index	-	95.67 (7.63)	75-100
Scottish Index of Multiple Deprivation (SIMD)^a	Quintile 1 - 10 Quintile 2 - 2 Quintile 3 - 7 Quintile 4 - 1 Quintile 5 - 10	-	-

^a Quintiles range from 1 (most deprived) to 5 (least deprived).

Coding reliability

For coding stages one and two, two researchers (JD and supervisor DD) independently coded the eight sample interviews (25% of the interviews), with Cohen’s κ of 0.96 ($p < .001$) and 0.89 ($p < .001$) at each stage. This ‘outstanding’ level of agreement (Landis & Koch, 1977) enabled the remaining interviews to be coded by a single researcher (JD).

Coding

The interviews generated 707 segments containing potential SOC strategies, which were subsequently coded as selection (194), optimisation (269) and compensation (337). At this stage, it was possible for an expression to be coded as more than one category, for example both selection and optimisation within the same segment.

Segments were then coded as to their relationship to stroke and whether they were the result of an active decision by the participant, rather than due to an inability to continue the behaviour. The examples provided below demonstrate situations where participants were forced to change their behaviour, rather than actively choosing to.

"I don't pick anything up now...because I've not got balance. If I lean forward my head just feels as if it's ready to explode."

"I can't do a thing...change a plug...I can change a plug with my eyes shut or do the papering and decorating, now it's all gone – everything is gone."

"I've had to stop reading books again because of the eyesight...the words all merging into one another."

"Shopping is a no...unless it's maybe just a loaf of bread in a carrier bag....I'm trying to hold onto the stick, go down the stairs, so you don't actually have a chance to carry anything."

In contrast, the examples below are suggested to demonstrate active use of selection strategies. Participants were able to complete the specific tasks or behaviours, however chose to change their priorities or reduce, give up or limit their activities.

"But the wife went in swimming in a pool in Canada but I didn't bother because I thought 'I don't need this, I don't need the complication of something happening."

"No, when I first had my stroke I thought I'll come home here and 'I'll fix, I'll sort this' and I was out cutting the grass and all the rest of it and people are saying 'You're doing too much' and....now we pay a guy to cut the grass...I'd go out and cut the grass one day and then I'd be in my bed for two or three days afterwards...to recover...it's not worth it...there's more to life than grass."

"I would normally get this floor washed every single week....and get the housework done. And this floor would be steam cleaned every week. Just, my get up and go has got up and left if you know what I mean as regards to that. I'll dust, I'll tidy up, I'll bring the brush through and I'll sweep the floor, but as for mopping it - no.....So I just do it at my own pace now. I make sure the place is tidy if there's anybody coming in but apart from that no."

This resulted in 539 expressions of selection (122), optimisation (237) and compensation (271) that were stroke-specific and based on the decision of the stroke survivor.

Analysis

1) Collation and labelling of strategies idiosyncratically described by participants

Following the above coding, stage one of the analysis involved translating strategies that were expressed in the participants' own words. This involved collating expressions that were describing the same strategy and labelling them using standard wording. The 539 expressions were collated into 270 labelled strategies (appendix 3.17).

For example, the following quotes were indicative of the selection strategy 'reducing the number of household tasks done in a day':

"I mean I only do maybe the hoovering and things like that. I mean the windows I used to do windows but we've got a window cleaner now who comes in and does both inside and outside ehm my wife she, she thinks I don't participate in the housework as much as I used to."

"I'll dust, I'll tidy up, I'll bring the brush through and I'll sweep the floor, but as for mopping it - no. No ehm the bathroom, it gets cleaned but not to the same...as I would have cleaned it before."

2) Collation of strategy groups generated in stage one and generation of strategy descriptors

The 270 labelled strategies were condensed further, collating strategies that described similar types of behaviour. For example, the following strategy descriptors were collated into the strategy 'seeking assistance from family, friends or carers with tasks such as dressing, bathing and looking after body parts, e.g. getting a chiropodist to cut your nails, going to the hairdresser for a blow dry or hiring a care assistant':

- Assistance with bathing and dressing and looking after body parts, e.g. nails
- Getting a chiropodist to cut nails
- Carer for dressing, cooking and washing

This resulted in a list of strategy descriptors within each SOC domain, i.e. a condensed list of selection strategies, optimisation strategies and compensation strategies (appendix 3.18).

3) *Developing categories of different selection, optimisation and compensation strategies*

The 149 strategy descriptors were collated into 23 different categories: seven selection categories, nine optimisation, and seven compensation categories. Categories and examples of strategies are displayed in Tables 3.2, 3.3 and 3.4, with the full list of strategies in appendix 3.18.

Categories of selection strategies included: focusing on the activities and goals that are most important to you; giving up activities that are no longer manageable; choosing or focussing on a new goal or activity; limiting an activity so that it is still manageable; simplifying and reducing your activities; only doing social or recreational activities that you choose and enjoy; and avoiding difficult situations that might cause anxiety or stress.

Categories of optimisation strategies included: working on optimising your health and fitness; practising rehabilitation techniques and activities; practising doing activities with your stroke related difficulties; learning a new technique or strategy to help you cope with your difficulties; investing more time and energy into activities when they take longer or are more difficult; planning activities and tasks in advance; pacing your activities by taking your time and avoiding doing too many things at once; resting and relaxing when necessary; and receiving emotional support from family and friends.

Categories of compensation strategies included: receiving assistance from others with everyday, mobility and household activities; using alternatives like aids, gadgets or technology to help you with everyday activities; using special techniques and aids to help you remember; doing activities using your unaffected side; changing the way your exercise, socialise or do your hobbies; changing the way you do everyday activities in the house; and changing the way you do activities outside.

Table 3.2: Stroke survivors' selection strategies

Category	Example of strategy descriptor within category	Example of strategy in participants' own words
Focusing on the activities and goals that are most important to you	Spending less time at work and more time with family	<i>"I mean I have, I have definitely changed my opinion on what's important in life. I used to spend an awful lot of time at work, I work 9-5 that's, that's all the company I work for pays me for and that's all, I won't shirk anything, I won't you know not do certain things but they don't own me outside of work now I mean I walk away from my desk at 5.30 now and that's it. And I also pay far more attention to what's important to me like what goes on in this house and my kids and things like that. Less, less, less work and more, more me time."</i>
Giving up activities that are no longer manageable	Avoiding situations that might negatively affect your health, e.g. where you might fall	<i>"I haven't been on my bike...I'm concerned that I go on the bike and just fire it over and land in the road you know."</i>
Choosing or focussing on a new goal or activity	Choosing a new activity, such as an education course or volunteering	<i>"The psychologist....said 'Well I really don't think your cognitive ability or whatever, your intelligence has been affected' but I always wondered maybe he was just being kind so I signed up for a course....also was just to prove that I could still learn...Yes so I proved to myself I can still take in and, and, and absorb and use it properly - new information."</i>
Limiting an activity so that it is still manageable	Only doing housework tasks that are manageable, for example, dusting but avoiding vacuuming	<i>"Occasionally I like the, a big fluffy....thing, I maybe about every couple of months I'll do the ceiling....(the Hoover)...It's too heavy."</i>

Category	Example of strategy descriptor within category	Example of strategy in participants' own words
Simplifying and reducing your activities	Reducing the number of household tasks you do in a day	<i>"I'll dust, I'll tidy up, I'll bring the brush through and I'll sweep the floor, but as for mopping it - no. No ehm the bathroom, it gets cleaned but not to the same....as I would have cleaned it before."</i>
Only doing social or recreational activities that you choose and enjoy	Only doing social activities that you enjoy and that are important to you, for example, going to bed and reading rather than going out socialising	<i>"My main coping strategy for life is going to bed at half seven - which is very boring but I love it! And I'm so tired I go to bed at half seven and I read for about an hour."</i>
Avoiding difficult situations that might cause anxiety or stress	Avoiding pushing yourself to the limits	<i>"As long as I can keep the house up to standards, there's no rushing about any more. I'm not going to push myself to the limits."</i>

Table 3.3: Stroke survivors' optimisation strategies

Category	Example of strategy within category	Example of strategy in participants' own words
Working on optimising your health and fitness	Improving your diet by reducing unhealthy food, snacking, large portions and alcohol intake	<i>"I did from, right from the outset say that 'This is never going to beat me'---and I probably have you know increased my fitness level quite a bit over the last 9 months...I've lost you know nearly two stone in weight... I mean I have definitely paid more attention to what I do and I am much fitter than I was."</i>
Practising rehabilitation techniques and activities	Doing physiotherapy exercises	<i>"But of course I've been doing these exercises and things so this right hand it getting a bit better."</i>
Practising doing activities with your stroke related difficulties	Practising using the weaker side of the body, even if it takes longer	<i>"I was trying the other day to use a power drill you know and that I mean you know, you either, well two things you do - you try and use your right hand, or you try and use, you adapt to using your left hand...it's like writing... use my left hand now."</i>
Learning a new technique or strategy	Learning new ways to relax, such as walking or meditation	<i>"On the advice of a stress counsellor....she suggested to...enter into meditation classes. So I've been going...now for about a year and a half...it really has helped and that was a step into the unknown...." (when discussing handling stress)</i>
Investing more time and energy into activities when they take longer or are more difficult	Paying more attention to tasks and activities that require concentration, such as reading, speaking or cooking	<i>"It's slightly more difficult than it was but it doesn't really make any odds, I just have to go over things again."</i>
Planning activities and tasks in advance	Planning and changing routes in advance to avoid things like uneven pavements, steep kerbs and stairs	<i>"I do plan routes now yeah. Certain things I like to avoid - busy streets or I like to avoid places if there's no drop kerbs and it was just a steep kerb I avoid that where possible and so I get to know this town fairly well."</i>

Category	Example of strategy within category	Example of strategy in participants' own words
Pacing your activities by taking your time and avoiding doing too many things at once	Slowing down and pacing activities such as washing and housework throughout the day or over a couple of days	<i>"I'm doing the same things only I'm doing them slower. A lot slower. I don't rush about anymore and if the washing needs done and I can't be bothered I'll do it tomorrow or whenever, I mean it's got to be done you know so I've learned that to just pace everything you know. It'll still be here tomorrow, I might not be but the washing will be!"</i>
Resting and relaxing when necessary	Taking frequent rests or naps during the day when required	<i>"I said 'I feel I've got to take a step backwards and not try to do as much as I'm doing and try and rest a bit more when I come home from work just rest, don't do anything' I was starting to do things like the housework, just, just, just rest and relax for a while and the same after preparing the meal even and just rest and relax and finding I had, had (laughs) to make myself do that you know?"</i>
Receiving emotional support from family and friends	Choosing to talk more with family and friends rather than bottling up your feelings	<i>"Just trying to like talk to (partner) and my parents a bit more. I like to bottle things up so I've been trying to actually tell them how I'm feeling rather than sitting here like...and he knows there's something wrong...I felt that talking has been the best."</i>

Table 3.4: Stroke survivors' compensation strategies

Category	Example of strategy within category	Example of strategy in participants' own words
Receiving assistance from others with everyday, mobility and household activities	Seeking assistance from family, friends or carers with tasks such as dressing, bathing and looking after body parts, e.g. getting a chiropodist to cut your nails, going to the hairdresser for a blow dry or hiring a care assistant	<i>"I'm normally alright, my issue is drying my hair and washing my hair. I do struggle with that. I've started going to the hairdressers to get a blow dry every so often just to take the pressure off me"</i>
Using alternatives like aids, gadgets or technology to help you with everyday activities	Using aids to help you with everyday activities, from walking aids, handrails and raised beds to reading aids such as clip lights and magnifying glasses	<i>"I've got a wheelie and the, the Acute group got me a big, well it's not, it's a wee bit bigger than that one and the council put a railing out the back door to help me to get out."</i>
Using special techniques and aids to help you remember	Developing your own memory reminders, for example, sticking reminders to the fridge or the mantelpiece	<i>"I tend to, I do things to remind me about things you know. If I put a bottle of beer in the freezer you know, I put a beer glass next to the fridge so that I recognise, so that I know there's a bottle of beer in the freezer because umpteen times I've forgotten about it and this solid block comes out."</i>
Doing activities using your unaffected side	Not using your affected side for dangerous tasks such as carrying hot drinks or a tray of glasses	<i>"I tend to use my right hand side more than my left hand side if I'm carrying bags again just the feeling - it's not, I'm just not comfortable holding things in that hand."</i>
Changing the way your exercise, socialise or do your hobbies	Changing your hobbies, for example, doing jigsaws if you can't do crosswords anymore	<i>"not having the concentration, the words all merging into one another and that was the reason why I went back to do jigsaws again."</i>

Category	Example of strategy within category	Example of strategy in participants' own words
Changing the way you do everyday activities in the house	Adapting cooking methods, for example, buying new potatoes that don't require peeling or buying pre-chopped carrots	<i>"I can cook but you tend to use one hand so things like peeling potatoes get difficult so you just use sort of a good one is some, new potatoes because basically they don't require any..., you don't peel them so you get on better with carrots and things like that you can get peeled carrots and diced or chopped carrots. So yeah these are all sort of ways of...making life a bit easier. But it is, yes it is an adaption to your previous lifestyle, I have to say."</i>
Changing the way you do activities outside	Doing shopping online rather than going to the shops or supermarket	<i>"I find it difficult being in super, big supermarkets. I do struggle with that. I find it difficult making choices and deciding what's the best option for me whereas if I do it online it's, it's alright, it's a lot easier for me online."</i>

3.4 Discussion

Through interviews with a wide range of stroke survivors, this study identified 149 different types of SOC strategies used by stroke survivors to adapt to their difficulties in the months and years following their stroke. These strategies were grouped into seven selection categories, nine optimisation and seven compensation categories. Examples of ways in which stroke survivors applied such strategies were varied and often innovative. For example, one participant chose to close all of his bank accounts except one; therefore simplifying an activity (managing his finances) and demonstrating selection. Another participant had limited strength and function in one hand, and so modified the activity of cutting his nails by sticking the nail clippers onto a hard surface so that he was able to push them downwards more easily (compensation). Whilst the findings were similar to those of SOC research in other contexts, there were also some unique examples of selection, optimisation and compensation that are perhaps particular to those living with the effects of stroke. It is suggested that the SOC model is indeed a useful model for understanding and categorising post-stroke adaptation.

As expected, selection strategies used by stroke survivors focused on choosing the most important activities and goals; giving up activities that were no longer manageable; limiting, simplifying or reducing activities; and choosing or focusing on new goals. These are comparable to the strategies used by older adults and others with chronic health conditions (Gignac et al., 2002; Janke et al., 2012; Rozario et al., 2011; Rush et al., 2011; Ryan et al., 2003; Wilhite et al., 2004). Stroke survivors, however, also utilised two additional types of selection strategy. Avoiding difficult situations that might cause stress or anxiety was a strategy used by several stroke survivors, who spoke about having little patience for people, situations or conversations that caused them stress. Only doing social or recreational activities that you choose and enjoy, emerged as a selection strategy that is both related to and distinct from 'choosing the most important activities and goals'. Stroke survivors were able to continue with leisure activities once they employed the selection strategy of choosing their preferred, most manageable and achievable activity, and still chose to do so instead of abandoning them altogether in favour of essential activities of daily living. Leisure (including physical activity) is one domain that has received considerable attention in the SOC literature (Evers et al., 2012; Hutchinson & Nimrod, 2012; Janke et al., 2012; Reuter et al., 2010; Ryan et al., 2003; Son & Janke, 2015; Son et al., 2009;

Ziegelmann & Lippke, 2007a, 2007b; Ziegelmann et al., 2006). Hutchinson and Nimrod (2012), for example, found that those living with a range of chronic health conditions were able to use leisure as a method of self-managing their health and the stresses associated with their illness. By utilising selection strategies such as setting goals and activities that were achievable and met their needs, individuals were able to manage the effects of their illness on everyday life. Similarly, Janke et al. (2012) identified commitment to leisure activities in order to improve health as a selection strategy in individuals with arthritis. Whilst leisure and physical activity were not specific focuses of the current study, helping stroke survivors to increase or maintain such activities through SOC may be an area that merits further investigation and may complement self-management programmes. This may be particularly important in situations where those experiencing difficulties give up physical activity in order to concentrate on essential activities of daily living, despite the need for physical activity for ongoing health (Rush et al., 2011).

The optimisation strategies expressed by stroke survivors were similar to the familiar examples of practising; planning activities and tasks in advance; pacing; resting when necessary; being emotionally supported by family and friends; and investing more time and energy into activities. Such strategies were also identified in older adults and those with vision loss, arthritis, multiple sclerosis and a range of other chronic illnesses (Gignac et al., 2002; Kelly et al., 2014; Rozario et al., 2011; Ryan et al., 2003; Wilhite et al., 2004). Working on optimising health and fitness was identified as an optimisation strategy by stroke survivors in this study, and by individuals with other chronic illnesses, however stroke survivors also discussed eating a healthy diet and taking the correct medication (Hutchinson & Nimrod, 2012; Rozario et al., 2011). Optimisation strategies vary according to context, and stroke survivors identified additional strategies that were unique to stroke, for example, learning a new technique or strategy to improve health and wellbeing (e.g. taking up meditation). This was not an optimisation strategy discussed in previous studies, although it may be similar in nature to efforts of education and learning about the condition adopted by individuals with multiple sclerosis (Wilhite et al., 2004).

Stroke survivors also employed a wide range of compensation strategies that were similar to those identified in previous SOC research (Hutchinson & Nimrod, 2012; Janke et al., 2012; Rozario et al., 2011; Rush et al., 2011; Ryan et al., 2003; Wilhite et al., 2004). Receiving assistance from others, making use of aids and gadgets, using the unimpaired

side of the body, and changing the way activities were performed were all techniques employed by stroke survivors to maintain functioning in a specific domain despite stroke-related impairments.

Distinguishing between optimisation and compensation requires some discussion, particularly as the example of 'investing time, effort and energy' has been mentioned previously as both an optimisation and compensation strategy (Freund & Baltes, 1998). All of the optimisation strategies in the current study were categorised as such because they represent ways in which stroke survivors enrich their reserves and allocate resources to achieve higher levels of functioning in specific domains or activities (P. Baltes & Baltes, 1990; Freund & Baltes, 1998). As discussed previously, compensation refers to substitutive processes that come into play when specific behavioural capacities are lost or substantially reduced (P. Baltes & Baltes, 1990). Freund and Baltes (1998) further distinguish between optimisation and compensation by suggesting that optimisation refers to positive outcomes, whereas compensation refers to avoiding negative outcomes. Instances where it is difficult to distinguish between optimisation and compensation strategies are common in the literature, particularly in the context of chronic illness (Rozario et al., 2011; Wilhite et al., 2004). Researchers have adopted various methods to address this; for example, Rozario et al. (2011) considered whether individuals had experienced functional losses before categorising as optimisation or compensation. Kelly et al. (2014) distinguished between optimisation and compensation by considering whether current means were utilised (optimisation) or whether new means were introduced (compensation). Wilhite et al. (2004), on the other hand, discussed the familiar example of persistence, encompassed by increased effort, energy and time allocation, as optimisation when the aim was goal achievement or compensation when the aim was to counteract loss.

Distinguishing between goal achievement and counteracting loss is the approach most consistent with the original premise of the SOC model. Applying this to stroke we must consider at what stage the stroke survivor is in the process of adapting to their post-stroke impairments. A strategy that was compensatory immediately after stroke, due to loss, may over time become an optimisation, goal striving strategy as the individual adjusts to life after stroke. This is demonstrated in the example of investing more time and effort into an activity, for example, continuing to perform housework even if it takes longer. Immediately post-stroke the individual may experience a loss in resources, for example mobility

difficulties and fatigue. In order to attempt housework they therefore have to invest more time and effort into the activity to counteract such losses. Over time, however, the act of taking time to perform the housework changes, from counteracting loss to allocating resources to achieve the goal of continuing with household chores. This can be further explained by considering the items chosen to represent optimisation and compensation in the SOC self-report questionnaire (P. Baltes et al., 1999; Freund & Baltes, 2002b). Optimisation examples include phrases such as “I make every effort to achieve a given goal”. In the context of stroke, this would appear to apply to efforts to continue performing household activities. In contrast, compensation examples include prefixes such as “when it becomes harder for me to get the same results” and “when things don’t go as well as they used to”. Whether the stroke survivors in the current study view their efforts as a means to achieve specific goals, or in comparison to pre-stroke circumstances and resources is unknown, although research into selection, optimisation and compensation in other chronic conditions suggests that achieving a level of acceptance helped participants draw on existing resources to optimise their ability to continue with their desired activities (Hutchinson & Nimrod, 2012). Based on these interpretations, and in line with previous research, the current study therefore categorised such goal striving strategies as optimisation, although it is acknowledged that this issue may be subject to further debate.

Strengths and limitations

The current study has a number of features that strengthen its contribution to SOC and stroke research. Using purposeful sampling, the study aimed to recruit a variety of stroke survivors, including those who were deemed to be coping well after their stroke and those who were not coping as well. It could be suggested that stroke survivors who were coping well post-stroke may have been more likely to volunteer to take part in the research. Unfortunately recruitment via a Stroke Liaison Nurse resulted in a lack of accuracy with regards to the number of stroke survivors invited to take part in the study. This does limit, somewhat, our ability to generalise the findings to the rest of the stroke population. Despite this, however, study participants included stroke survivors living across a wide range of socioeconomic areas, including some of the most and least deprived areas in Greater Glasgow and Clyde. Stroke survivors also had a breadth of experience adapting to stroke, having been living with the effects of their stroke for up to five years. Stroke survivors with aphasia and language impairments were also included in the study. Such

inclusion helped to ensure that the results reflected a wide range of post-stroke circumstances, an issue particularly important as stroke is associated with disability in more domains than other common conditions such as heart, respiratory or musculoskeletal disorders (Adamson et al., 2004). It is acknowledged, however, that the participants did not vary in all aspects of their post-stroke functioning and were relatively independent. Stroke survivors who were experiencing difficulties with independence may have been less likely to volunteer to take part in the study and may have been living in supported accommodation such as nursing or care homes. Future research should explore the variations in selection, optimisation and compensation strategies that exist in stroke survivors living in different caring environments.

Due to potential variability in post-stroke impairment, it was also necessary to employ a more systematic method of interviewing stroke survivors than was seen in previous SOC research. The majority of previous studies adopted open questioning, such as asking about 'efforts made to continue participation in leisure activities' and 'ways in which they coped with constraints and changes' (Hutchinson & Nimrod, 2012; Janke et al., 2012). In contrast, Gignac et al. (2002), included four standard questions designed to elicit the behaviours adopted to cope with 24 specific activities in four domains of everyday life. Despite a more systematic approach, the authors suggest that participants may not have been able to recall all of the behavioural adaptations they employed to cope with their arthritis, and that a checklist method may result in the recall of more behaviours. The current study modified such an approach and used a semi-structured interview. By systematically prompting participants to discuss all of the potential difficulties they faced, the current study aimed to identify as many SOC strategies as possible, not only those that were most salient to the stroke survivor at that particular time.

The current study was also designed to improve on the analysis of previous SOC research. As discussed in chapter two, several qualitative studies with older adults and those with chronic health conditions failed to provide detailed descriptions or discussed reliability regarding how they classified adaptation strategies as SOC. As such, the interpretations of what constituted selection, optimisation or compensation were subjective and there were instances where the same strategy was coded under different categories of SOC. By providing a clear and detailed description of the analysis process, the current study attempted to improve the reliability of qualitative SOC research. Despite improvements in

methodology and analysis, and high reliability between coders, difficulties were faced in the identification of SOC strategies and future work is required to address this. In particular, researchers have called for further research into the discriminant content validity of selection, optimisation and compensation and a focus on the exploration of overlapping strategies (Gignac et al., 2002).

Future directions

It is evident that stroke survivors use a wide range of selection, optimisation and compensation strategies to adapt and live with their post-stroke impairments. The challenge therefore is to establish how the SOC model can be used effectively within the context of stroke. Donnellan and O'Neill (2014) suggest that SOC can play an important role in stroke rehabilitation, providing a model to help stroke survivors and healthcare professionals identify and work towards achievable goals. The authors identify aspects of the model that they suggest complement stroke rehabilitation, including its person-centred focus which allows people to focus on individual goals; its potential use as a common language between stroke survivors and various healthcare professionals; and its potential for ensuring that rehabilitation continues when stroke survivors move from acute settings into the community. The authors state that a stroke rehabilitation intervention should be developed based on the SOC model; however to-date there has been no such SOC research in the context of stroke.

One potential avenue for SOC and stroke may be the integration of selection, optimisation and compensation into stroke self-management programmes. As previously discussed, self-management programmes have been developed for a range of chronic illnesses, with improvements in self-efficacy identified as an important mechanism responsible for positive outcomes from such programmes (Jones & Riazi, 2011; Lorig & Holman, 2003). Key components of self-management programmes that can improve self-efficacy include allowing skills mastery through action planning and problem solving, providing vicarious experiences through peers, experience sharing and group problem solving, and verbal/social persuasion from peers and healthcare professionals (Jones, 2006; Jones & Riazi, 2011; Lorig & Holman, 2003). With researchers suggesting that selection, optimisation and compensation processes can complement such methods of self-efficacy enhancement, incorporating SOC into self-management programmes may be beneficial (Ireland & Arthur, 2006). The optimal method of doing so, however, requires further

research. Additionally, exploring how individuals choose which selection, optimisation and compensation strategies to employ may aid such research. Those living with multiple sclerosis, for example, indicated that they discovered and developed adaptation strategies through determination, trial and error, education, support and encouragement, exploring options, and observing others (Wilhite et al., 2004).

It may be that the SOC model can also be used as a model for individualised interventions for stroke survivors. As discussed in chapter two, interventions based on SOC are emerging, particularly in the fields of leisure, physical activity and some chronic health conditions. Gellert et al. (2013), for example, introduced SOC 'strategy training' in older adults with the aim of improving physical activity. An intervention booklet included examples of selection, optimisation and compensation, and participants were asked to adapt these to their own context. Greater improvements in physical activity were found in the SOC intervention group, compared to those who did not receive the booklet. Future research should aim to develop and test such personalised interventions with a range of stroke survivors.

Conclusion

The current study improves on the methodology of qualitative SOC research, applying systematic analysis to identify the selection, optimisation and compensation strategies adopted by stroke survivors to adjust to life post-stroke, and reporting on the reliability of this analysis. As with research into SOC strategy use in other chronic conditions, stroke survivors were found to develop a range of adaptation strategies that could be categorised according to the SOC model. These included focusing on the most important goals and activities, working towards goals and activities using a range of optimisation strategies, and employing compensatory behaviours and aids to continue functioning despite a loss of resources.

Two important avenues of future research were identified: improving the reliability of SOC strategy use identification, and exploring SOC interventions in the context of stroke. Despite improvements in methodology and analysis in the current study, identifying SOC strategies from qualitative research continues to be relatively subjective. Previous researchers have commented on this issue, with Gignac et al. (2002) calling for examination of the discriminant content validity of selection, optimisation and compensation. Finally, future research should aim to explore the development and efficacy of stroke rehabilitation

interventions based on the SOC model. Improvements in long-term stroke rehabilitation are required, and it is suggested that the SOC model may have a role to play in such improvements.

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4 Exploring the content validity of stroke-related selection, optimisation and compensation strategies using discriminant content validation methods

Abstract

Background: Applying a theory such as the Selection, Optimisation and Compensation model successfully is dependent upon the ability to operationalise theoretical constructs reliably. Whilst SOC could be used to categorise the adaptation strategies used by stroke survivors (Chapter 3), a systematic review of studies employing the SOC model revealed limitations in SOC measurement and analysis (Chapter 2). In particular, limitations were identified in the analyses of qualitative findings, and researchers have called for methodological improvements in the form of reliable and replicable analysis.

The aim of this study is to utilise the method of Discriminant Content Validation (DCV) to examine if the post-stroke adaptation strategies, generated from qualitative interviews with stroke survivors, reflect the theoretical SOC constructs.

Method: Ten expert judges rated the extent to which the 149 elicited post-stroke adaptation strategies matched the theoretical definitions of selection, optimisation and compensation. The expert judges were researchers and healthcare professionals working in psychology or stroke research. Wilcoxon Signed Rank tests were conducted to determine whether strategies were significantly categorised as selection, optimisation or compensation or a combination of strategies.

Findings: Seventy eight percent of the stroke-related SOC strategies were matched to the theoretical definition of at least one of selection, optimisation or compensation. Out of the 149 strategies, 18 were significantly classified as selection, 42 were significantly classified as optimisation and 60 as compensation. Five strategies were classified as more than one type of strategy.

Discussion: The classification of strategies using DCV methodology represents a more robust method of analysis than seen in previous SOC research. Whilst the categorisation of strategies as selection, optimisation or compensation was similar to the coding results from chapter three, DCV analysis was able to confirm the validity of the strategies. Future

research should focus on using these stroke-related SOC strategies to inform post-stroke interventions.

4.1 Background and rationale

The Selection, Optimisation and Compensation model has been explored using a range of methods and in various populations, including those with chronic health conditions. The systematic review presented in chapter two described a variety of methods used to examine the relationships between SOC use and outcomes and explored the SOC strategies adopted by those experiencing loss of resources. The latter was of particular interest, with studies identifying the use of SOC strategies to adapt to changing circumstances, including in chronic health conditions such as arthritis, multiple sclerosis and visual impairment (Hutchinson & Nimrod, 2012; Janke et al., 2012; Rozario et al., 2011; Ryan et al., 2003; Wilhite et al., 2004). Such qualitative studies often identified specific examples of selection, optimisation and compensation that were relevant to the individual health condition.

To-date, however, there has been limited application of the model to stroke. The single quantitative study identified in the review utilised the generic SOC self-report measure but concluded that it was inappropriate for use with stroke survivors and too generic to provide meaningful information about adapting to sudden onset disability (Donnellan et al., 2012; Donnellan & O'Neill, 2014). The qualitative interviews conducted and described in chapter three aimed to progress SOC research in the context of stroke by eliciting the behavioural adaptations adopted by stroke survivors and determining if these could be categorised according to the Selection, Optimisation and Compensation model. As reported in chapter three, stroke survivors used a range of post-stroke adaptation strategies, which could be categorised as SOC in a similar way to other chronic health conditions. Further research is, however, necessary in order to improve the analysis of SOC research, and explore how the SOC model can be translated into useful interventions for stroke survivors.

Applying a model such as the Selection, Optimisation and Compensation model successfully is dependent on how the model is operationalised, for example, how the theoretical constructs are translated into strategies that can be understood by stroke survivors, healthcare professionals and researchers (Johnston et al., 2014). One particular issue, identified in the systematic review, is the reliability of the method used to classify strategies as selection, optimisation or compensation; several studies failed to provide a clear descriptions of the method used. Interpretations of strategies were often subjective, there were overlaps between strategies, and debate surrounding what constituted optimisation and compensation. This led to researchers calling for further research into the discriminant

content of selection, optimisation and compensation and a focus on the exploration of overlapping strategies (Gignac et al., 2002).

Exploring the content validity of the strategies elicited from stroke survivors in chapter three is therefore the next step in this SOC research. Content validity refers to the degree to which items, typically of an assessment measure such as a questionnaire, reflect the particular construct they are designed to assess (Haynes, Richard, & Kubany, 1995). Commonly discussed in the context of self-report questionnaires, content validity should also be examined for other methods of assessments such as observing behaviour (Haynes et al., 1995). Methods for establishing content validity can therefore be applied to the strategies identified in chapter three, in order to determine whether they reflect the theoretical constructs of selection, optimisation and compensation. For example, Johnston et al. (2014) developed a six stage method for determining discriminant content validity (DCV), which establishes whether items reflect a single, or more than one construct. This method may be ideal for assessing the content validity of the stroke-related SOC categories and exploring potential overlap between the constructs of selection, optimisation and compensation. Doing so may lead to the development of SOC condition-specific self-report questionnaires, or provide better understanding of the model for use in the development and testing of SOC interventions.

DCV methodology has previously been used to examine existing frameworks and measures. For example, expert judges were asked to rate whether theoretical behaviour change constructs related to the domains defined in the Theoretical Domains Framework (TDF) (Cane, O'Connor, & Michie, 2012). The findings were then used to refine the framework. DCV has also been used to construct new questionnaires; Huijg, Gebhardt, Crone, Dusseldorp, and Pesseau (2014) developed items to assess the constructs within the TDF. Expert judges and DCV steps were used to establish the extent to which each item measured its corresponding theoretical construct. In addition, DCV methodology was used to identify which outcomes from the International Classification of Functioning, Disability and Health (ICF) (World Health Organisation, 2001) were measured by health outcome instruments such as the Chronic Pain Grade Questionnaire and other orthopaedic outcome measures (Dixon, Pollard, & Johnston, 2007; Pollard, Johnston, & Dieppe, 2006). The authors were able to identify how well the health outcome instruments measured the ICF

outcomes of impairments, activity limitations and participation restrictions, including whether items in the questionnaires measured more than one ICF outcome.

Study aim

Use of DCV methodology is therefore becoming more widespread, as researchers seek to ensure that measurement instruments are valid and measure the theoretical constructs they aim to capture. The aim of this study was to use Discriminant Content Validation methods to examine if the post-stroke adaptation strategies generated from qualitative interviews with stroke survivors, reflect the theoretical constructs of selection, optimisation and compensation.

4.2 Method

Design

The current study will apply discriminant content validity methodology; a clear and replicable six stage method for determining DCV (as described by Johnston et al. (2014)). This DCV method involves judges rating the extent to which measurement items reflect particular theoretical constructs. In the context of the current study the strategies elicited from stroke survivors in chapter three are such items, to be judged as to the extent that they reflect the theoretical constructs of selection, optimisation and compensation.

Participants and recruitment

The participants in this study were 10 researchers and healthcare professionals working in the fields of psychology or stroke care/research, who acted as expert judges. Further participant characteristics are described in detail within the results section of this chapter.

Participants were recruited through emailing professional contacts with details of the study. Participant were eligible to take part in the study if they were over 18 years of age, able to complete electronic or paper copies of the study task (as preferred) and were a researcher or healthcare professional working in the fields of psychology or stroke. Ten of the thirteen participants approached (77%) agreed to take part in the study.

Materials and Measures

Demographics: Participants provided details of their age, gender, job title and area of research/work.

Experience: Participants also indicated their experience of working with stroke survivors and working with the Selection, Optimisation and Compensation model. The following categories of experience were provided: none, a little, some, quite a lot, a great deal.

SOC Discriminant Content Validation (DCV) Task (appendices 4.1 and 4.2): Participants were presented with the theoretical definitions of the selection, optimisation and compensation constructs (see below; Appendix 4.1). Definitions of selection, optimisation and compensation were drawn from discussions about the model (P. Baltes & Baltes, 1990; Freund & Baltes, 1998). Examples of selection, optimisation and compensation strategies were also provided, collated from previous research into SOC strategy use, including the

development of the SOC self-report questionnaire (Table 4.1; Appendix 4.1) (P. Baltes et al., 1999; Freund & Baltes, 2002b; Gignac et al., 2002).

Selection involves an individual focusing on areas of life, goals and activities which they determine are most important to them. Typically in older age, this involves restricting involvement in certain goals, activities or particular areas of life, as a consequence of changing available resources. Selection can involve avoiding one particular area of life altogether or restricting the activities performed within several different areas of life. Selection can also involve new or changed goals or activities. **Optimisation** involves ways in which an individual enriches, enhances or refines their resources, therefore optimising their performance in their desired activities and areas of life. Optimisation strategies will depend on the goal in question and can vary from exercise to ways of increasing confidence in ability. **Compensation** involves substituting or compensating in order to continue functioning when resources or abilities become critically low. The use of alternative ways to achieve a goal can include modifying an activity or technological aids, such as a walking stick.

Table 4.1 Strategy examples provided to participants as part of DCV task

Selection	Optimisation	Compensation
- Focusing on most important goals/areas of life	- Acquiring new skills or resources	- Modifying activities
- Committing to a goal	- Practicing skills or activities	- Receipt of help from others
- Forming new goals	- Investing time or effort in a task	- Use of assistive devices or gadget
- Restricting or limiting an activity	- Focusing attention	
- Performing an activity less often	- Planning activities	
- Giving up/avoiding an activity		

The above theoretical definitions, examples of strategies and completed judgements of two hypothetical strategies were provided on a separate sheet, such that participants could refer to these throughout the task (Appendix 4.1).

Participants were also presented with the list of 149 different self-management strategies, obtained from analysis of qualitative interviews with stroke survivors (chapter three) (Appendix 4.2). Participants judged whether each strategy matched each of the theoretical

definitions of selection, optimisation and compensation. Participants also indicated how confident they were about each decision on a scale that ranged from 0% to 100% in increments of 10. Thus, participants made 447 Yes/No judgements (three judgements for each of the 147 strategies) and provided 447 confidence ratings.

Procedure

Ethical approval was obtained from the University of Strathclyde School of Psychological Sciences and Health ethics committee (appendix 4.3).

Potential participants were sent an information sheet (appendix 4.4) and consent form (appendix 4.5). Participants who wished to take part in the study were asked to complete the consent form and return it to the researcher. The consent form confirmed that the participant had fully read the information sheet and understood that their participation was voluntary. Participants were then sent a paper/electronic copy of the Discriminant Content Validation task (appendix 4.2), including descriptions and examples of the selection, optimisation and compensation constructs (appendix 4.1). Participants were asked to complete the task and return it in a pre-paid envelope within one month. Participants who did not return the task were sent one email reminder within two weeks of the return deadline. Upon receipt of the completed task, the participant was emailed a debrief information sheet summarising the study (appendix 4.6).

Statistical analysis

Each item was classified as to whether it matched the theoretical definitions of selection, optimisation and compensation and as such these judgements were coded as 1 for a match and -1 for no match. Each participant also provided a confidence rating for each judgement, which was multiplied by the corresponding judgement to provide a weighted judgement score. For example, a strategy that a participant was confident was selection may receive a weighted judgement score of +1 (1*100% confidence), whereas a strategy that the participant judged to be compensation but with less certainty may receive a score of +0.5 (1*50% confidence). Such weighted judgements were used for all subsequent analysis. Missing data was defined prior to analysis.

Each participant made 447 different judgements in total, three for each of the 149 different items. Reliability of agreement between participants was assessed using intra-class correlation coefficients (ICC) (two-way mixed model) with measure of consistency.

Johnston et al. (2014) state that either one-sample *t*-tests or a non-parametric alternative should be used to test the content validity of the items. In the current study, the data was not normally distributed, therefore non-parametric Wilcoxon Signed Rank tests were used to classify whether each item was judged to be selection, optimisation or compensation. Wilcoxon Signed Rank tests were conducted against a dummy variable of zero, and selected in place of one sample tests in order to calculate Z scores.

As per the methodology of Huijg et al. (2014), the Benjamini and Hochberg (1995) method of controlling the false discovery rate (FDR) was applied to correct for multiple tests. This method of correcting for multiple tests was chosen over the Hochberg (1988) method of controlling the family-wise error rate suggested by Johnston et al. (2014), as controlling for the FDR results in greater statistical power and fewer significant results being rejected, particularly when a large number of hypotheses are being tested (Benjamini & Hochberg, 1995). A strategy was classified significantly as selection, optimisation or compensation if its mean rating was significantly greater than zero, after the above Benjamini and Hochberg (1995) method was applied.

4.3 Results

Participants

Of the 10 participants, five were senior academics, including Lecturer, Senior Lecturer, Reader, and Professor. Four were junior academics such as PhD researchers and Research Fellows. One was an Occupation Therapist working in stroke rehabilitation. Nine of the participants were female and one was male, with a mean age of 42.5 years (SD 14.5). Participants were asked to indicate their experience working with stroke survivors and of working with the SOC model using the following categories: none, a little, some, quite a lot, a great deal. Only two participants had no experience working with stroke survivors, with the majority (eight) having a little to a great deal of experience. The majority (eight) of participants had no experience working with the SOC model, with only one participant reporting quite a lot of experience working with the model. Participant characteristics are displayed in Table 4.2.

Table 4.2 Participant characteristics

	Frequencies	Mean (SD)	Range
Gender	Female – 9	-	-
	Male - 1		
Age (years)	-	42.50 (14.50)	24-70
Profession	Senior academic- 5	-	-
	Junior academic- 4		
	Healthcare professional– 1		
Area of work	Chronic disease/disability – 3	-	-
	Cognition and social behaviour – 1		
	Stroke – 1		
	Health psychology/health behaviour – 3		
	Psychometrics – 1 Psychology - 1		
Experience of working with stroke survivors	None - 2	-	-
	A little - 3		
	Some - 2		
	Quite a lot - 2		
	A great deal - 1		
Experience of working with the SOC model	None - 8	-	-
	A little - 1		
	Some - 0		
	Quite a lot - 1		
	A great deal - 0		

Reliability

The Intra-Class Correlation Coefficients for the constructs of selection, optimisation and compensation were 0.40 (95% CI 0.34-0.47), 0.40 (95% CI 0.34-0.47), and 0.62 (95% CI 0.57-0.68) respectively. ICC values of between 0.21 and 0.41 indicate fair agreement whereas values of >0.61 indicate good to excellent agreement (Cane et al., 2012; Huijg et al., 2014; Landis & Koch, 1977). There was therefore better agreement between judges for compensation, compared to selection or optimisation items.

Analysis was conducted to determine whether having experience working with either the SOC model or stroke survivors influenced performance in the task. Eight judges indicated that they had no experience using the SOC model and were subsequently classified as the 'non-SOC group'. Only two judges indicated either a little or quite a lot of experience with the model, and were classified as the 'SOC group'. The group who were familiar with the SOC model appeared to perform better with regards to consistency of ratings (Table 4.3). Overall, agreement within the SOC group ranged from 0.59 for optimisation items to 0.75 for compensation items, indicating moderate to excellent agreement (Landis & Koch, 1977). Agreement within the group who were not familiar with the SOC model, however, was good for compensation but only fair for selection and optimisation items. Furthermore the confidence intervals between the two groups do not overlap for selection and optimisation, indicating systematic differences between the groups in the reliability of their rating performance. It is unclear, however, whether the differences between the two groups were due to the judges' familiarity of the SOC model, or the fact that the group who were most familiar only contained two participants. Due to the low number of judges in the 'SOC group', caution must be applied when interpreting the findings.

Table 4.3: Intra-class correlation coefficients (SOC group vs. Non-SOC group)

	Intra-class Correlation Coefficients (95 % confidence intervals)	
	SOC group	Non-SOC group
Selection	0.66 (0.56 - 0.74)	0.36 (0.30 - 0.43)
Optimisation	0.59 (0.48 - 0.69)	0.37 (0.30 - 0.44)
Compensation	0.75 (0.67 - 0.81)	0.61 (0.56 - 0.68)

Five judges indicated that they had none or a little experience working with stroke survivors, whereas five had some to a great deal of experience. As seen in Table 4.4, there were no systematic differences in rating performance between the group who had experience in the field of stroke and those who did not have experience.

Table 4.4: Intra-class correlation coefficients (SSE group vs. Non-SSE group)^a

	Intra-class Correlation Coefficients (95 % confidence intervals)	
	SSE group	Non-SSE group
Selection	0.41 (0.33 - 0.49)	0.39 (0.32 - 0.48)
Optimisation	0.34 (0.27 - 0.43)	0.44 (0.36 - 0.52)
Compensation	0.63 (0.56 - 0.69)	0.60 (0.53 - 0.67)

^a SSE Group = five judges with some to a great deal of stroke survivor experience; Non-SSE group = five judges with none or a little stroke survivor experience

Discriminant Content Validation task analysis

Strategies classified as selection, optimisation and compensation

Prior to conducting the Discriminant Content Validation analysis, missing data was defined. Four ratings were missing in total, one from selection and three from optimisation. Missing ratings were from a range of participants, rather than one particular participant.

After application of the Benjamini and Hochberg (1995) method, the Wilcoxon Signed Rank tests indicated that 78% of the strategies were significantly classified as at least one of the theoretical constructs of selection, optimisation and compensation; 18 strategies were significantly classified as selection (Table 4.5), 42 strategies were significantly classified as optimisation (Table 4.6), and 60 strategies were significantly classified as compensation (Table 4.7). Five strategies were classified as more than one type of strategy indicating that, as expected, not all stroke-related SOC strategies have discriminant content validity (Table 4.8). For example, concentrating energy on everyday activities such as washing and dressing was classified as both selection and optimisation, i.e. the stroke survivor *selected* to perform the activities and *optimised* their ability to do so by focusing their efforts.

Similarly socialising with friends and family in the house rather than going out is an example of a strategy that was classified as both selection and compensation, indicating that the stroke survivor *selected* to continue socialising however modified this socialising (*compensation*).

In addition, the results of the DCV analysis can also be compared to the original classification of strategies in chapter three. Classification of strategies as compensation appeared most similar; following DCV analysis, 90% of the strategies originally classified as compensation in chapter three were significantly classified as compensation. Of the six no longer classified as compensation, four were not significantly classified as any strategy type. The remaining two had previously been classified as both optimisation and compensation and so remained within the category of optimisation. Sixty percent of the strategies originally classified as optimisation in chapter three were significantly classified as optimisation following the DCV analysis. Of those no longer classified as optimisation, 20 were not significantly classified as any strategy type, two were significantly classified as selection and four as compensation. Finally, 47% of the strategies originally classified as selection in chapter three were significantly classified as selection following the DCV analysis. Of those no longer classified as selection, 13 were not significantly classified as any strategy type and two were significantly classified as compensation. Three had been originally classified as also either optimisation or compensation and remained so. Tables 4.5-4.7 indicate the DCV analysis, alongside the previous classification of each strategy as from chapter three.

The DCV analysis not only provides data on which strategies participants judged to reflect the theoretical constructs of selection, optimisation and compensation, but also indicates which strategies the judges were confident were *not* SOC strategies. Participants significantly classified 19 strategies as *not* selection (Table 4.9), 21 as *not* compensation (Table 4.10) and only 1 as *not* optimisation (Table 4.11).

Table 4.5 Strategies classified as selection, ranked in order of Z score

Selection strategies^a	Previous classification	Z	p^b
Only doing social activities that you enjoy and that are important to you, for example, going to bed and reading rather than going out socialising	Selection	-2.844	0.004
Continuing preferred social activities but spending less time on them, for example, playing fewer games of bowls or playing 9 holes on the golf course rather than 18	Selection	-2.844	0.004
Spending less time at work and more time with family	Selection	-2.842	0.004
Giving up activities that are too tiring, for example, doing the gardening	Selection	-2.842	0.004
Reducing the number of activities you take part in to try and cope with fatigue	Selection	-2.840	0.005
Avoiding situations that might negatively affect your health, e.g. where you might fall	Selection	-2.825	0.005
Avoiding people who make you stressed or anxious	Selection	-2.825	0.005
Giving up doing chores and tasks for other people	Selection	-2.825	0.005

Selection strategies ^a	Previous classification	Z	p ^b
Socialising with friends and family in the house rather going out	Compensation	-2.821	0.005
Limiting conversation to that which interests you	Selection	-2.820	0.005
Avoiding stressful situations	Selection	-2.814	0.005
Choosing to talk more with family and friends rather than bottling up your feelings	Optimisation	-2.814	0.005
Reducing the number of household tasks you do in a day	Selection	-2.809	0.005
Spending more time and energy on the important things in life	Selection	-2.713	0.007
Changing your role in the family, for example socialising with family more rather than trying to solve all the family problems	Selection	-2.657	0.008
Paying attention to health problems and seeking medical assistance if necessary	Optimisation	-2.505	0.012
Socialising with friends more in your spare time	Selection	-2.453	0.014
Concentrating energy on everyday activities such as washing and dressing	Selection	-2.419	0.016

Selection strategies^a	Previous classification	Z	p^b
Doing more indoor activities (e.g. crosswords) than outdoor activities (e.g. fishing)	Selection	-2.400	0.016
<i>Choosing a new exercise, for example, an exercise class designed for stroke survivors</i>	<i>Selection and optimisation</i>	-2.311	0.021
<i>Only doing housework tasks that are manageable, for example, dusting but avoiding vacuuming</i>	<i>Selection</i>	-2.302	0.021
<i>Limiting an activity so that it is still manageable, for example continuing driving but at a slower speed, or doing word searches if you are unable to read a book</i>	<i>Selection</i>	-2.099	0.036
<i>Building up to a goal, for example, walking a little more every day</i>	<i>Optimisation</i>	-2.003	0.045

^a Strategies in bold were previously categorised as a different strategy type in chapter three.

^b Strategies in italics were not significant at .05 level after Benjamini and Hochberg (1995) method for controlling the false discovery rate was applied.

Table 4.6 Strategies classified as optimisation, ranked in order of Z score

Optimisation strategies^a	<i>Previous classification</i>	Z	p^b
Repeatedly practising tasks such as getting in and out of the shower	Optimisation	-2.919	.004
Training your concentration with mental tasks such as crosswords and jigsaws	Optimisation	-2.919	.004
Practising using your senses, for example reaching for objects in a bucket of sand to help feeling in your hands	Optimisation	-2.873	.004
Practising balance and movement using Wii Fit and other computer games	Optimisation	-2.871	.004
Learning new ways to relax, such as walking or meditation	Optimisation	-2.848	.004
Thinking about things and planning in advance, for example planning what to take into the shower to avoid having to come in and out more than once	Optimisation	-2.848	.004
Repeating certain movements frequently, for example, hand exercises	Optimisation	-2.842	.004
Doing exercise when you have spare time, for example, physiotherapy exercises when watching TV at night	Optimisation	-2.831	.005

Optimisation strategies^a	<i>Previous classification</i>	Z	p^b
Exercising more to improve strength, fitness or for rehabilitation	Optimisation	-2.831	.005
Choosing a new exercise, for example, an exercise class designed for stroke survivors	Selection and optimisation	-2.831	.005
Using techniques such as planning and practising to improve your confidence in your abilities	Optimisation	-2.831	.005
Using household tasks to practice movement, for example, repeatedly opening and closing pegs when hanging out the washing	Optimisation	-2.829	.005
Investing more time and effort into activities, for example, buttering toast, rather than asking for help	Optimisation	-2.829	.005
Practising speech and language therapy tasks such as reading newspapers or doing puzzles	Optimisation	-2.829	.005
Practising a hobby to try and improve	Optimisation	-2.827	.005
Working with physiotherapists to learn new techniques, such as going up and down stairs	Optimisation	-2.825	.005

Optimisation strategies^a	<i>Previous classification</i>	Z	p^b
Practising relaxation techniques, such as meditation, to help manage stress	Selection and optimisation	-2.825	.005
Planning your day for when you'll be at your best, for example if you are most awake and alert in the mornings then plan to have important meetings at this time	Optimisation	-2.823	.005
Trying not to rely on aids all of the time, for example, practising walking without a stick in the house when safe to do so	Optimisation	-2.823	.005
Organising your days' activities to make sure you have enough time, for example, by getting up earlier in the day	Optimisation	-2.821	.005
Planning tasks which you find difficult, for example, if you are going to lie on the floor then plan how you will get back up	Optimisation	-2.821	.005
Doing physiotherapy exercises	Optimisation	-2.82	.005
Continuing to use your weaker hand rather than giving up using it altogether	Optimisation	-2.818	.005

Optimisation strategies^a	<i>Previous classification</i>	Z	p^b
Organising meals in advance in case you need help from others, for example, help with opening jars	Optimisation and compensation	-2.816	.005
Making an effort to try things out and see if you can manage them	Optimisation	-2.816	.005
Going over things, such as important documents or letters, more than once	Optimisation	-2.816	.005
Concentrating energy on everyday activities such as washing and dressing	Selection	-2.816	.005
Cooking and planning meals in advance and freezing them	Optimisation and compensation	-2.814	.005
Persevering with difficult activities rather than giving up	Optimisation	-2.809	.005
Learning and practising new ways of doing things, such as special dressing techniques taught by occupational therapists	Optimisation	-2.712	.007
Doing activities when you have the energy and feel ready to do them	Optimisation	-2.705	.007

Optimisation strategies^a	<i>Previous classification</i>	Z	p^b
Focusing on one activity at a time	Optimisation	-2.689	.007
Practising using the weaker side of the body, even if it takes longer	Optimisation	-2.676	.007
Learning to do something in a different way and practising this new way, for example a new way of playing bowls, exercising or using lifts and managing stairs	Optimisation and compensation	-2.669	.008
Using exercise to get used to the way your body moves after stroke	Optimisation	-2.662	.008
Challenging yourself, for example, trying more difficult speech and language therapy tasks	Optimisation	-2.662	.008
Learning a new communication technique, for example, breaking down a word in your head before saying it	Optimisation	-2.662	.008
Continuing to do things for yourself by allowing yourself more time to do them	Optimisation	-2.609	.009
Paying more attention to tasks and activities that require concentration, such as reading, speaking or cooking	Optimisation	-2.555	.011

Optimisation strategies^a	<i>Previous classification</i>	Z	p^b
Planning activities for earlier in the day and avoiding evening activities, so that you can rest and relax	Optimisation	-2.409	.016
Developing your own memory reminders, for example, sticking reminders to the fridge or the mantelpiece	Compensation	-2.405	.016
Having a regular exercise routine	Optimisation	-2.363	.018
<i>Trying to conserve energy when doing more than one task in a row, for example, when you know you will have to cook after going food shopping</i>	<i>Optimisation</i>	-2.251	0.024
<i>Following active activities such as walking with resting activities such as reading</i>	<i>Optimisation</i>	-2.251	0.024
<i>Moving frequently to prevent stiffness or numbness</i>	<i>Optimisation</i>	-2.149	0.032

^a Strategies in bold were previously categorised as a different strategy type in chapter three.

^b Strategies in italics were not significant at .05 level after Benjamini and Hochberg (1995) method for controlling the false discovery rate was applied

Table 4.7 Strategies classified as compensation, ranked in order of Z score

Compensation strategies ^a	Previous classification	Z	p ^b
Choosing an alternative way of doing an activity, for example having a shower or using a basin to wash when you are unable to get in and out of the bath	Compensation	-2.97	0.003
Using aids to help you with everyday activities, from walking aids, handrails and raised beds to reading aids such as clip lights and magnifying glasses	Compensation	-2.97	0.003
Seeking assistance from family, friends or carers with tasks such as eating, dressing, bathing and looking after body parts, e.g. getting a chiropodist to cut your nails, going to the hairdresser for a blow dry or hiring a care assistant	Compensation	-2.913	0.004
Changing the way you do everyday tasks, for example, hanging washing inside or in a greenhouse rather than on the washing line, or sticking nail clippers to a work surface in order to cut nails	Compensation	-2.877	0.004
Using speech and language therapy aids such as pencil grips and conversation booklets	Compensation	-2.873	0.004
Cutting up food into small pieces before starting to eat	Compensation	-2.871	0.004

Compensation strategies^a	Previous classification	Z	p^b
Seeking help to understand documents and official letters	Compensation	-2.871	0.004
Learning and practising new ways of doing things, such as special dressing techniques taught by occupational therapists	Optimisation	-2.871	0.004
Lifting lighter items with your affected hand and heavier items with your unaffected hand	Compensation	-2.871	0.004
Using gadgets to help with everyday activities, from trolleys to transport items about indoors, to kitchen gadgets such as a potato peeler or a slow cooker	Compensation	-2.871	0.004
Doing tasks using the unaffected side of your body when you are no longer able to use the affected side at all	Compensation	-2.859	0.004
Getting assistance from friends, family or paid help with tasks such as cooking, shopping, housework, gardening, getting in and out of a car etc....	Compensation	-2.850	0.004
Using transport such as a taxi or the train when you are no longer able to use the bus	Compensation	-2.848	0.004
Using smaller and lighter household appliances, for example, a small vacuum cleaner	Compensation	-2.848	0.004

Compensation strategies^a	Previous classification	Z	p^b
Using aids at work such as ergonomic chairs and writing shelves	Compensation	-2.848	0.004
Listening to audio books rather than reading	Compensation	-2.844	0.004
Using the shopping trolley to balance or lean on when shopping	Compensation	-2.844	0.004
Chewing and eating using the unaffected side of your mouth	Compensation	-2.844	0.004
Using mobile phone assistance, such as Siri or autocorrect feature, to write and send text messages	Compensation	-2.844	0.004
Moving wallet or purse to the pocket where it can be most easily reached	Compensation	-2.844	0.004
Sitting down to get dressed rather than standing	Compensation	-2.840	0.005
Eating and cutting food one-handed, using a fork only	Compensation	-2.840	0.005
Sitting on a certain side of the car so that you can use your stronger leg when getting out of the car	Compensation	-2.840	0.005
Receiving assistance at work, such as reminders to take breaks or help with difficult tasks	Compensation	-2.836	0.005

Compensation strategies ^a	Previous classification	Z	p ^b
Moving your bedroom to a room which is more appropriate, for example easier to heat or more accessible	Compensation	-2.831	0.005
Lifting and carrying less, for example, carrying fewer bags of shopping	Selection	-2.831	0.005
Using an alternative product, such as 'baby shampoo' due to problems closing your eyes properly in the shower	Compensation	-2.831	0.005
Asking for assistance when out of the house, e.g. asking staff members to help when paying in a shop or asking taxi driver for assistance with a seatbelt	Compensation	-2.831	0.005
Eating softer food which is easy to eat and cut	Compensation	-2.831	0.005
Using electric devices as an alternative, for example an electric shaver or toothbrush rather than a razor or standard toothbrush	Compensation	-2.831	0.005
Adapting cooking methods, for example, buying new potatoes that don't require peeling or buying pre-chopped carrots	Compensation	-2.831	0.005

Compensation strategies ^a	Previous classification	Z	p ^b
Using aids to help you exercise, such as floats when swimming, or a hoist that allows you to get in and out of the pool	Compensation	-2.831	0.005
Only wearing clothes that are easy to put on, for example, elasticated trousers, polo shirts or using shoe buttons	Compensation	-2.831	0.005
Developing your own memory reminders, for example, sticking reminders to the fridge or the mantelpiece	Compensation	-2.829	0.005
Using car roof rails to assist in getting in and out of a car	Compensation	-2.827	0.005
Doing tasks such as shopping or housework in short bursts, with breaks in between activities	Optimisation	-2.827	0.005
Using a service for those with disabilities, such as MyBus instead of the standard bus service	Compensation	-2.827	0.005
Carrying one item at a time	Selection and compensation	-2.825	0.005
Using a bike as a way of independent transport when no longer able to drive	Compensation	-2.825	0.005

Compensation strategies ^a	Previous classification	Z	p ^b
Transferring your body bottom first, for example, when getting in and out of a car	Compensation	-2.825	0.005
Stopping or pausing during an activity to allow you to get your balance	Compensation	-2.823	0.005
Not using your affected side for dangerous tasks such as carrying hot drinks or a tray of glasses	Compensation	-2.821	0.005
Using a rucksack to carry shopping	Compensation	-2.820	0.005
Learning to do something in a different way and practising this new way, for example a new way of playing bowls, exercising or using lifts and managing stairs	Optimisation and compensation	-2.820	0.005
Only carrying small or light items, for example, carrying 'bread and eggs' when shopping rather than large/heavy items	Selection	-2.820	0.005
Using a dictaphone or mobile phone to record important conversations or make notes	Compensation	-2.820	0.005
Leaving extra space between yourself, other people and objects when moving	Compensation	-2.820	0.005
Turning head fully when crossing the road or tilting head when watching TV	Compensation	-2.820	0.005

Compensation strategies^a	Previous classification	Z	p^b
Asking the bus driver not to move the bus until you are seated	Compensation	-2.816	0.005
Cooking microwave or oven meals rather than cooking from scratch	Compensation	-2.816	0.005
Socialising with friends and family in the house rather going out	Compensation	-2.814	0.005
Always using traffic lights to cross roads	Compensation	-2.812	0.005
Going to bed earlier to cope with tiredness	Optimisation	-2.812	0.005
Simplifying activities, for example, reducing the number of bank accounts you have	Selection	-2.810	0.005
Doing shopping online rather than going to the shops or supermarket	Compensation	-2.739	0.006
Using a mobile phone calendar or regular calendar to keep track of appointments and set reminders	Compensation	-2.721	0.007
Working from home when necessary	Compensation	-2.717	0.007
Allowing family and friends to help by motivating you to do things	Optimisation	-2.712	0.007

Compensation strategies ^a	Previous classification	Z	p ^b
Slowing down and pacing activities such as washing and housework throughout the day or over a couple of days	Optimisation	-2.451	0.014
Using an electronic device such as an iPad, Kindle, tablet or phone to read and type books and documents	Compensation	-2.419	0.016
<i>Changing your hobbies, for example, doing jigsaws if you can't do crosswords anymore</i>	<i>Selection and compensation</i>	<i>-2.311</i>	<i>0.021</i>
<i>Using headphones to block out unwanted noise</i>	Compensation	<i>-2.307</i>	<i>0.021</i>
<i>Organising meals in advance in case you need help from others, for example, help with opening jars</i>	<i>Optimisation and compensation</i>	<i>-2.302</i>	<i>0.021</i>
<i>Limiting an activity so that it is still manageable, for example continuing driving but at a slower speed, or doing word searches if you are unable to read a book</i>	<i>Selection</i>	<i>-2.159</i>	<i>0.031</i>
<i>Changing your expectations about certain things, for example, no longer doing all the housework in the one day</i>	<i>Optimisation</i>	<i>-2.145</i>	<i>0.032</i>

Compensation strategies^a	Previous classification	Z	p^b
<i>Only doing exercise that is manageable, for example, using an exercise bike in the house rather than hill walking, or swimming instead of doing a strenuous exercise class</i>	<i>Selection</i>	-1.999	0.046
<i>Planning and changing routes in advance to avoid things like uneven pavements, steep kerbs and stairs</i>	<i>Optimisation</i>	-1.962	0.05

^a Strategies in bold were previously categorised as a different strategy type in chapter three.

^b Strategies in italics were not significant at .05 level after Benjamini and Hochberg (1995) method for controlling the false discovery rate was applied

Table 4.8 Strategies classified as indicating more than one SOC strategy

Strategy	Z score (p value) for judgements against each construct definition^a		
	Selection	Optimisation	Compensation
Concentrating energy on everyday activities such as washing and dressing	-2.419 (.016)	-2.816 (.005)	n.s
Socialising with friends and family in the house rather than going out	-2.821 (.005)	n.s	-2.814 (.005)
Developing your own memory reminders, for example, sticking reminders to the fridge or the mantelpiece	n.s	-2.405 (.016)	-2.829 (.005)
Learning and practising new ways of doing things, such as special dressing techniques taught by occupational therapists	n.s	-2.712 (.007)	-2.871 (.004)
Learning to do something in a different way and practising this new way, for example a new way of playing bowls, exercising or using lifts and managing stairs	n.s	-2.669 (.008)	-2.820 (.005)

^a n.s = not significant; the item was not a match to the definition of the theoretical construct.

Table 4.9: Strategies significantly classified as *not* selection

Strategies significantly classified as <i>not</i> selection	Z	p
Stopping or pausing during an activity to allow you to get your balance	-2.403	0.016
Using speech and language therapy aids such as pencil grips and conversation booklets	-2.505	0.012
Using aids to help you with everyday activities, from walking aids, handrails and raised beds to reading aids such as clip lights and magnifying glasses	-2.821	0.005
Learning and practising new ways of doing things, such as special dressing techniques taught by occupational therapists	-2.458	0.014
Using a rucksack to carry shopping	-2.419	0.016
Using an alternative product, such as 'baby shampoo' due to problems closing your eyes properly in the shower	-2.361	0.018
Asking for assistance when out of the house, e.g. asking staff members to help when paying in a shop or asking taxi driver for assistance with a seatbelt.	-2.515	0.012
Receiving assistance at work, such as reminders to take breaks or help with difficult tasks	-2.520	0.012

Strategies significantly classified as <i>not</i> selection	Z	p
Allowing family and friends to help by motivating you to do things	-2.812	0.005
Using aids at work such as ergonomic chairs and writing shelves	-2.827	0.005
Using electric devices as an alternative, for example an electric shaver or toothbrush rather than a razor or standard toothbrush	-2.814	0.005
Using aids to help you exercise, such as floats when swimming, or a hoist that allows you to get in and out of the pool	-2.814	0.005
Asking the bus driver not to move the bus until you are seated	-2.620	0.009
Using mobile phone assistance, such as Siri or autocorrect feature, to write and send text messages	-2.623	0.009
Sitting on a certain side of the car so that you can use your stronger leg when getting out of the car	-2.812	0.005
Moving wallet or purse to the pocket where it can be most easily reached	-2.814	0.005
Leaving extra space between yourself, other people and objects when moving	-2.814	0.005
Turning head fully when crossing the road or tilting head when watching TV	-2.507	0.012

Strategies significantly classified as <i>not</i> selection	Z	p
Transferring your body bottom first, for example, when getting in and out of a car	-2.818	0.005

Table 4.10: Strategies significantly classified as *not* optimisation

Strategies significantly classified as <i>not</i> optimisation	Z	p
Giving up activities that are too tiring, for example, doing the gardening	-2.567	0.010

Table 4.11: Strategies significantly classified as *not* compensation

Strategies significantly classified as <i>not</i> compensation	Z	p
Repeatedly practising tasks such as getting in and out of the shower	-2.842	0.004
Training your concentration with mental tasks such as crosswords and jigsaws	-2.848	0.004
Repeating certain movements frequently, for example, hand exercises	-2.825	0.005
Practising a hobby to try and improve	-2.829	0.005
Challenging yourself, for example, trying more difficult speech and language therapy tasks	-2.821	0.005
Trying not to rely on aids all of the time, for example, practising walking without a stick in the house when safe to do so	-2.717	0.007
Investing more time and effort into activities, for example, buttering toast, rather than asking for help	-2.820	0.005
Practising speech and language therapy tasks such as reading newspapers or doing puzzles	-2.814	0.005
Building up to a goal, for example, walking a little more every day	-2.844	0.004

Strategies significantly classified as <i>not</i> compensation	Z	p
Socialising with friends more in your spare time	-2.823	0.005
Practising balance and movement using Wii Fit and other computer games	-2.816	0.005
Only paying attention to things that interest you	-2.409	0.016
Doing physiotherapy exercises	-2.453	0.014
Choosing a new activity, such as an education course or volunteering	-2.470	0.013
Exercising more to improve strength, fitness or for rehabilitation	-2.816	0.005
Making an effort to try things out and see if you can manage them	-2.814	0.005
Practising using your senses, for example reaching for objects in a bucket of sand to help feeling in your hands	-2.713	0.007
Trying not to overdo physiotherapy and exercise during rehabilitation (-2.809	0.005
Improving your diet by reducing unhealthy food, snacking, large portions and alcohol intake	-2.505	0.012

Strategies significantly classified as <i>not</i> compensation	Z	p
Choosing a new exercise, for example, an exercise class designed for stroke survivors	-2.820	0.005
Using techniques such as planning and practising to improve your confidence in your abilities	-2.608	0.009

4.4 Discussion

This study aimed to advance SOC research by applying the method of Discriminant Content Analysis to the stroke-related SOC strategies elicited in chapter three. Whilst the strategies had previously been coded as selection, optimisation and compensation, methodological weaknesses in the analysis of previous qualitative SOC research resulted in calls for improved and transparent methods of SOC analysis. DCV methodology was considered to be appropriate for this purpose, as it has successfully been utilised to reliably establish the content validity of existing measures and for the development of new questionnaires designed to assess theoretical constructs (e.g. (Cane et al., 2012; Dixon et al., 2007; Huijg et al., 2014)).

In total, the DCV analysis resulted in 78% of the stroke-related SOC strategies from chapter three being significantly classified as selection, optimisation or compensation. Out of the 149 strategies, 18 were significantly classified as selection, 42 were significantly classified as optimisation and 60 as compensation. As expected, some strategies were classified as more than one strategy type. Furthermore, classifications of strategies following the DCV analysis could be compared to the original classifications in chapter three. Ninety percent of the compensation strategies, 60% of the optimisation strategies and 47% of the selection strategies retained their original classification following DCV analysis. It should be noted, however, that there were only 34 strategies originally classified as selection, compared to 67 optimisation and 58 compensation strategies. Therefore, the 47% actually refers to fewer changed selection strategies (18) following DCV analysis than optimisation (27).

It would appear therefore that whilst the qualitative interviews and coding process conducted in chapter three were successful in eliciting and categorising stroke-related SOC strategies, the discriminant content validation analysis was a useful methodology for further examining the validity of such strategies.

Strengths, limitations and future research

The use of an established method of examining content validity was a strength of this study. However, there are a number of issues that require discussion before conclusions can be drawn from the findings and on the efficacy of using DCV methodology to analyse the theoretical content of qualitative data. Unlike other DCV studies, the current study

suffered from poor agreement between raters. For selection and optimisation in particular, the intra-class correlation coefficient of 0.40 indicates only 'fair' agreement (Landis & Koch, 1977). Whilst this is perhaps not surprising given that participants were asked to allocate 149 strategies to three constructs, previous studies have placed similar or larger burdens on participants and achieved better consistency of ratings. Huijg et al. (2014), for example, asked judges to allocate 79 items to up to 14 theoretical constructs. Similarly, a study by Pollard et al. (2006) involved allocating 342 items to three constructs. Both studies achieved moderate to excellent agreement between judges, despite Huijg et al. (2014) reporting that participants found the task challenging. It is likely that the complexity of the SOC model contributed to the inconsistency between participants, particularly since only two judges had experience working with the model. The elicited strategies may also have contributed to this inconsistency, as despite undertaking modifications in their translation from stroke survivors' idiosyncratic wording, they lacked clarity and conciseness compared to typical questionnaire items, and several may straddle the boundaries of the theoretical constructs. Such reliability issues may have contributed to some of the differences between the original classifications of the strategies as in chapter three, and the results of the DCV analysis.

Future studies wishing to utilise DCV methodology to analyse SOC research will need to carefully consider the choice of judges recruited for the task. Haynes et al. (1995) suggest that tasks should be completed by a mixture of judges who are both expert and representative of the target population. Johnston et al. (2014) agree that judges should reflect the target population, however, they should also possess the literacy required to understand the often complex definitions of the theoretical constructs. In the current study, judges possessed a range of stroke survivor experience; however, it is likely that a higher number of judges with SOC experience would have improved the reliability of the findings. For example, judges who were more familiar with the model may have increased confidence in identifying examples of strategies that could be categorised as more than one strategy type, e.g. both optimisation and compensation. As discussed in chapters two and three, the same strategy can be either optimisation or compensation, depending on whether it is performed in response to loss. For example, 'investing time, effort and energy' has been mentioned previously as both an optimisation and compensation strategy (Freund & Baltes, 1998). The previous chapter therefore acknowledged that a strategy may

be utilised as optimisation or compensation, depending on what stage the stroke survivor is in the process of adapting to their post-stroke impairments. For example, a behaviour that was compensatory immediately after stroke, due to loss, may over time become an optimisation, goal striving strategy as the individual adjusts to life after stroke. In theory, judges were able to classify a strategy as more than one type, for example as both optimisation and compensation, however few strategies emerged as significantly classified as more than one strategy type. This may have been because judges were on the whole unfamiliar with the SOC model and therefore lacked expertise. In addition, the lack of context provided for each strategy may have influenced how the strategies within this DCV study were interpreted.

Reliability in the study may therefore have been improved by targeting judges who were, for example, international experts with greater working experience of the model. There was some evidence for this within the current study, as better agreement was indeed found between judges who had more experience working with the SOC model. This does, however, need to be interpreted with caution due to the low numbers within the more experienced group. Alternatively, it may be that judges who were more familiar with the model judge strategies based on their preconceived ideas of selection, optimisation and compensation, rather than using the theoretical definitions provided. Nevertheless, the fair to moderate agreement between judges did produce significant results, and findings may benefit future stroke-related SOC research.

The study did not meet the criteria of including judges who were representative of the stroke population as it was felt that the DCV task was inappropriate for use with stroke survivors. Future research incorporating the stroke-related SOC strategies into an intervention will be subjected to feasibility and acceptability evaluations in order to combat this limitation.

It is also possible that the wording of the strategies and the theoretical definitions provided may have influenced judges' decisions. For example, sample optimisation strategies provided to the judges included the words 'practising' and 'planning'. It may be that strategies that subsequently included such words were automatically categorised as optimisation. Future research may wish to compare the categorisation of strategies which are still expressed in the words of the stroke survivor.

Furthermore, the theoretical definitions and examples provided to the judges were developed based on previous SOC interpretations and research (P. Baltes & Baltes, 1990; Freund & Baltes, 1998; Gignac et al., 2002). As has been discussed in detail within previous chapters, interpreting strategies as selection, optimisation or compensation can be problematic and subjective. It is hoped that the definitions provided clear instructions to the judges, however future work should pilot these with a small number of participants to ensure they are correctly interpreted.

Conclusion

Discriminant Content Validation methodology was used to successfully categorise stroke-related SOC strategies as selection, optimisation or compensation. In doing so, the current study confirmed the content validity of the strategies elicited from interviews with stroke survivors, including exploring overlapping strategies. Future research could aim to utilise the strategies to develop a domain-specific SOC measure in the context of stroke, or incorporate these strategies into a post-stroke intervention.

5 Developing and exploring the feasibility and acceptability of a 'Life after stroke help-sheet': an intervention for stroke survivors based on the Selection, Optimisation and Compensation model

Abstract

Background: According to previous research, the use of selection, optimisation and compensation strategies is primarily adaptive and adopting SOC strategies is a technique used by individuals to help them adapt to changing circumstances. The SOC model may therefore have utility for informing a stroke-specific intervention, helping stroke survivors minimise their losses, maximise their gains and come to terms with the long-term consequences of stroke. To-date no study has explored the development of a SOC intervention in the context of stroke.

Evidence from goal-setting and self-management in stroke, alongside previous SOC interventions, provides insight into how the SOC model might be applied to the context of stroke. The SOC model may provide a model which can guide planning within goal-setting or self-management. Furthermore, a number of researchers have suggested that training in SOC strategy use and providing examples of SOC strategies may aid goal attainment and adaptation. Insights into each of these approaches can be applied to the context of stroke.

The aim of this study was to develop an intervention based on the SOC model for use in stroke. The study also aimed to conduct preliminary feasibility and acceptability analyses with a small number of stroke survivors in order to further refine the intervention.

Method: A help-sheet based intervention was developed which provided stroke survivors with explanations of selection, optimisation and compensation, alongside examples of stroke-specific SOC strategies. Previous interviews with 30 stroke survivors elicited the stroke-specific SOC strategies (chapter three), 18 of which were subsequently classified as selection, 42 as optimisation and 60 as compensation by Discriminant Content Validation analysis (chapter four); these were used as example strategies on the help-sheet. Following explanations of selection, optimisation and compensation, participants were interviewed about their experiences of using SOC, including how they felt about previous SOC use and

whether they experienced any difficulties doing so. Participants were asked whether they wished to try any of the SOC strategies provided on the help-sheet. Participants were interviewed again two weeks later and asked about their experience of using the help-sheet. Acceptability data was collected in the form of an anonymous questionnaire. Feasibility was examined through recruitment data and time taken per interview.

The help-sheet was piloted with four male and one female stroke survivors, between two and 42 months post-stroke. The mean length of time post-stroke was 25 months ($SD = 15$). Participants were aged between 58 and 71 years.

Results: The recruitment rate varied between nine percent and 50% when recruitment was by Stroke Research Nurses at one weekly clinic or via a pool of stroke survivors who had previously taken part in research respectively. Each interview took around 20-30 minutes to complete. Two participants completed the acceptability questionnaires, and reported that they found the intervention to be acceptable. There were, however, difficulties with the help-sheet implementation, with participants either reporting few post-stroke difficulties, or that they had already adjusted well to their post-stroke impairments and were content with their current situation. None of the participants selected to try any of the strategies listed on the help-sheet and receive a second interview. Several reported that they had previously already adopted a number of the strategies.

Discussion: This study was the first to develop and examine the feasibility and acceptability of a SOC intervention in the context of stroke. The intervention appeared to be acceptable to stroke survivors; however, there were difficulties with its implementation which means this finding should be interpreted with caution. Stroke survivors at later stages post-stroke had already formed adaptation strategies, and despite experiencing some difficulties, were reluctant to try new strategies. Several participants reported difficulties setting goals, and the reluctance to select SOC strategies may have stemmed from this. In addition, the feasibility of a 20-30 minute intervention, which may be feasible within a dedicated health psychology service, is unlikely to be so for delivery by acute ward nurses. Further consideration of the intervention's implementation in practice is required.

Further work on modifying the SOC intervention is therefore necessary. The intervention might benefit from a greater focus initially on identifying problems and goals, before moving onto the SOC concepts and example strategies. It may be helpful to incorporate

SOC training within a framework based on the International Classification of Functioning, Disability and Health. This may allow stroke survivors to identify and use the SOC concepts and example strategies to address a range of post-stroke difficulties that not only include impairments but also difficulties in activities and participation restrictions, in a structured manner. Future research should aim to draw upon these findings, modify the SOC stroke intervention and pilot it within a larger sample of stroke survivors.

5.1 Background and rationale

To-date, research into the Selection, Optimisation and Compensation model (P. Baltes & Baltes, 1990) has mainly focused on two avenues of study: examining the relationships between the use of selection, optimisation and compensation strategies and outcomes, and use of the model to describe how individuals adapt to changing circumstances. A systematic review (chapter two) found that older adults adopted a number of varied SOC strategies to adapt to age- and health-related losses, for example when faced with difficulties in activities of daily living due to osteoarthritis (Gignac et al., 2002). In addition, the review found that individuals who utilised SOC strategies reported better outcomes. Indeed, the use of SOC strategies was positively associated with a range of indicators of subjective wellbeing, health, and physical activity outcomes in older adults and those with chronic health conditions (Evers et al., 2012; Freund & Baltes, 1998, 2002b; Jopp & Smith, 2006; Reuter et al., 2010; Ziegelmann & Lippke, 2007a, 2007b).

Given that the use of SOC strategies appears to be primarily adaptive, and that adopting SOC strategies is a technique used by individuals to help them adapt to changing circumstances, it is evident the model may also have utility in informing behaviour change interventions. Implementing ways to increase SOC strategy use may result in increases in positive health behaviours and other patient valued outcomes, by helping individuals to maximise their gains and minimise their losses. Such interventions based on SOC are slowly emerging, although their theoretical underpinnings and methods of delivery are varied (Alonso-Fernández et al., 2015; Alonso et al., 2013; Evers et al., 2012; Gellert et al., 2013; Ziegelmann et al., 2006).

In addition, no study to-date has explored the development of a SOC intervention in the context of stroke. As discussed in some detail in chapters one and three, helping stroke survivors come to terms with the long-term consequences of stroke remains an important research priority (James Lind Alliance, 2016; Pollock et al., 2014). Previous research suggests that the SOC model may have utility for informing a stroke-specific intervention with this aim, as stroke survivors use a range of SOC strategies to help them adapt to their post-stroke difficulties (chapters three and four). The next phase of research is therefore to determine how best the SOC model can be applied to the context of post-stroke adaptation and how the stroke-specific SOC strategies elicited previously can be integrated into

rehabilitation efforts. In order to do so, we must first examine how SOC could be operationalised within the context of stroke rehabilitation.

Operationalisation of SOC within the context of stroke

Goal-setting and planning

According to rehabilitation guidelines, goal-setting should be included within clinical practice (Royal College of Physicians, 2016; The Scottish Intercollegiate Guidelines Network (SIGN), 2010). The process of goal-setting is described as the identification of individual goals that have meaningful value to the stroke survivor, and should be a collaborative process between the stroke survivor and clinical team (Royal College of Physicians, 2016; The Scottish Intercollegiate Guidelines Network (SIGN), 2010). Evidence for goal-setting in practice includes systematic reviews of the effectiveness of the goal-setting process and reviews of patient goal-setting experiences (Levack et al., 2006; Rosewilliam et al., 2011; Sugavanam et al., 2013). Goal-setting has been found to aid patients in becoming involved in the rehabilitation process, improve motivation and have positive effects on satisfaction and goal attainment (Levack et al., 2006; Rosewilliam et al., 2011; Sugavanam et al., 2013). Levack et al. (2006), however, do warn that despite such positive findings, there are a number of studies finding no evidence of the positive effects of goal-setting on clinical outcomes with the authors calling for improved methodology within studies.

Systematic reviews have highlighted a number of barriers to implementing the goal-setting process in clinical practice. A common theme was the mismatch between goals which the patient sought to achieve, and goals set by the healthcare professional (Rosewilliam et al., 2011; Sugavanam et al., 2013). This may be because the patient has unrealistic expectations about the stroke recovery process, compares themselves to pre-stroke functioning, or sets broader goals relating to social needs. In contrast, the healthcare professional commonly uses their professional experience to set specific, short-term goals in relation to post-stroke functioning (Rosewilliam et al., 2011; Sugavanam et al., 2013). Such a mismatch of goals is likely exacerbated by a lack of person-centred goal-setting in practice. Rosewilliam et al. (2011) found that whilst healthcare professionals believed they practiced person-centred goal-setting, most patients felt they had limited control and involvement in goal-setting. Similarly, Sugavanam et al. (2013) suggested that patients believed their involvement in goal-setting was poor, in contrast to healthcare professionals

who believed patients had greater involvement. Indeed, a study of person-centred goal-setting in a stroke ward found that patients felt disempowered and that person-centred goal-setting was not adopted (Rosewilliam, Sintler, Pandyan, Skelton, & Roskell, 2016).

It would appear, therefore, that lack of patient involvement in the setting of goals in stroke rehabilitation is common. Potential reasons for this have been identified and include: patient confusion about the goal-setting process and lack of explicit goal-setting information; patients being unable to participate in the goal-setting process due to cognitive and language difficulties; patients unable to accept their post-stroke circumstances; staff time constraints; and lack of a suitable framework and strategies to guide the person-centred goal-setting process (Rosewilliam et al., 2011; Rosewilliam et al., 2016; Sugavanam et al., 2013). Goal-setting researchers agree that there is little agreement on the best way to undertake goal-setting, with multiple goal-setting methods and a lack of theoretical explanation and an explicit goal-setting framework to follow (Levack et al., 2006; Rosewilliam et al., 2011; Sugavanam et al., 2013). Scobbie and colleagues (Scobbie, Dixon, & Wyke, 2011; Scobbie, McLean, Dixon, Duncan, & Wyke, 2013; Scobbie, Wyke, & Dixon, 2009) suggest that this state of affairs leaves stroke rehabilitation professionals at a disadvantage, required to implement person-centred goal-setting processes, but without a guiding framework and related explanation as to why such a framework will be effective. The researchers describe the development and initial testing of a goal-setting framework, based on Social Cognitive Theory (Bandura, 1977), Goal-setting Theory (Latham & Locke, 2007) and the Health Action Process Approach (R. Schwarzer, 1992) (Figure 5.1). The 'goal-setting and action-planning practice framework' (G-AP) draws on the theoretical constructs of self-efficacy, outcome expectancies, goal attributes, action planning and coping planning (Scobbie et al., 2011). As seen in figure 5.1, the practice framework guides clinicians through four stages, from negotiating and setting the goals, to implementing action plans and coping plans in order to achieve the goals. Appraisal also plays a role in the framework, leading to either goal attainment or goal re-negotiation.

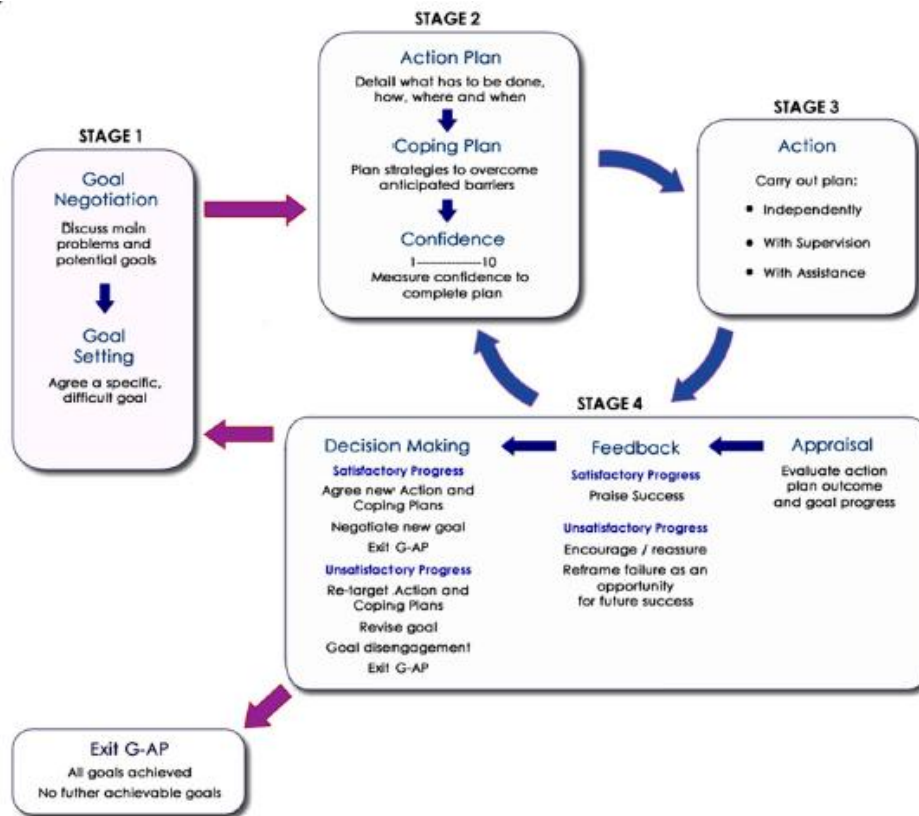


Figure 5.1: G-AP framework (Scobbie et al., 2013), used with permission

During its evaluation, multidisciplinary healthcare professionals who were part of a community based rehabilitation team implemented the G-AP framework (Scobbie et al., 2013). Patients taking part in the goal-setting process using this framework stated that identifying goals and action plans improved their motivation to perform rehabilitation activities, and that achieving these goals increased their confidence. The patients were also provided with a G-AP written record of their action plans, enabling them to retain written information about their goals and refer to it in their own time, thus acting as ‘homework’ (Scobbie et al., 2011; Scobbie et al., 2013). In addition, healthcare professionals felt that the G-AP framework resulted in the process becoming simultaneously more focused and patient-centred, with patients in control and participating in the rehabilitation process (Scobbie et al., 2013). An evaluation of G-AP indicated that, all of the goals were set through patient-healthcare professional collaboration and the framework was found to be flexible to personal and changing circumstances (Scobbie et al., 2011).

The planning components of the G-AP framework merit further discussion and explanation in order to demonstrate how the SOC model may be operationalised within the stroke goal-

setting context and how it may contribute to improving the efficacy of goal-setting interventions for this population. The construct of planning is frequently discussed within the context of motivation versus volition phases of behaviour change. These two distinct phases exist within various models, including the Health Action Process Approach (R. Schwarzer, 1992) and 'Rubicon' Model of Action Phases (H. Heckhausen & Gollwitzer, 1987). The phases refer to a period of *goal-setting*, where individuals select a specific goal or behaviour, and a period of *goal striving*, where strategies are implemented to realise these goals (Achtziger & Gollwitzer, 2008; H. Heckhausen, 1991; H. Heckhausen & Gollwitzer, 1987; J. Heckhausen & Heckhausen, 2008). Difficulties in the goal striving phase can include problems initiating the goal behaviour and problems tackling barriers to performing the behaviour (Gollwitzer & Sheeran, 2006; H. Heckhausen, 1991; J. Heckhausen & Heckhausen, 2008). Planning has been proposed as an effective strategy for overcoming such difficulties, particularly when planning is broken down into the sub-constructs of action planning and coping planning (Sniehotta, Schwarzer, Scholz, & Schüz, 2005).

Action planning involves setting a plan specifying when, where and how to achieve a specific goal or behaviour (Gollwitzer, 1993). This may consist of forming an implementation intention; by linking specific situations to a goal-related behaviour, cues are created to perform a behaviour when a situation arises (Gollwitzer, 1999). For example, the implementation intention "if I am offered a cigarette in a social situation, I will refuse and remind the individual that I am a non-smoker" links a specific situation with the goal-related behaviour of refusing a cigarette. Such implementation intentions have an 'if-then' contingency and intervention participants are often provided with pre-set plans to select from (Sniehotta, 2009). In addition to implementation intentions, more global action planning is frequently utilised in Health Psychology interventions (Sniehotta, 2009). Rather than using an 'if-then' contingency, such action plans have a 'when, where and how' format that involves an individual specifying where and when they are going to perform a particular behaviour (Carraro & Gaudreau, 2013; Hagger & Luszczynska, 2014). Action plans often refer to a wider behavioural goal, rather than a single behavioural act and are typically generated by the participant (Carraro & Gaudreau, 2013; Hagger & Luszczynska, 2014; Sniehotta, 2009). For example, the action plan "At the party on Friday, I will inform my friends and family that I am now a non-smoker" specifies when, where and how the

individual plans to enact the goal-related behaviour of informing their peers that they have stopped smoking, which links to the target behaviour of stopping smoking. Carraro and Gaudreau (2013) suggest that, unlike implementation intentions, the structure of action plans often vary. This is not surprising given their self-generative nature and the fact that a range of methods can be employed to elicit such action plans. Nevertheless, action plans and implementation intentions are frequently combined during reviews of the effect of planning on health behaviours (Hagger & Luszczynska, 2014; Sniehotta, 2009).

Coping planning has been proposed as an additional planning component and involves anticipating barriers to performing a behaviour, and employing pre-determined strategies to combat these barriers (Sniehotta et al., 2005). As a second sub-construct of planning, coping planning is frequently combined with action planning within health behaviour change interventions. Upon generating an action plan, individuals subsequently anticipate those barriers which would prevent successful completion of this plan, and implement strategies to cope with such barriers (R. Schwarzer, 2016; Sniehotta et al., 2005). A review of coping planning within health behaviour change interventions found that a combination of action planning and coping planning was more effective in changing behaviour than action planning alone (Kwasnicka, Penseu, White, & Sniehotta, 2013).

Altogether, planning has been found to be an effective behaviour change technique for a range of health behaviours, including smoking cessation (Armitage, 2008), alcohol reduction (Armitage, 2009), resuming of functional activity following joint replacement (Orbell & Sheeran, 2000) and physical activity following cardiac rehabilitation (Sniehotta, Scholz, & Schwarzer, 2006). Meta-analytical reviews have found a medium-large effect of planning on goal attainment (Gollwitzer & Sheeran, 2006) and significant effects ranging from small-large on specific health behaviours such as physical activity (Bélanger-Gravel, Godin, & Amireault, 2013; Carraro & Gaudreau, 2013) and healthy eating (Adriaanse, Vinkers, De Ridder, Hox, & De Wit, 2011). Such effectiveness, combined with simple and inexpensive methods of delivery, has resulted in planning becoming one of the most common behaviour change techniques utilised in health behaviour change interventions (Hagger & Luszczynska, 2014). Despite such positive findings, planning and implementation intention researchers have identified a number of additional directions for planning research (Hagger et al., 2016). These include exploring ways of eliciting self-regulatory problems prior to planning; identifying intra-personal factors, plan formats and delivery

modes moderating the effectiveness of planning; exploring collaborate versus individual planning; further research with participants experiencing low intention or low self-efficacy; and exploring the effectiveness of combining planning with other intervention techniques (Hagger et al., 2016).

It is evident that including action planning and coping planning within the rehabilitation goal-setting context has merit. However, whilst the G-AP goal-setting framework described above was well-received, there were some barriers to its implementation that centred around difficulties with the planning process. Fidelity to the coping planning aspect of the process was poor, with the author suggesting that coping plans were not recorded or discussed with patients (Scobbie et al., 2013). Healthcare professionals suggested that this was a new area for them and was not yet routine practice, with the authors responding that future training would focus on providing more information regarding coping planning and its importance. It may also be, however, that patients have difficulty in identifying barriers to completing their action plans. Research indicates that effective coping planning is based on previous experience; individuals must have the knowledge and experience to predict possible barriers and opportunities to overcome these (R. Schwarzer, 2016; Sniehotta et al., 2005). Sniehotta et al. (2005), for example, found that coping planning predicted physical activity behaviour in cardiac rehabilitation patients, but only as their experience in physical activity after rehabilitation increased over time. In a study of Proactive Coping Planning stroke survivors reported difficulties in spontaneously identifying goals, potential barriers and solutions (Tielemans et al., 2014). Whilst individuals themselves can become 'experts' in their circumstances according to Sniehotta et al. (2005), having limited experience about the effects of stroke in everyday life was identified by stroke survivors as a barrier to engaging in coping planning (Tielemans et al., 2016).

Research therefore suggests that help should be given to individuals in order to assist them in coping planning. Assistance provided to individuals in coping planning interventions can vary, ranging from requiring the individual to self-generate barriers and plans, to interviewer-assisted methods and providing pre-specified barriers and plans (Sniehotta, 2009). In a systematic review of coping planning interventions, Kwasnicka et al. (2013) found that using pre-specified plans had a significant positive effect on behaviour change, however coping planning was less effective when individuals were not provided with support. Planning researchers agree that aiding individuals in developing coping plans is

advantageous, with Sniehotta et al. (2005) calling for rehabilitation services to promote and assist in coping planning.

Selection, optimisation and compensation may have utility as a model to help rehabilitation professionals guide stroke survivors through the action planning and coping planning components of the goal-setting progress. Combining the SOC model with other behaviour changes theories and techniques is common in SOC intervention research (Alonso-Fernández et al., 2015; Alonso et al., 2013; Gellert et al., 2013; Muller, Heiden, Herbig, Poppe, & Angerer, 2016). This is a logical approach given that SOC was originally proposed as a 'meta-theory' or 'meta-model', with an overarching notion of mastery and adaptation but variations in the specific manifestations of SOC were envisaged, depending on the setting within which the model is applied (M. Baltes & Carstensen, 1996; P. Baltes & Baltes, 1990). Freund and Baltes (2000) therefore state that the model must be embedded within a theoretical framework before it can be applied to a specific setting. SOC research to-date has typically discussed SOC use in the context of an action-theoretical framework, where SOC strategy use is implemented to achieve personal goals (Freund & Baltes, 2000; Ouweland et al., 2007). It is not surprising therefore that studies have combined SOC with behaviour change theories that also focus on goal achievement. For example, a number of studies have suggested that combinations of planning and SOC strategy use may influence health behaviour change and therefore achievement of health-related goals (Dugas, Gaudreau, & Carraro, 2012; Evers et al., 2012; Gellert et al., 2013; Reuter et al., 2010; Ziegelmann et al., 2006).

The rationale for combining SOC and planning techniques in interventions becomes clear when we consider the results of studies that have examined the relationships between planning, SOC strategy use and goal attainment (Dugas et al., 2012; Evers et al., 2012; Reuter et al., 2010; Ziegelmann & Lippke, 2007a; Ziegelmann et al., 2006). Ziegelmann et al. (2006), for example, explored the interplay between planning, SOC use and physical activity in an interviewer-assisted versus self-administered planning intervention. Following discharge from orthopaedic rehabilitation, participants were asked to select physical activities to pursue, generate an action plan for each activity, anticipate barriers to completing each activity and develop coping plans to overcome such barriers. Coping plans were coded as to whether they reflected loss-based selection or compensation. The interviewer-assisted condition resulted in better physical activity outcomes, partially due to

the action plans generated. In addition, loss-based selection and compensation coping plans predicted physical activity, over and above action planning, four weeks after discharge from the rehabilitation programme. The authors concluded that healthcare professionals could be trained in motivational interviewing approaches and use various examples of selection and compensation in order to assist patients with the generation of coping plans (Ziegelmann et al., 2006). Evers et al. (2012) agreed that helping individuals to generate coping plans would have beneficial effects, particularly when SOC strategy use was low. The authors elicited coping plans in women over 70, designed to overcome barriers to attending a specific physical activity class. Coping plans were elicited either with the assistance of an interviewer, or through a self-planning task. Participants were subsequently asked to consider whether they had used SOC strategies during the course of the physical activity programme and planning intervention. The interviewer-assisted participants generated more coping plans than those in the self-administered condition. Use of the SOC strategies optimisation and compensation were found to predict attendance at the class, over and above the number of coping plans generated. Optimisation and compensation were found to moderate the relationship between coping planning and attendance; coping plans had a stronger effect on attendance at the class when use of optimisation and compensation were low (Evers et al., 2012).

SOC strategy use has also been examined as a mediator between planning and goal attainment (Dugas et al., 2012; Reuter et al., 2010; Ziegelmann & Lippke, 2007a). Reuter et al. (2010), for example, assessed action planning, coping planning and SOC use in employees of varying ages within a railway company. The study found that planning was more beneficial to middle-aged and older adults compared to younger adults, in helping them to achieve their physical activity goal. It was concluded that this effect was due to the mediating role of SOC, i.e. higher use of SOC strategies by the middle-aged and older adults, which helped them translate their plans into physical activity behaviours (Reuter et al., 2010). Similarly, Dugas et al. (2012) found that use of compensation fully mediated the relationship between planning and physical activity goal attainment in undergraduate students. The authors suggest that planning resulted in individuals prioritising goals and preparing for use of compensatory strategies to achieve their goals. In addition SOC strategy use mediated the relationship between coping planning and physical activity goal

attainment in orthopaedic rehabilitation patients, with action planning predicting SOC strategy use (Ziegelmann & Lippke, 2007a).

Ziegelmann and Lippke (2007a) provided some rationale for the mediating role of SOC by conceptualising strategy use as the present-oriented aspect of planning, distinct from the anticipatory nature of action planning and coping planning. This is in accordance with Reuter et al. (2010) who viewed SOC strategy use as the vehicle through which plans are translated into action. Whilst the use of SOC strategies were found to be beneficial within these planning interventions, the mechanisms through which SOC strategy use might be increased were not directly tested. The studies suggest that strategy training or embedding SOC within planning interventions would be beneficial, helping individuals to identify SOC strategies that would facilitate the translation of action plans and coping plans into behaviour (Dugas et al., 2012; Evers et al., 2012; Reuter et al., 2010; Ziegelmann & Lippke, 2007a; Ziegelmann et al., 2006).

It is clear from the above research that there is interplay between SOC strategy use, planning and goal attainment. Integrating the SOC model within goal-setting interventions that include planning components (such as the G-AP framework) may have benefit for stroke survivors. As previously mentioned, rehabilitation professionals involved in evaluating the G-AP framework had difficulty implementing the coping planning component. Ziegelmann et al. (2006) suggest that coping planning should involve loss-based selection or compensation strategies and so knowledge of these constructs may guide healthcare professionals and stroke survivors in generating coping plans. Indeed, knowledge of the entire SOC model may be beneficial at all stages of planning, from goal-setting (elective and loss-selection), action planning (optimisation and compensation) and coping planning (loss-based selection and compensation). In addition, stroke survivors may have difficulty identifying barriers and related coping plans, particularly if they are early in the rehabilitation process and do not yet have experience of the difficulties they may face in, for example, the home environment. Kwasnicka et al. (2013) concluded that using pre-specified plans were particularly effective in behaviour change. The stroke-specific SOC strategies elicited from stroke survivors (chapter three) may act as pre-specified examples that can be drawn from and adapted to the stroke survivors' personal circumstances. Finally, failure to achieve goals may have negative consequences for stroke survivors during the goal-setting process. For example, evaluation of the G-AP framework found that

healthcare professionals had concerns about explicitly addressing situations where goals were not achieved, suggesting that this may have a negative impact on the individual. Scobbie et al. (2011) suggested that reframing the situation in a positive way may be a useful strategy to address this concern. Again, applying the SOC model to the planning process within goal-setting may have a role to play here. For example, the construct of loss-based selection refers to restructuring the goal system due to loss, e.g. giving up unobtainable goals and identifying new goals. Framing the non-achievement or abandonment of goals in this way represents an adaptive, rather than a maladaptive strategy as it allows for redirection towards achievable goals (Freund & Baltes, 2002a). Discussing goal non-attainment in the context of SOC may, therefore, counteract the potential negative impact on self-efficacy due to failing to carry out an action plan or achieve a goal. Based on the above, it is suggested that the Selection, Optimisation and Compensation model may provide a model which can guide planning within goal-setting in stroke clinical practice. Figure 5.2 demonstrates how SOC could be integrated within goal-setting and planning theories and interventions. Further work on establishing the implementation and efficacy of such an approach is necessary.

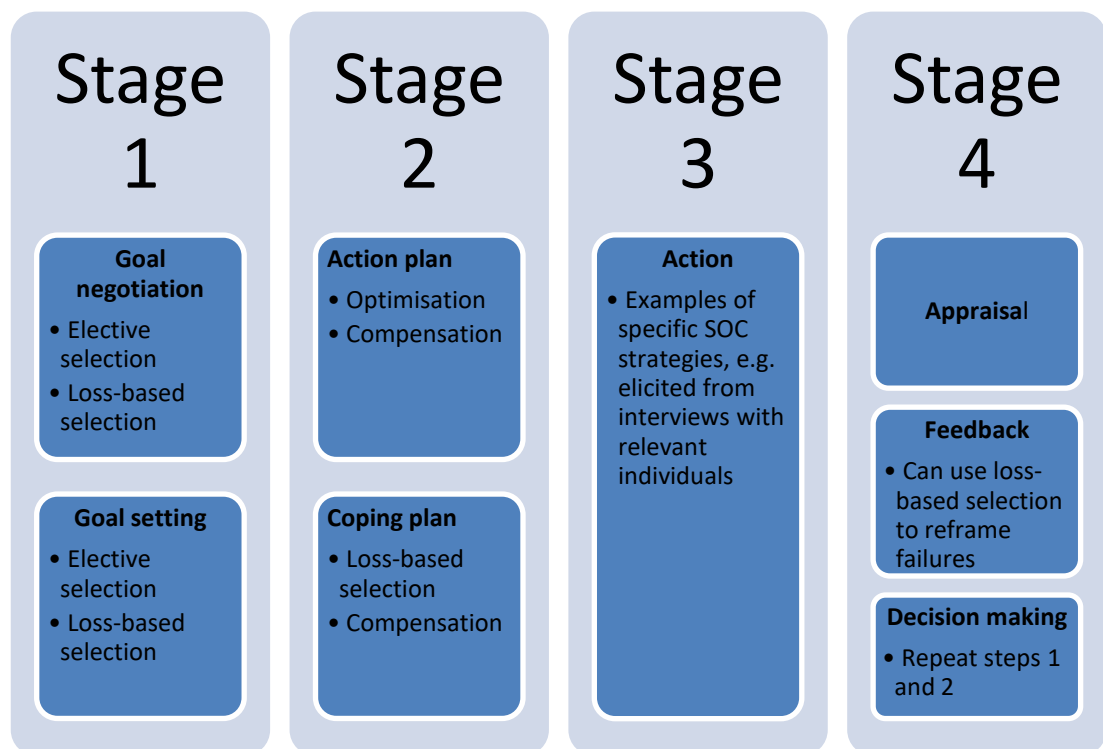


Figure 5.2: Potential integration of SOC into goal-setting and planning theories and interventions

Self-management

Stroke clinical guidelines state that stroke survivors should be provided with self-management support, aimed at increasing their self-efficacy through providing them with the skills and knowledge required to manage the long-term consequences of living with stroke (Royal College of Physicians, 2016). Briefly described in chapters one and three, five core skills were suggested to enable someone to effectively self-manage their chronic condition: problem solving, decision making, utilising resources, forming a patient/healthcare provider partnership, and taking action (Lorig & Holman, 2003). These are promoted through their incorporation into self-management interventions, designed to address and improve such self-management skills. During such interventions, for example, problem solving skills are addressed through instructing individuals in identifying their perceived problems, generating potential solutions, implementing such solutions and evaluating the process (Lorig & Holman, 2003). Implementing solutions to problems may specifically take the form of action plans. Improvements in problem solving and decision making skills may result from this process. In addition, individuals can be provided with the knowledge and skills required to make decisions about perceived changes in their health or symptoms, knowledge about where and how to access resources, and how to form effective partnerships with healthcare professionals (Lorig & Holman, 2003). Self-management programmes differ from the previously described goal-setting practices, as they often take place following the acute phase of stroke and focus on longer term outcomes through improvements in control variables, such as self-efficacy or perceived behavioural control (Jones & Riazi, 2011). For example, stroke self-management programmes which seek to improve self-efficacy may include components that allow individuals to draw upon the four sources of self-efficacy described by Bandura (1977): mastery experiences, vicarious experiences, verbal persuasion and (re)interpreting physiological symptoms (Bandura, 1977; Jones & Riazi, 2011).

A number of self-management programmes have been developed and evaluated, including those by the Stanford Patient Education Research Centre, such as the generic Chronic Disease Self-management Program (CDSMP) and condition specific programmes tailored towards arthritis (Lorig, Mazonson, & Holman, 1993), HIV/AIDS (Gifford, Laurent, Gonzales, Chesney, & Lorig, 1998), diabetes (Lorig, Ritter, Villa, & Armas, 2009) and chronic pain (Andersen et al., 2015). Available in several languages, the self-management programmes

have reported beneficial effects, with improvements including increased self-efficacy and self-reported reductions in healthcare utilisation, health distress and fatigue (Lorig, Ritter, et al., 2001; Lorig, Sobel, Ritter, Laurent, & Hobbs, 2001; Lorig et al., 1999). Such interventions typically include topics such as cognitive symptom management (e.g. relaxation), dealing with emotions, information about community services, communication with healthcare professionals, problem solving, and decision making (Lorig et al., 1999). Other components include action planning, feedback, modelling of behaviours and adaptation strategies by peers, and reinterpreting physiological symptoms (Lorig et al., 1999).

Research into self-management programmes with stroke survivors is less prevalent and stroke-specific programmes have not been tested within large-scale randomised controlled trials (Jones et al., 2013; Parke et al., 2015). The CDSMP (described above), for example, was moderately adapted for stroke survivors by adding a stroke-specific information session to the end of the six week programme (Kendall et al., 2007). Findings showed that those who only received standard rehabilitative care (control group) reported an initial decline in outcomes between three and 12 months post-stroke. In contrast stroke survivors who attended the two hour weekly sessions did not report much variation in quality of life for the domains of family roles, self-care, work productivity, and fine motor tasks in activities of daily living, over a 12 month period. Unfortunately there were no significant effects of the intervention on self-efficacy or quality of life domains including mood, social roles or energy (Kendall et al., 2007).

The CDSMP was modified to a greater extent through incorporating common themes identified by stroke survivors, carers and healthcare professionals (Damush et al., 2011). Stroke survivors attending a veteran hospital were randomly allocated to either the stroke-specific self-management intervention, or standard care condition (control). Consistent with the theoretical basis of the CDSMP, this stroke-specific intervention included components designed to improve self-efficacy, including verbal persuasion, modelling and vicarious experiences, and reinterpreting physiological symptoms. Topics included stroke education about typical post-stroke impairments, education and rehabilitation services; in addition to recovery from stroke, adapting to post-stroke impairments, adopting new roles and accessing stroke community resources (Damush et al., 2011). Components included goal-setting, action planning and feedback, which were provided through six telephone

calls over 12 weeks. Stroke survivors receiving standard care were provided with stroke education, in addition to six telephone calls where they were asked about their symptoms. There were significant differences between the groups in their self-efficacy for communicating with a physician following the programme, with stroke survivors receiving the intervention reporting an improvement whilst control recipients reported a decrease. A similar pattern was reported for the stroke-specific quality of life sub-scales of social roles and work, with the intervention participants improving whilst the control participants reported declines. There were, however, some significant quality of life differences between the groups prior to the intervention; the intervention participants reported lower scores for overall stroke-specific quality of life and the subscales of mobility, thinking, energy and work. This may have played a role in the intervention group's improvement in these constructs. Unfortunately there were no significant differences in self-management behaviours such as frequency of exercise, social, recreation or relaxation activities; self-efficacy for managing stroke symptoms; or other aspects of quality of life.

Going beyond modifications to the Stanford CDSMP, Jones and colleagues developed the stroke-specific 'Bridges' self-management programme (Jones, 2017; Jones et al., 2016; Jones et al., 2009; McKenna et al., 2015). Again, based on the construct of self-efficacy, the programme takes a workbook approach and draws on previous qualitative work with stroke survivors. Workbook sections include vignettes describing stroke survivors who have experienced a range of post-stroke difficulties. Experiences described include strategies implemented by stroke survivors to cope with common post-stroke problems and examples of different strategies used to maintain and enhance activity and participation. A diary section is also included such that stroke survivors can set and record small personal goals each week. In addition, the start of the workbook requires stroke survivors to reflect on their own personal successes. The workbook programme was designed to incorporate mastery, vicarious experience and feedback, as per the suggested determinants of self-efficacy. Although the programme has been the subject of several further research projects including development of the intervention for use in a group setting, updates to ensure it is accessible for those with cognitive and communication difficulties, and integration into one acute stroke unit in London, much of the evaluation of the programme is still ongoing (Jones, 2017). An initial evaluation with only 10 participants found some improvements in self-efficacy, however self-efficacy had begun to improve before baseline and prior to the

introduction of the workbook (Jones et al., 2009). In addition, no improvements were found in functional activity, participation or mood. Further evaluation has consisted of small feasibility studies, during which 12 stroke survivors and 40 stroke survivors received the intervention per study (Jones et al., 2016; McKenna et al., 2015). During the former, the Bridges stroke self-management programme (Bridges SSMP) was delivered for one hour weekly over six weeks (McKenna et al., 2015). A control group was formed by stroke survivors receiving standard care consisting of information on stroke, rehabilitation input from healthcare professionals, goal-setting, discharge planning, and advice on other services and benefits. There were no clear overall benefits of the self-management programme; for example, the control group showed greater improvements in mood following discharge, whereas the Bridges SSMP group showed greater improvements in social integration and functional ability. In addition, the Bridges SSMP group showed more improvements in self-efficacy upon completing the sessions, however, this decreased at follow up three months later whereas the control group demonstrated further improvements (McKenna et al., 2015). Another feasibility study using cluster-randomisation of community rehabilitation teams allocated 40 participants to receive the Bridges SSMP, compared to standard rehabilitative care. No significant differences were found on any of the outcome measures including self-efficacy, mood or functional ability (Jones et al., 2016).

A number of other stroke-specific self-management interventions have been developed, and summarised by several systematic reviews (Fryer et al., 2016; Lennon, McKenna, & Jones, 2013; Parke et al., 2015; Warner, Packer, Villeneuve, Audulv, & Versnel, 2015). In addition to the self-efficacy based interventions described above, programmes have been developed based upon other control variables, constructs and techniques such as perceived control, problem solving, and proactive coping planning. Using the construct of perceived control as a theoretical basis, Johnston and colleagues created the stroke workbook, designed to increase perceived control by providing information, teaching coping skills and guiding self-management tasks (Frank, Johnston, Morrison, Pollard, & MacWalter, 2000; Johnston et al., 2007; Morrison, Johnston, MacWalter, & Pollard, 1998). Implemented over five weeks, the workbook contained information about stroke risk factors and recovery, coping skills, task materials for goal-setting, diary sheets and an audio CD For relaxation and breathing. Telephone contact was provided to monitor goals and provide encouragement

(Johnston et al., 2007). The intervention had a significant effect on recovery from disability and confidence in recovery. Unfortunately, there were no significant differences due to the intervention for anxiety, depression, satisfaction with care or perceived control, and confidence in recovery did not mediate the effect of the intervention on recovery from disability.

The National Stroke Foundation (Australia) has also developed a stroke-specific self-management programme. 'Getting your life back on track after stroke' is a stroke-specific self-management programme that did not exclude stroke survivors with communication, cognitive or severe physical impairments (Battersby et al., 2009; Cadilhac et al., 2011). Topics covered during the eight week programme included the stroke journey, healthy lifestyles (leisure, social support, finances, working with healthcare professionals) and where to go from here. Components included practical problem solving and ability to identify and access resources in the local community. No significant differences were found between the intervention and control groups on outcome measures including quality of life, mood or engagement in life. Similarly, A. Lund et al. (2012) found no significant differences in quality of life or anxiety and depression between their lifestyle and physical activity intervention, compared to those who attended the physical activity classes alone.

Visser and colleagues (Visser et al., 2016; Visser, Heijenbrok-Kal, van 't Spijker, Ribbers, & Busschbach, 2013) also explored Problem-Solving Therapy (PST) as an intervention to improve problem solving and health-related quality of life in stroke survivors attending rehabilitation. Delivered by Neuropsychologists 1.5 hours per week, stroke survivors took part in group sessions involving goal and problem definition, generation of multiple solutions, consideration of solution consequences, and implementation and evaluation of solutions. In a randomised-controlled trial comparing the PST to standard care, task-oriented and avoidant coping improved in the PST group from baseline to six months, compared to decreases in the control group. There were no significant differences between the groups at 12 month follow up and stroke-specific health-related quality of life did not change over the 12 months for either group. There was a greater improvement in health-related quality of life using an alternative measure (EuroQol-5D-5L) between baseline and six months for the PST group than the control group, however again there were no significant differences between the groups at 12 months. The authors concluded that, in agreement with Darlington et al. (2007), flexible coping was required, consisting of

behavioural/cognitive problem solving techniques and social diversions such as distraction, seeking company and speaking to others. Unfortunately, the evidence base surrounding this type of intervention remains limited; there was no long-term effect on quality of life, and the intervention required delivery by a Neuropsychologist, which limits its application to a large number of stroke survivors in everyday rehabilitation settings.

Finally, Tielemans and colleagues (Tielemans et al., 2014; Tielemans et al., 2016; Tielemans et al., 2015) conducted detailed process and efficacy analyses of *'Plan ahead!'*, their Proactive Coping self-management intervention for stroke survivors (n=58 stroke survivors and 28 partners). The authors describe proactive planning as anticipating potential barriers and possible solutions prior to undertaking an activity. The intervention appears to be similar to coping planning, however it has a less structured approach. For example, one participant reported a goal of losing weight, however, rather than developing action plans and coping plans relating to this goal, barriers to achieving the goal were identified first. These included having no time or energy to cook healthy meals at the end of the day and not being sure if cycling a bike was yet possible. 'Proactive coping plans' were solutions identified to overcome such barriers and were developed in combination with the rest of the group, for example, preparing meals in small steps during the day, using easier ingredients such as pre-peeled potatoes and asking the physiotherapist about cycling. The intervention had no significant beneficial effects for stroke survivors and the authors concluded that the programme should not be implemented (Tielemans et al., 2015).

Evidence from the individual interventions, therefore, appears to suggest that there are no clear benefits of self-management interventions for stroke survivors, despite the recommendation for self-management support in clinical guidelines. Indeed, it was surprising that the above interventions reported so few positive effects on control variables such self-efficacy, despite several using the construct as a theoretical basis and incorporating mechanisms to improve self-efficacy into the programmes. It could be, however, that the small sample sizes present in self-management studies account for the lack of significant findings. A recent Cochrane review of self-management programmes for stroke survivors (Fryer et al., 2016) pooled the data on self-efficacy outcomes from four interventions (Hoffmann et al., 2015; Jones et al., 2016; Kendall et al., 2007; McKenna et al., 2015) and the data on quality of life outcomes from six interventions (Harwood et al., 2012; Jones et al., 2016; Kendall et al., 2007; A. Lund et al., 2012; McKenna et al., 2015; Tielemans

et al., 2015). The authors concluded that self-management programmes for stroke survivors resulted in significant improvements in self-efficacy, although the quality of the evidence was low (Fryer et al., 2016). In addition, the review concluded that there was moderate quality evidence of self-management programmes resulting in significant improvements in quality of life for stroke survivors, despite no individual study providing evidence for such beneficial effects (Fryer et al., 2016). Overall, self-management programmes had no significant effects on activity limitations, anxiety or depression for stroke survivors. The review does, however, state that individual studies demonstrated some positive results on these constructs using different measures. For example, using a larger sample size (n=100), Johnston et al. (2007) reported a significant effect of a stroke workbook intervention on recovery from disability. The above findings suggest that extending stroke self-management research past the piloting and feasibility stages and into larger trials is justified. As has been previously discussed in chapter one, however, there was considerable variation in each of the interventions within in the meta-analysis, with studies including a 90 minute self-directed task to set rehabilitation goals in activities of daily living (Harwood et al., 2012), a proactive coping and planning intervention over 10 weeks (Tielemans et al., 2015) and a lifestyle intervention based on the Canadian Occupational Performance Measure delivered over 10 months (A. Lund et al., 2012). Indeed, studies were included within the review if they contained at least one of the following components: problem solving, goal-setting, decision making, self monitoring, coping with the condition, or 'alternative method designed to facilitate behaviour change and improvements in physical and psychological functioning'. It is suggested therefore that the review can only conclude that some form of post-stroke support containing at least one of the above components is beneficial for self-efficacy and quality of life.

Overall, the existing stroke self-management literature has failed to achieve many of the hypothesised beneficial outcomes. In particular, it was surprising that self-efficacy was influenced by so few of the programmes, given that it is the theoretical basis of several self-management studies. This may be because improvement in control cognitions is not the mechanism through which self-management programmes improve outcomes in stroke survivors. It may also be that exposure to the suggested sources of self-efficacy are not effective within this population, or are not being implemented appropriately within the stroke-specific self-management programmes. Performance accomplishments are

suggested to be a source of self-efficacy beliefs, with successful 'mastery experiences', where an individual is successful in performing a behaviour or achieving a goal, improving self-efficacy (Bandura, 1977). Action planning and problem solving (similar to coping planning) have both been identified as components to increase mastery experiences within self-management (Jones, 2006; Lorig & Holman, 2003). Stroke survivors should, for example, be encouraged to set specific action plans, identify problems and make adjustments when necessary (Jones, 2006). The difficulties of action planning and coping planning within the stroke population have, however, been previously discussed in the context of goal-setting. With regards to action planning, for example, there are potential negative consequences on self-efficacy if an individual fails to achieve their action plan, with repeated failures lowering self-efficacy (Bandura, 1977). The processes through which stroke survivors within some of the self-management studies set and achieved action plans were not addressed and it is unknown how many failed to achieve their goals. However, the idea that such failure to achieve original goals is common in stroke was used as the rationale for one self-management study, based on Proactive Coping (Tielemans et al., 2014). Effective coping planning, or problem solving, must therefore accompany such action planning in order to combat potential negative effects on self-efficacy. Again, however, the difficulties of coping planning with stroke survivors have previously been identified; Tielemans et al. (2016) reported that lack of experience with stroke consequences was a barrier to effective coping planning, and a recent systematic review found that coping planning should be aided in order to achieve positive outcomes (Kwasnicka et al., 2013). Again, few self-management studies described the process through which stroke survivors were aided in their coping planning.

Vicarious experience, another proposed source of self-efficacy beliefs, consists of seeing others achieve mastery experiences (Bandura, 1977). Such modelling of goal behaviours by others can increase an individual's confidence that they can also perform the activity or behaviour. Jones (2006) suggests that video or written material that includes stroke survivor stories about successfully self-managing may act as a source of vicarious experience. The optimal methods through which stroke survivors attending self-management programmes can best be exposed to vicarious experience is, however, unclear. Harwood et al. (2012), for example, found no beneficial effects for stroke survivors of a DVD that included messages about overcoming adversity, and engaging in

meaningful activity and participation. It may be that vicarious experiences need to contain specific examples relating to the stroke survivors' particular difficulties in order to effectively improve self-efficacy.

The above difficulties, coupled with the lack of positive findings resulting from existing self-management programmes, suggests that self-management for stroke survivors should take a different focus than that of other chronic health conditions and that a new model is required to teach stroke survivors self-management skills. Stroke is a sudden onset condition, with often varied, serious and lifelong consequences that require stroke survivors to both recover and adapt simultaneously. In addition, stroke interventions need to take into account the range of post-stroke impairments and psychosocial difficulties that can be faced by stroke survivors (Jones et al., 2013). In a systematic meta-review of stroke self-management support, Parke et al. (2015) acknowledge that a new model of stroke self-management is required, which is flexible enough to respond to the various needs of stroke survivors and can be integrated across stroke care environments as stroke survivors move through stroke rehabilitation, from primary to community care and beyond.

The SOC model may be an ideal model to guide stroke self-management, through its focus on maximising gains and minimising losses to achieve goal attainment. In the context of stroke, the self-management skill of 'taking action' refers to setting goals and achieving tasks (Parke et al., 2015). Training individuals in goal-setting and using the SOC model to 'take action' and achieve these goals may be an avenue for future self-management research. Exposure to the self-efficacy source of performance accomplishments could be achieved through SOC-guided action planning and coping planning, the benefits of which have been described previously in the context of goal-setting. Implementing the SOC model in this way would provide a model to guide the process, allow for access to pre-specified stroke-related SOC strategies (as elicited in chapter three) and encourage the reframing of goal non-attainment in an adaptive way using loss-based selection and compensation. Further research is necessary to develop and explore the efficacy of self-management approaches based on the SOC model.

SOC training interventions

SOC 'training' interventions may provide some insight into how the SOC model may be used to guide self-management, although none have applied a SOC intervention to the context

of stroke. Three interventions have been developed that examine 'training' in the use of SOC strategies (Alonso-Fernández et al., 2015; Alonso et al., 2013; Gellert et al., 2013; Muller et al., 2016). Two have combined SOC training with planning, in the contexts of physical activity in older adults and goal-setting in nurses (Gellert et al., 2013; Muller et al., 2016). One intervention combined SOC training with Acceptance and Commitment Therapy (ACT) in older adults with chronic pain (Alonso-Fernández et al., 2015; Alonso et al., 2013). Within the context of planning, Gellert et al. (2013) compared an 'age-neutral' versus 'age-tailored' intervention in older adults seeking to improve or maintain their physical activity. 'Age-neutral' consisted of action planning and coping planning: setting a general physical activity goal, developing up to three action plans specifying when, where and how to achieve this goal, identifying up to three barriers and developing coping plans to address these barriers. Participants were also asked to envision former successful experiences in order to improve self-efficacy. 'Age-tailored' participants completed the above steps, in addition to SOC 'training', where they were provided with descriptions of the SOC constructs, alongside examples of each. Participants were asked to adapt the examples to their own context and write them down. Description of each construct in the physical activity context included performing an activity in a different way (compensation), including physical activity into the goal hierarchy and committing to these goals (elective selection), working on goal-relevant means to achieve these physical activity goals (optimisation) and altering physical activity goals after a loss (loss-based selection). 'Age-tailored' participants also took part in a task designed to establish the immediate and emotional effects of physical activity, in accordance with Socioemotional Selectivity Theory (SST) (Carstensen, 1995). The intervention had a significant effect on change in physical activity between six months post-intervention and 12 months post-intervention. Those who received the SOC training and SST task reported a greater increase in their physical activity during this time than those who received the planning and self-efficacy intervention only.

Similarly within the context of planning, Muller et al. (2016) implemented SOC training with nurses, involving developing a personal project based on a goal of improving coping with a job demand or utilising a job resource. Taking place over six sessions, participants chose their goal (selection), developed an action plan in an 'if-then' format to achieve the goal (optimisation) and identified alternative strategies to deal with barriers to achieving the

goal (compensation). Participants were given information about goal-setting, work stress, SOC, and action planning, alongside a diary to monitor their project. There were no significant differences between participants who took part in the intervention and those who were assigned to a wait-list control group on the outcomes of work ability, mental well-being or job control. There was, however, one significant interaction effect; the authors reported significant positive effects of the intervention on mental well-being, but only for those that reported low job control.

Finally, SOC training was incorporated with Acceptance and Commitment Therapy (ACT) in older adults with chronic pain residing in nursing homes (Alonso-Fernández et al., 2015; Alonso et al., 2013). The authors suggest that SOC complements ACT due to the latter's focus on undertaking activities in accordance with the individual's personal values and desires. SOC strategies may aid individuals in selecting, prioritising and performing such activities. Older adults with chronic musculoskeletal pain took part in either ACT plus SOC training, or a 'minimal support' group. The intervention consisted of nine, two hour sessions, with the SOC training component consisting of learning and practising coping styles based on selection, optimisation and compensation. For example, learning to prioritise activities based on personal importance and learning about compensation techniques such as alternative ways to perform an activity or reach a goal, use technical aids or ask for help. Comparing pre- and post-intervention scores, the intervention group reported improvements in use of selection strategies and pain acceptance, and decreases in pain catastrophizing, pain anxiety, depression, and pain interference with mood and walking ability. The control group experienced none of these benefits, instead reporting a decrease in the use of compensation.

Findings from all three of the interventions appear promising, however, the context, delivery and content of each intervention varied. The SOC interventions were also designed in such a way that it was difficult to determine which of the intervention components were effective in helping to achieve goal attainment. For example, the ACT and SOC combined intervention contained only two SOC sessions out of a programme of nine, and there were no significant changes in self-reported optimisation and compensation strategy use within the intervention group (Alonso-Fernández et al., 2015). In addition, SOC workshop and written material were also provided to the alternative 'minimal support' group which makes it difficult to have confidence in the positive findings. In contrast,

Gellert et al. (2013) compared SOC training and planning to an identical planning task, such that the unique effects of SOC could be examined. However, the SST task was also combined with SOC training, and the authors agree that process analyses are required for future SOC interventions in order to test the unique effects of intervention components.

An intervention for stroke survivors based on the Selection, Optimisation and Compensation model

It is clear from previous research that there is interplay between the SOC model, goal-setting and goal planning. To-date, however, no research has operationalised the SOC model into an intervention for post-stroke rehabilitation, either in the fields of goal-setting, self-management or as a 'SOC training' intervention. The above discussions have summarised the application of SOC within clinical practice, for example, to guide goal-setting. The benefits of incorporating the SOC model to guide goal-setting in stroke clinical practice remains an area that merits further research. However, the acute setting is an area that already receives much of the research and intervention focus, according to Jones (2006). A review of the qualitative experiences of stroke survivors found that the acute post-stroke recovery period was dominated by medical, physical and functional rehabilitation, with stroke survivors experiencing a lack of awareness of life after stroke and how best to manage at various stages of recovery (Pearce et al., 2015). Coming to terms with the long-term consequences of stroke is one of the top research priorities identified by The James Lind Alliance, and remains a focus of the current research (James Lind Alliance, 2016; Pollock et al., 2014).

Using the SOC model to develop a post-stroke intervention, similar to the SOC training interventions described above, may allow stroke survivors to continue setting goals and using SOC processes as they transfer from the acute to the home environment and adapt to living with the long-term consequences of their condition (Donnellan & O'Neill, 2014). In addition, Donnellan and O'Neill (2014) identify four further factors that they suggest support the suitability of the SOC model as the basis of a rehabilitation intervention for stroke survivors. A number of these factors have previously been discussed in the context of goal-setting. The authors acknowledge that the SOC model has a goal oriented focus, which may aid stroke survivors in the person-centred identification of goals and allow for a common language between stroke survivors and healthcare professionals. Use of the model may also help to reframe the use of adaptive strategies such as compensatory aids in

a positive way. Donnellan and O'Neill (2014) agree that the model encourages strategies such as loss-based selection and compensation in order to achieve goals, rather than focusing explicitly on the loss or deficit that led to their necessity. In addition, they suggest that using the model as a framework might help stroke survivors counteract self-regulatory deficits experienced after stroke, as the process of selection, optimisation and compensation operates as a self-regulatory mechanism.

Furthermore, a number of researchers have suggested that training in SOC strategy use and providing examples of the strategies may aid goal attainment and adaptation (Dugas et al., 2012; Evers et al., 2012; Gellert et al., 2013; Muller et al., 2016; Reuter et al., 2010; Ziegelmann & Lippke, 2007a; Ziegelmann et al., 2006). Unfortunately, two of the SOC training interventions experienced drop-out rates of around 52%, resulting in between 19 and 27 participants only completing the studies (Alonso-Fernández et al., 2015; Muller et al., 2016). In one case this was despite modifications following a pilot study, such as making the content easier to understand (Alonso-Fernández et al., 2015; Alonso et al., 2013). Two factors which may have responsible for such low completion rates are the intensity of the intervention, and difficulty with the concepts and other content. Alonso-Fernández et al. (2015), for example, notes that the Acceptance and Commitment Therapy components of their intervention require adequate cognitive and verbal ability, and participants did report leaving the study due to difficulty completing some of the homework tasks. Similarly, Muller et al. (2016) agrees that their goal-setting and action planning tasks may have been challenging, with participants reporting that they left the study as it did not meet their expectations. Presenting the SOC constructs and examples to individuals in a way that is understood could prove difficult, particularly if cognitive and language difficulties are present. Gellert et al. (2013) achieved better completion rates (86%), however this may have been due to the shorter intensity of their planning intervention. Participants only took part in two planning sessions and one follow up session over 12 months (Gellert et al., 2013). This is considerably less than both the personal projects planning approach and ACT combined approach, where participation involved sessions lasting between 0.5 and eight hours, for a number of weeks (Alonso-Fernández et al., 2015; Muller et al., 2016). Reasons provided for dropping out of the latter interventions included lack of time, volume of work and losing interest in the study.

Indeed, all of the SOC intervention researchers have called for further research into the optimal methods of delivering such training, including shorter interventions (Alonso-Fernández et al., 2015), reducing content but compromising with online learning and larger groups (Muller et al., 2016), and investigating interactive workshops and feedback on strategy use (Gellert et al., 2013). Muller et al. (2016) do warn, however, that short SOC interventions may not be effective as they may hinder appropriate goal selection. This may be important for contexts where individuals are required to carefully prioritise among competing goals, such as in the workplace, in comparison to relatively simple goals such as increasing physical activity. The participants in the physical activity intervention may already have been clear on their physical activity goals prior to starting the intervention. Indeed, it was noted that baseline physical activity levels, education and health were high within this study, with lower baseline physical activity participants more likely to drop-out of the intervention.

The potential benefits of using the SOC model to guide a stroke self-management intervention have also been previously described. For example, use of the SOC model to train individuals in goal-setting, SOC-guided action planning and coping to induce performance accomplishments, reframing goal non-attainment in an adaptive way and using stroke-specific SOC examples as a source of vicarious experience. Again, however, existing stroke self-management programmes have limitations relevant to the current research. A number of previous stroke self-management programmes may have been too difficult, leading to low engagement with the intervention and high drop-out rates. Johnston et al. (2007), for example, agree that their tasks may have been too difficult for some participants. The authors report that although 72% of their participants completed the intervention, a large proportion of the tasks were not completed as directed. In addition, 41% of those who dropped out did so either because they were too unwell or were no longer interested in the intervention. Difficulty completing self-management tasks has been identified as a particularly pertinent issue for stroke survivors given their potential cognitive and communication difficulties (Lennon et al., 2013). Higher completion rates were reported in the Bridges SSMP, however, the authors identify potential gatekeeping issues whereby participants were excluded by healthcare teams for no clear reasons, leading the authors to suspect less 'compliant' and more 'challenging' participants did not take part (Jones et al., 2016; McKenna et al., 2015). For example, in one study only 18% of

screened participants were judged by clinicians to be eligible for the programme (McKenna et al., 2015). Johnston et al. (2007), on the other hand, specifically attempted to exclude as few participants as possible from the intervention. This approach was also taken by Cadilhac et al. (2011) who reported a 52% completion rate for their self-management intervention. The authors do, however, note that this low figure was primarily due to drop-outs following baseline measurement but prior to commencing the intervention. Of those who did begin the programme, more completed the stroke-specific programme in comparison to the generic programme. Finally, Damush et al. (2011) achieved a 95% completion rate however this less intensive intervention consisted of just six, 20 minute phone calls over 12 weeks.

Positive findings have been reported from less intensive interventions. Harwood et al. (2012), for example, reported positive findings from a stroke-specific 'Take Charge' self-directed rehabilitation intervention, consisting of setting personal goals in a number of domains, including physical, communication, emotional/mood, information needs and secondary prevention. The session lasted 80 minutes, with stroke survivors completing a booklet detailing goals in each domain, specific objectives, and details of when and how they were going to achieve the objective. The stroke survivor was encouraged to continue to use the booklet to set their own goals as an ongoing process, and 83% completed the intervention. After 12 months, stroke survivors who completed the Take Charge session reported higher quality of life (measured via the physical component of the SF-36), and higher independence (measured via Modified Rankin Score). The authors stress that the therapist who delivered the session provided no input other than providing the booklet, listening and facilitating the process (Harwood et al., 2012). It is suggested that the stroke survivors and their families were able to take ownership of their adaptation strategies and recovery. Qualitative research suggests that 'taking charge' was important for individuals with stroke, whether this relates to solely managing their own health, or acknowledging that there were situations where assistance from others was required (McPherson, Brander, Taylor, & McNaughton, 2004). This concept seems in congruence with the SOC model.

Use of the SOC model as the basis for a brief post-stroke intervention is therefore merited, particularly if it is able to draw upon the goal attainment and planning components that were suggested to be linked to SOC processes in the context of goal-setting. In addition,

use of example SOC strategies as sources of self-efficacy beliefs may improve stroke survivors' self-management skills. A help-sheet delivery format may combat the limitations of existing SOC training and stroke self-management interventions described above. Further work on establishing the content, delivery, feasibility and acceptability of such an intervention is necessary.

Study aim

The aim of this study was to develop an intervention based on the SOC model for use in post-stroke settings. The study also aimed to conduct preliminary feasibility and acceptability analyses with a small number of stroke survivors in order to further refine the intervention.

Funding

Permission was granted for funds from the Minor Research Award provided by CHSS (chapter three) to be utilised for researcher travel.

5.2 Method

Design

A 'Life after Stroke' help-sheet was developed in order to address the concept of adapting to life post-stroke (Figure, 5.3, appendix 5.1). A help-sheet style intervention was selected, based on the finding that a lower intensity booklet was acceptable to stroke survivors, and resulted in significant improvements in quality of life and independence (Harwood et al., 2012). In order to incorporate the SOC training aspect, descriptions of selection, optimisation and compensation were provided, in a similar manner to Gellert et al. (2013) (see Materials and Measures for full help-sheet development and intervention description).

The help-sheet was piloted with five stroke survivors, using a case study design, in order to examine the help-sheet implementation, feasibility and acceptability.

Participants and recruitment

Participants were four male and one female stroke survivors, between two and 42 months post-stroke at time of interview. The mean length of time post-stroke at interview was 25.2 months (SD = 14.9). Further participant characteristics are discussed in detail within the results section of this chapter.

Participants were recruited through Greater Glasgow and Clyde stroke research nurses. Stroke Research Nurses working in NHS Greater Glasgow and Clyde were approached with details of the study. Stroke Research Nurses identified and approached stroke survivors attending outpatient stroke clinics, providing them with an information pack (appendices 5.2 and 5.3). Participants were also recruited via a pool of stroke survivors who had previously taken part in stroke research at the University of Strathclyde and had consented to being approached about future studies. Potential participants were posted a similar information pack as above (appendices 5.4 and 5.5).

The principal inclusion criteria for participants were a confirmed diagnosis of stroke (ICD10 codes 160 - 167); minimum 18 years of age; able to provide informed consent and spoke English as a first language. It should also be noted that an original inclusion criterion that stated participants should be between two and 12 months post-stroke was modified due to poor recruitment via outpatient stroke clinics. Adding in the additional recruitment method of approaching a pool of stroke survivors who had previously taken part in stroke

research at the University of Strathclyde resulted in the inclusion of participants who were a minimum of one month post-stroke, with no upper limit. The consequences of including stroke survivors who had experienced a stroke more than one year before taking part in the study are discussed later within this chapter.

The exclusion criteria were standard to any study of assessment in stroke survivors – those with substantial psychiatric or cognitive problems that precluded informed consent were excluded, as were participants with a potentially terminal medical condition. Non-English speakers were also excluded from the study. No additional assessments were performed as part of participant screening, rather the stroke research nurse judged the suitability of the participants based on the inclusion and exclusion criteria.

Participants who wished to take part in the study were asked to complete the consent form (appendices 5.3 or 5.5) and post it to the researcher. The consent form confirmed that the participant had fully read the information sheet and understood that their participation was voluntary. Upon receiving the consent form, participants were contacted by telephone, given the opportunity to ask questions and a date arranged for face-to-face consent and interview to take place.

Materials and Measures

Demographics: demographic information was collected and included age, gender, length of time post-stroke at interview, living arrangements and postcode.

The Barthel Index (Mahoney & Barthel, 1965): The Barthel Index assesses the degree of independence in performing basic activities of daily living (Mahoney & Barthel, 1965; Quinn et al., 2011). Independence in 10 self-care abilities of feeding, bathing, grooming, dressing, continence (bowels and bladder), toilet use, transfers (bed to chair and back), mobility and stairs is rated, with an overall score of 0-100. Higher scores indicate more independence. The Barthel Index is used to assess outcome in stroke (Quinn et al., 2009; D. T. Wade & Collin, 1988).

Montreal Cognitive Assessment (Nasreddine et al., 2005) (version 7.2_alternative): Cognitive impairment was measured using the Montreal Cognitive Assessment (MoCA); a score below 26 indicates mild cognitive impairment on the 30-point measure. Eight cognitive domains are covered: short-term memory recall, visuospatial abilities, aspects of

executive function, attention, concentration and working memory, language, and orientation to time and place. The measure is suggested to be the most practical tool for screening for mild cognitive impairment in stroke survivors, with excellent sensitivity and an administration time of less than 10 minutes (Blackburn et al., 2013; Lincoln et al., 2011; Nasreddine et al., 2005; Pendlebury et al., 2010).

EQ-5D-5L (Herdman et al., 2011): Health status was measured by the EQ-5D-5L, developed to provide a measure of health. The measure contains five dimensions of mobility, self-care, usual activities, pain/discomfort and anxiety/depression. Participants are asked to indicate severity of problems in each dimension, with scores ranging from '1' (no problems), to '5' (extreme). Participants also self-rate their health using a visual analogue scale ranging from 0-100, with a higher score indicating better self-rated health. Overall the measure provides a description of the participant's health profile and their overall self-rated health (van Reenen & Janssen, 2015). The EQ-5D-5L can be used in the evaluation of health care and health care interventions, including economic evaluations (van Reenen & Janssen, 2015).

Frenchay Activities Index (FAI) (Derick T Wade, Legh-Smith, & Hewer, 1985): Extended activities of daily living were measured using the FAI. The measure contains 15 extended activities of daily living including preparing meals, washing up, washing clothes, light and heavy housework, local shopping, social outings, walking outside for more than 15 minutes, pursuing a hobby, driving/using a bus, travel outings, gardening, household DIY, reading books, and gainful work. Participants are asked to indicate the frequency of how often they perform each activity in either the past three or past six months (depending on the activity in question). An overall score of 0-45 can be obtained, with higher scores indicating greater frequency of performing these activities (Derick T Wade et al., 1985). The FAI has been found to be a useful measure for assessing functional status of stroke survivors (Schuling, de Haan, Limburg, & Groenier, 1993).

Generalized Self-efficacy Scale (GES) (R. Schwarzer & Jerusalem, 1995): The GES is a 10 item measure designed to assess perceived self-efficacy. Items refer to participants' abilities to cope with difficulties and problems. Responses are scored from '1' (not at all true) to '4' (exactly true). An overall score of 10-40 can be obtained, with higher scores indicate higher general perceived self-efficacy.

SOC short-form (P. Baltes & Baltes, 1990; Freund & Baltes, 2002a) (appendix 5.6): Use of selection, optimisation and compensation strategies was measured using the generic SOC self-report tool, which contains instances of elective selection, loss-based selection, optimisation and compensation in a forced choice ‘person A-person B’ format. Respondents must select whether they would behave most like ‘person A’ the prototypical SOC example, or ‘person B’ the non-SOC example. The SOC-48 and SOC-12 ask respondents to think about their lives overall, including things they want to improve and things they are satisfied with and want to maintain. The measure can provide a score for each SOC subscale, or a SOC composite score. Responses are scored as ‘1’ when participants select the SOC strategy or ‘0’ when participants select the non-SOC alternative. Higher scores therefore indicate higher endorsement of SOC behaviours (Freund & Baltes, 2002a).

‘Life after Stroke’ SOC help-sheet

Development

The ‘Life after Stroke’ help-sheet (Appendix 5.1; Figure 5.3) contains examples of selection, optimisation and compensation, which were taken from previous qualitative interviews with stroke survivors and Discriminant Content Validation analysis (chapters three and four). For the concept of selection, the strategies that were significantly classified as selection were ranked in order of significance, using the z-scores that emerged from the previous DCV analysis, and the top eight chosen for the help-sheet (Table 5.1). Selection examples were prefaced by the statement: *It may help to change your goals so that you can focus on the most important ones. Here are some ways other stroke survivors have told us they have done this.*

The concept of optimisation contained several categories including practising, planning, learning something new, exercising and increasing effort or attention. In order to ensure that strategies selected for the help-sheet covered the breadth of such categories, between two and four strategies were chosen per category. This process was similar to that of selection, where strategies were ranked in order of significance, using the z-scores that emerged from the previous DCV analysis. The top four strategies were chosen within each of the categories of practising, and exercising and moving, and the top two within the category of planning (Table 5.2). In addition, some strategies were selected for their general nature that might appeal to a wider range of stroke survivors, rather than solely

focused particular impairment. For example, within the category of planning, the strategy *making sure you get the right balance between activities and resting* was chosen as a general strategy relating to planning and pacing. Within the category learning something new and giving more effort or attention, one top strategy was selected using the process of z-score ranking described above, alongside one further general strategy. *Developing your own memory reminders, for example, sticking reminders to the fridge or the mantelpiece* was chosen, as the other learning strategies referred to specific therapy rehabilitation (e.g. Physiotherapy, Occupational Therapy) and *continuing to do things for yourself by allowing yourself more time to do them* was chosen as a general strategy relating to giving more effort or attention. Optimisation examples were prefaced by the statement: *You may have to work towards a certain goal or activity. Here are some ways other stroke survivors have told us they have done this.*

Regarding compensation, the process was again similar to that of selection. The 60 strategies that were significantly classified as compensation via previous DCV analysis were ranked in order of significance using z-scores, with the top 11 chosen for the help-sheet (Table 5.3). Optimisation examples were prefaced by the statement: *You may have to find another way of doing something. Here are some ways other stroke survivors have told us they have done this.*



Life after stroke

Choosing goals or activities

It may help to change your goals so that you can focus on the most important ones. Here are some ways other stroke survivors have told us they have done this:

- Spending less time at work and more time with family
- Only doing social activities that you enjoy and that are important to you, for example, going to bed and reading rather than going out socialising
- Reducing the number of activities you take part in to try and cope with fatigue
- Avoiding situations that might negatively affect your health, e.g. where you might fall
- Continuing preferred social activities but spending less time on them, for example, playing fewer games of bowls or playing 9 holes on the golf course rather than 18
- Avoiding people who make you stressed or anxious
- Giving up doing chores and tasks for other people
- Giving up activities that are too tiring, for example, doing the gardening

Figure 5.3: Life after stroke help-sheet (page 1)

Table 5.1: Selection strategies chosen for help-sheet

Selection strategy ^a

Only doing social activities that you enjoy and that are important to you, for example, going to bed and reading rather than going out socialising

Continuing preferred social activities but spending less time on them, for example, playing fewer games of bowls or playing 9 holes on the golf course rather than 18

Spending less time at work and more time with family

Giving up activities that are too tiring, for example, doing the gardening

Reducing the number of activities you take part in to try and cope with fatigue

Avoiding situations that might negatively affect your health, e.g. where you might fall

Avoiding people who make you stressed or anxious

Giving up doing chores and tasks for other people

^a Selection strategies ranked in order of z-score, with top eight selected for inclusion in the help-sheet.

Table 5.2: Optimisation strategies chosen for help-sheet, with reasons

Optimisation strategy	Reason for inclusion
Category: Practising	
Repeatedly practising tasks such as getting in and out of the shower	Most significant optimisation strategy in the category of practising, classified via DCV analysis
Training your concentration with mental tasks such as crosswords and jigsaws	Most significant optimisation strategy in the category of practising, classified via DCV analysis
Practising using your senses, for example reaching for objects in a bucket of sand to help feeling in your hands (Most significant optimisation strategy in the category of practising, classified via DCV analysis
Repeating certain movements frequently, for example, hand exercises	Most significant optimisation strategy in the category of practising, classified via DCV analysis

Category: Planning

Thinking about things and planning in advance, for example planning what to take into the shower to avoid having to come in and out more than once

Most significant optimisation strategy in the category of planning, classified via DCV analysis

Planning your day for when you'll be at your best, for example if you are most awake and alert in the mornings then plan to have important meetings at this time

Most significant optimisation strategy in the category of planning, classified via DCV analysis

Making sure you get the right balance between activities and resting

Chosen as a general strategy relating to planning and pacing^a

Category: Learning something new

Learning new ways to relax, such as walking or meditation

Most significant optimisation strategy in the category of learning something new, classified via DCV analysis

Developing your own memory reminders, for example, sticking reminders to the fridge or the mantelpiece

Chosen as other learning strategies referred to specific therapy rehabilitation (e.g. Physiotherapy, Occupational Therapy)

Category: Exercising and moving

Doing exercise when you have spare time, for example, physiotherapy exercises when watching TV at night	Most significant optimisation strategy in the category of exercising and moving, classified via DCV analysis
Choosing a new exercise, for example, an exercise class designed for stroke survivors	Most significant optimisation strategy in the category of exercising and moving, classified via DCV analysis
Practising balance and movement using Wii Fit and other computer games	Most significant optimisation strategy in the category of exercising and moving, classified via DCV analysis
Exercising more to improve strength, fitness or for rehabilitation	Most significant optimisation strategy in the category of exercising and moving, classified via DCV analysis

Category: Giving more effort or attention

Continuing to do things for yourself by allowing yourself more time to do them	Chosen as a general strategy relating to giving more effort or attention
Continuing to use your weaker hand rather than giving up using it altogether	Most significant optimisation strategy in the category of giving more effort or attention, classified via DCV analysis top

^a Strategy was originally identified as a significant optimisation strategy, classified via DCV analysis. This was, however, subsequently identified as an error after implementation of the help-sheet. The strategy will therefore be removed from the optimisation category in future applications of the help-sheet. Chapter four correctly states that this strategy was not significantly classified as either selection, optimisation or compensation following DCV analysis.

Table 5.3: Compensation strategies chosen for help-sheet

Compensation strategy^a

Choosing an alternative way of doing an activity, for example having a shower or using a basin to wash when you are unable to get in and out of the bath

Using aids to help you with everyday activities, from walking aids, handrails and raised beds to reading aids such as clip lights and magnifying glasses

Seeking assistance from family, friends or carers with tasks such as eating, dressing, bathing and looking after body parts, e.g. getting a chiropodist to cut your nails, going to the hairdresser for a blow dry or hiring a care assistant

Changing the way you do everyday tasks, for example, hanging washing inside or in a greenhouse rather than on the washing line, or sticking nail clippers to a work surface in order to cut nails

Using speech and language therapy aids such as pencil grips and conversation booklets

Cutting up food into small pieces before starting to eat

Seeking help to understand documents and official letters

Learning and practising new ways of doing things, such as special dressing techniques taught by occupational therapists

Lifting lighter items with your affected hand and heavier items with your unaffected hand

Using gadgets to help with everyday activities, from trolleys to transport items about indoors, to kitchen gadgets such as a potato peeler or a slow cooker

Doing tasks using the unaffected side of your body when you are no longer able to use the affected side at all

^a Compensation strategies ranked in order of z-score, with top 11 selected for inclusion in the help-sheet.

Procedure

Ethical approval was obtained from the NHS West of Scotland Research Ethics Committee 3 under the title 'Examining the process, feasibility and acceptability of the 'Selection, Optimisation and Compensation (SOC)' help-sheet intervention for stroke survivors' (appendices 5.7-5.8). NHS management approval for the study was obtained from NHS Greater Glasgow and Clyde Research and Development team. The University of Strathclyde was the study sponsor. An information letter was sent to each participant's GP, informing them about the aim of the study and providing researcher contact details for further information (appendix 5.9).

Visit one

Participants took part in the study in their own homes. Prior to commencing the study, the study procedure was explained and demographic information recorded, including age, gender, postcode, education history and living arrangements. Visit one followed a semi-structured interview approach, with the procedure discussed below (see also appendices 5.1 and 5.10). The visits were recorded using a small digital recorder.

Selection

First, selection was introduced using the following prefix and questions:

"Some stroke survivors experience difficulty following a stroke and because of this they might have to give up some activities, focus on their most important ones or choose new goals or activities.

- *Do you think this is something that you have done/might do since having a stroke?*
- *Can you tell me more about how you feel about doing this?*
- *Have you had/can you think of any difficulties doing this?"*

Stroke-specific selection strategies were then presented using the help-sheet (Figure 5.3, Appendix 5.1). The participant and researcher discussed the strategies, and the participant was subsequently asked:

- *"Do you think you might like to try any of these/do they interest you?"*
- *Can you pick one of these and see if you can try it over the next two weeks?"*

Optimisation

This process was repeated for optimisation, using the following prefix:

“The next thing I would like to talk about is how stroke survivors work towards achieving goals and activities. There can be many different ways of doing this.”

Again, following a discussion about optimisation strategies, participants were presented with optimisation strategies using the help-sheet. Participants were asked the same questions regarding choosing optimisation strategies as with selection.

Compensation

Finally, compensation was introduced using the following prefix:

“Sometimes stroke survivors find they are no longer able to do things the way they used to, so they either change the way they do it or accept some form of help.”

Again, following a discussion about compensation, participants were presented with compensation strategies using the help-sheet. Participants were asked the same questions regarding choosing compensation strategies as with selection and optimisation.

Participants could select strategies on the help-sheet to try, or come up with their own based on the SOC constructs discussed. Participants were left with a personalised copy of the SOC help-sheet (appendix 5.1).

Participants also completed up to six short measures: the Barthel Index, Montreal Cognitive Assessment, European Quality of Life measure, Frenchay Activities Index, Generalized Self-efficacy Scale and the Selection, Optimisation and Compensation short-form measure (appendix 5.6). A summary of each measure is provided below. This study aimed to examine the acceptability of the intervention; therefore it was not the purpose of the study to examine changes in these measures over time. Rather, information such as participants' acceptability of completing such measures was recorded.

Visit two

Visit two also followed a semi-structured interview approach, with the procedure discussed below and presented in appendix 5.11.

Selection

First, participants were asked to discuss their experience of using selection strategies:

“Last time we met we spoke about some ways that stroke survivors have changed the way they do things since having a stroke. Some stroke survivors experience difficulty following a stroke and because of this they might have to give up some activities, focus on their most important ones or choose new goals or activities. You chose to try doing this.”

The following questions were used as a guide to this discussion:

- *“Did you try doing this?”*
- *Were there times when it came in useful?”*
- *What were the outcomes of doing this?”*
- *Do you feel you benefited from doing this?”*
- *Did you have any difficulty doing this?”*
- *Were there any things that made it difficult for you to do this?”*
- *Did doing this make you feel more confident in adjusting to your stroke?”*
- *Would you like to say anything else about it?”*

Optimisation

The above questions were also used to guide the optimisation discussion, using the following prefix:

“We also spoke about how stroke survivors work towards achieving goals and activities. You chose to try doing this.”

Compensation

Finally, the above questions were also used to guide the compensation discussion, using the following prefix:

“We also spoke about when stroke survivors find they are no longer able to do things the way they used to and so they either change the way they do it or accept some form of help. You chose to try doing this.”

An acceptability questionnaire was given to all participants at the end of the study, to be posted back to a separate member of the research team (appendix 5.12). This questionnaire asked for participants’ opinions about whether they understood the help-sheet and whether they found it useful, alongside the following questions:

- 1) Did the visits and help-sheet change the way you acted?
- 2) Did the visit and help-sheet make you feel more confident in adjusting to life after a stroke?

- 3) Did you find the experience tiring?
- 4) Did the visits and help-sheet change the way you thought about life after a stroke?

Participants were provided with a debrief information sheet at the end of the study (appendix 5.13)

Analysis

The research aim was to develop the SOC help-sheet intervention and examine its acceptability and feasibility. Acceptability data was therefore collated from the participants' experiences about using the help-sheet, both in the form of an anonymous questionnaire and researcher notes. Feasibility was examined through recruitment data and time taken per session.

5.3 Results

Participants

The help-sheet was piloted with a small sample of stroke survivors in order to refine the intervention and explore acceptability and feasibility issues. Participants were four male and one female stroke survivors, between two and 42 months post-stroke at time of interview. The mean length of time post-stroke at interview was 25.2 months (SD = 14.9). Participants were aged between 58 and 71 years, with a mean age of 64.6 (SD = 6.0). Three of the participants lived alone whilst two lived with their spouse/partner. Participant characteristics are displayed in Table 5.4.

Table 5.4: Participant characteristics

Participant (number) ^a	Edith (1)	Ray(2)	James (3)	Brian (4)	Charles (5)
Gender	Female	Male	Male	Male	Male
Age	71	70	65	58	59
Living arrangement	Alone	With spouse	Alone	With spouse	Alone
Length of time post-stroke (months)	2	24	42	25	33
Scottish Index of Multiple Deprivation (SIMD) quintile ^b	1	3	5	1	1

^a Pseudonyms were created for participant anonymity.

^b The Scottish Index of Multiple Deprivation quintiles can be calculated from participant postcodes and refer to the area in which they live, in terms of employment, income, health, education, access to services, crime and housing. Quintiles range from 1 (most deprived) to 5 (least deprived).

Feasibility

Participant recruitment originally took place via Stroke Research Nurses and the Scottish Stroke Research Network. Unfortunately, only one participant was recruited via this method over five months. The Stroke Research Nurses were recruiting from one weekly clinic, and reported that recruitment was slow due to a high number of ineligible patients that were either too frail, had experienced Transient Ischemic Attacks or had no residual post-stroke difficulties.

The one participant recruited via the original method represented a 9% response rate from the information packs distributed by the Stroke Research Nurses. The recruitment method was therefore modified and potential participants were approached from a pool of 10 stroke survivors who had previously taken part in research at the University of Strathclyde. Of these, five responded and four were entered into the study. One potential participant was deemed too unwell to take part and was not consented into the study. Whilst this method was successful in that the target number of participants were recruited, alternative recruitment methods should be sought for future research in order to ensure that the sample is not self-selecting and is representative of the general stroke population. Each interview session took around 20-30 minutes to complete.

Implementation

Individual descriptions of the implementation of the help-sheet with each participant are provided below, alongside a table detailing participant scores on each measure (Table 5.5). Overall, only one participant (Edith) selected to try some of the strategies and report back after two weeks. This participant, however, later experienced fatigue and felt they could not continue with the study. No other participants selected to try any of the strategies. Potential reasons are discussed within the implementation description for each participant, below, with general implications discussed later in the chapter.

Table 5.5: Participant scores on each measure

Measure	Participant (number)^a				
	Edith (1)	Ray (2)	James (3)	Brian (4)	Charles (5)
Barthel Index	90	95	100	100	95
EQ-5D-5L	16	7	12	10	-
EQ-5D-5L Visual Analogue Scale	70	90	60	60	-
SOC-SF	4	4	10	7	-
Frenchay Activities Index	17	17	27	-	-
MoCA	18	-	-	-	-
GES	33	-	-	-	-

^a Pseudonyms were created for participant anonymity.

Participant 1: Edith¹

Edith was a 71 year old female who lived alone, having experienced a stroke two months prior to the intervention. She was functionally independent according to her score on the Barthel Index, only requiring some assistance with stairs and transferring from a bed to a chair. Edith also reported high generalised self-efficacy. Edith had low scores on the SOC measure, identifying with two of the optimisation strategies, one of the elective selection and one of the loss-based selection strategies. This may, however, have been due to difficulty completing the questionnaire, as Edith indicated that she found the questions

¹ Pseudonyms were created for participant anonymity.

confusing. This may also have been due to the cognitive impairments experienced by Edith, with difficulties in visuospatial/executive function, attention, language and delayed recall and orientation according to the MoCA. Edith also received a low score on the Frenchay Activities Index, carrying out activities of daily living but few social/recreational activities. Edith did not wish to complete any further measures, which consisted of health status and depression, as she felt the process was becoming too much for her.

Upon discussing selection, Edith did not feel she had to give up any activities due to experiencing a stroke. Edith still reported taking part in fitness classes and couldn't identify giving up any activities. She reported being slower with activities such as housework but used the strategies of slowing down and pacing herself. She also reported some balance difficulties but stated she was happy slowing down. Upon looking at the help-sheet, Edith stated that she always tried to avoid people that make her stressed and anxious and relayed stories about previous incidences.

Upon discussing optimisation, Edith reported that she didn't practice anything but did plan in advance, e.g. for an upcoming trip and everyday activities. Edith reported that there was nothing in the optimisation section of the help-sheet that interested her.

Upon discussing compensation, Edith reported she was going to buy a lighter vacuum cleaner as the current one was becoming too heavy. She also reported that the strategy of clip lights would be useful and that she was going to purchase some. Edith didn't feel any other compensation strategies were necessary. Edith agreed to keep the help-sheet and be contacted again for a follow up visit, however upon contact two weeks later Edith withdrew from the study due to fatigue. The session lasted 30 minutes.

Participant 2: Ray

Ray was a 70 year old male who lived with his spouse and experienced a stroke two years prior to the intervention. He was functionally independent, only requiring some assistance with transferring. Similar to Edith, Ray also had low scores on the SOC measures, identifying with three optimisation strategies and one loss-based selection strategies. Ray also had a similarly low score on the Frenchay Activities Index as Edith, although this appeared to be due to the fact that his spouse performed all of the household activities. Ray was able to do light gardening and have travel and social outings. Ray scored low on the EQ5DL measure, indicating good health, and only had slight problems with walking

about and usual activities, reporting high self-rated health. The participant did not complete measures for MoCA or generalised self-efficacy.

Upon discussing selection, Ray indicated that he had cut down gardening, fishing and doing tasks such as gardening and maintenance for others. However Ray also indicated whilst he performed activities at a slower pace, he was coping fine and that everything had gotten easier as he progressed through recovery. Upon discussing optimisation Ray indicated that he no longer strived to do new things as taking his time with activities was sufficient and that he had adjusted to life post-stroke. Ray's wife also reported that she knew Ray would no longer improve and that they had adjusted and were content with current situation.

Ray reported some previously adopted compensation strategies such as using a rotavator to turn soil in the garden, assistance from his wife with difficult dressing tasks, carrying things using his stronger hand and using handrails. Again, he did not see the need for further strategy use and stated that there was nothing on the list that interested him. Ray agreed to keep the help-sheet but did not feel he would try anything from it. This reluctance to utilise any of the strategies may have stemmed from the fact that Ray reported that he was coping well post-stroke, had previously adopted SOC strategies, and had high self-rated health. The session lasted 25 minutes.

Participant 3: James

James was a 65 year old male who lived alone and had experienced a stroke three and half years previously. James was functionally independent according to the Barthel Index and scored higher than previous participants on the Frenchay Activities Index and SOC measure. With regard to regular activities, James was able to take part in activities of daily living, social outings and hobbies but outsourced gardening and heavy housework to a paid service. James identified with three instances each of elective selection, loss-based selection and optimisation and one of compensation. James also reported moderate difficulties with walking and usual activities, and slight difficulties with washing, dressing, pain, discomfort, anxiety and depression.

Upon discussing selection, James reported that he had used most of the strategies listed on the help-sheet, however, many of these were through necessity rather than choice. James reported that stroke survivors were often forced into giving up activities in order to concentrate on others very quickly post-stroke, often within the first couple of months.

James reported that he did indeed spend more time with his family, only did activities that he enjoyed (due to the difficulties entailed when he had to plan activities in advance) and gave up doing chores and tasks for others. James felt that the help-sheet covered many things regarding selection. James expressed previous difficulties with setting goals immediately post-stroke, as he didn't know what he could and could not do. He felt the process was trial and error but quickly discovered that doing some activities, such as gardening, would be counterproductive.

Upon discussing optimisation, James reported initial difficulties pacing, particularly with walking, but felt he was now able to do this. James also reported using other optimisation strategies like going to his fitness class at a particular time of day, when he had the most energy. James also reported that he already used a number of compensation strategies, for example employing a gardener, housekeeper and helper to do DIY and household tasks. James did not wish to try any of the help-sheet strategies, as he felt he had adapted well already. The reluctance to utilise any of the strategies may, again, have stemmed from the fact that James had previously adopted a number of SOC strategies and reported doing so earlier post-stroke. Overall, James reported that most adaptations had occurred by two months post-stroke, which was when his son returned to his own home. James reported that there were some things he had only recently started to think about but he couldn't remember off-hand what they were. The session lasted 30 minutes.

Participant 4: Brian

Brian was a 58 year old male, who experienced a stroke two years previously. He lived with his spouse and children and was functionally independent. Brian differed from the previous two participants in that he did not report satisfaction with his post-stroke adjustment.

Although he was independent in basic activities of daily living and reported taking part in a range of extended activities, he also reported difficulties with regards to his self-reported health and health-related quality of life; indicating problems performing usual activities and being moderately anxious or depressed. Furthermore, through the discussion it emerged that he perceived he had given up a lot following his stroke, changing from an independent individual who was an active member of the community, helped all of his neighbours, and took part in a number of physical activities and hobbies such as cycling, hill-walking and fishing. Brian stated "I had to give up quite a lot. I can't do anything now without my wife. I'm scared to go anywhere. I'm still scared to this day to go anywhere without a

companion...my wife's had to change too...normally I'm independent and do it myself...it's quite hard." Brian frequently made reference to these changes, the things he had given up and that he found this difficult.

Brian reported high SOC use, identifying with one elective selection strategy and two of each of loss-based selection, optimisation and compensation. When discussing selection, Brian reported giving up a great deal, however later reported still participating in hobbies such as fishing. The main difference appeared to be that there was always a friend or family member present during these tasks, whereas they would previously have been carried out alone. Brian reported that he had used a few of the example selection strategies since having his stroke, including spending more time with his family, giving up doing chores and tasks for other people, reducing the amount of activities due to fatigue, and avoiding people who made him stressed or anxious. Brian couldn't identify any further strategies he would like to try.

When discussing optimisation, Brian reported previous use of some of the example strategies such as walking around the block to build up to his walking goal. Brian also planned his activities in advance, for example, when he wanted to go fishing. Brian didn't feel they would find any of the example optimisation strategies useful.

When discussing compensation, Brian reported already using walking aids and asking family for help but felt he didn't need any further compensation strategies. Brian identified balance and concentration as ongoing problems but felt still able to carry out his hobby of fishing. Brian did not feel anything on the help-sheet would be useful for him at his current stage of recovery. He reported feeling very lucky since having his stroke, in that he had little functional impairment. However, he felt it would be useful for other stroke survivors. Brian did not wish to try out any of the strategies therefore a second visit was not arranged. The session lasted 20 minutes.

Participant 5: Charles

Participant Charles was a 59 year old male who lived alone and who had experienced a stroke two and a half years previously. He scored high on the Barthel Index, with only some difficulties climbing stairs. Charles, however, subsequently self-reported severe problems walking about, moderate problems washing and dressing and that he was unable to perform his usual activities. Charles also reported slight pain, discomfort, anxiety and

depression. Charles was unable to complete the remaining measures due to cognitive difficulties and a reading impairment.

Upon discussing selection, Charles reported that all of his hobbies had stopped and that he had tried to adapt. Charles discussed changing his priorities to everyday activities, such as getting up, dressed and having something to eat. Charles reported he already used some of the example selection strategies such as spending more time with his family, doing less to cope with fatigue, avoiding potentially negative health situations and giving up doing things for others.

Upon discussing optimisation, Charles said that he had not set any goals as he concentrated on getting himself better. He had practised writing but was unable to write, however he did practise using the stairs and used a hand ball for hand exercises. He also reported planning events such as going to a family party. Charles reported using more time and effort for activities and planned when to take a rest and how to perform activities such as getting dressed.

Charles reported using some of the compensation strategies such as asking for help and using gadgets in the kitchen and walking aids. Charles stated that the doctor had told him he wasn't going to get any better so he had a different lifestyle now and tried to keep it stress free. Regarding the help-sheet, Charles didn't want to retain the help-sheet as he was unable to read it. He felt that it wouldn't have been of use immediately post-stroke as people were focused on surviving, however thought it may be useful to stroke survivors once they returned home. The session lasted 25 minutes.

Acceptability

As seen in Tables 5.5 and 5.6, there were a number of measures that could not be completed by participants. This was either due to fatigue, reluctance or inability to complete self-report measures due to visual/reading impairments. The brief measures which could be completed with researcher assistance, such as the Barthel Index, were completed more often. Four participants completed the SOC measure, however expressed confusion around what the questions meant. Anonymous feedback reported that some of the questions were the same but worded differently, and that they didn't understand some of them. Future research should seek to identify which outcomes a SOC intervention may be able to influence, and aim to ensure related outcome measures are suitable for stroke survivors.

Table 5.6: Summary of measures

Measure	No. participants able to complete measure	Mean (SD)	Range
Barthel Index	5	96 (4.18)	90-100
EQ-5D-5L	4	11.25 (3.77)	7-16
EQ-5D-5L Visual Analogue Scale	4	70 (14.14)	60-90
SOC-SF	4	6.25 (2.87)	4-10
Frenchay Activities Index	3	20.33 (5.77)	17-27
MoCA	1	18	-
GES	1	33	-
Acceptability questionnaire	2	-	-

Two participants completed the acceptability questionnaire. Both participants reported that they understood and found the SOC discussion helpful. One participant reported that they understood the help-sheet whereas one reported that they only understood some of it. Both participants reported that they found the help-sheet helpful. Participants either felt the help-sheet changed the way they acted on some things, or not at all. One participant found it difficult to concentrate during the visits however the other reported

that it was not tiring. One participant reported that the help-sheet made them more confident in adjusting to life after stroke while the other did not. Finally, one participant reported the help-sheet changed the way they thought about life after a stroke, while the other did not. It should also be noted that as no participant opted to try the strategies, these may reflect socially desirable responses.

5.4 Discussion

This study sought to develop and examine the feasibility and acceptability of an intervention for stroke survivors based on the SOC model. The help-sheet intervention included discussion of the concepts of selection, optimisation and compensation and stroke-specific examples of each strategy type. Overall the help-sheet appeared to be acceptable to the stroke survivors who provided feedback. However, no participants selected to try any of the strategies and report back after two weeks, indicating both issues with its implementation and that caution must be applied when drawing conclusions from the acceptability findings. For example, one participant reported that they found the help-sheet beneficial, despite not attempting any of the strategies, whilst at the same time reporting that they did not always understand the help-sheet. Despite making the acceptability questionnaire anonymous, there may be an element of social desirability in the participant responses about the acceptability of the intervention.

There were also some help-sheet implementation barriers that raise important issues regarding future implementation. The one participant that was in the early stages of post-stroke recovery reported few difficulties and did not feel that any of the strategies would be useful post-stroke. Despite this, cognitive difficulties were apparent from the Montreal Cognitive Assessment, and she later withdrew from the study due to fatigue. This suggests that cognitive impairment will play a role in understanding the SOC concepts, particularly in self-evaluation of post-stroke impairments and how the strategies can be applied. One further participant experienced cognitive and communication impairments that prevented him from reading the help-sheet. Clearly, there is a need for further manifestations of a SOC intervention for those with cognitive difficulties. It may be that SOC is not suitable for those with more severe cognitive and communication impairments. Alternatively, it may be that the materials and concepts can be modified further, following guidelines for those with communication difficulties (Dryden, 2015; National Institute for Health Research Clinical Research Network: Stroke, 2014; Stroke Association, 2012). A co-production

approach could be utilised for this aim, with stroke survivors providing input on the materials and intervention delivery. In addition, a structured goal-setting approach, such as the Bangor Goal-setting Interview, may be beneficial in order to explore and set person-centred goals, examine progress and problem-solve barriers (Clare et al., 2012). Overall, this may require a longer intervention period; taking into account the need for assessment of capability and person-centred goals, issues such as fatigue and possible multi-disciplinary input.

The remaining study participants were all further on within their post-stroke journeys, having experienced a stroke between two and three and a half years previously. This was recognised as a barrier to the help-sheet implementation as two felt they had already adjusted well to their post-stroke impairments and were content with their current situation. None of these participants selected to try any of the strategies listed on the help-sheet. This may suggest that modifications are required to ensure the intervention can target remaining post-stroke difficulties. Despite still experiencing some difficulties, stroke survivors in the current study were reluctant to try new strategies. This may have been, as some suggested, because they felt they were no longer going to improve and were focusing on functional impairments. Several participants also, however, reported difficulties setting goals, and the reluctance to select SOC strategies may have stemmed from this. Difficulties with selecting meaningful goals was identified as a potential problem for shorter, less intensive SOC interventions and the current study supports this conclusion (Muller et al., 2016). Further work on modifying the SOC intervention may be necessary, such that it has a greater focus on initially identifying problems and goals, before moving onto the SOC concepts and example strategies. Indeed, presenting the strategies prior to selecting a specific goal detracted from the focus of the session, as participants tended to concentrate on their previous experience of these strategies. It may be helpful to incorporate SOC training within a framework based on the International Classification of Functioning, Disability and Health (World Health Organisation, 2001). This may allow stroke survivors to identify and use the SOC concepts and example strategies to address a range of post-stroke difficulties that not only include impairments but also difficulties in activities and participation restrictions, in a structured manner.

Alternatively, the intervention may not be beneficial to stroke survivors who have already adapted to living with the long-term consequences of their stroke. In the current study, all

participants reported that they had previously adopted some of the strategies, with one participant reporting that they did so within one to two months post-stroke. Participants reported that they did so through trial and error, until they knew what worked well. This supports the suggestion that individuals are able to participate in effective coping planning once they have gained experience and knowledge of potential barriers (R. Schwarzer, 2016; Sniehotta et al., 2005). Having limited experience of life after stroke, however, emerged as a barrier to coping planning in stroke survivors (Tielemans et al., 2014; Tielemans et al., 2016) and Sniehotta et al. (2005) found that coping planning only predicted physical activity behaviour in cardiac rehabilitation patients as their experience in this area increased over time. Future research should aim to include participants earlier after a stroke event, such that the utility of the stroke-specific SOC strategies as a coping planning aid can be fully examined. Furthermore, implementation of the help-sheet during the later stages also raises an ethical question surrounding whether discussing post-stroke difficulties and encouraging participants to adopt strategies to address these is appropriate, particularly if stroke survivors have been working towards their own perception of adjustment and do not wish to disrupt their current coping. Certainly the timing of the intervention requires further research and it may be that this issue is not as relevant during the earlier stages after the initial stroke experience. Indeed, the fact that participants were on average two years post-stroke is a limitation of the current study. This was likely a result of difficulties with recruitment and is discussed in more detail, below.

Implementing the help-sheet and the concepts of selection, optimisation and compensation at an earlier stage post-stroke may also help stroke survivors in their framing of their behaviour as necessity versus choice. As indicated in the findings of the current study, participants often indicated they had been forced to adopt some of the help-sheet strategies. One participant, for example, stated that he had used most of the strategies listed on the help-sheet through necessity. This was also particularly evident in the context of another participant, who reported that he had already carried out a number of the strategies listed on the help-sheet and listed a number of behaviours that were similar to the SOC processes, in particular loss-based selection and optimisation. This participant reported giving up a number of activities, reducing the number of activities he took part in to try and cope with fatigue, avoiding situations that might negatively affect his health, e.g. where he might fall and giving up doing chores and tasks for other people. He also

continued to do activities around the house and continued some physical activities but with a companion. In addition, he reported increased effort in activities, planning in advance and occasionally using a walking aid. Despite reporting such high SOC use, being independent in activities of daily living, and taking part in a range of hobbies and activities, he reported issues with quality of life, anxiety and depression. It may be, therefore that his perception of his use of loss-based selection was negative, as he made frequent references to change/giving up and statements that he found this difficult. In contrast he did not indicate such negative perceptions about planning (optimisation) or use of a walking aid (compensation). Indeed, Ouwehand et al. (2007) suggest that optimisation and compensation appear to be the predominantly relevant strategies for combating losses and achieving successful ageing. Loss-based selection may have a differential relationship with outcomes than the other SOC strategies. For example, loss-based selection was not associated with successful ageing in one study, and was negatively associated with adherence to an exercise programme and arthritis-related health in others (Evers et al., 2012; Janke et al., 2009; Son & Janke, 2015; Tovel & Carmel, 2013). This may differ depending on the individual's perceptions regarding their reasons for employing loss-based selection. Rozario et al. (2011) suggested that those living with chronic health conditions often reframed their behaviour as an active choice despite constraints that meant an activity could no longer be performed. In contrast, however, others did not frame their behaviour as being under their control and instead recognised that their limitations forced them to give up activities (Hutchinson & Nimrod, 2012). Donnellan and O'Neill (2014) suggest that the SOC model may aid rehabilitation by reframing the use of selection and compensation as an adaptive choice, rather than a necessity. Future research should include measures of or discussion surrounding the interpretation of such strategies.

Regarding the feasibility of the intervention, recruitment in the current study was slow and participant response rate from stroke clinics was only 9%. A multi-centre study will likely be required in order to recruit a larger sample size in future studies. When examining the Bridges SSMP, Jones et al. (2016) recruited from four clinical sites over 13 months and recruited 78 patients in total. The authors performed subsequent power sample calculations and suggested that recruitment should take place from nine clinical sites per arm of the trial. Following the necessary modifications of the current intervention, piloting will be required in order to enable similar power calculations to be carried out. Regarding

improving the participant response rate, it may have been that the current study information packs, which contained eight pages of information, were off-putting to potential participants. Whilst all of the contained information was necessary as per NHS ethical guidelines, future studies should seek to ensure that study information is accessible to as many stroke survivors as possible. The recently developed resources for enabling stroke survivors with aphasia to take part in research may be of use in this regard (National Institute for Health Research Clinical Research Network: Stroke, 2014).

Whether the length of the SOC intervention is feasible within the context of stroke rehabilitation depends on the settings in which the intervention is applied and the necessary further modifications. As an intervention delivered in a community setting, 30 minutes may be acceptable and feasible. Further research is however required to determine if such an intervention would be feasible within the acute settings. Jones et al. (2016), for example, suggests that self-management programmes should be integrated within existing stroke rehabilitation routines in order to be more cost-effective. The authors found that costs for such self-management programmes varied depending on the resources used within the site, but did not measure whether staff felt it was feasible to implement. Mäkelä, Gawne, and Jones (2014), on the other hand, examined the feasibility of the Bridges Stroke Self-Management Programme within acute stroke wards and found that 71% of staff involved felt that they had enough time to introduce self-management. Similar work is necessary in order to progress stroke-related SOC research.

Strengths and limitations

This study was the first to apply the SOC model within a stroke-specific intervention and findings will greatly contribute to the evidence base and future research of SOC in the context of stroke. Difficulty with recruitment, however, was a limitation in the current study. A low response rate from stroke clinics and the suggestion that stroke survivors may be unable and unwilling to initially participate in research resulted in recruitment being modified to include longer-term stroke survivors who had previously taken part in research. The sample recruited may therefore not be representative of the general stroke population. Despite this, the sample appeared to have a range of scores on completed measures. In addition, the implementation difficulties, which will be used to modify the intervention, were similar in both the shorter and longer-term stroke survivors.

The lack of a structured framework to identify post-stroke difficulties and areas of change was a limitation of the current study. As previously discussed, this may have prevented stroke survivors from effectively identifying remaining impairments and difficulties, instead focusing on the example SOC strategies provided. Nevertheless, this finding does contribute to the SOC literature, providing support for the Muller et al. (2016) suggestion that less intensive SOC interventions may hinder appropriate goal selection. These findings can therefore be used to modify the intervention in future research.

A final limitation is that despite the SOC strategies included in the help-sheet being elicited from stroke survivors (chapter three) and further validated via the Discriminant Content Validation analysis (chapter four), there is still a lack of robust evidence into the utility of each help-sheet strategy in improving outcomes. Although stroke survivors in chapter three were using these strategies and they were categorised as selection, optimisation and compensation, there was little input from healthcare professionals as to their view into whether stroke survivors *should* be using such strategies and whether, in their experience, such strategies were helpful. It may therefore have been helpful to have multi-disciplinary input throughout the study as a whole. One Occupational Therapist and one Physiotherapist were interviewed during the qualitative interviews described in chapter three, with their responses as to what they would recommend to patients experiencing difficulties coded as selection, optimisation and compensation. Healthcare professionals could also, however, have reviewed the finalised SOC help-sheet. This would have provided further evidence as to their suitability and potential usefulness for stroke survivors.

Conclusion

This study was the first to develop and examine the feasibility and acceptability of a SOC intervention in the context of stroke. Drawing on findings from goal-setting, self-management and SOC training, a help-sheet style intervention was developed to introduce stroke survivors to the concepts of selection, optimisation and compensation. In addition, it also aimed to allow stroke survivors the opportunity to try SOC strategies elicited previously from other stroke survivors. The study identified several modifications that could be made to the intervention in order to improve its implementation and possible efficacy in future studies. This included a greater focus on the identification of potential areas of change or post-stroke difficulties, prior to introducing the SOC concepts and

strategies. Future research could aim to draw upon these findings and pilot the SOC intervention in a larger sample of stroke survivors.

6 General discussion

Summary of thesis

This thesis explored the Selection, Optimisation and Compensation model (P. Baltes & Baltes, 1990) as a model for post-stroke adaptation. *Chapter one* provided an introduction to stroke, detailing stroke prevalence and the range of potential impairments and difficulties faced by stroke survivors. It was noted that stroke mortality rates are decreasing, resulting in an increasing number of stroke survivors who are living with the long-term consequences of stroke (British Heart Foundation, 2015; ISD Scotland, 2017; Stroke Association, 2017). Stroke is a heterogeneous condition, associated with a wider range of impairments and higher odds of reporting severe disability than heart, digestive, musculoskeletal or respiratory conditions (Adamson et al., 2004). In addition to adapting to such impairments, stroke survivors often have to make lifestyle changes, deal with stroke recurrence fears and manage a range of emotions surrounding experiencing such a sudden, serious health event (Burton, 2000; Dowswell et al., 2000; Pearce et al., 2015). It is not, therefore, surprising that stroke has been described as a “complex coping situation”, with stroke survivors often perceiving that it has impacted on almost every aspect of everyday life (Burton, 2000; Carlsson et al., 2009; Dowswell et al., 2000; Salter et al., 2008).

Chapter one also provided an overview of the guidelines, action plans and policies surrounding the prevention, treatment and rehabilitation of stroke in the UK and Scotland, including: the Better Heart Disease and Stroke Care Action Plan (NHS Scotland, 2009) and its successor the Stroke Improvement Plan (The Scottish Government, 2014); National Clinical Guidelines for Stroke (Royal College of Physicians, 2016); and the Scottish Intercollegiate Guidelines Network guidelines for management of patients with stroke (SIGN 118, The Scottish Intercollegiate Guidelines Network (SIGN) (2010)). Whilst all of these policies and guidelines provide detailed and evidence-based recommendations for stroke prevention and acute care, there are fewer recommendations surrounding long-term care, and the few that do exist centre on self-management support. There are still, however, unanswered questions with regards to self-management research in the context of stroke (Jones et al., 2013; Parke et al., 2015). Stroke-specific self-management programmes do exist but have not been subjected to large-scale randomised controlled trials and their efficacy is still unclear. Such a lack of evidence relating to this stage of post-

stroke recovery is disappointing, particularly as helping stroke survivors come to terms with the long-term consequences of stroke has been identified as a top research priority (James Lind Alliance, 2016; Pollock et al., 2014).

The Selection, Optimisation and Compensation model (P. Baltes & Baltes, 1990) was introduced as a potential model to guide post-stroke adaptation, with the thesis initially focusing on reviewing previous applications of the model. In *chapter two*, therefore, a systematic review provided an overview of the use of the SOC model within the contexts of ageing and health. Following a systematic database search and hand-searching of eligible studies, 54 studies met the review inclusion criteria. The review found that the relationship between SOC strategies and outcomes were examined in a number of populations, including older adults and those with chronic health conditions such as arthritis, stroke and those undergoing orthopaedic rehabilitation. There were generally positive relationships between SOC strategy use and outcomes, however, the review revealed a range of methodological limitations within the existing evidence base. Some of these limitations surrounded SOC strategy measurement, as this varied from standardised questionnaires to interpretation of adaptations as selection, optimisation or compensation, and the reliability was often unclear. Situation/population specific measures of SOC were also lacking, which may have contributed to the finding that SOC strategy use did not predict functional ability, depression or health-related quality of life, in stroke survivors (Donnellan et al., 2012). The review also summarised the strengths and weakness of the emerging interventions based on the SOC model; however, none have been developed for use with stroke survivors and the optimal method of translating the SOC concepts into a feasible and acceptable intervention that is understood by stroke survivors remained unclear.

Following, the systematic review, therefore, a mixed methods approach was adopted. This involved qualitative exploration of SOC strategy use by stroke survivors, coupled with analysis via reliable coding and additional quantitative methods. Such an approach was deemed appropriate as it allowed for a wider breadth of findings than could be achieved using a questionnaire approach to SOC measurement. It is suggested that the generic measure of SOC strategy use is not able to capture the range of adaptations adopted by stroke survivors to cope with their post-stroke difficulties, and that alternative approaches are necessary in order to understand SOC within different contexts (Donnellan et al., 2012; Kelly et al., 2014). *Chapter three*, therefore, presented qualitative SOC, theory-based

interviews to explore how stroke survivors adapted to life after stroke. Thirty stroke survivors, between three and 65 months post-stroke, took part in a semi-structured interview. One Occupational Therapist and one Physiotherapist working in stroke rehabilitation were also interviewed. Activities and body functions from the International Classification of Functioning, Disability and Health (ICF) Core Measurement Set for Stroke (Geyh et al., 2004) were used to prompt the stroke survivors to discuss the strategies they employed to adapt to their post-stroke difficulties. Strategies were coded against the theoretical definitions of selection, optimisation and compensation strategies, with two researchers independently coding 25% of the interviews. The study concluded that, consistent with SOC strategy use in other chronic conditions, stroke survivors were found to develop a range of adaptation strategies that could be categorised according to the SOC model. These including focusing on the most important goals and activities, working towards goals and activities using a range of optimisation strategies, and employing compensatory behaviours and aids to continue functioning despite a loss of resources.

Applying a theory such as the Selection, Optimisation and Compensation model successfully is dependent upon the ability to operationalise theoretical constructs reliably. *Chapter four* therefore introduced Discriminant Content Analysis, with the aim of addressing some of the methodological limitations surrounding the analysis of SOC, and reliably determining whether the stroke-specific strategies identified in the qualitative interviews could be categorised as selection, optimisation and compensation. Ten expert judges rated the extent to which the 149 elicited post-stroke adaptation strategies matched the theoretical definitions of selection, optimisation and compensation. The expert judges were researchers and healthcare professionals working in psychology or stroke research. Wilcoxon Signed Rank tests were conducted to determine whether strategies were significantly categorised as selection, optimisation or compensation or a combination of strategies. Seventy eight percent of the stroke-related SOC strategies identified in the previous interviews were matched to the theoretical definition of at least one of selection, optimisation or compensation. Out of the 149 strategies, 18 were significantly classified as selection, 42 were significantly classified as optimisation and 60 as compensation. Five strategies were classified as more than one type of strategy. The classification of strategies using DCV methodology represents a more robust method of analysis than seen in previous SOC research. Whilst the categorisation of strategies as selection, optimisation or

compensation was similar to the coding results from chapter three, DCV analysis was able to confirm the validity of the strategies.

Combining findings from the systematic review, qualitative interviews, and DCV analysis, it was concluded that the use of selection, optimisation and compensation strategies is primarily adaptive and that adopting SOC strategies is a technique used by stroke survivors to help them adapt to changing circumstances. Evidence from goal-setting and self-management in stroke, alongside previous SOC interventions, provided insight into how the SOC model might be applied to the context of stroke. *Chapter five* therefore presented the development of an intervention based on the SOC model for use in stroke, alongside preliminary feasibility and acceptability analyses. A help-sheet based intervention was developed through reviewing the evidence surrounding stroke self-management and SOC training interventions. In addition, the stroke-specific SOC strategies identified from the qualitative interviews and DCV analysis were used as example strategies. The help-sheet was piloted with four male and one female stroke survivors, between two and 42 months post-stroke at time of interview. This study was the first to develop and examine the feasibility and acceptability of a SOC intervention in the context of stroke. The study concluded that stroke survivors at later stages post-stroke had already formed adaptation strategies, and despite experiencing some difficulties, were reluctant to try new strategies. In addition, several participants reported difficulties setting goals, and it was determined that reluctance to select SOC strategies may have stemmed from this. Further work on modifying the SOC intervention was suggested as a future step.

Overall, this thesis explored the application of the Selection, Optimisation and Compensation model in the context of stroke. A systematic review of the SOC model in the contexts of ageing and health identified a number of studies employing the model within various health conditions; however, little research was identified within the field of stroke. It was suggested that the SOC model may have utility within stroke rehabilitation due to its focus on minimising losses and maximising gains within a person-centred, goal-oriented model. Through conducting qualitative interviews and employing DCV analysis, this thesis determined that the post-stroke adaptation efforts adopted by stroke survivors could be categorised according to the SOC model. The challenge was therefore to establish how the SOC model could be used effectively within the context of stroke. Through developing, and testing the feasibility and acceptability of a stroke-specific SOC intervention, this thesis

contributed to SOC research in the context of stroke and identified directions for future research.

Implications and future directions for Selection, Optimisation and Compensation model research

The research presented within this thesis raises some important issues and implications with regards to SOC research. The first implications surround the methodology of SOC research. As discussed in detail following the systematic review of SOC within the contexts of ageing and health (chapter two), a self-report measure (SOC 48/SOC-12) was developed as a domain-general measure of SOC (P. Baltes et al., 1999; Freund & Baltes, 2002b). Chapter two provided a full overview of use of the domain-general measure, concluding that when it was utilised in older adults, there were positive relationships between use of SOC strategies and 'good' outcomes (Chou & Chi, 2002a, 2002b; Freund & Baltes, 1998, 2002b; Jopp & Smith, 2006; Okabayashi, 2014). It was also, however, noted that there was a lack of evidence surrounding the optimal way of measuring SOC strategy use in the context of chronic health. Indeed, within the context of stroke the generic measure had low internal reliability, and its use resulted in a high amount of missing data in the context of depression (Donnellan et al., 2012; Weiland et al., 2011). It may be inappropriate for use with some groups, as individuals must be able to recognise and report mental representations that are consistent with the items in the measure suggested to reflect the SOC processes. Such self-report measures may also capture more general attitudes, rather than the specific range of adaptation behaviours adopted by individuals with chronic health conditions (Kelly et al., 2014; Ouwehand et al., 2007). The systematic review (chapter two) also provided an overview of the qualitative approaches to examining SOC strategy use, reviewing several studies that conducted interviews in the context of older adults/chronic health and classified examples of adaptation strategies as selection, optimisation and compensation. However, qualitative approaches to examining SOC strategy use also experienced methodological problems; the analysis process was not always adequately described and subjective interpretations of SOC resulted in discrepancies.

Based on such an overview, it was concluded that the mixed methods approach adopted in this thesis may help to overcome the challenges faced with regards to SOC measurement. Findings from the SOC interviews (chapter three) suggest that using a qualitative method was indeed appropriate in order to elicit the wide range of creative efforts adopted by

stroke survivors, which would not have been captured via the generic SOC self-report measure. Indeed, 539 stroke-specific occurrences of selection, optimisation and compensation strategies were identified. Categories of SOC strategies identified included focussing on new goals, limiting and reducing goals, practising, planning and pacing activities, and receiving assistance in the form of help from others, using mobility aids or employing special techniques. These findings are in accordance with those of Gignac et al. (2002), who identified 3876 instances of SOC in 208 older adults with osteoarthritis. Qualitative interviews using the SOC model as an analysing framework appear, therefore, to be an effective method of highlighting the adaptiveness of stroke survivors in their efforts to adjust post-stroke. This finding has implications for future SOC research, as it both adds to a limited evidence base surrounding qualitative SOC research and demonstrates that qualitative research should be adopted in future studies where the investigation of specific SOC strategies is of interest. The systematic review highlighted only 15 studies which included qualitative SOC analysis of self-reported behaviour and none which had been conducted in the context of stroke (chapter two).

Further methodological issues emerged from the thesis that have implications with regards to future SOC research. Firstly, the systematic review highlighted that whilst most qualitative studies appeared to identify similar selection, optimisation and compensation strategies within various contexts, there were instances where behaviour was coded differently between studies. Distinguishing between optimisation and compensation emerged as a particular consistent methodological difficulty, both from the systematic review and upon reflection from the coding of the qualitative interviews. It is suggested that the strategy types can empirically be distinguished, as indicated from the DCV analysis; however, it would be useful for SOC researchers to develop and agree on a strategy codebook to ensure that analysis is consistent between studies. Secondly, the systematic review highlighted that few existing qualitative studies reported on the reliability of their analysis. Finally, the methodology of the majority of qualitative studies prevents the examination of the relationships between SOC strategy use and outcomes, demonstration of which would be helpful if we wish to promote the application of the model in the context of chronic health (Freund & Baltes, 1998).

This thesis aimed to address the above issues through exploring the use of Discriminant Content Validation analysis to establish whether the identified behaviours reflected the

theoretical definitions of selection, optimisation and compensation (chapter four). Seventy eight percent of the stroke-related SOC strategies were matched to the theoretical definition of at least one of selection, optimisation or compensation. With regards for implications for future research, this method appears to be a reliable way to improve the methodology of qualitative SOC research. There was, however, below moderate agreement using this method with regards to the strategies of selection and optimisation. As the DCV study indicated better agreement between judges with more experience of the model, future studies may be able to improve on this by using judges more experienced with SOC. Future research should build upon these findings, for example, such a technique may be useful for creating the SOC strategy codebook discussed above.

Using such mixed methods, as described above, is in accordance with more recent SOC research, where the focus appears to be moving away from cross-sectional exploration of SOC using the generic self-report measure, to introducing alternative methods of identifying and interpreting SOC strategy use and its relationship to outcomes. For example, Carpentieri, Elliott, Brett, and Deary (2017) aimed to combine qualitative identification of what they termed 'SOC talk' and quantifying this, such that they could examine relationships between SOC strategy use relating to physical function, well-being and physical functioning. Similar to Gignac et al. (2002) and the research presented within this thesis, Carpentieri et al. (2017) employed qualitative (content and narrative) analysis to identify the various ways in which older adults utilised SOC within their everyday lives. The authors were then able to split their 33 participants into groups consisting of high well-being/low physical functioning and low well-being/high physical functioning. Those in the high well-being group reported above average use of SOC, whilst those in the low well-being group reported lower SOC use. Carpentieri et al. (2017) suggests that using mixed methods allowed them to identify specific SOC behaviours from the perspectives of older adults whilst still exploring the relationship between SOC use and outcomes. In another recent study, Yuen and Vogtle (2016) applied the coding scheme developed by Gignac et al. (2002) to interviews with older adults. Through quantifying the SOC strategies identified from these interviews, Yuen and Vogtle (2016) were able to use multiple regression to explore the relationship between SOC use, multi-morbidity and disability. Current research therefore seems to support the implication of this thesis that a mixed method approach to SOC research has merit and should be adopted in future research, in order to both explore

the diverse range of SOC strategies within specific contexts and their relationship with positive outcomes.

Finally, the studies within this thesis have demonstrated that the SOC model is a potentially useful model for exploring adaptation and as the theoretical basis for an intervention in the context of stroke. Some of the rationale behind the use of the SOC model as the theoretical basis of this thesis is due to the lack of theory-based evidence as to how stroke survivors can be aided in coping or adjusting to their new circumstances. In particular, a systematic review of coping after stroke found that only four out of 14 studies referenced a coping theory or model, and that it was not possible to determine a typical coping response, nor which coping strategies were most effective (Donnellan et al., 2006). Whilst future directions for SOC research in the context of stroke are discussed later within this chapter, it is therefore helpful here to consider how the SOC model differs from other dominant models/theories, what SOC adds to the general coping and adaptation literature, and discuss how the utility of various models can be compared. These considerations all contribute to a wider discussion about the conceptual considerations of the SOC model, future directions and associated research implications.

Prior to considering where the SOC model sits, and comparing the model in relation to other goal-setting theories and within the field of coping, adaptation and self-regulation, it should be emphasised that the SOC model is described as a 'meta-theory'. It typically therefore requires incorporation within a specific theoretical framework before it is applied to a specific stage of development (P. Baltes, 1997; P. Baltes & Baltes, 1990; Freund & Baltes, 2000). This is often seen as one of the benefits of the model, in that it can extend a broad scope; the selection, optimisation and compensation processes can be specified within different theories and various domains of functioning (Boerner & Jopp, 2007). As such, however, it is not possible to conceptualise the SOC model as belonging within one specific field. Consideration can, however, be given as to how the SOC model can be conceptualised or integrated within a range of theories and frameworks, in order to consider future directions for SOC model research.

Due to its development and research within the field of lifespan development, the SOC model has had limited comparison to other models or theories within the context of coping and adaptation. However, the most common application of the model, and indeed the

approach utilised within this thesis, is on active and conscious SOC strategy use within an action-theoretical approach (P. Baltes, 1997; Freund & Baltes, 2000). Such an action-theoretical framework considers the definition and operation of the SOC processes within the field of personal goal-related action, i.e. goal selection and goal pursuit (P. Baltes, 1997; Freund & Baltes, 2000, 2002b). Researchers have therefore indicated that the SOC model complements models of coping, problem solving, self-development and goal adjustment, and that future research could consider the integration of such models (Jopp & Smith, 2006). Furthermore, whilst there have been few direct comparisons of the SOC model with coping models, it has been recognised that as a life span model it can address both general developmental self-regulation and coping with major life change and loss (Boerner & Jopp, 2007; Haase et al., 2013). As such, there have been attempts to compare the SOC model with other developmental regulation models that can also be applied within such a context of change and loss (Boerner & Jopp, 2007; Freund & Baltes, 2002b; Haase et al., 2013). Such comparisons have been made through conceptual and empirical attempts to review and integrate the models. Considering such research can aid researchers in determining the added value of selecting one model for use over another, demonstrate in which contexts the SOC model may be of added benefit in comparison to others utilised within the fields of adaptation, coping and developmental regulation, and provide suggestions for future research.

The similarities and differences between models such as the SOC model, Dual-process model (Brandtstadter & Renner, 1990b), Model of Primary and Secondary Control (J. Heckhausen & Schulz, 1993) and its successor the Motivational Theory of Lifespan Development (J. Heckhausen, Wrosch, & Schulz, 2010) have had some, albeit limited, review (Boerner & Jopp, 2007; Freund & Baltes, 2002b; Haase et al., 2013; Riediger & Ebner, 2007). In one of the few studies which attempts to integrate the above models, Boerner and Jopp (2007) suggest that all of the constructs within the SOC model, Dual-process model and Model of Primary and Secondary Control centre around two factors of improvement/maintenance and reorientation. Improvement/maintenance comes into play when an individual can take an active role in and has the opportunity to adapt to change, whilst reorientation involves adjustment to non-alterable situations. Riediger and Ebner (2007), however, state that combining the above constructs into a focus on improvement/maintenance and reorientation results in the loss of the conceptual

distinction and functional ability of improvement versus maintenance, and fails to take into account the importance of selection. In addition, researchers agreed that integrating the models in this way was not yet possible due to a lack of varied and systematic studies exploring the predictions from each study (Boerner & Jopp, 2007; Riediger & Ebner, 2007).

More recently, Haase et al. (2013) attempted an empirical integration the SOC model, Dual-process Model (Brandtstadter & Renner, 1990b) and the Motivational Theory of Lifespan Development (MTD) (J. Heckhausen et al., 2010). The authors suggest that the 11 constructs from the above three theories can be integrated into processes of goal engagement, goal disengagement and meta-regulation. The constructs from the Dual-process model and MTD were similarly matched into these three processes (see Figure 6.1, below). Findings suggested that whilst the various theory-specific constructs did indeed centre around the processes of goal engagement, disengagement and meta-regulation, each construct uniquely contributed to each process. The authors concluded that all of the theories therefore involved such processes, but that future research should continue to study the theory-specific constructs where it was appropriate to the specific research question.

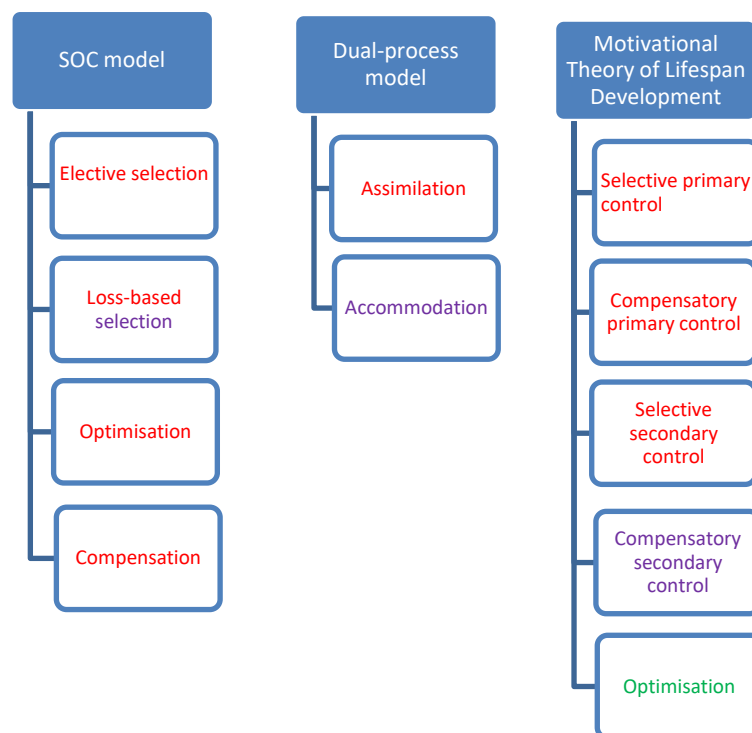


Figure 6.1: Potential integration of three developmental regulation models according to Haase et al. (2013) (Constructs coded as goal engagement (red), goal disengagement (purple) and meta-regulation (green)).

Whilst Figure 6.1 demonstrates that the SOC model can sit alongside and potentially be integrated with other developmental regulation models (Haase et al., 2013), the SOC model is also displayed individually within the figure to demonstrate its uniqueness within this field. Through attempting to integrate the models, the authors also highlighted key differences which demonstrate the unique contribution of SOC to the literature. Firstly, Boerner and Jopp (2007) state that both the Dual-process model and Model of Primary and Secondary Control do not explicitly specify goal-setting processes. Rather, both accommodative and assimilative coping tendencies within the Dual-process model may include some aspects of goal selection indirectly. For example, whilst Flexible Goal Adjustment within the Dual-process model may include some aspects of goal-setting, Freund and Baltes (2002b) and Boerner and Jopp (2007) argue that this primarily refers to cognitive restructuring of the goal hierarchy in response to obstacles. In contrast, goal-setting processes within the SOC model are more explicit and can involve the setting of goals without the consideration of such barriers or a discrepancy, i.e. where there has been no loss of resources (Boerner & Jopp, 2007; Freund & Baltes, 2002b). Maintaining a focus on goal-setting through elective and loss-based selection has implications for the utility of the model, with Boerner and Jopp (2007) concluding that research with an interest in goal-setting may benefit more from utilising the SOC model compared to other models. This may have particular relevance within the field of chronic health. For example, within the context of stroke rehabilitation, goal-setting has previously been discussed as an integral process that should be included within clinical practice (Royal College of Physicians, 2016; The Scottish Intercollegiate Guidelines Network (SIGN), 2010). A model which includes goal-setting strategies may therefore complement such goal-setting processes within the context of an intervention.

A continued focus on selecting goals and striving towards them is therefore one of the key ways in which the SOC model may differ from other coping and developmental models which are centred around disengaging from goals in response to deficits. For example, the Dual-process model suggests that moving from assimilative to accommodative coping will occur as individuals age, and that this shift will have beneficial effects; whereas the use of both constructs simultaneously can have negative effects (Boerner & Jopp, 2007). In contrast, the SOC model proposes that selection, optimisation and compensation are adaptive when used in orchestration and that use of all the processes can continue to be

adaptive as individuals age or experience a reduction in abilities/resources following a health event. This may suggest that the SOC model has added benefit within some contexts, for example, when individuals have to strive towards rehabilitation goals whilst adjusting to irreversible losses and changed circumstances. Indeed, within the context of stroke, Darlington et al. (2007) concluded that both assimilative and accommodative forms of coping were essential for good quality of life, providing a mixture of pursuing important goals and adjusting goals when necessary. There have been no interventions to-date, however, targeting coping in stroke survivors using the Dual-process model and Freund and Baltes (2002b) agree that whilst the models are conceptually similar, they are theoretically and statistically different. For example, within a study utilising the generic SOC self-report measure, the authors found that SOC use independently predicted a range of outcomes, even when assimilative and accommodation coping were controlled.

Further, researchers agree that the models differ and are not all equal in their utility of addressing adaptation to major life change and loss (Boerner & Jopp, 2007; Riediger & Ebner, 2007). In addition to the added benefits of the SOC model described above, researchers suggest the SOC model can be used to categorise strategies more concretely, i.e. to determine what specifically individuals do when setting goals, striving towards goals and adapting to challenges and loss. Findings and implications from the research contained within this thesis suggests that the SOC model can indeed be used to describe the concrete strategies people use when faced with particular challenges.

It is suggested therefore that the SOC model had added value to the field of coping, adaptation and developmental regulation. In particular the SOC model has a continued focus on use of all of the SOC processes, including selection of goals, despite reductions in resources that may occur with age or the experience on a serious health event. Furthermore, the model can be used effectively to categories the concrete strategies utilised by individuals to set goals, work towards goals and adapt to losses. Further research is, however, required to compare the utility of each model in specific contexts. Riediger and Ebner (2007) suggest that when selecting an appropriate model for use within studies, there needs to be congruence between the research question and the intended scope of the model. Examining the utility of such models within a study will subsequently involve determining if the theoretical constructs (e.g. selection, optimisation and compensation) are sufficient within the particular context, determining the domain specific

content of such constructs and evaluating any necessary modifications or additions that would be required in order to answer the research question (Riediger & Ebner, 2007).

Whilst the above suggests that the SOC model may sit alongside other developmental theories and models, it may be that this is not the case within the fields of planning and goal-setting. Rather, the goal-setting research summarised within chapter five suggests that the SOC processes should be integrated with planning and goal-setting frameworks. Chapter five demonstrated how the SOC model could be integrated with goal-setting frameworks such as the G-AP goal-setting framework (Scobbie et al., 2011), with knowledge of selection aiding goal negotiation and goal-setting; and optimisation, compensation and loss-based selection aiding action planning and coping planning (see also Figure 5.2). At the stage of carrying out goal-related actions, SOC can also play a role; previous authors have conceptualised SOC strategy use as the concrete behaviours through which plans are translated into action (Reuter et al., 2010). A number of studies have also suggested that planning and SOC strategy use can be combined in order to influence health behaviour change and therefore achievement of health-related goals (Dugas et al., 2012; Evers et al., 2012; Gellert et al., 2013; Reuter et al., 2010; Ziegelmann et al., 2006). This suggests that SOC may have more utility in informing interventions when combined with planning and goal-setting theories, as an aid for goal selection, action planning, coping planning, and identifying SOC strategies that would facilitate the translation of action plans and coping plans into behaviour (Dugas et al., 2012; Evers et al., 2012; Reuter et al., 2010; Ziegelmann & Lippke, 2007a; Ziegelmann et al., 2006). Indeed, some of the findings and limitations highlighted within the stroke-specific SOC intervention (chapter five) may have occurred as a result of the lack of a structured planning/goal-setting framework. It is therefore suggested that the SOC model can provide added value to the field of goal-setting, however, it may be vital to ensure it is appropriately integrated within relevant goal-setting and planning frameworks in order to ensure maximum efficacy.

Implications and future directions for SOC research in the context of stroke

In order to review the implications and future directions for SOC research in the context of stroke, it is helpful to summarise some of the model's conceptual and methodological considerations which might influence the application of the model in the field of chronic illness. The exploration of how and whether the SOC processes change over time may be

an important consideration, particularly if the aim of future research is to increase the use of SOC strategies by stroke survivors. Issues such as whether the SOC processes are considered as stable or dynamic processes, how these may change over time and at different stages of illness, and the interplay between SOC processes, outcomes and variables such as resources are all relevant considerations.

As a lifespan model, the premise of the SOC model is that varying combinations of selection, optimisation and compensation can be used as life-management processes, for example, to aid an individual in achieving successes despite gains and losses across the lifetime. It is therefore suggested that the SOC processes are considered as dynamic and their use dependent on variables such as context and the cultural and social environment (Freund & Baltes, 2002b). For example, how SOC-related behaviours change over time has primarily been researched with respect to changes across the lifespan, i.e. from young- to middle-adulthood and then on into old age (Freund, 2006; Freund & Baltes, 1998, 2002b; Li et al., 2001). The model hypothesises that younger and middle-aged adults will seek out growth and maintenance opportunities whilst older adults will report a preference for compensatory activities (P. Baltes, 1997). Such age-related differences in SOC were discussed within the systematic review (chapter two), with researchers findings that SOC use differed depending on the age of study participants. Freund and Baltes (1998) and Freund and Baltes (2002b), for example, found that older adults reported engaging in less SOC-related behaviour. Indeed, Freund and Baltes (2002b) found that SOC use increased from young to middle-adulthood before decreasing in older adulthood. This may be because, as discussed previously within this thesis, SOC behaviours are constrained by the limited resources available in old age, with SOC use itself requiring effort and dependent upon available resources. These findings suggest that SOC use is dynamic and can vary according to factors such as age and social, physical and cognitive resources.

Despite the suggestion that SOC use is context-dependent, it should be noted that the development of the generic SOC self-report measure (P. Baltes et al., 1999; Freund & Baltes, 2002b) appears to operationalise SOC into what could be considered relatively stable general traits. There is the possibility that ability/willingness to use SOC overall remains stable over time, with the combinations of selection, optimisation and compensation changing dependent on the variables described above. Boerner and Jopp (2007) suggest that this may be the case, with differences between individuals in their

tendency to use more or less SOC throughout life. The authors suggest that that such general dispositional-like SOC tendencies may be influenced by other personal and contextual variables (Boerner & Jopp, 2007). However, this has not to-date been tested over time using longitudinal trials. Researchers have, however, considered the relationships between SOC use and other stable individual-difference constructs such as personality traits (Freund & Baltes, 2002b). Freund and Baltes (2002b) found that SOC use, as measured through the generic self-report measure, was positively correlated with the personality and cognitive style variables of Extraversion, Conscientiousness and Hierarchical Thinking. They suggest, however, that these factors contribute to, but do not fully account for, differences in SOC behaviour. Indeed, over 50% of the variance in SOC use remained unexplained despite consideration of such potential predictor variables. The authors therefore suggest that SOC use, and in particular what combinations of selection, optimisation and compensation individuals use, is indeed context dependent. Such evidence suggests that SOC processes should be considered as dynamic and context-dependent. However, further longitudinal studies are required to investigate how the use of SOC strategies develops and changes over time and in varying contexts, e.g. changes in resource availability (Freund & Baltes, 2002b).

The suggestion that SOC use can change over time has particular implications for the use of the model within the context of stroke and other illnesses. Despite this, few studies have examined changes in SOC use over the course of illness trajectories and the two exceptions to this had contrasting results (Donnellan et al., 2012; Weiland et al., 2011). Weiland et al. (2011) concluded that SOC use was dynamic and state dependent, as it increased following treatment for depressive disorders; however, Donnellan et al. (2012) found few changes in SOC use over time in stroke survivors who were interviewed at one month and one year post-stroke. Both of these studies had methodological weaknesses, including a high amount of missing data in the former study which may suggest patients had been unable to report SOC use immediately upon admission to hospital. Similarly, Donnellan et al. (2012) experienced poor reliability with the generic SOC self-report measure utilised within their study. It is evident therefore that, again, further research involving longitudinal studies are required to examine how SOC use evolves within the context of illness experience such as a stroke (Donnellan et al., 2012). There may be differences between changes in SOC strategy use over time in those experiencing general ageing, and those who have experienced such a

sudden, potentially life-changing health event. It could also be theorised that the utility of various strategies could differ depending on the timepoint in recovery. For example, selection and compensation may have more utility in the earlier stages of stroke recovery, when adapting to loss of resources and ability, whilst optimisation and striving for new goals could be beneficial at a later stage. Such findings could contribute to the development of stroke-specific SOC interventions, through further examining typical SOC adaptation responses to stroke and subsequently determining when such an intervention would be most efficacious.

In addition to the above, the assertion that SOC use may be dependent on factors such as resource availability also has particular implications for the use of the model within the context of stroke, and merits further investigation. Within the field of ageing, Lang et al. (2002) found that older adults who were rich in sensorimotor, cognitive and social resources were more likely to display behavioural patterns indicative of SOC than those who lacked such resources. Jopp and Smith (2006) also found that whilst those poor in resources used SOC less often than those rich in resources, there were inter-individual differences in SOC use within the resource poor group that indicated there were other variables influencing SOC use. Furthermore, when resources were extremely limited, for example, in those over 80 years of age, SOC strategy use became particularly beneficial. Such a protective, buffer effect of SOC strategy use has previously been discussed in detail within this thesis. The role that resource availability plays in SOC use and subsequent outcomes has not yet been explored in the field of SOC and chronic illness. Future research could seek to determine whether SOC use after stroke is dependent on resources, and if so, which type of resources (for example, social, cognitive or functional ability) are required in order for stroke survivors to utilise selection, optimisation and compensation effectively. Such findings could be combined with future stroke-specific SOC interventions, as Jopp and Smith (2006) suggest that focusing on either resources or SOC strategy use in isolation prevents understanding of why some resource poor individuals used SOC strategies and other did not. The authors speculate that control beliefs may play a role in individuals' motivation to use SOC strategies (Jopp & Smith, 2006).

Indeed, the exploration of the interplay between SOC processes, outcomes and variables that may act as antecedents, mediators or moderators in these relationships are important research considerations which can help inform stroke-specific SOC interventions, but have

yet to be examined. In particular, it is important to consider whether SOC has direct effects on outcomes within the context of stroke, or whether it operates as a mediator/moderator, and the variables which also play a role within these relationships. As discussed within the systematic review (chapter two), it is primarily in the context of work that such antecedents, mediators, and moderators, such as job autonomy and burnout, have been examined (Moghimi et al., 2016). Outside of this field, few studies make reference as to *how* they theorise SOC may influence outcomes. For example, the systematic review (chapter two) found good quality evidence that the use of selection, optimisation and compensation strategies was positively associated with a range of indicators of subjective wellbeing and negatively associated with depression in older adults (Chou & Chi, 2002b; Freund & Baltes, 1998, 2002b; Janke & Davey, 2006; Jopp & Smith, 2006; Okabayashi, 2014; Tovel & Carmel, 2013; Wurm et al., 2013). However the mechanisms through which SOC use was associated with such outcomes was not researched. An exception to this was within the domain of exercise and orthopaedic rehabilitation, where the role of exercise was found to mediate the relationship between SOC strategy use and orthopaedic and subjective wellbeing outcomes (Ziegelmann & Lippke, 2007a, 2007b). Within the context of stroke, identifying potential mediating variables can shed light on what we can expect the mechanisms of a SOC intervention to be in improving outcomes for stroke survivors. It is evident therefore that further stroke-specific SOC research would be beneficial both to explore the conceptual issues surrounding the SOC model and to help inform future intervention development.

In addition, another primary implication that has emerged from this thesis is that further research is required into how we can best operationalise SOC into a useable framework or intervention in the context of stroke. Relatively few studies have included the SOC model as the theoretical basis of an intervention. SOC 'training' has been the most popular and has been combined with Acceptance and Commitment Therapy, employed within a planning and physical activity intervention and employed within the context of improving coping in nurses (Alonso-Fernández et al., 2015; Alonso et al., 2013; Gellert et al., 2013; Muller et al., 2016). Whilst there were some positive findings, two of the interventions suffered from over 50% attrition rates and participants reported difficulties with the homework, concepts and intensity of the interventions (Alonso-Fernández et al., 2015; Alonso et al., 2013; Muller et al., 2016).

The final study within this thesis contributed to the evidence base through the examination of a Life after Stroke SOC Help-sheet, suggested as a brief, low intensity form of SOC training, using descriptions of the SOC concepts as per (Gellert et al., 2013). Unfortunately, no participants opted to utilise the strategies and some experienced difficulty understanding the concepts. This highlights that the timing of the delivery of a post-stroke intervention appears to be crucial. Only one participant was in the early stages of post-stroke recovery, with the remaining four between two and four years post-stroke. This was a study limitation relating to sample and recruitment, however, it does provide some information about which stroke survivors might be suitable for such an intervention. The majority of the stroke survivor study participants felt they had adapted well to their impairments, were content with their current situation, had already adopted some of the strategies through trial and error or felt they had few residual difficulties. This suggests that the intervention is not appropriate for those who have already made the necessary adaptations that enable them to live well with the long-term consequences of their stroke. However, Jones et al. (2013) acknowledges that during the early stages of post-stroke recovery, individuals may be focused on functional recovery, and not yet ready to take control of their circumstances. Furthermore, at this stage stroke survivors are often found to view recovery in comparison to their lives pre-stroke (Rosewilliam et al., 2011). Potential participants recruited early after stroke may therefore be preoccupied with therapy rehabilitation, for example, physiotherapy to improve functional ability, rather than focusing on life after stroke. The timing of when to implement such an intervention was found to be an issue requiring discussion in stroke self-management studies. Damush et al. (2011), for example, found that some stroke survivors required time to adjust to their new situation and felt they were not able to attend a programme early post-stroke. The authors suggested that recruitment should also take place outside of the acute phase, in order to capture participants at later stages of their post-stroke journey. It is evident that future research should address the optimal time to apply a SOC intervention in the context of stroke, striking a balance between intervening before the stroke survivor is able to participate, and before they feel unwilling to make any further post-stroke adaptations.

Another implication is that further work is needed to make the SOC concepts understandable and meaningful for stroke survivors. Difficulties self-evaluating post-stroke impairments, understanding the SOC concepts and how they can be applied appeared to be

relevant for some of the stroke survivors within both the qualitative interviews and intervention study (chapters three and five). The mean MoCA cognitive ability score of participants within the qualitative interviews was less than 26, indicating that on average participants were experiencing some cognitive impairment. In addition, participants within the intervention study reported some cognitive impairment and that they found the SOC questions confusing. Upon reflection, this is somewhat unsurprising given that cognitive impairment in stroke survivors is common and as a result stroke survivors report difficulties and confusion with processes such as goal-setting (Rosewilliam et al., 2011; Rosewilliam et al., 2016; Sugavanam et al., 2013). In addition, difficulty completing self-management tasks has been identified as an issue for stroke survivors and a limitation of previous self-management interventions (Johnston et al., 2007; Lennon et al., 2013). Finally, presenting the SOC constructs and examples themselves to individuals in a way that is understood could prove difficult, particularly if cognitive and language difficulties are present. Previous SOC studies have found poor completion rates that could be suggested to be a result of difficulty and poor understanding (Alonso-Fernández et al., 2015; Muller et al., 2016). As the studies within this thesis experienced similar difficulties with both the goal-setting process and SOC understanding, it is clear that cognitive capacity requires careful consideration in future SOC studies within the context of stroke.

It may be that SOC is not suitable for those with more severe cognitive and communication impairments. Alternatively, it may be beneficial to modify the intervention materials, following guidelines for those with communication difficulties (Dryden, 2015; National Institute for Health Research Clinical Research Network: Stroke, 2014; Stroke Association, 2012). These could be combined with a structured goal-setting approach that is developed and tailored for the context of stroke. Overall, it is clear that a balance is required between ensuring that stroke survivors are guided through the process effectively, and ensuring that the intensity of the intervention does not limit the involvement of those experiencing cognitive impairment.

There are several other suggestions as to how future research can operationalise SOC in the context of stroke. Firstly, it is clear from the evidence summarised in chapter five that there is interplay between SOC strategy use, planning and goal attainment. Based on these findings, it was suggested that the Selection, Optimisation and Compensation model may provide a model which can guide planning within goal-setting in stroke clinical practice. For

example, knowledge about elective selection may aid goal-setting, optimisation may aid action planning, and loss-based selection and compensation aid coping planning. This does merit investigation through further research. However, goal-setting within clinical practice typically remains focussed on the acute and early rehabilitation stage of stroke. Jones et al. (2013) states that concentrating on clinical and functional SMART goals prevents self-discovery and problem solving, which are both vital to long-term self-management of psychosocial goals.

Embedding SOC within a more holistic, self-management approach may be more beneficial to the longer term psychosocial needs of stroke survivors. The five core self-management skills identified by Lorig and Holman (2003) have previously been discussed. In summary within the context of stroke, these may translate to generating and implementing practical solutions to problems (problem solving); ensuring one has accurate information about stroke recovery and prevention in order to make appropriate care decisions (decision making); being able to locate and utilise stroke and health resources (resource use); having a collaborative relationship with healthcare professionals so that they can provide guidance and information (forming patient/professional partnership); and taking action to change their behaviour through strategies such as action planning, coping planning and goal-setting (taking action) (Joice, 2012). A potential avenue for future research includes the development and evaluation of an intervention that incorporates training in these five skills, using SOC as a guiding model. The Medical Research Council (MRC) guidelines for the development and evaluation of complex interventions iterate the importance of ensuring clarity of the intervention outcome, and how the intervention seeks to bring about a change in outcome (Medical Research Council., 2006). The research priority of helping stroke survivors come to terms with living with the long-term consequences of stroke may guide the research outcomes, however, in practice this may lead to several outcomes based on the individual limitations, beliefs and aims of stroke survivors. As has previously been discussed, recovery from stroke is a complex, multidimensional process specific to each individual, their various post-stroke difficulties, and how they perceive these within their lives (Carlsson et al., 2009). A personal projects intervention, such as that conducted by Muller et al. (2016) may be able to take the heterogeneity of stroke into account. Stroke survivors could focus their project on, for example, a difficulty relating to an activity limitation or participation restriction. Guiding the stroke survivor through the process of

selection, optimisation and compensation in order to target this difficulty may help them to develop self-management skills of problem solving, decision making, resource use, taking action, and if necessary, forming relationships with healthcare professionals.

Modifying the Life after Stroke Help-sheet into a simpler format, such as that created by Chellingsworth, Kishita, and Laidlaw (2016) may have utility in exploring SOC for this purpose with stroke survivors (Figure 6.2). The authors utilised this worksheet when combining SOC with low intensity Cognitive Behavioural Therapy for older adults, as an aid to assisting individuals to adapt to changing circumstances. Furthermore, the solutions generated may tap into the other forms of self-management support identified within stroke guidelines, such as stroke exercise classes and peer support (NHS Scotland, 2009; Royal College of Physicians, 2016; The Scottish Government, 2014; The Scottish Intercollegiate Guidelines Network (SIGN), 2010). It is suggested that future research continues to progress the SOC model within the context of stroke, developing a self-management intervention to improve activity limitations and participation restrictions in order to help stroke survivors adapt to living with the long-term consequences of stroke.

Selective optimisation and compensation (SOC) worksheet

Select it down	Sometimes, we are faced with losses that challenge our quality of life. Consider what activity/role/hobby you have given up or reduced as a result of a loss of physical ability and is there a way to select part of the activity to ensure you optimise your experience of it. Consider ideas here:
Optimise it	Thinking of the activity and options you considered above. Is the way in which you selected to do it going to increase your use of the activity and hopefully provide opportunity for you to optimise it as a result. Write down how it may help you to optimise it here:
Compensate for it	Can you compensate for the loss in some way by adding in something to help that will enable you to do more of the activity? Is there a way of making use of certain support tools, aids or strategies that can help you to still do the activity. Write down ideas that can help you to compensate here:

Figure 6.2: SOC worksheet for use with older adults (Chellingsworth et al., 2016), used with permission

Thesis strengths and limitations

Overall, this thesis explored the use of the Selection, Optimisation and Compensation model as a potential model for post-stroke rehabilitation and to help stroke survivors come to terms with living with the long-term consequences of stroke. Individual study strengths and limitations have been discussed within each chapter, therefore those relating to the thesis as a whole will be discussed in the following section.

Both the methodology relating to how the research was undertaken and the contribution of the research to the stroke and SOC evidence base are important thesis strengths. The Medical Research Council (MRC) provides guidelines for the development and evaluation of such complex interventions and detail the work that should be undertaken within the four key stages of development, feasibility/piloting, evaluation and implementation (Craig et al.,

2008; Medical Research Council., 2006). With regards to development, three processes have been identified, consisting of identifying the existing evidence base, identifying/developing appropriate theory, and modelling the process and outcomes (Craig et al., 2008; Medical Research Council., 2006). Through following a logical and coherent process, the research carried out throughout this thesis contributes to these stages. For example, the limitations of existing post-stroke interventions and the potential contribution of SOC to stroke rehabilitation have been reviewed in detail. This led to further exploration of SOC in the context of stroke through qualitative interviews, which both sought to test whether SOC was a suitable model for categorising post-stroke adaptation efforts, and introduce improvements to the analysis of SOC strategies. All of this work contributed to the development and early evaluation of the Life after Stroke Help-sheet. It is hoped that future research will draw on the findings from these studies, refine the stroke-specific SOC intervention, and move on towards the feasibility and evaluation phases.

A limitation of this research is that it was not possible to utilise the findings from the qualitative SOC interviews to analysis the relationships between SOC strategy use and outcomes, or to develop a stroke-specific SOC self-report measure. As has previously been discussed, the generic SOC measure may not have validity or utility within specific contexts such as adaptation to stroke. Researchers have called for the development of a stroke-specific measure of SOC strategy use and suggest that linking SOC strategy use to outcomes is important if we are to promote the model as adaptive (Donnellan et al., 2012; Freund & Baltes, 1998). The mixed method SOC studies (Carpentieri et al., 2017; Gignac et al., 2002; Yuen & Vogtle, 2016) do attempt to address this issue through combining qualitative and quantitative analysis, however, their limitations include cross-sectional design, small sample sizes and lack of sophisticated statistical testing. Future research should draw on findings, such as those from the SOC qualitative interviews, and develop a measure that will allow for reliable testing of the relationships between SOC use in stroke survivors and outcomes. This will lend weight to the promotion of the model for successful post-stroke adaptation.

Personal reflections on challenges and opportunities throughout the completion of this thesis

This thesis comprised a systematic review, a quantitative Discriminant Content Validation study, and two NHS research studies consisting of qualitative interviews and a pilot intervention. Completing two NHS research studies presented excellent research opportunities to conduct SOC research within the context of stroke. Receiving NHS ethical and research and development approval enabled the study to recruit from a clinical stroke population and provided me with personal experience becoming familiar with various NHS processes and working with clinical staff on recruitment. I was able to attend NHS Good Clinical Practice training, which aided efficient management of the recruitment process, including monitoring and addressing recruitment concerns.

Conducting research in an NHS setting was not, however, without its challenges. Both NHS studies experienced recruitment challenges, with slow recruitment via NHS stroke clinical teams. This was not unexpected given that the specific NHS sites used were excellent research centres; this meant that the needs of the study had to be balanced with the capacity of the clinical staff and that pools of potential participants were shared with several competing trials. With regards to the SOC qualitative interviews (chapter three), study recruitment was ultimately achieved with the aid of Stroke Liaison Nurses. With regards to the SOC intervention (chapter five), however, slow recruitment coupled with time constraints meant that the study inclusion criteria had to be altered. The potential limitations that occurred as a result of this have been discussed previously within chapter five.

Receiving a Minor Research Award from Chest Heart & Stroke Scotland was also a significant opportunity within this thesis. The award allowed for professional interview transcription during the SOC qualitative interviews and researcher travel during both the SOC qualitative interviews and SOC intervention. Receiving professional interview transcription in particular was extremely beneficial to the research, as it allowed me to focus on other research tasks. Without this, I would have faced the challenge and time pressure of transcribing a large number of interviews. In addition, the CHSS award resulted in eligibility for inclusion within the Scottish Stroke Research Network and consequently recruitment assistance via the Stroke Research Nurses. Whilst the NHS recruitment challenges detailed above remained, the additional recruitment support was welcomed.

Overall conclusion

This thesis has presented the case for the SOC model as a model that may have utility within post-stroke adaptation, and described its potential within goal-setting, self-management and as SOC training. As a summary, the model was suggested to be appropriate in the context of stroke as it consists of processes that allow individuals experiencing loss, such as that experienced after stroke, to maintain activity in areas of life that are important to them, the use of SOC strategies appears to be adaptive and the model has a goal-oriented focus, which supports goal-setting.

Four studies were conducted in order to explore the SOC model in the context of stroke. First, systematically reviewing the SOC model within the contexts of ageing and health and then conducting qualitative interviews and Discriminant Content Validation analysis to elicit and analyse the SOC strategies adopted by stroke survivors. Finally, these findings were used to develop a brief Life after Stroke Help-sheet guided by the SOC processes. Overall, these studies provides strength to the argument that the SOC model is indeed appropriate for the aim of helping stroke survivors come to terms with living with the long-term consequences of stroke. Further refinements are, however, necessary in the operationalisation of the SOC model into a post-stroke intervention.

7 References

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8 Appendices

Appendix 2.1: Effective Public Health Practice Project (EPHPP) Quality Assessment Tool for Quantitative Studies

QUALITY ASSESSMENT TOOL FOR QUANTITATIVE STUDIES



COMPONENT RATINGS

A) SELECTION BIAS

(Q1) Are the individuals selected to participate in the study likely to be representative of the target population?

- 1 Vary likely
- 2 Somewhat likely
- 3 Not likely
- 4 Can't tell

(Q2) What percentage of selected individuals agreed to participate?

- 1 80 - 100% agreement
- 2 60 - 79% agreement
- 3 less than 60% agreement
- 4 Not applicable
- 5 Can't tell

RATE THIS SECTION	STRONG	MODERATE	WEAK
See dictionary	1	2	3

B) STUDY DESIGN

Indicate the study design

- 1 Randomized controlled trial
- 2 Controlled clinical trial
- 3 Cohort analytic (two group pre + post)
- 4 Case-control
- 5 Cohort (one group pre + post (before and after))
- 6 Interrupted time series
- 7 Other specify _____
- 8 Can't tell

Was the study described as randomized? If NO, go to Component C.

No Yes

If Yes, was the method of randomization described? (See dictionary)

No Yes

If Yes, was the method appropriate? (See dictionary)

No Yes

RATE THIS SECTION	STRONG	MODERATE	WEAK
See dictionary	1	2	3

C) CONFOUNDERS

- (01) Were there important differences between groups prior to the intervention?
1 Yes
2 No
3 Can't tell

The following are examples of confounders:

- 1 Race
- 2 Sex
- 3 Marital status/family
- 4 Age
- 5 SES (income or class)
- 6 Education
- 7 Health status
- 8 Pre-intervention score on outcome measure

- (02) If yes, indicate the percentage of relevant confounders that were controlled (either in the design (e.g. stratification, matching) or analysis)?
1 80 – 100% (most)
2 60 – 79% (some)
3 Less than 60% (few or none)
4 Can't Tell

RATE THIS SECTION	STRONG	MODERATE	WEAK
See dictionary	1	2	3

D) BLINDING

- (01) Was (were) the outcome assessor(s) aware of the intervention or exposure status of participants?
1 Yes
2 No
3 Can't tell

- (02) Were the study participants aware of the research question?
1 Yes
2 No
3 Can't tell

RATE THIS SECTION	STRONG	MODERATE	WEAK
See dictionary	1	2	3

E) DATA COLLECTION METHODS

- (01) Were data collection tools shown to be valid?
1 Yes
2 No
3 Can't tell

- (02) Were data collection tools shown to be reliable?
1 Yes
2 No
3 Can't tell

RATE THIS SECTION	STRONG	MODERATE	WEAK
See dictionary	1	2	3

F) WITHDRAWALS AND DROP-OUTS

- (Q1) Were withdrawals and drop-outs reported in terms of numbers and/or reasons per group?
- 1 Yes
 - 2 No
 - 3 Can't tell
 - 4 Not Applicable (i.e. one time surveys or interviews)
- (Q2) Indicate the percentage of participants completing the study. (If the percentage differs by groups, record the lowest).
- 1 80 -100%
 - 2 60 -79%
 - 3 less than 60%
 - 4 Can't tell
 - 5 Not Applicable (i.e. Retrospective case-control)

RATE THIS SECTION	STRONG	MODERATE	WEAK	
See dictionary	1	2	3	Not Applicable

G) INTERVENTION INTEGRITY

- (Q1) What percentage of participants received the allocated intervention or exposure of interest?
- 1 80 -100%
 - 2 60 -79%
 - 3 less than 60%
 - 4 Can't tell
- (Q2) Was the consistency of the intervention measured?
- 1 Yes
 - 2 No
 - 3 Can't tell
- (Q3) Is it likely that subjects received an unintended intervention (contamination or co-intervention) that may influence the results?
- 4 Yes
 - 5 No
 - 6 Can't tell

H) ANALYSES

- (Q1) Indicate the unit of allocation (circle one)
- community organization/institution practice/office individual
- (Q2) Indicate the unit of analysis (circle one)
- community organization/institution practice/office individual
- (Q3) Are the statistical methods appropriate for the study design?
- 1 Yes
 - 2 No
 - 3 Can't tell
- (Q4) Is the analysis performed by intervention allocation status (i.e. intention to treat) rather than the actual intervention received?
- 1 Yes
 - 2 No
 - 3 Can't tell

GLOBAL RATING

COMPONENT RATINGS

Please transcribe the information from the gray boxes on pages 1-4 onto this page. See dictionary on how to rate this section.

A	SELECTION BIAS	STRONG	MODERATE	WEAK
		1	2	3
B	STUDY DESIGN	STRONG	MODERATE	WEAK
		1	2	3
C	CONFOUNDERS	STRONG	MODERATE	WEAK
		1	2	3
D	BLINDING	STRONG	MODERATE	WEAK
		1	2	3
E	DATA COLLECTION METHOD	STRONG	MODERATE	WEAK
		1	2	3
F	WITHDRAWALS AND DROPOUTS	STRONG	MODERATE	WEAK
		1	2	3
				Not Applicable

GLOBAL RATING FOR THIS PAPER (circle one):

- | | | |
|---|----------|----------------------------|
| 1 | STRONG | (no WEAK ratings) |
| 2 | MODERATE | (one WEAK rating) |
| 3 | WEAK | (two or more WEAK ratings) |

With both reviewers discussing the ratings:

Is there a discrepancy between the two reviewers with respect to the component (A-F) ratings?

No Yes

If yes, indicate the reason for the discrepancy

- | | |
|---|---|
| 1 | Oversight |
| 2 | Differences in interpretation of criteria |
| 3 | Differences in interpretation of study |

Final decision of both reviewers (circle one):

- | | |
|---|----------|
| 1 | STRONG |
| 2 | MODERATE |
| 3 | WEAK |

Appendix 2.2: Effective Public Health Practice Project (EPHPP) Quality Assessment Tool for Quantitative Studies Dictionary

The purpose of this dictionary is to describe items in the tool thereby assisting raters to score study quality. Due to under-reporting or lack of clarity in the primary study, raters will need to make judgements about the extent that bias may be present. When making judgements about each component, raters should form their opinion based upon information contained in the study rather than making inferences about what the authors intended.

A) SELECTION BIAS

(Q1) Participants are more likely to be representative of the target population if they are randomly selected from a comprehensive list of individuals in the target population (score very likely). They may not be representative if they are referred from a source (e.g. clinic) in a systematic manner (score somewhat likely) or self-referred (score not likely).

(Q2) Refers to the % of subjects in the control and intervention groups that agreed to participate in the study before they were assigned to intervention or control groups.

B) STUDY DESIGN

In this section, raters assess the likelihood of bias due to the allocation process in an experimental study. For observational studies, raters assess the extent that assessments of exposure and outcome are likely to be independent. Generally, the type of design is a good indicator of the extent of bias. In stronger designs, an equivalent control group is present and the allocation process is such that the investigators are unable to predict the sequence.

Randomized Controlled Trial (RCT)

An experimental design where investigators randomly allocate eligible people to an intervention or control group. A rater should describe a study as an RCT if the randomization sequence allows each study participant to have the same chance of receiving each intervention and the investigators could not predict which intervention was next. If the investigators do not describe the allocation process and only use the words 'random' or 'randomly', the study is described as a controlled clinical trial.

See below for more details.

Was the study described as randomized?

Score YES, if the authors used words such as random allocation, randomly assigned, and random assignment.

Score NO, if no mention of randomization is made.

Was the method of randomization described?

Score YES, if the authors describe any method used to generate a random allocation sequence.

Score NO, if the authors do not describe the allocation method or describe methods of such as alternation, case record numbers, dates of birth, day of the week, and any allocation procedure that is entirely transparent before assignment, such as an open list of random numbers of assignments.

If NO is scored, then the study is a controlled clinical trial.

Was the method appropriate?

Score YES, if the randomization sequence allowed each study participant to have the same chance of receiving each intervention and the investigators could not predict which intervention was next. Examples of appropriate approaches include assignment of subjects by a central office unaware of subject characteristics, or sequentially numbered, sealed, opaque envelopes.

Score NO, if the randomization sequence is open to the individuals responsible for recruiting and allocating participants or providing the intervention, since those individuals can influence the allocation process, either knowingly or unknowingly.

If NO is scored, then the study is a controlled clinical trial.

Controlled Clinical Trial (CCT)

An experimental study design where the method of allocating study subjects to intervention or control groups is open to individuals responsible for recruiting subjects or providing the intervention. The method of allocation is transparent before assignment, e.g. an open list of random numbers or allocation by date of birth, etc.

Cohort analytic (two group pre and post) An observational study design where groups are assembled according to whether or not exposure to the intervention has occurred. Exposure to the intervention is not under the control of the investigators. Study groups might be non-equivalent or not comparable on some feature that affects outcome.

Case control study

A retrospective study design where the investigators gather 'cases' of people who already have the outcome of interest and 'controls' who do not. Both groups are then questioned or their records examined about whether they received the intervention exposure of interest.

Cohort (one group pre + post (before and after))

The same group is pretested, given an intervention, and tested immediately after the intervention. The intervention group, by means of the pretest, act as their own control group.

Interrupted time series

A time series consists of multiple observations over time. Observations can be on the same units (e.g. individuals over time) or on different but similar units (e.g. student achievement scores for particular grade and school). Interrupted time series analysis requires knowing the specific point in the series when an intervention occurred.

c) **CONFOUNDERS**

By definition, a confounder is a variable that is associated with the intervention or exposure and causally related to the outcome of interest. Even in a robust study design, groups may not be balanced with respect to important variables prior to the intervention. The authors should indicate if confounders were controlled in the design (by stratification or matching) or in the analysis. If the allocation to

intervention and control groups is randomized, the authors must report that the groups were balanced at baseline with respect to confounders (either in the text or a table).

D) BLINDING

(Q1) Assessors should be described as blinded to which participants were in the control and intervention groups. The purpose of blinding the outcome assessors (who might also be the care providers) is to protect against detection bias.

(Q2) Study participants should not be aware of (i.e. blinded to) the research question. The purpose of blinding the participants is to protect against reporting bias.

E) DATA COLLECTION METHODS

Tools for primary outcome measures must be described as reliable and valid. If 'face' validity or 'content' validity has been demonstrated, this is acceptable. Some sources from which data may be collected are described below:

Self reported data includes data that is collected from participants in the study (e.g. completing a questionnaire, survey, answering questions during an interview, etc.).

Assessment/Screening includes objective data that is retrieved by the researchers. (e.g. observations by investigators).

Medical Records/Vital Statistics refers to the types of formal records used for the extraction of the data.

Reliability and validity can be reported in the study or in a separate study. For example, some standard assessment tools have known reliability and validity.

F) WITHDRAWALS AND DROP-OUTS

Score **YES** if the authors describe BOTH the numbers and reasons for withdrawals and drop-outs.

Score **NO** if either the numbers or reasons for withdrawals and drop-outs are not reported.

The percentage of participants completing the study refers to the % of subjects remaining in the study at the final data collection period in all groups (i.e. control and intervention groups).

G) INTERVENTION INTEGRITY

The number of participants receiving the intended intervention should be noted (consider both frequency and intensity). For example, the authors may have reported that at least 80 percent of the participants received the complete intervention. The authors should describe a method of measuring if the intervention was provided to all participants the same way. As well, the authors should indicate if subjects received an unintended intervention that may have influenced the outcomes. For example, co-intervention occurs

when the study group receives an additional intervention (other than that intended). In this case, it is possible that the effect of the intervention may be over-estimated. Contamination refers to situations where the control group accidentally receives the study intervention. This could result in an under-estimation of the impact of the intervention.

H) ANALYSIS APPROPRIATE TO QUESTION

Was the quantitative analysis appropriate to the research question being asked?

An intention-to-treat analysis is one in which all the participants in a trial are analyzed according to the intervention to which they were allocated, whether they received it or not. Intention-to-treat analyses are favoured in assessments of effectiveness as they mirror the noncompliance and treatment changes that are likely to occur when the intervention is used in practice, and because of the risk of attrition bias when participants are excluded from the analysis

Component Ratings of Study:

For each of the six components A – F, use the following descriptions as a roadmap.

A) SELECTION BIAS

Strong: The selected individuals are very likely to be representative of the target population (Q1 is 1) **and** there is greater than 80% participation (Q2 is 1).

Moderate: The selected individuals are at least somewhat likely to be representative of the target population (Q1 is 1 or 2); **and** there is 60 - 79% participation (Q2 is 2). 'Moderate' may also be assigned if Q1 is 1 or 2 and Q2 is 5 (can't tell).

Weak: The selected individuals are not likely to be representative of the target population (Q1 is 3); **or** there is less than 60% participation (Q2 is 3) **or** selection is not described (Q1 is 4); **and** the level of participation is not described (Q2 is 5).

B) DESIGN

Strong: will be assigned to those articles that described RCTs and CCTs.

Moderate: will be assigned to those that described a cohort analytic study, a case control study, a cohort design, or an interrupted time series.

Weak: will be assigned to those that used any other method or did not state the method used.

C) CONFOUNDERS

Strong: will be assigned to those articles that controlled for at least 80% of relevant confounders (Q1 is 2); **or** (Q2 is 1).

Moderate: will be given to those studies that controlled for 60 – 79% of relevant confounders (Q1 is 1) **and** (Q2 is 2).

Weak: will be assigned when less than 60% of relevant confounders were controlled (Q1 is 1) **and** (Q2 is 3) **or** control of confounders was not described (Q1 is 3) **and** (Q2 is 4).

D) BLINDING

Strong: The outcome assessor is not aware of the intervention status of participants (Q1 is 2); **and** the study participants are not aware of the research question (Q2 is 2).

Moderate: The outcome assessor is not aware of the intervention status of participants (Q1 is 2); **or** the study participants are not aware of the research question (Q2 is 2); **or** blinding is not described (Q1 is 3 and Q2 is 3).

Weak: The outcome assessor is aware of the intervention status of participants (Q1 is 1); **and** the study participants are aware of the research question (Q2 is 1).

E) DATA COLLECTION METHODS

Strong: The data collection tools have been shown to be valid (Q1 is 1); **and** the data collection tools have been shown to be reliable (Q2 is 1).

Moderate: The data collection tools have been shown to be valid (Q1 is 1); **and** the data collection tools have not been shown to be reliable (Q2 is 2) **or** reliability is not described (Q2 is 3).

Weak: The data collection tools have not been shown to be valid (Q1 is 2) **or** both reliability and validity are not described (Q1 is 3 and Q2 is 3).

F) WITHDRAWALS AND DROP-OUTS - a rating of:

Strong: will be assigned when the follow-up rate is 80% or greater (Q2 is 1).

Moderate: will be assigned when the follow-up rate is 60 – 79% (Q2 is 2) **OR** Q2 is 5 (N/A).

Weak: will be assigned when a follow-up rate is less than 60% (Q2 is 3) or if the withdrawals and drop-outs were not described (Q2 is 4).

Appendix 2.3: Methodological quality of quantitative studies

Authors (country)	Design	Selection bias	Study design	Confounders	Blinding	Data collection methods	Withdrawals and dropouts	Overall methodological quality
Alonso et al. (2013) (Spain)	RCT	Weak	Strong	Weak	Moderate	Strong	Moderate	Weak
Alonso-Fernández et al. (2015) (Spain)	RCT	Moderate	Strong	Strong	Moderate	Strong	Weak	Moderate
Bieri et al. (2015) (Switzerland)	Cross-sectional	Weak	Weak	N/A	N/A	Weak	N/A	Weak
Carmichael et al. (2015) (USA)	Prospective cohort	Moderate	Weak	N/A	N/A	Strong	Moderate	Moderate
Chou and Chi (2002b) (China)	Cross-sectional	Moderate	Weak	N/A	N/A	Strong	N/A	Moderate
Chou and Chi (2002a) (China)	Cross-sectional	Strong	Weak	N/A	N/A	Strong	N/A	Moderate
Donnellan et al. (2012) (Ireland)	Longitudinal	Moderate	Weak	N/A	N/A	Moderate	Moderate	Moderate
Evers et al. (2012) (Germany)	RCT	Weak	Strong	Strong	Moderate	Strong	Strong	Moderate
Freund (2006) (Germany)	Experimental	Weak	Weak	Strong	Moderate	Strong	Strong	Weak
Freund and Baltes (1998) (Germany)	Cross-sectional	Moderate	Weak	N/A	N/A	Strong	N/A	Moderate
Freund and Baltes (2002b) (Germany)	Longitudinal	Strong	Weak	N/A	N/A	Strong	Strong	Moderate
Freund and Baltes (2002a)(Germany)	Cross-sectional	Weak	Weak	N/A	N/A	Weak	N/A	Weak
Gellert et al. (2013) (Germany)	RCT	Weak	Strong	Strong	Moderate	Strong	Strong	Moderate

Authors (country)	Design	Selection bias	Study design	Confounders	Blinding	Data collection methods	Withdrawals and dropouts	Overall methodological quality
Gignac et al. (2000) (Canada)	Qualitative and cross-sectional	Weak	Weak	N/A	N/A	Weak	N/A	Weak
Gignac et al. (2002) (Canada)	Qualitative and cross-sectional	Weak	Weak	N/A	N/A	Weak	N/A	Weak
Haase et al. (2013) (USA/Germany)	Cross-sectional	Strong	Weak	N/A	N/A	Strong	N/A	Moderate
Hahn and Lachman (2015) (USA)	Longitudinal	Weak	Weak	N/A	N/A	Weak	Weak	Weak
Janke and Davey (2006) (USA)	Longitudinal	Moderate	Weak	N/A	N/A	Weak	Weak	Weak
Janke et al. (2009) (USA)	Cross-sectional	Weak	Weak	N/A	N/A	Weak	N/A	Weak
Janse et al. (2015) (Netherlands)	Longitudinal	Weak	Weak	N/A	N/A	Weak	Strong	Weak
John and Lang (2012) (Germany)	Cross-sectional	Moderate	Weak	N/A	N/A	Weak	N/A	Weak
Jopp and Smith (2006) (Germany)	Cross-sectional & longitudinal	Moderate	Weak	Strong	N/A	Strong	Weak	Weak
Lang et al. (2002) (Germany)	Longitudinal	Moderate	Weak	N/A	N/A	Weak	Strong	Weak
Li et al. (2001) (Germany)	Experimental	Moderate	Weak	N/A	N/A	Moderate	Strong	Moderate
D. Lund et al. (2014) (USA)	Intervention description/development ^a	N/A	N/A	N/A	N/A	N/A	N/A	N/A
Okabayashi (2014) (Japan)	Cross-sectional	Moderate	Weak	N/A	N/A	Strong	N/A	Moderate
Opitz et al. (2014) (USA)	Experimental	Weak	Weak	N/A	Weak	Moderate	N/A	Weak

Authors (country)	Design	Selection bias	Study design	Confounders	Blinding	Data collection methods	Withdrawals and dropouts	Overall methodological quality
Penningroth and Scott (2012) (USA)	Cross-sectional	Weak	Weak	N/A	N/A	Weak	N/A	Weak
Pickard et al. (2009) (USA)	Cross-sectional	Weak	Weak	N/A	N/A	Strong	N/A	Weak
Reuter et al. (2010) (Germany)	Longitudinal	Moderate	Weak	N/A	N/A	Strong	Weak	Weak
Rose et al. (2008) (USA)	RCT description/development	Moderate	Strong	N/A	N/A	Weak	N/A	Moderate
Scheibner and Leathem (2012) (New Zealand)	Cross-sectional	Weak	Weak	N/A	N/A	Moderate	N/A	Weak
Son et al. (2009) (USA)	Cross-sectional	Weak	Weak	N/A	N/A	Weak	N/A	Weak
Son and Janke (2015) (USA)	Cross-sectional	Moderate	Weak	N/A	N/A	Strong	N/A	Moderate
Tovel and Carmel (2013) (Israel)	Longitudinal	Weak	Weak	N/A	N/A	Weak	Strong	Weak
Viglund et al. (2013) (Sweden)	Cross-sectional	Weak	Weak	N/A	N/A	Weak	N/A	Weak
Weiland et al. (2011) (Germany)	Longitudinal	Moderate	Weak	N/A	N/A	Strong	Strong	Moderate
Wurm et al. (2013) (Germany)	Longitudinal	Moderate	Weak	N/A	N/A	Strong	Strong	Moderate
Ziegelmann and Lippke (2007a) (Germany)	Longitudinal	Weak	Weak	N/A	N/A	Strong	Weak	Weak
Ziegelmann and Lippke (2007b) (Germany)	Longitudinal	Weak	Weak	N/A	N/A	Strong	Weak	Weak

Authors (country)	Design	Selection bias	Study design	Confounders	Blinding	Data collection methods	Withdrawals and dropouts	Overall methodological quality
Ziegelmann et al. (2006) (Germany)	RCT, with longitudinal analysis of SOC	Weak	Strong	N/A	Moderate	Weak	Moderate	Weak

^a Study was description of intervention development therefore methodology not subject to quality assessment.

Appendix 2.4: Methodological quality of qualitative studies

Authors (country)	Methodological quality ^a	Notes regarding quality ^b
DiLauro et al. (2015) (Canada)	Credibility ✘ Transferability ✓ Dependability ✘ Confirmability ✓	Reflective researcher, triangulation (team of researchers) Adequate description of sample and setting Lack of description of analysis and audit trail Check with expert colleagues about ideas and interpretation of data, peer review for decision points, reflective researcher
Greenwood et al. (2010) (UK)	Credibility ✓ Transferability ✓ Dependability ✘ Confirmability ✘	Range of participants, members checks, triangulation (team of researchers) Adequate description of sample and setting Lack of description of analysis and audit trail Check with participants about ideas and interpretation of data, check with expert colleagues about ideas and interpretation of data
Hutchinson and Nimrod (2012) (Canada)	Credibility ✘ Transferability ✓ Dependability ✘ Confirmability ✘	Range of participants, member checks Adequate description of sample and setting Lack of description of analysis and audit trail Check with participants about ideas and interpretation of data
Janke et al. (2012) (USA)	Credibility ✓ Transferability ✓ Dependability ✓ Confirmability ✓	Member checks, triangulation (team of researchers), range of participants Adequate description of sample and setting Clear explanation of data analysis Check with participants about ideas and interpretation of data, check with expert colleagues about ideas and interpretation of data, team of experts

Authors (country)	Methodological quality ^a	Notes regarding quality ^b
Kelly et al. (2014) (USA)	Credibility ✘ Transferability ✔ Dependability ✔ Confirmability ✘	Range of participants Adequate description of sample and setting Clear explanation of data analysis None
Kleiber and Nimrod (2009) (USA)	Credibility ✔ Transferability ✔ Dependability ✘ Confirmability ✘	Member checks, range of participants, reflective researchers Adequate description of sample and setting Lack of description of analysis and audit trail Check with participants about ideas and interpretation of data, reflective researcher
Lien et al. (2015) (USA)	Credibility ✘ Transferability ✔ Dependability ✘ Confirmability ✘	Range of participants, triangulation (variety of methods) Adequate description of sample and setting Lack of description of analysis and audit trail Check with expert colleagues about ideas and interpretation of data
Nasvadi and Vavrik (2007) (Canada)	Credibility ✘ Transferability ✔ Dependability ✘ Confirmability ✘	None Adequate description of sample and setting Lack of description of analysis and audit trail None
Rozario et al. (2011) (USA)	Credibility ✘ Transferability ✔ Dependability ✘ Confirmability ✘	Range of participants Adequate description of sample and setting Lack of description of analysis and audit trail Team of researchers

Authors (country)	Methodological quality ^a	Notes regarding quality ^b
Rush et al. (2011) (Canada)	Credibility ✘ Transferability ✓ Dependability ✓ Confirmability ✘	None Adequate description of sample and setting Clear explanation of data analysis None
Ryan et al. (2003) (Canada)	Credibility ✘ Transferability ✓ Dependability ✘ Confirmability ✘	None Adequate description of sample and setting Lack of description of analysis and audit trail None
van der Goot et al. (2015)	Credibility ✓ Transferability ✓ Dependability ✓ Confirmability ✓	Member checks, reflective researchers, range of participants Adequate description of sample and setting Clear explanation of data analysis Reflective researcher, member checks, peer review for decision points, team of experts
Wilhite et al. (2004) (Germany)	Credibility ✓ Transferability ✓ Dependability ✓ Confirmability ✓	Member checks, range of participants, triangulation (team of researchers) Adequate description of sample and setting Clear explanation of data analysis Check with participants about ideas and interpretation of data, check with expert colleagues about ideas and interpretation of data, team of experts

^a ✓ indicates criteria met, ✘ indicates criteria not met or issue not addressed.

^b Study should demonstrate at least half of the ideal study characteristics as described in the guidelines as related to that criterion (Credibility = 5 criteria in total; Confirmability = 5 criteria in total)

Appendix 3.1: SOC qualitative interviews Participant Information Sheet (NHS)



Dear <insert name>

My name is Jennifer Dryden and I am a PhD student at the University of Strathclyde. I would like to invite you to take part in a research study which I have organised as part of my PhD research called 'Examining the coping strategies of stroke survivors'.

You are receiving this study invite because you are a stroke survivor and your treating clinical team have posted you this information pack on behalf of myself.

If you are interested in reading more about the study and how to get involved then please read the rest of this information sheet for further information. Otherwise, many thanks for taking the time to read this and you may throw this information pack away. Please feel free to contact me if you have any questions about the study.

Yours sincerely,
Jennifer Dryden (PhD student)

School of Psychological Sciences and Health
University of Strathclyde, Graham Hills Building
40 George Street
Glasgow, G1 1QE
Telephone: 0141 548 4284
Email: jennifer.dryden@strath.ac.uk

Information about the research:

Examining the coping strategies of stroke survivors

We would like to invite you to take part in our research study. Before you decide, we would like you to read over this information sheet. It will help you to understand:

- why we are doing this research.
- what it will involve.

Please take some time to read over this information and talk to others about the study if you wish. You can contact myself, Jennifer Dryden, if you have any questions about the study. My contact details are listed at the end.

If after reading this information, you wish to take part in the study, please fill in the enclosed consent form and post it back to us in the prepaid envelope provided.

What is the purpose of this study?

Stroke survivors often find that their body has changed since having a stroke and that they may face new difficulties, such as with walking or speaking. You might have made changes in your life to cope with these difficulties. At the moment we do not know a lot about how stroke survivors cope after having a stroke. In this study we will ask you what you find difficult since having a stroke and about changes you might have made to cope with these difficulties. This information could help us teach other stroke survivors how to cope and improve their lives after having a stroke.

Why have I been invited to take part?

You have been invited to take part because you are a stroke survivor.

Do I have to take part?

No, you don't have to take part. Participation in this study is voluntary. Take some time to read this information sheet and consider if you wish to take part in the study. If you do wish to take part, please fill in the enclosed consent form and post it back to us in the prepaid envelope provided.

You may withdraw from this study at any time without giving a reason and without any consequences.

What will happen to me if I take part

You will be asked to take part in 1 interview, which will last a maximum of 1 ½ hours or if you prefer you can take part in 2 shorter interviews. The researcher will come to your house to interview you or we can arrange for the interview to take place somewhere convenient for you. You can choose to have a family member or carer present during the interview.

During the interview we will discuss some common problems faced by stroke survivors. We will ask you to tell us what you find difficult since having a stroke. We will then ask you to tell us if you have made changes in your life because of these problems. The interview will be recorded using a small digital recorder.

We will also ask your clinical team to share some information from your medical records with us. The information we will ask for are your scores on the following: The Barthel Index, The Montreal Cognitive Assessment, The National Institute of Health Stroke Scale and the Oxfordshire Community Stroke Project Classification. These are standard tests used when someone has had a stroke and should already be in your records.

We ask for this information so we can describe who is participating in this study. We will not have access to your medical records nor will your clinical team share any additional medical information with us.

In the event that we cannot get this information from your clinical team, we will ask if we can perform two of the tests ourselves during the interview: The Barthel Index and The Montreal Cognitive Assessment. These are short tests and will take approximately 5-10 minutes to complete in total.

What are the possible benefits of taking part?

You may gain a greater understanding of how you have changed your life since having a stroke. We cannot promise the study will help you but the information we get from this study could help improve the lives of other stroke survivors in the future.

What are the possible disadvantages and risks of taking part?

There are no risks associated with taking part in this study. However, as we are interested in exploring the difficulties faced by stroke survivors, there is a possibility that we may be discussing information that you find upsetting, such as continence and intimacy. We have kept such questions to a minimum and you do not have to answer any questions which make you feel uncomfortable. You are also free to stop the interview and leave the study at any time without giving a reason. There will be no consequences if you decide to withdraw from the study.

If during the interview you find any particular issues upsetting, we may ask you if you want us to share this information with your clinical team so that you may receive further support. This will only happen with your permission.

What happens when the research study stops?

After completing your interview you will be given information explaining the ideas behind this study. If you would like further information you can contact any of the research team.

Once the study is complete we will analyse the interviews and will submit the results of the study for publication in a scientific journal. No information will be published that can identify you personally.

We will ask you if you would be willing to be contacted in the future about taking part in further research. This is entirely voluntary and you are under no obligation to be contacted about or participate in future research.

What if there is a problem?

If you have any questions or concerns, during or after the study, you can contact any of the research team. If you wish to contact an independent person with questions or concerns you can contact:

Secretary to the University Ethics Committee
Research & Knowledge Exchange Services
University of Strathclyde
Graham Hills Building
50 George Street
Glasgow
G11 6NT
Telephone: 0141 548 3707
Email: ethics@strath.ac.uk

Will my taking part in the study be kept confidential?

Yes. We will follow ethical and legal practice and all information about you will be handled in confidence. Your interview will be recorded using audio recording equipment and will be securely stored on a password protected computer. Only the research team will have access to identifiable data, which will be destroyed after 12 months. The information that we get from your interview will be made anonymous so you cannot be identified. The anonymised interviews will be transcribed into text and will be stored securely for a period of 3 years and then destroyed.

The University of Strathclyde is registered with the Information Commissioner's Office who implements the Data Protection Act 1998. All personal data on participants will be processed in accordance with the provisions of the Data Protection Act 1998.

What happens if I don't want to carry on with the study?

You may leave the study at any time without having to give a reason. You can do so by contacting any member of the research team. The contact details are listed below.

What will happen to the results of the research study?

We plan to submit the results for publication in a scientific journal.

Who is organising and funding the research?

The research is being organised by the chief investigator Jennifer Dryden. Jennifer is undertaking this study as part of her PhD training. The research is funded jointly by the University of Strathclyde and Chest Heart & Stroke Scotland.

Who has reviewed the study?

All research in the NHS is looked at by an independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed and given favourable opinion by the NHS Research ethics committee and The University of Strathclyde ethics committee.

What happens next?

If you want to take part in the study, please fill in the enclosed consent form and post it back to us in the prepaid envelope provided. Once we receive this form we will contact you to arrange an interview time. We will also answer any questions you may have about the study and please ask us if there is anything that is not clear.

If you do not want to be involved, thank you very much for your time – there is nothing more that will be asked of you.

Contact details

Chief Investigator:

Jennifer Dryden
School of Psychological Sciences and Health
University of Strathclyde
Graham Hills Building
40 George Street
Glasgow, G1 1QE
Telephone: 0141 548 4284
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Supervisory Team:

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Professor Madeleine Grealy
School of Psychological Sciences and Health
University of Strathclyde
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Dr Terry Quinn
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Walton Building
Glasgow Royal Infirmary
Glasgow, G4 0SF
Telephone: 01412114976
E-mail: terry.quinn@glasgow.ac.uk

Appendix 3.2: SOC qualitative interviews participant consent form (NHS)



CONSENT FORM

Title of Project: Examining the coping strategies of stroke survivors.

Name of Researcher: Jennifer Dryden

Please initial all boxes

I confirm that I have read and understand the information sheet dated 16/04/13 (version 2) for the above study. I have had time to think about the information, ask questions and have had any questions answered to my satisfaction.

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 being affected.

I understand that data collected during the study may be looked at by individuals from the research team, from regulatory authorities or from the NHS Trust. I understand that this data will be made anonymous so that I cannot be identified from or linked to the data.

I understand that the results of some standard stroke assessment measures will be passed to the research team by my treating clinical team. I consent to this sharing of information and understand that the research team will not have access to any additional medical information.

I consent to my interview being recorded using audio recording equipment.

I agree to take part in the above study.

Are you willing to being contacted by the research team about future research? This is entirely voluntary and will not affect participation in this study.

Yes

No

Name (please print)

Date

Signature

Telephone number (the research team will contact you to arrange the interview)

This section to be filled in by researcher only

Name of Person taking consent
Signature

Date

Volunteering for stroke research:

'Examining the coping strategies of stroke survivors'



1. What is the research?

- a) What do you find difficult since having a stroke?
- b) How do you cope with these difficulties?

2. What do volunteers do?



Interview: 1 hour



3. Can I volunteer?

YES if you have had a stroke

YES if you had your stroke over 3 months ago

YES if you are over 18

4. What now?

Talk or write to Jennifer Dryden



0141 548 4284



Jennifer.dryden@strath.ac.uk



Dear Sir/Madam

My name is Jennifer Dryden and I am a PhD student at the University of Strathclyde. I would like to invite you to take part in a research study which I have organised as part of my PhD research called 'Examining the coping strategies of stroke survivors'.

You are receiving this study invite because you are a stroke survivor.

If you are interested in reading more about the study and how to get involved then please read the rest of this information sheet for further information. Otherwise, many thanks for taking the time to read this and you may throw this information pack away. Please feel free to contact me if you have any questions about the study.

Yours sincerely,
Jennifer Dryden (PhD student)

School of Psychological Sciences and Health
University of Strathclyde
Graham Hills Building
40 George Street
Glasgow, G1 1QE
Telephone: 0141 548 4284
Email: jennifer.dryden@strath.ac.uk

Information about the research:

Examining the coping strategies of stroke survivors

We would like to invite you to take part in our research study. Before you decide, we would like you to read over this information sheet. It will help you to understand:

- why we are doing this research.
- what it will involve.

Please take some time to read over this information and talk to others about the study if you wish. You can contact myself, Jennifer Dryden, if you have any questions about the study. My contact details are listed at the end.

If after reading this information, you wish to take part in the study, please fill in the enclosed consent form and post it back to us in the prepaid envelope provided.

What is the purpose of this study?

Stroke survivors often find that their body has changed since having a stroke and that they may face new difficulties, such as with walking or speaking. You might have made changes in your life to cope with these difficulties. At the moment we do not know a lot about how stroke survivors cope after having a stroke. In this study we will ask you what you find difficult since having a stroke and about changes you might have made to cope with these difficulties. This information could help us teach other stroke survivors how to cope and improve their lives after having a stroke.

Why have I been invited to take part?

You have been invited to take part because you are a stroke survivor.

Do I have to take part?

No, you don't have to take part. Participation in this study is voluntary. Take some time to read this information sheet and consider if you wish to take part in the study. If you do wish to take part, please fill in the enclosed consent form and post it back to us in the prepaid envelope provided.

You may withdraw from this study at any time without giving a reason and without any consequences.

What will happen to me if I take part

You will be asked to take part in 1 interview, which will last a maximum of 1 ½ hours or if you prefer you can take part in 2 shorter interviews. The researcher will come to your house to interview you or we can arrange for the interview to take place somewhere convenient for you. You can choose to have a family member or carer present during the interview.

During the interview we will discuss some common problems faced by stroke survivors. We will ask you to tell us what you find difficult since having a stroke. We will then ask you to tell us if you have made changes in your life because of these problems. The interview will be recorded using a small digital recorder.

We will also ask to perform two short assessments after the interview: The Barthel Index and the Montreal Cognitive Assessment. These are standard tests used when someone has had a stroke. These are short tests and will take approximately 5-10 minutes in total to complete.

We will also ask for the following information: date of birth, postcode, gender and living arrangements. We ask for this information so we can describe our participants. No identifiable information will be seen by anyone out with the research team.

What are the possible disadvantages and risks of taking part?

There are no risks associated with taking part in this study. However, as we are interested in exploring the difficulties faced by stroke survivors, there is a possibility that we may be discussing information that you find upsetting, such as continence and intimacy. We have kept such questions to a minimum and you do not have to answer any questions which make you feel uncomfortable. You are also free to stop the interview and leave the study at any time without giving a reason. There will be no consequences if you decide to withdraw from the study.

What are the possible benefits of taking part?

You may gain a greater understanding of how you have changed your life since having a stroke. We cannot promise the study will help you but the information we get from this study could help improve the lives of other stroke survivors in the future.

What happens when the research study stops?

After completing your interview you will be given information explaining the ideas behind this study. If you would like further information you can contact any of the research team.

Once the study is complete we will analyse the interviews and will submit the results of the study for publication in a scientific journal. No information will be published that can identify you personally.

We will ask you if you would be willing to be contacted in the future about taking part in further research. This is entirely voluntary and you are under no obligation to be contacted about or participate in future research.

What if there is a problem?

If you have any questions or concerns, during or after the study, you can contact any of the research team. If you wish to contact an independent person with questions or concerns you can contact:

Secretary to the University Ethics Committee
Research & Knowledge Exchange Services
University of Strathclyde
Graham Hills Building
50 George Street
Glasgow
G11 6NT
Telephone: 0141 548 3707
Email: ethics@strath.ac.uk

Will my taking part in the study be kept confidential?

Yes. We will follow ethical and legal practice and all information about you will be handled in confidence. Your interview will be recorded using audio recording equipment and will be securely stored on a password protected computer. Only the research team will have access to identifiable data, which will be destroyed after 12 months. The information that we get from your interview will be made anonymous so you cannot be identified. The anonymised interviews will be transcribed into text and will be stored securely for a period of 3 years and then destroyed.

The University of Strathclyde is registered with the Information Commissioner's Office who implements the Data Protection Act 1998. All personal data on participants will be processed in accordance with the provisions of the Data Protection Act 1998.

What happens if I don't want to carry on with the study?

You may leave the study at any time without having to give a reason. You can do so by contacting any member of the research team. The contact details are listed below.

What will happen to the results of the research study?

We plan to submit the results for publication in a scientific journal.

Who is organising and funding the research?

The research is being organised by the chief investigator Jennifer Dryden. Jennifer is undertaking this study as part of her PhD training. The research is funded jointly by the University of Strathclyde and Chest Heart & Stroke Scotland.

Who has reviewed the study?

All research conducted by the University of Strathclyde and the NHS is looked at by a group called a Research Ethics Committee, to protect your interests. This study has been reviewed and given favourable opinion by the NHS research ethics committee and The University of Strathclyde ethics committee.

What happens next?

If you want to take part in the study, please fill in the enclosed consent form and post it back to us in the prepaid envelope provided. Once we receive this form we will contact you to arrange an interview time. We will also answer any questions you may have about the study and please ask us if there is anything that is not clear.

If you do not want to be involved, thank you very much for your time – there is nothing more that will be asked of you.

Contact details

Chief Investigator:

Jennifer Dryden

School of Psychological Sciences and Health

University of Strathclyde

Graham Hills Building

40 George Street

Glasgow, G1 1QE

Telephone: 0141 548 4284

Email: jennifer.dryden@strath.ac.uk

Supervisory Team:

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School of Psychological Sciences and Health

University of Strathclyde

Graham Hills Building

40 George Street

Glasgow, G1 1QE

Telephone: 0141 548 2571

Email: diane.dixon@strath.ac.uk

Professor Madeleine Grealy

School of Psychological Sciences and Health

University of Strathclyde

Graham Hills Building

40 George Street

Glasgow, G1 1QE

Telephone: 0141 548 4885

Email: madeleine.grealy@strath.ac.uk

Dr Terry Quinn
Institute of Cardiovascular and Medical Sciences
Walton Building
Glasgow Royal Infirmary
Glasgow, G4 0SF
Telephone: 01412114976
E-mail: terry.quinn@glasgow.ac.uk

Appendix 3.5: SOC qualitative interviews participant consent form (groups)



CONSENT FORM

Title of Project: Examining the coping strategies of stroke survivors.

Name of Researcher: Jennifer Dryden

Please initial boxes

I confirm that I have read and understand the information sheet dated 13/01/14 (version 1) for the above study. I have had time to think about the information, ask questions and have had any questions answered to my satisfaction.

I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason.

I understand that data collected during the study may be looked at by individuals from the research team. I understand that this data will be made anonymous so that I cannot be identified from or linked to the data.

I consent to my interview being recorded using audio recording equipment.

I agree to take part in the above study.

Are you willing to being contacted by the research team about future research? This is entirely voluntary and will not affect participation in this study.

Yes

No

Name (please print)

Date

Signature

Telephone number (the research team will contact you to arrange the interview)

This section to be filled in by researcher only

Name of Person taking consent Date
Signature

Appendix 3.6: SOC qualitative interviews NHS REC Notice of Favourable Opinion, with conditions

WoSRES
West of Scotland Research Ethics Service



Miss Jennifer Dryden
PhD student
School of Psychological Sciences and Health
University of Strathclyde
Graham Hills Building
40 George Street
Glasgow
G1 1QE

West of Scotland REC 4
Ground Floor - Tennent Building
Western Infirmary
38 Church Street
Glasgow
G11 6NT

Date 16 April 2013
Direct line 0141 211 2102
E-mail sharon.macgregor@ggc.scot.nhs.uk

Dear Miss Dryden

Study title: Adaptation to stroke: Examining post-stroke coping strategies using a model of successful aging
REC reference: 13/WS/0082
Protocol number: UEC13/15
IRAS project ID: 120904

The Research Ethics Committee reviewed the above application at the meeting held on 05 April 2013. Thank you for attending to discuss the application.

We plan to publish your research summary wording for the above study on the NRES website, together with your contact details, unless you expressly withhold permission to do so. Publication will be no earlier than three months from the date of this favourable opinion letter. Should you wish to provide a substitute contact point, require further information, or wish to withhold permission to publish, please contact the Co-ordinator Mrs Sharon Macgregor, sharon.macgregor@ggc.scot.nhs.uk.

Ethical opinion

Ethical issues raised by the Committee in private discussion, together with responses given by the researcher when invited into the meeting

- It was noted that the researchers plan for the stroke liaison nurses to contact potential participants by telephone before sending out the information pack. It was suggested by the Committee that this step is missed out and the nurses send the pack directly to all their patients. This also prevents the potential bias of recruiting only patients who the clinical team think might do well in the study.
- If, however, you decide to retain the original recruitment method, it was suggested that the nurses approach potential participants face-to-face at a clinic visit as some patients have speech problems and may not want to use the telephone.
- The Committee asked whether a lone worker policy will be put in place before the

researcher makes home visits. You confirmed that risk assessments will be carried out and a policy put in place before she makes home visits.

- There were concerns that the interviews could last up to 3 hours and that this far too long for some participants. You advised that if this is the case, the sessions can be split into two.
- The Committee asked how the researchers will define cognitive impairment. You advised that there will be no additional screening as they will rely on the clinical team to do this.

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.

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).

Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission ("R&D approval") should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements.

Guidance on applying for NHS permission for research is available in the Integrated Research Application System 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 approvals from host organisations

- 1. In the Participant Information Sheet (PIS), participants should be advised that they can split the interview into shorter sessions if they prefer.**
- 2. It should also be stated in the PIS that any upsetting discussions may be shared with the clinical team.**

It is 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).

You should notify the REC in writing once all conditions have been met (except for site approvals from host organisations) and provide copies of any revised documentation with updated version numbers. The REC will acknowledge receipt and provide a final list of the approved documentation for the study, which can be made 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.

Approved documents

The documents reviewed and approved at the meeting were:

<i>Document</i>	<i>Version</i>	<i>Date</i>
Covering Letter	-	
Evidence of insurance or indemnity	-	26 February 2013
Interview Schedules/Topic Guides	1	18 March 2013
Investigator CV	-	04 March 2013
Other: The Barthel Index		
Other: MoCA Test	7.2	
Other: Stroke Survivor Difficulty Checklist	1	18 March 2013
Other: Letter from funder	-	19 February 2013
Other: CI's Certificate of Attendance - GCP	-	14 February 2013
Other: D Dixon's CV	-	22 February 2013
Other: M Grealy's CV	-	15 February 2013
Other: T Quinn's CV	-	15 February 2013
Other: E-mail of support from Christine McAlpine	-	28 February 2013
Participant Consent Form	1	18 March 2013
Participant Information Sheet	1	18 March 2013
Participant Information Sheet: Debrief	1	18 March 2013
Protocol	1	18 March 2013
Questionnaire: Interview Satisfaction	1	18 March 2013
REC application	-	18 March 2013

Membership of the Committee

The members of the Ethics Committee who were present at the meeting are listed on the attached sheet.

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 NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

Feedback

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.

Further information is available at National Research Ethics Service website > After Review

13/WS/0082	Please quote this number on all correspondence
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We are pleased to welcome researchers and R & D staff at our NRES committee members' training days – see details at <http://www.hra.nhs.uk/hra-training/>

With the Committee's best wishes for the success of this project.

Yours sincerely



for
Dr Brian Neilly
Chair

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"*

Copy to: *Helen Baigrie, University of Strathclyde*

Appendix 3.7: SOC qualitative interviews NHS REC Notice of Favourable Opinion

WoSRES
West of Scotland Research Ethics Service



Miss Jennifer Dryden
PhD student
School of Psychological Sciences and Health
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Graham Hills Building
40 George Street
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West of Scotland REC 4

Ground Floor - Tennent Building
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38 Church Street
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Date 17 April 2013

Direct line 0141 211 2102
E-mail sharon.macgregor@ggc.scot.nhs.uk

Dear Miss Dryden

Study title: Adaptation to stroke: Examining post-stroke coping strategies using a model of successful aging
REC reference: 13/WS/0082
Protocol number: UEC13/15
IRAS project ID: 120904

Thank you for your letter of 16 April 2013. I can confirm the REC has received the documents listed below and that these comply with the approval conditions detailed in our letter dated 16 April 2013.

Documents received

The documents received were as follows:

Document	Version	Date
Covering Letter		16 April 2013
Participant Consent Form	2	16 April 2013
Participant Information Sheet	2	16 April 2013
Protocol	2	16 April 2013

Approved documents

The final list of approved documentation for the study is therefore as follows:

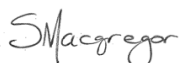
Document	Version	Date
Covering Letter	-	
Covering Letter		16 April 2013
Evidence of insurance or indemnity	-	26 February 2013

Interview Schedules/Topic Guides	1	18 March 2013
Investigator CV	-	04 March 2013
Other: The Barthel Index		
Other: MoCA Test	7.2	
Other: Stroke Survivor Difficulty Checklist	1	18 March 2013
Other: Letter from funder	-	19 February 2013
Other: CI's Certificate of Attendance - GCP	-	14 February 2013
Other: D Dixon's CV	-	22 February 2013
Other: M Grealy's CV	-	15 February 2013
Other: T Quinn's CV	-	15 February 2013
Other: E-mail of support from Christine McAlpine	-	28 February 2013
Participant Consent Form	2	16 April 2013
Participant Information Sheet: Debrief	1	18 March 2013
Participant Information Sheet	2	16 April 2013
Protocol	2	16 April 2013
Questionnaire: Interview Satisfaction	1	18 March 2013
REC application	-	18 March 2013

You should ensure that the sponsor has a copy of the final documentation for the study. It is the sponsor's responsibility to ensure that the documentation is made available to R&D offices at all participating sites.

13/WS/0082	Please quote this number on all correspondence
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Yours sincerely



Mrs Sharon Macgregor
Committee Co-ordinator

Copy to: Helen Baigrie, University of Strathclyde
Dr Erica Packard, NHS Greater Glasgow and Clyde

Appendix 3.8: NHS REC Approval of substantial amendment 1

WoSRES
West of Scotland Research Ethics Service



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www.nhsggc.org.uk

Date 6 November 2013
Direct line 0141-211-1722
Fax 0141-211-1847
e-mail Wosrec4@ggc.scot.nhs.uk

Dear Miss Dryden

Study title:	Adaptation to stroke: Examining post-stroke coping strategies using a model of successful aging
REC reference:	13/WS/0082
Protocol number:	UEC13/15
Amendment number:	AM01
Amendment date:	15 October 2013
IRAS project ID:	120904

The following amendment was reviewed by the Sub-Committee in correspondence.

Ethical opinion

The Sub-Committee approved the following amendment:

- Change to the recruitment procedure - Scottish Stroke Research Network, Research Nurses will now recruit potential participants from stroke survivors who are attending stroke clinics.

The members of the Committee taking part in the review gave a favourable ethical opinion of the amendment on the basis described in the notice of amendment form and supporting documentation.

Approved documents

The documents reviewed and approved at the meeting were:

Document	Version	Date
Covering Letter	email	15 October 2013
Notice of Substantial Amendment (non-CTIMPs)	AM01	15 October 2013
Protocol	3	17 October 2013

Membership of the Committee

The members of the Committee who took part in the review are listed on the attached sheet.

R&D approval

All investigators and research collaborators in the NHS should notify the R&D office for the relevant NHS care organisation of this amendment and check whether it affects R&D approval of the research.

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.

We are pleased to welcome researchers and R & D staff at our NRES committee members' training days – see details at <http://www.hra.nhs.uk/hra-training/>

13/WS/0082:	Please quote this number on all correspondence
-------------	--

Yours sincerely



**For Dr Brian Neilly
Chair**

Enclosures: List of names and professions of members who took part in the review

*Copy to: Dr Erica Packard, R&D Office, Tennent Building, Western Infirmary
Helen Baigrie, University of Strathclyde*

Appendix 3.9: NHS REC Approval of substantial amendment 2

WoSRES
West of Scotland Research Ethics Service



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Date 3 February 2014
Direct line 0141-211-1722
Fax 0141-211-1847
e-mail Wosrec4@ggc.scot.nhs.uk

Dear Miss Dryden

Study title:	Adaptation to stroke: Examining post-stroke coping strategies using a model of successful aging
REC reference:	13/WS/0082
Protocol number:	UEC13/15
Amendment number:	AM02
Amendment date:	13 January 2014
IRAS project ID:	120904

The above amendment was reviewed by the Sub-Committee in correspondence.

Ethical opinion

The Sub-Committee were happy to approve the following amendment:

In addition to the current recruitment method from NHS, this study will also now recruit from community support groups, run by, or affiliated with, Chest, Heart and Stroke Scotland (CHSS).

The members of the Committee taking part in the review gave a favourable ethical opinion of the amendment on the basis described in the notice of amendment form and supporting documentation.

Approved documents

The documents reviewed and approved at the meeting were:

Document	Version	Date
Covering Letter	AM02 email	17 January 2014
Notice of Substantial Amendment (non-CTIMPs)	AM02	13 January 2014
Protocol	4	13 January 2014
Participant Information Sheet: Groups	1	13 January 2014

Participant Consent Form: Groups	1	13 January 2014
Information Leaflet	1	13 January 2014
CHSS Advert	1	13 January 2014

Membership of the Committee

The members of the Committee who took part in the review are listed on the attached sheet.

R&D approval

All investigators and research collaborators in the NHS should notify the R&D office for the relevant NHS care organisation of this amendment and check whether it affects R&D approval of the research.

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.

We are pleased to welcome researchers and R & D staff at our NRES committee members' training days – see details at <http://www.hra.nhs.uk/hra-training/>

13/WS/0082:	Please quote this number on all correspondence
--------------------	---

Yours sincerely



For **Dr Brian Neilly**
Chair

Enclosures: *List of names and professions of members who took part in the review*

Copy to: *Dr Erica Packard, R&D Office, Tennent Building
Helen Baigrie, University of Strathclyde*

Appendix 3.10: SOC interview

Activities and Participation

I'm going to ask you about some different activities. Some of these activities you might find difficult since having a stroke. You may find them so difficult that you are no longer able to do them. I'm going to go through each activity and ask if you have difficulty with it since having a stroke.

State each item, present the corresponding card to the participant and provide examples if the participant is unclear about what an item means. Items which participants indicate they have difficulty with or are unable to do should be recorded by keeping the corresponding card and marking it on the checklist.

Mobility

1. *Changing your body position, for example, moving yourself so you are lying down or sitting.*
2. *Keeping your body position the same, for example, when you are sitting for a while or lying in your bed.*
3. *Transferring yourself, for example, moving from one chair to another.*
4. *Lifting and carrying things*
5. *Walking*
6. *Moving around in any way except walking, for example, jogging or swimming.*
7. *Moving around places, for example, from room to room in your house or outside.*
8. *Using transportation, for example, public transport or being driven in a car or taxi*
9. *Driving*
10. *Hand use, such as picking up, grasping and letting go.*
11. *Using both your hand and your arm, for example picking up, grasping, catching or throwing.*

Show the participant the items they have indicated they find difficult (including those which they are no longer able to do) by showing them the corresponding cards.

These activities are all to do with your mobility – which of these things do you feel is the most important to you? What about the second most important? What about the third most important?

Keep the cards which the participant indicates are most important and record them on the checklist.

You have told me that you have difficulty with these activities. Because you find these difficult you might have stopped doing some of them, or you might have changed the way you do them. For example, some people have difficulty walking after having a stroke and so might either stop walking or use a walking aid, such as a stick.

Restate item(s) and ask:

i) Are you able to do this activity since having a stroke?

No: ii) Is there anything that you do instead of this activity?

Yes: iii) Have you changed the way that you do this since having a stroke?

iv) Do you need assistance from another person or do you need a special gadget or piece of equipment in order to do this?

Communication

1. Speaking.
2. Conversation.
3. Understanding messages, for example someone speaking to you, writing something down for you or even a gesture.
4. Giving out your own messages without speaking or writing, for example shaking your head or drawing.
5. Using devices to communicate, such as a computer or a telephone

Show the participant the items they have indicated they find difficult (including those which they are no longer able to do) by showing them the corresponding cards.

These activities are all to do with your communication – which of these things do you feel is the most important to you? What about the second most important?

Keep the cards which the participant indicates are most important and record them on the checklist.

You have told me that you have difficulty with these activities. Because you find these difficult you might have stopped doing some of them, or you might have changed the way you do them. For example, some people have difficulty walking after having a stroke and so might either stop walking or use a walking aid, such as a stick.

Restate item(s) and ask:

i) Are you able to do this activity since having a stroke?

No: ii) Is there anything that you do instead of this activity?

Yes: iii) Have you changed the way that you do this since having a stroke?

iv) Do you need assistance from another person or do you need a special gadget or piece of equipment in order to do this?

Using your knowledge

1. Listening, for example, to the radio or other people.
2. Learning things, such as learning how to hold cutlery again or how to play a new game.
3. Focussing your attention.
4. Reading.
5. Writing.
6. Calculating, for example using maths to solve sums.

Show the participant the items they have indicated they find difficult (including those which they are no longer able to do) by showing them the corresponding cards.

These activities are all to do with using your knowledge – which of these things do you feel is the most important to you? What about the second most important?

Keep the cards which the participant indicates are most important and record them on the checklist.

You have told me that you have difficulty with these activities. Because you find these difficult you might have stopped doing some of them, or you might have changed the way you do them. For example, some people have difficulty walking after having a stroke and so might either stop walking or use a walking aid, such as a stick.

Restate item(s) and ask:

i) Are you able to do this activity since having a stroke?

No: ii) Is there anything that you do instead of this activity?

Yes: iii) Have you changed the way that you do this since having a stroke?

iv) Do you need assistance from another person or do you need a special gadget or piece of equipment in order to do this?

At home and in the community

1. Preparing meals
2. Doing housework
3. Shopping.
4. Organising your daily routine, for example how and when you are going to do things and making sure you have enough energy to do them.
5. Social events and community life such as attending social clubs or weddings/funerals.
6. Recreation and leisure – things you do in your spare time for leisure e.g. games such as chess or cards, sports, arts and culture (cinema, theatre) crafts, hobbies, socialising.

Show the participant the items they have indicated they find difficult (including those which they are no longer able to do) by showing them the corresponding cards.

These activities are all to do with being at home and in your community – which of these things do you feel is the most important to you? What about the second most important?

Keep the cards which the participant indicates are most important and record them on the checklist

You have told me that you have difficulty with these activities. Because you find these difficult you might have stopped doing some of them, or you might have changed the way you do them. For example, some people have difficulty walking after having a stroke and so might either stop walking or use a walking aid, such as a stick.

Restate item(s) and ask:

i) Are you able to do this activity since having a stroke?

No: ii) Is there anything that you do instead of this activity?

Yes: iii) Have you changed the way that you do this since having a stroke?

iv) Do you need assistance from another person or do you need a special gadget or piece of equipment in order to do this?

Caring for yourself

1. Washing yourself
2. Dressing
3. Eating, including chewing, swallowing and biting.
4. Looking after your body parts, for example teeth, hair, skin or nails.
5. Looking after your health, for example eating well, exercising or asking for help with any health issues.
6. Going to the toilet, for example, managing to get there and cleaning yourself.

Show the participant the items they have indicated they find difficult (including those which they are no longer able to do) by showing them the corresponding cards.

These activities are all to do with caring for yourself – which of these things do you feel is the most important to you? What about the second most important?

Keep the cards which the participant indicates are most important and record them on the checklist.

You have told me that you have difficulty with these activities. Because you find these difficult you might have stopped doing some of them, or you might have changed the way you do them. For example, some people have difficulty walking after having a stroke and so might either stop walking or use a walking aid, such as a stick.

Restate item(s) and ask:

i) Are you able to do this activity since having a stroke?

No: ii) Is there anything that you do instead of this activity?

Yes: iii) Have you changed the way that you do this since having a stroke?

iv) Do you need assistance from another person or do you need a special gadget or piece of equipment in order to do this?

Relationships

1. Interacting with people in appropriate ways, for example, showing respect and tolerance.
2. Relationships with people out with your family, for example neighbour, carer or friend
3. Relationships with your family.
4. Intimate relationships, such as relationships with a partner or spouse including your sexual relationship.

Show the participant the items they have indicated they find difficult (including those which they are no longer able to do) by showing them the corresponding cards.

These activities are all to do with your relationships – which of these things do you feel is the most important to you? What about the second most important?

Keep the cards which the participant indicates are most important and record them on the checklist.

You have told me that you have difficulty with these activities. Because you find these difficult you might have stopped doing some of them, or you might have changed the way you do them. For example, some people have difficulty walking after having a stroke and so might either stop walking or use a walking aid, such as a stick.

Restate item(s) and ask:

i) Are you able to do this activity since having a stroke?

No: ii) Is there anything that you do instead of this activity?

Yes: iii) Have you changed the way that you do this since having a stroke?

iv) Do you need assistance from another person or do you need a special gadget or piece of equipment in order to do this?

Work and money

Some of the questions in this section might not apply to you so I'm going to ask you whether you are currently:

- Working (**GO TO 1.**)
- Not working due to health issues (**GO TO 3.**)
- Retired (**GO TO 3.**)
- Unemployed (**GO TO 2.**)

1. Doing your job. For example, performing the tasks required of you, getting to work on time or being supervised/supervising.
2. Looking for a job? Such as selecting a job, writing an application form, going for an interview etc...
3. Basic money transactions, such as paying for something in a shop.
4. Looking after your finances so that you are comfortable in the future.

Show the participant the items they have indicated they find difficult (including those which they are no longer able to do) by showing them the corresponding cards.

These activities are all to do with work and money – which of these things do you feel is the most important to you? What about the second most important?

Keep the cards which the participant indicates are most important and record them on the checklist.

You have told me that you have difficulty with these activities. Because you find these difficult you might have stopped doing some of them, or you might have changed the way you do them. For example, some people have difficulty walking after having a stroke and so might either stop walking or use a walking aid, such as a stick.

Restate item(s) and ask:

i) Are you able to do this activity since having a stroke?

No: ii) Is there anything that you do instead of this activity?

Yes: iii) Have you changed the way that you do this since having a stroke?

iv) Do you need assistance from another person or do you need a special gadget or piece of equipment in order to do this?

Body Functions

Now I'm going to ask you to think about your body and how it works. You might feel as if some of the things you were able to do before you had a stroke are more difficult now, such as exercising or remembering things. Your body may no longer be able to act the way that it used to. Similar to before, I'm going to go through some items and ask you if you have difficulty with them since having a stroke.

State each item, present the corresponding card to the participant and provide examples if the participant is unclear about what an item means. Items which participants indicate they have difficulty with should be recorded by keeping the corresponding card and marking it on the checklist

Your brain

1. Memory, both long term and short term.
2. Attention, for example, concentrating on one thing or moving your attention from one thing to another.
3. Sleep, for example getting to sleep, the amount of sleep you get and the quality of it.
4. Energy levels
5. Motivation, how much motivation you have to act.
6. Appetite, desire for things, for example, food or drink.
7. Cravings, sudden urge to consume things.
8. Impulse control, resisting sudden urges to do something.
9. Awareness of time, where you are and who you are.
10. Awareness and alertness, so how awake and alert you feel.
11. Time management
12. Coming up with ideas
13. Judgement, for example, sometimes you have to judge a situation to form an opinion.
14. Problem-solving

Show the participant the items they have indicated they find difficult (including those which they are no longer able to do) by showing them the corresponding cards.

These are all to do with how your brain works– which of these things do you feel is the most important to you? What about the second most important? What about the third most important?

Keep the cards which the participant indicates are most important and record them on the checklist.

You have told me that you have difficulty with these body functions. Because you have difficulty with these you might not be able to do them anymore or you might need help with them. For example, some people have difficulty with their memory after having a stroke so they might not be able to remember certain things and may ask their partner to help them remember.

Restate item(s) and ask:

i) Are you able to do this since having a stroke?

No: ii) Is there anything that you do instead of this?

Yes: iii) Have you changed the way that you do this since having a stroke?

iv) Do you need assistance from another person or do you need a special gadget or piece of equipment in order to do this?

Your emotions

1. Emotion, this is feeling the right emotions at the right time, controlling these emotions and the ability to feel a range of emotions e.g. happy and sad.
2. Being Outgoing and sociable
3. Confidence
4. Optimism
5. Being cooperative, for example, being cooperative and friendly towards others.
6. Being responsible
7. Calmness, for example being calm and composed rather than being irritable and moody.
8. Being open to new experiences
9. Being dependable and trustworthy
10. Handling stress such as a crisis, distractions or responsibility.

Show the participant the items they have indicated they find difficult (including those which they are no longer able to do) by showing them the corresponding cards.

These are all to do with your emotions– which of these things do you feel is the most important to you? What about the second most important? What about the third most important?

Keep the cards which the participant indicates are most important and record them on the checklist.

You have told me that you have difficulty with these body functions. Because you have difficulty with these you might not be able to do them anymore or you might need help with them. For example, some people have difficulty with their memory after having a stroke so they might not be able to remember certain things and may ask their partner to help them remember.

Restate item(s) and ask:

i) Are you able to do this since having a stroke?

No: ii) Is there anything that you do instead of this?

Yes: iii) Have you changed the way that you do this since having a stroke?

iv) Do you need assistance from another person or do you need a special gadget or piece of equipment in order to do this?

Your senses

1. Vision
2. Problems around your eye, e.g. eyelid or muscles which effect eye movement
3. Using your senses, for example smelling, tasting, touching and spatial awareness.
4. Sensing the position of your body parts, for example, being able to sense where your arms are and what they are doing or feeling.
5. Sensing temperature, vibrations and pressure.
6. Pain

Show the participant the items they have indicated they find difficult (including those which they are no longer able to do) by showing them the corresponding cards.

These are all to do with your senses– which of these things do you feel is the most important to you? What about the second most important?

Keep the cards which the participant indicates are most important and record them on the checklist.

You have told me that you have difficulty with these body functions. Because you have difficulty with these you might not be able to do them anymore or you might need help with them. For example, some people have difficulty with their memory after having a stroke so they might not be able to remember certain things and may ask their partner to help them remember.

Restate item(s) and ask:

i) Are you able to do this since having a stroke?

No: ii) Is there anything that you do instead of this?

Yes: iii) Have you changed the way that you do this since having a stroke?

iv) Do you need assistance from another person or do you need a special gadget or piece of equipment in order to do this?

How your body works

1. Exercise, for example do you have difficulty with how much exercise you can do, how tired you get and how out of breath you get.
2. Going to the toilet, this time can you tell me if you have difficulty with the frequency and control you have over going to the toilet, both urinating and defecating?
3. Sex, including becoming aroused and engaging in sex.
4. Moving your joints –moving them and how stable they are.
5. Muscle power - strength of your muscles and how long you can use them for.
6. Reflexes
7. Control over movement, so how much control you have over movement and whether you have control over moving parts of your body without meaning to.
8. How you move, for example the pattern in which you walk or move.

Show the participant the items they have indicated they find difficult (including those which they are no longer able to do) by showing them the corresponding cards.

These are all to do with how the rest of your body works– which of these things do you feel is the most important to you? What about the second most important?

Keep the cards which the participant indicates are most important and record them on the checklist.

You have told me that you have difficulty with these body functions. Because you have difficulty with these you might not be able to do them anymore or you might need help with them. For example, some people have difficulty with their memory after having a stroke so they might not be able to remember certain things and may ask their partner to help them remember.

Restate item(s) and ask:

i) Are you able to do this since having a stroke?

No: ii) Is there anything that you do instead of this?

Yes: iii) Have you changed the way that you do this since having a stroke?

iv) Do you need assistance from another person or do you need a special gadget or piece of equipment in order to do this?

Appendix 3.11: Stroke survivor interview checklist

Participant identification number:

Mobility	Difficult	Importance
Changing your body position		
Keeping your body position the same		
Transferring your body		
Lifting and carrying things		
Walking		
Moving around (not walking)		
Moving around places		
Using transportation		
Driving		
Hand use		
Hand and arm use		

Communication	Difficult	Importance
Speaking		
Conversation		
Understanding messages		
Giving out messages without speaking or writing		
Using devices to communicate		

Using your knowledge	Difficult	Importance
Listening		
Learning things		
Focussing your attention		
Reading		
Writing		
Calculating		

At home and in the community	Difficult	Importance
Preparing meals		
Housework		
Shopping		
Organising your daily routine		
Social and community events		
Leisure		

Caring for yourself	Difficult	Importance
Washing yourself		
Dressing		
Eating		
Looking after your body parts		

Looking after your health		
Going to the toilet		

Relationships	Difficult	Importance
Interacting with people		
Relationships outside the family		
Relationships with your family		
Spousal or partner relationship		

Work and money	Difficult	Importance
Doing your job		
Looking for a job		
Money transactions		
Looking after your finances		

Your brain	Difficult	Importance
Memory		
Attention		
Sleep		
Energy level		
Motivation		
Appetite		
Cravings		
Impulse control		
Awareness of time, place and yourself.		

Awareness and alertness		
Time management		
Coming up with ideas		
Judgement		
Problem solving		

Your emotions	Difficult	Importance
Emotions		
Being outgoing and sociable		
Confidence		
Optimism		
Being cooperative		
Being responsible		
Calmness		

Being open to new experiences		
Being dependable and trustworthy		
Handling stress		

Your senses	Difficult	Importance
Vision		
Problems around your eye		
Using your senses		
Sensing the position of your body parts		
Sensing temperature, vibrations and pressure		
Pain		

What your body can do	Difficult	Importance
Exercise		
Going to the toilet		
Sex		
Moving your joints and their stability		
Muscles power		

Reflexes		
Control over movement		
How you move		

Changing your body

position

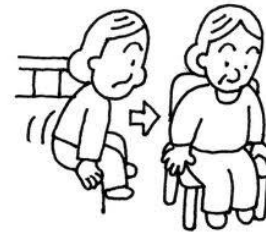


Keeping your body position

the same



Transferring your body



Lifting and carrying things



Summary information about the research:

Examining the coping strategies of stroke survivors

Thank you for taking part in this study about the coping strategies of stroke survivors. Stroke survivors often find that their body has changed since having a stroke and that these changes can make life more difficult. The ways in which people cope with these difficulties are known as ‘coping strategies’. This study is trying to find out what coping strategies are used by stroke survivors. This is important because we may be able to teach other stroke survivors helpful coping strategies which will improve their lives.

This study is also trying to find out if an interview is a good way to find out about these coping strategies. We have asked you to tell us how you feel about the interview and we will use this information in future studies.

Feel free to contact me or any of the research team if you have any questions. The contact details for all the research team members are on the back of this page.

Thank you very much for taking part.

Contact details

Chief Investigator:

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Appendix 3.14: Participant information sheet (healthcare professionals)

SCHOOL OF PSYCHOLOGICAL SCIENCES & HEALTH



Participant Information Sheet

Title of the study: Examining the use of strategies for stroke survivors' rehabilitation

Introduction

My name is Jennifer Dryden and I am a 2nd year PhD student and trainee health psychologist at the University of Strathclyde. I am working with Dr Diane Dixon and Professor Madeleine Grealy in the School of Psychological Sciences and Health. You are being invited to take part in a research study. Before you decide whether to take part, it is important for you to understand why the research is being carried out and what it will involve. Please take the time to read this information sheet carefully. You will find further information about the nature of the study and what is expected from participants below. If, after reading, you have any questions, please contact a member of the research team who will be happy to answer them for you. Thank you for taking the time to consider participating in the study.

What is the purpose of this investigation?

The aim of this study is to investigate the various strategies that are used to help stroke survivors adjust to life post-stroke.

Do you have to take part?

No, you do not have to take part. Participation in this study is voluntary. You may withdraw from this study at any time without giving a reason. You may also withdraw your data from the study at any time without providing a reason.

What will you do in the project?

You are invited to take part in one interview, which can take place at either your work place or your home. We are interested in the various methods used to help stroke survivors adjust in many different areas of their lives. We will therefore ask you about methods which you feel, in your experience, have been particularly helpful or unhelpful when working with stroke survivors. We will ask about these in relation to a range of different activities and body functions which stroke survivors often experience difficulty with.

The interview will last no more than one hour and will be recorded using a small digital recorder.

You will receive no payment or reimbursement for your participation in this study.

Why have you been invited to take part?

We are looking for healthcare professionals and researchers who currently work with stroke survivors or have worked with stroke survivors in the past.

What happens to the information in the project?

The information you supply will remain confidential, and will be securely stored on a password protected computer. Your data will not be stored directly with your name, but with a code so that if you wish to withdraw your data, the researcher may identify your data.

The University of Strathclyde is registered with the Information Commissioner's Office who implements the Data Protection Act 1998. All personal data on participants will be processed in accordance with the provisions of the Data Protection Act 1998.

What happens next?

If you wish to take part, please complete the attached consent form and return it to the researcher. If you do not wish to take part, thank you for your time.

This investigation was granted ethical approval by the School of Psychological Sciences and Health Ethics Committee.

Researcher Contact Details:

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Chief Investigator Details:

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If you have any questions/concerns, during or after the investigation, or wish to contact an independent person to whom any questions may be directed or further information may be sought from, please contact:

Dr James Baxter
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Graham Hills Building
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Appendix 3.15: Participant consent form (healthcare professionals)

SCHOOL OF PSYCHOLOGICAL SCIENCES & HEALTH



Consent form

Title of the study:

Examining the use of strategies for stroke survivors' rehabilitation

Name of Researcher: Jennifer Dryden

- I confirm that I have read and understood the information sheet for the above project and the researcher has answered any queries to my satisfaction.
- I understand that my participation is voluntary and that I am free to withdraw from the project at any time, without having to give a reason and without any consequences.
- I understand that I can withdraw my data from the study at any time.
- I understand that any information recorded in the investigation will remain confidential and no information that identifies me will be made publicly available.
- I consent to being a participant in the project

- I consent to being audio recorded as part of the project Yes/ No

(PRINT NAME)	
Signature of Participant:	Date:

Telephone number (the research team will contact you to arrange the interview)

Appendix 3.16: Debrief sheet (healthcare professionals)

SCHOOL OF PSYCHOLOGICAL SCIENCES & HEALTH



Participant Debrief Sheet

Title of the study: Examining the use of strategies for stroke survivors' rehabilitation

Thank you for taking part in this study on the various strategies that can be used to help stroke survivors adjust to life post-stroke. As you know, stroke survivors often find that their body has changed since having a stroke and that these changes can make life more difficult. We have already spoken to stroke survivors about the techniques which they find helpful and we will now combine these with the additional information from this study of healthcare professionals' experiences of working with stroke patients.

We aim to use this information to develop a help sheet and planning intervention to help stroke survivors choose which strategies might be useful in helping them to achieve a range of goals. This intervention will include asking stroke survivors to set individual goals and then use the suggested strategies to help them reach these goals. It is suggested that integrating examples of strategies into such a planning intervention will be more beneficial than simple planning alone. We will be testing the acceptability and feasibility of such an intervention in a future study. Thank you once again for taking part in this study. If you have any further questions, please contact the research team below.

Researcher Contact Details:

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If you have any questions/concerns, during or after the investigation, or wish to contact an independent person to whom any questions may be directed or further information may be sought from, please contact:

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Appendix 3.17: List of original 270 labelled strategies

Selection

1. Spending less time at work and more time with family
2. Reducing the number of activities you take part in to combat fatigue
3. Only doing social activities that you enjoy
4. Avoiding stressful situations
5. Lifting and carrying less, for example, shopping
6. Simplify activities, for example, reducing the number of bank accounts
7. Reducing the number of household tasks done in a day
8. Doing more indoor activities (e.g. crosswords) than outdoor (e.g. fishing)
9. Continuing preferred social activities but spending less time on them, for example, playing fewer games of bowls or playing 9 holes on the golf course rather than 18
10. Only doing housework that is manageable, for example, avoiding hoovering
11. Limiting conversation to that which interests you
12. Only carrying smaller items when shopping, for example, 'bread and eggs' rather than a 'big shop'
13. Avoiding situations that might impact negatively on health, e.g. where you might fall
14. Only doing exercise that is manageable, for example, using the exercise bike in the house rather than hill walking or swimming instead of strenuous exercise class
15. Only paying attention to things that interest you
16. Carrying one item at a time from room to room
17. Avoiding interaction with people who induce stress or anxiety
- ~~18. Lifting and carrying light items only Merge with 12~~
19. Cooking simple meals
20. Only wearing certain items of clothing, such as polo shirts, which are easy to put on
21. Avoiding sleep during the day to combat night sleep problems
22. Spending more time/energy on the important things in life
23. Limiting activity to that which is manageable, for example, word searches if unable to read a book or keeping driving speed below 50 miles per hour
24. Only going outside during the day and avoiding night time excursions
- ~~25. Limiting activities to that which are most important to you, for example, going to bed and reading rather than going out socialising Merge with 3~~
26. Concentrating energy on activities of daily living, for example, washing and dressing
27. Avoiding doing activities in the evening so you can rest and relax
28. Giving up doing tasks and chore for other people and concentrating on yourself, for example, no longer shopping for mother
29. Recognising what you can and can't do
- ~~30. Going up and down the stairs less – delete as barrier~~
31. Going to a stroke exercise class – reworded as 28 on other sheet
32. Giving up activities that are too tiring, for example 'there's more to life than grass'
- ~~33. Taking up a new exercise, merge with 31 (28)~~
34. Changing your role in the family, for example, more socialising rather than being the 'problem solver' or 'fixer'
35. Starting a new course
- ~~36. Volunteering in your spare time merge with 35~~

37. Seeing friends more in your spare time
38. Going to a stroke social or communication group
39. Taking up a new hobby, for example, doing jigsaws if unable to do crosswords anymore
- ~~40. Going shopping with companion to get out of the house – merge with 241~~
41. Changing standards of certain activities that are no longer achievable, e.g. not doing entire housework in the one day
- ~~42. Focussing on what's important in your life merge with 22~~
43. Doing relaxing activities, such as going out for 'fresh air', during the day
44. Avoiding pushing yourself to the limits
- ~~45. Socialising more with family and friends – merge with 37~~
46. Choosing to talk more with family and friends rather than bottling up feelings

Optimisation

47. Working on adapting and practising activities rather than relying on gadgets or aids
48. Trying not to rely on unnecessary aids, for example, practising walking without a stick in the house when safe to do so
49. Trying not to rely on unaffected limbs, for example, giving up use of affected hand altogether
50. Investing more time and effort into activities, for example, buttering toast, rather than receiving help
51. Allowing more time for activities such as reading, writing and dressing
52. Making an effort to try out things and see if they are doable 'unlock all the doors and then we're going to find out, it might take time'
53. Going over things such as documents or letters more than once
54. Challenging yourself with activities such as speech and language therapy tasks 'The fear has not won, but if you don't challenge it, it will always win'
55. Paying more attention to tasks and activities, e.g. cooking, speaking or reading 'focus and make a mental note and be aware of making that note'
56. Persevering with difficulty activities rather than giving up
57. Putting more care and concentration into difficult activities, such as carrying delicate items or crossing the road
58. Learning and practising new ways of doing things, such as dressing techniques taught by occupational therapists
59. Building up activities, for example, walking more each day
60. Repetition of certain actions, such as hand movements
61. Practising relaxing techniques, such as mindfulness meditation, to manage stress
62. Working with physiotherapists to learn walking techniques, such as going up and down stairs
63. Practising speech and language therapy techniques, such as reading newspapers or doing puzzles
64. Learning a new speech and language therapy technique, for example, breaking down a word into sections
65. Repeated practice of an activity, such as writing, or getting in and out of the shower
66. Doing sensory practice, for example, feeling and lifting objects out of a bucket of sand
67. Learning to do a social activity in a different way because of a difficulty
- ~~68. Practising activities such as going in lifts, driving and managing stairs with new impairments – merge with 67~~

69. Using household tasks to practice movement, such as opening and closing close pegs when hanging out washing
70. Learning a new stress reducing technique, such as mindfulness meditation
71. Practising using affected hand even if it takes longer, for example using it during washing or when typing 'you've got to use it as much as you can'
72. Training concentration with tasks such as jigsaws and word searches
73. Practising balance and movement using technology such as WiFit or other computer games
74. Practising a hobby to try to improve
75. Doing physiotherapy exercises, for example, moving paperclips between bottles
76. Planning routes in advance to avoid things such as uneven pavements, steep kerbs or stairs
77. Organising your days' activities with enough time, for example, getting up earlier in the day
- ~~78. Planning to do activities earlier to avoid late evening tiredness — merge with 27~~
79. Thinking about things and planning in advance
- ~~80. Planning tasks which require more care, for example planning what to take into the shower to avoid coming in and out frequently — merge with 79~~
81. Organising meals in advance in case you need help from others, for example, help with opening jars
82. Planning your work day around optimal abilities, for example, if you feel better in the morning then plan important meetings for then
83. Cooking and planning meals in advance and freezing them
84. Using lists to plan tasks such as shopping in advance
- ~~85. Planning sleep, for example, limiting sleep during the day to combat sleeplessness at night — merge with 21~~
86. Planning certain activities around impairment, for example, if you are going onto the floor plan how to get back up
87. Taking frequent rest or naps during the day when required
88. Following active activities such as walking with sedentary activities such as reading
89. Taking a break from difficult activities to relax, for example, playing with the cat for 5 minutes when you are having trouble concentrating
90. Taking it easy in the house the day before a busy day
91. Getting the right balance of resting and activities 'I've got that happening, but on the other hand, in order to be able to do that you've got to take something back. You've got to compensate somewhere else' 'I can't run all day and then run at night time'
92. Doing activities when you have the energy and feel ready to do them
- ~~93. Resting or relaxing before or after activities — merge with 88, 90~~
94. Doing tasks such as shopping in short burst
95. Focusing on one activity at a time
96. Trying not to overdo exercise and physiotherapy during rehabilitation
97. Doing things at a comfortable pace
- ~~98. Breaking tasks up with breaks in between, e.g. get dressed then rest, have breakfast then rest, etc... — merge with 94~~
- ~~99. Taking breaks when needed — merge with 94~~
100. Avoiding having a strict list of goals to achieve in the one day
101. Slowing down and pacing activities such as washing and housework throughout the day or over a couple of days
- ~~102. Avoid trying to do too much — merge with 44~~

- 103. Saving energy to do certain tasks such as cooking after food shopping 'make sure I'm ready to do that and not too tired'
- 104. Going to bed earlier to combat fatigue
- ~~105. Using exercise to combat stress, for example, walking to relax yourself—merge with 70~~
- 106. Moving frequently to prevent stiffness or numbness
- 107. Frequent walking to get used to new way of walking
- ~~108. Doing exercise as rehabilitation, for example swimming, walking or hand movements—merge with 109~~
- 109. Doing exercise to try and improve strength
- ~~110. Using exercise to get used to new impairments, for example, going to a stroke specific exercise class—merge with 107~~
- 111. Doing exercise when you have spare time, for example physiotherapy exercises when watching the TV at night
- ~~112. Exercising to improve fitness and control weight—merge with 109~~
- 113. Having a daily exercise routine
- ~~114. Learning a new skill such as meditation or relaxation techniques—merge with 70~~
- 115. Using techniques such as practice or planning to improve confidence in your abilities
- 116. Improving your diet to include healthier options
- ~~117. Improving health by reducing unhealthy snacking throughout the day—merge with 116~~
- 118. Ensuring you are eating and drinking right to avoid fatigue
- ~~119. Looking after your health by giving up or reducing alcohol intake merge with 116~~
- ~~120. Improving health by reducing portion sizes merge with 116~~
- 121. Paying more attention to health problems and visiting the doctor if necessary

Compensation

- 122. Using a bike or alternative means of independent transport as no longer able to drive
- 123. Using alternative Johnston 'baby soap' when unable to close eyes properly in the shower
- 124. Having a shower rather than a bath
- ~~125. Having a bath rather than a shower—merge with 124~~
- 126. Using a taxi or train rather than using the bus
- ~~127. Using alternative clothing, for example, elasticated trousers, polo shirts rather than normal shirts—merge with 20~~
- 128. Adapting cooking methods, for example, buying new potatoes that don't require peeling or buying already chopped or diced carrots
- 129. Using a microwave or oven rather than cooking from scratch
- 130. Using an electric shaver rather than a razor
- 131. Moving bedroom to a room which is easier to heat or more accessible
- 132. Using online shopping rather than going to the supermarket
- 133. Using smaller, lighter appliances such as the Hoover
- ~~134. Using an electric toothbrush rather than a manual toothbrush—merge with 130~~
- 135. Using the MyBus service rather than the standard bus service
- 136. Using your non affected side for tasks such as eating or lifting when it's not possible to use the affected hand/arm
- 137. Lifting the lightest items with the affected side and heaviest with the unaffected
- 138. Not using the affected hand for 'dangerous tasks', such as carrying hot drinks or a tray of glasses

- ~~139. Using the unaffected side to do tasks such as getting up or changing body position — merge with 136~~
140. Chewing and eating on the unaffected side of the mouth due to numbness
141. Using I pads for reading as you can make the text larger
142. Using a cordless phone to save walking
143. Using a mobile phone to record notes
144. Using a Notebook or computer to type notes rather than writing
145. Using a calculator for mathematics – merge with 142
- ~~146. Using a Kindle/Ipad to read newspapers — merge with 141~~
147. Daylight strip for reading documents
148. Using phone calendar to keep track of appointments or dates
149. Using Siri to type and send messages
150. Using dictionary on phone when typing
151. Using a slow cooker so you don't have to stand over the cooker
152. Listening to audio books rather than reading
153. Always using the Green Man to cross at traffic lights
- ~~154. Setting alarms for events, activities and reminders — merge with 148~~
- ~~155. Use of TENS machine for pain (?) — delete as unsure of evidence base~~
- ~~156. Increasing font size on phone — merge with 141~~
- ~~157. Using Iphone calendar to organise daily routine — merge with 148~~
158. Using a dictaphone to record conversations
- ~~159. Clip on lights for reading — merge with 147~~
160. Use of headphones to block out unwanted noise
- ~~161. Talking clock — merge with 142~~
- ~~162. Buzzer entry on front door — merge with 142~~
163. Walking aids, for example, walking stick, zimmer, wheelie, wheelchair, tripod
164. Using a trolley to push items about indoors rather than carrying
165. Use of rucksack when going to the shops
166. Using handrails beside the toilet
- ~~167. Using a stick to swirl washing in the bath — delete as unlikely to be useful to majority~~
168. Specialist ergonomic seats for work
- ~~169. Specialist writing shelf for work — merge with 168~~
- ~~170. Use of extra pillows to 'prop up' in bed — merge with 181~~
- ~~171. Button for shoes which you flick lace over — merge with 20~~
172. Use of kitchen aids, for example, potato peeler, fork peeler
- ~~173. Memory aids such as putting a glass next to the fridge when you have put beer in the freezer — merge with 180~~
- ~~174. Using a diary, calendar or planner — merge with 148~~
- ~~175. Use of handrails in the bath or shower — merge with 166~~
- ~~176. Having a stool or seat in the shower — merge with 181~~
177. Magnifying glass
178. Using the shopping trolley to balance or bear weight
- ~~179. Using handrails beside doors or up stairways — merge with 166~~
180. Keeping notes of appointments on the fridge or mantelpiece
181. Raised seat on toilet
182. Use of car roof rails to get in and out
- ~~183. Raised bed — merge with 181~~

184. Special grip cutlery for eating — merge with 172
185. Pencil/pen grips for writing
186. Writing notes or lists — merge with 84
187. Using floats in the swimming pool, or a hoist/special stairs
188. Using a swimming pool hoist or large stairs to get in and out of water — merge with 187
189. Conversation aids, for example, writing down key words or using a communication booklet — merge with 185
190. Disability badge for the car — removed as not everyone will be eligible
191. Chair raisers for sofas or beds — merge with 181
192. Bath chair which swings your legs in — merge with 181
193. Bath board over bath for sitting on when in the shower — merge with 181
194. Prism for increasing font size — merge with 177
195. Keeping one walking stick at the bottom of the stairs and one at the top — merge with 163
196. Walking poles such as Leckie sticks — merge with 163
197. Increased reliance on using a phone/watch as unaware of passing of time — merge with 148
198. White stick to tell people you have visual problems — delete as not using strategy to achieve anything
199. Memory aids, such as looking at your pillbox to remind you what day of the week it is — merge with 180
200. Doing T'ai Chi sitting rather than standing — merge with 67
201. Getting in and out of the car and transferring bottom first rather than feet first
202. Modifying route to shops to avoid stairs — merge with 76
203. Using a basin for washing rather than getting in and out of bath — merge with 124
204. Going up stairs on all fours then using railing to pull up on the half landing — delete as unsure if safe!
205. Stopping activity/pausing until you get your balance
206. Chopping food one handed with a fork or cutting with a fork only
207. Exaggerating 'wide berthing' when walking past people
208. Sticking nail clippers to work surface to cut nails and pushing down with heel of hand — merge with 227
209. Only using a fork to eat — merge with 206
210. Sticking to certain easy to eat food, e.g soft food. Curries
211. Cutting up food into small pieces before starting to eat
212. Sitting on certain side of the car so can use unaffected legs to get out
213. Changing cooking to microwave or simply meals and avoiding cooking big meals — merge with 19
214. Socialising with friends in the house rather than going out
215. Changing swimming activity e.g. breaststroke rather than front crawl, back not front — merge with 67
216. Changing usual sleeping position — impairment — can't sleep on other side — remove
217. Changing shopping habits to carry fewer, lighter bags — merge with 5, 12
218. Cutting up food before starting to eat — merge with 211
219. Tilting head when watching TV/reading
220. Using elbows to change body position — merge with 136
221. Carrying light bags instead of heavy when shopping — merge with 5, 12, 217
222. Doing a social activity, e.g. bowls, in a different way of impairment — bowling from the wrist — merge with 67

- 223. Sitting down to get dressed rather than standing
- 224. ~~Slowing down speech to be understood—impairment—remove~~
- 225. Avoiding having conversation around other loud noises
- 226. ~~Dealing with/focussing on one problem at a time—merge with 95~~
- 227. Hanging washing in the greenhouse rather than on the clothes line as unable to run outside when it starts to rain
- 228. ~~Lying down more, for example, when watching television, rather than sitting—impairment—remove~~
- 229. ~~Taking extra care to look at money when paying, rather than relying on touch—impairment, remove~~
- 230. Fully turning your head when looking to cross the road—merge with 219
- 231. ~~Lifting slightly more money than required in case of miscalculation while shopping—remove as might not be good to advise people to do this, comes under planning~~
- 232. ~~Sitting down while cooking—merge with 181~~
- 233. ~~Making sure fingers are out of the way when chopping food—merge with 57~~
- 234. Moving things to pocket nearest to unaffected hand
- 235. Walking in the pool for rehabilitation rather than swimming—merge with 112
- 236. ~~Changing driving behaviour, for example, not changing lanes and driving slower—merge with 23~~
- 237. Working at home when required
- 238. ~~Doing a relaxing activity, such as walking, to help speech—merge with 105,70~~
- 239. Getting help with housework
- 240. Getting help getting in and out of cars, transferring body
- 241. Getting assistance with travelling, e.g. a lift
- 242. ~~Getting assistance with shopping and carrying shopping—merge with 239~~
- 243. ~~Assistance with tasks such as lifting and picking things up—merge with 240~~
- 244. ~~Assistance with walking—merge with 240~~
- 245. Assistance with bathing and dressing and looking after body parts, e.g. nails
- 246. ~~Having someone with you when going outside the house—merge with 241~~
- 247. ~~Assistance with gardening, e.g. paying someone else to cut the grass—merge with 239~~
- 248. Assistance with cooking and cutting food
- 249. ~~Carer for dressing, cooking and washing—merge with 245~~
- 250. ~~Cleaner for help with housework—merge with 239~~
- 251. ~~Getting a chiropodist to cut nails, merge with 245~~
- 252. ~~Wife/family doing any writing, cooking, finances, housework, shopping—merge with 239~~
- 253. ~~Family taking you for shopping—merge with 239~~
- 254. ~~Family help with shaving, cutting toenails, merge with 245~~
- 255. Asking taxi driver for help with seatbelt/shopping—
- 256. ~~Having shop assistants assist with paying for things—merge with 255~~
- 257. ~~Going to the hairdressers for a blow dry—merge with 245~~
- 258. Having support at work to remind to take breaks
- 259. ~~Help with lifting and moving/handling at work—merge with 258~~
- 260. ~~Help paying for things in shops—merge with 255~~
- 261. ~~Neighbours help with housework/bins in and out—merge with 239~~
- 262. ~~Help with certain aspects of activities such as cufflinks, buttons, washing windows, hoovering, draining potatoes, ironing,—merge with 239, 240~~
- 263. Help with reading/understanding documents

- ~~264.Children taking on additional responsibilities, e.g. dressing—delete as unlikely to affect most, merge with ‘stop doing chores for others’—28~~
- 265.Help with motivation, push to do things
- ~~266.Help with reminders to walk in a certain way—deleted~~
- 267.Help from bus drivers –don’t move bus until seated
- ~~268.Help from family with benefits/official letters—merge with 263~~
- ~~269.Help with getting up during the night—merge with 240~~
- ~~270.Help with medication reminders—merge with 248~~

Appendix 3.18: Final list of strategy descriptors and categories

Categories and strategies

Selection

Focusing on the activities and goals that are most important to you

- Spending less time at work and more time with family
- Spending more time and energy on the important things in life
- Concentrating energy on everyday activities such as washing and dressing
- Giving up doing chores and tasks for other people
- Only paying attention to things that interest you
- Changing your role in the family, for example socialising with family more rather than trying to solve all the family problems
- Only doing social activities that you enjoy and that are important to you, for example, going to bed and reading rather than going out socialising

Giving up activities that are no longer manageable

- Only going outside during the day and not at night time
- Giving up doing chores and tasks for other people
- Avoiding situations that might negatively affect your health, e.g. where you might fall
- Only doing exercise that is manageable, for example, using an exercise bike in the house rather than hill walking, or swimming instead of doing a strenuous exercise class
- Giving up activities that are too tiring, for example, doing the gardening
- Recognising what you can and can't do
- Only doing housework tasks that are manageable, for example, dusting but avoiding vacuuming

Choosing or focussing on a new goal or activity

- Choosing a new exercise, for example, an exercise class designed for stroke survivors
- Choosing a new activity, such as an education course or volunteering
- Going to a stroke survivor social or communication group
- Changing your hobbies, for example, doing jigsaws if you can't do crosswords anymore
- Practising relaxation techniques, such as meditation, to help manage stress
- Socialising with friends more in your spare time

Limiting an activity so that it is still manageable

- Only doing housework tasks that are manageable, for example, dusting but avoiding vacuuming
- Only carrying small or light items, for example, carrying 'bread and eggs' when shopping rather than large/heavy items
- Lifting and carrying less, for example, carrying fewer bags of shopping
- Limiting conversation to that which interests you
- Carrying one item at a time
- Only going outside during the day and not at night time
- Cooking simple meals
- Only doing exercise that is manageable, for example, using an exercise bike in the house rather than hill walking, or swimming instead of doing a strenuous exercise class
- Doing more indoor activities (e.g. crosswords) than outdoor activities (e.g. fishing)
- Limiting an activity so that it is still manageable, for example continuing driving but at a slower speed, or doing word searches if you are unable to read a book
- Continuing preferred social activities but spending less time on them, for example, playing fewer games of bowls or playing 9 holes on the golf course rather than 18

Simplifying and reducing your activities

- Lifting and carrying less, for example, carrying fewer bags of shopping
- Reducing the number of household tasks you do in a day
- Reducing the number of activities you take part in to try and cope with fatigue
- Simplifying activities, for example, reducing the number of bank accounts you have
- Continuing preferred social activities but spending less time on them, for example, playing fewer games of bowls or playing 9 holes on the golf course rather than 18

Only doing social or recreational activities that you choose and enjoy

- Only doing social activities that you enjoy and that are important to you, for example, going to bed and reading rather than going out socialising
- Only paying attention to things that interest you
- Limiting conversation to that which interests you

Avoiding difficult situations that might cause anxiety or stress

- Avoiding people who make you stressed or anxious
- Avoiding stressful situations
- Avoiding pushing yourself to the limits
- Avoiding having a conversation around loud noises

Optimisation

Working on optimising your health and fitness

- Doing physiotherapy exercises
- Doing exercise when you have spare time, for example, physiotherapy exercises when watching TV at night
- Exercising more to improve strength, fitness or for rehabilitation
- Ensuring you are eating and drinking well to avoid fatigue
- Using exercise to get used to the way your body moves after stroke
- Improving your diet by reducing unhealthy food, snacking, large portions and alcohol intake
- Practising balance and movement using WiFit and other computer games
- Using household tasks to practice movement, for example, repeatedly opening and closing pegs when hanging out the washing
- Choosing a new exercise, for example, an exercise class designed for stroke survivors
- Paying attention to health problems and seeking medical assistance if necessary
- Having a regular exercise routine
- Moving frequently to prevent stiffness or numbness

Practising rehabilitation techniques and activities

- Training your concentration with mental tasks such as crosswords and jigsaws
- Using household tasks to practice movement, for example, repeatedly opening and closing pegs when hanging out the washing
- Practising using your senses, for example reaching for objects in a bucket of sand to help feeling in your hands
- Doing physiotherapy exercises
- Doing exercise when you have spare time, for example, physiotherapy exercises when watching TV at night
- Exercising more to improve strength, fitness or for rehabilitation
- Practising balance and movement using WiFit and other computer games
- Repeating certain movements frequently, for example, hand exercises
- Practising speech and language therapy tasks such as reading newspapers or doing puzzles

- Practising relaxation techniques, such as meditation, to help manage stress
- Challenging yourself, for example, trying more difficult speech and language therapy tasks

Practising doing activities with your stroke related difficulties

- Investing more time and effort into activities, for example, buttering toast, rather than asking for help
- Adapting your behaviour rather than relying on gadgets or aids
- Continuing to use your weaker hand rather than giving up using it altogether
- Repeatedly practising tasks such as getting in and out of the shower
- Learning to do something in a different way and practising this new way, for example a new way of playing bowls, exercising or using lifts and managing stairs
- Practising using the weaker side of the body, even if it takes longer
- Trying not to rely on aids all of the time, for example, practising walking without a stick in the house when safe to do so
- Practising a hobby to try and improve
- Learning and practising new ways of doing things, such as special dressing techniques taught by occupational therapists

Learning a new technique or strategy to help you cope with your difficulties

- Learning a new communication technique, for example, breaking down a word in your head before saying it
- Learning and practising new ways of doing things, such as special dressing techniques taught by occupational therapists
- Working with physiotherapists to learn new techniques, such as going up and down stairs
- Learning new ways to relax, such as walking or meditation
- Learning to do something in a different way and practising this new way, for example a new way of playing bowls, exercising or using lifts and managing stairs

Investing more time and energy into activities when they take longer or are more difficult

- Practising using the weaker side of the body, even if it takes longer
- Making an effort to try things out and see if you can manage them
- Continuing to do things for yourself by allowing yourself more time to do them
- Investing more time and effort into activities, for example, buttering toast, rather than asking for help
- Being extra careful with difficulty activities, such as carrying delicate items or crossing the road
- Paying more attention to tasks and activities that require concentration, such as reading, speaking or cooking
- Going over things, such as important documents or letters, more than once
- Adapting your behaviour rather than relying on gadgets or aids
- Persevering with difficult activities rather than giving up
- Focusing on one activity at a time
- Challenging yourself, for example, trying more difficult speech and language therapy tasks

Planning activities and tasks in advance

- Cooking and planning meals in advance and freezing them
- Organising your days' activities to make sure you have enough time, for example, by getting up earlier in the day
- Planning activities for earlier in the day and avoiding evening activities, so that you can rest and relax
- Trying not to sleep during the day so that you can sleep better at night

- Thinking about things and planning in advance, for example planning what to take into the shower to avoid having to come in and out more than once
- Planning your day for when you'll be at your best, for example if you are most awake and alert in the mornings then plan to have important meetings at this time
- Organising meals in advance in case you need help from others, for example, help with opening jars
- Planning and changing routes in advance to avoid things like uneven pavements, steep kerbs and stairs
- Using lists and notes to plan tasks such as shopping in advance
- Planning tasks which you find difficult, for example, if you are going to lie on the floor then plan how you will get back up
- Using techniques such as planning and practising to improve your confidence in your abilities

Pacing your activities by taking your time and avoiding doing too many things at once

- Focusing on one activity at a time
- Building up to a goal, for example, walking a little more every day
- Following active activities such as walking with resting activities such as reading
- Avoiding pushing yourself to the limits
- Changing your expectations about certain things, for example, no longer doing all the housework in the one day
- Slowing down and pacing activities such as washing and housework throughout the day or over a couple of days
- Trying to conserve energy when doing more than one task in a row, for example, when you know you will have to cook after going food shopping
- Doing things at a comfortable pace
- Avoiding having a strict list of tasks or goals to achieve in one day
- Making sure you get the right balance between activities and resting
- Doing activities when you have the energy and feel ready to do them
- Doing tasks such as shopping or housework in short bursts, with breaks in between activities
- Taking it easy in the house the day before a busy day
- Taking breaks during difficult or stressful activities, for example playing with the cat for 5 minutes to relax
- Trying not to overdo physiotherapy and exercise during rehabilitation

Resting and relaxing when necessary

- Planning activities for earlier in the day and avoiding evening activities, so that you can rest and relax
- Making sure you get the right balance between activities and resting
- Avoiding having a strict list of tasks or goals to achieve in one day
- Trying to conserve energy when doing more than one task in a row, for example, when you know you will have to cook after going food shopping
- Practising relaxation techniques, such as meditation, to help manage stress
- Learning new ways to relax, such as walking or meditation
- Doing some relaxing activities during the day, such as going out for fresh air
- Trying not to overdo physiotherapy and exercise during rehabilitation
- Going to bed earlier to cope with tiredness
- Taking frequent rests or naps during the day when required

- Taking breaks during difficult or stressful activities, for example playing with the cat for 5 minutes to relax

Receiving emotional support from family and friends

- Going to a stroke survivor social or communication group
- Choosing to talk more with family and friends rather than bottling up your feelings
- Allowing family and friends to help by motivating you to do things

Compensation

Receiving assistance from others with everyday, mobility and household activities

- Seeking help to understand documents and official letters
- Asking the bus driver not to move the bus until you are seated
- Receiving assistance at work, such as reminders to take breaks or help with difficult tasks
- Seeking assistance from family, friends or carers with tasks such as dressing, bathing and looking after body parts, e.g. getting a chiropodist to cut your nails, going to the hairdresser for a blow dry or hiring a care assistant
- Asking for assistance when out of the house, e.g. asking staff members to help when paying in a shop or asking taxi driver for assistance with a seatbelt.
- Getting assistance from friends, family or paid help with tasks such as cooking, shopping, housework, gardening, getting in and out of a car etc...
- Using a service for those with disabilities, such as MyBus instead of the standard bus service

Using alternatives like aids, gadgets or technology to help you with everyday activities

- Using aids to help you with everyday activities, from walking aids, handrails and raised beds to reading aids such as clip lights and magnifying glasses
- Using gadgets to help with everyday activities, from trolleys to transport items about indoors, to kitchen gadgets such as a potato peeler or a slow cooker
- Using an electronic device such as an iPad, Kindle, tablet or phone to read and type books and documents
- Using a dictaphone or mobile phone to record important conversations or make notes
- Using mobile phone assistance, such as Siri or autocorrect feature, to write and send text messages
- Using electric devices as an alternative, for example an electric shaver or toothbrush rather than a razor or standard toothbrush
- Using speech and language therapy aids such as pencil grips and conversation booklets
- Using the shopping trolley to balance or lean on when shopping
- Using smaller and lighter household appliances, for example, a small vacuum cleaner
- Using headphones to block out unwanted noise
- Only wearing clothes that are easy to put on, for example, elasticated trousers, polo shirts or using shoe buttons
- Using aids to help you exercise, such as floats when swimming, or a hoist that allows you to get in and out of the pool
- Using aids at work such as ergonomic chairs and writing shelves
- Using car roof rails to assist in getting in and out of a car
- Listening to audio books rather than reading
- Using a rucksack to carry shopping
- Always using traffic lights to cross roads

- Using an alternative product such as 'baby shampoo' due to problems closing your eyes properly in the shower
- Using a mobile phone calendar or regular calendar to keep track of appointments and set reminders

Using special techniques and aids to help you remember

- Using a mobile phone calendar or regular calendar to keep track of appointments and set reminders
- Using lists and notes to plan tasks such as shopping in advance
- Developing your own memory reminders, for example, sticking reminders to the fridge or the mantelpiece

Doing activities using your unaffected side

- Doing tasks using the unaffected side of your body when you are no longer able to use the affected side at all
- Not using your affected side for dangerous tasks such as carrying hot drinks or a tray of glasses
- Chewing and eating using the unaffected side of your mouth

Changing the way your exercise, socialise or do your hobbies

- Learning to do something in a different way and practising this new way, for example a new way of playing bowls, exercising or using lifts and managing stairs
- Changing your hobbies, for example, doing jigsaws if you can't do crosswords anymore
- Socialising with friends and family in the house rather going out

Changing the way you do everyday activities in the house

- Organising meals in advance in case you need help from others, for example, help with opening jars
- Cooking and planning meals in advance and freezing them
- Carrying one item at a time
- Cooking simple meals
- Adapting cooking methods, for example, buying new potatoes that don't require peeling or buying pre-chopped carrots
- Cooking microwave or oven meals rather than cooking from scratch
- Lifting lighter items with your affected hand and heavier items with your unaffected hand
- Changing the way you do everyday tasks, for example, hanging washing inside or in a greenhouse rather than on the washing line, or sticking nail clippers to a work surface in order to cut nails
- Sitting down to get dressed rather than standing
- Chewing and eating using the unaffected side of your mouth
- Eating softer food which is easy to eat and cut
- Choosing an alternative way of doing an activity, for example having a shower or using a basin to wash when you are unable to get in and out of the bath
- Cutting up food into small pieces before starting to eat
- Eating and cutting food one-handed, using a fork only
- Turning your head fully when crossing the road or tilting head when watching TV
- Stopping or pausing during an activity to allow you to get your balance
- Doing shopping online rather than going to the shops or supermarket
- Moving your bedroom to a room which is more appropriate, for example easier to heat or more accessible
- Working from home when necessary

Changing the way you do activities outside

- Transferring your body bottom first, for example, when getting in and out of a car
- Sitting on a certain side of the car so that you can use your stronger leg when getting out of the car
- Leaving extra space between yourself, other people and objects when moving
- Stopping or pausing during an activity to allow you to get your balance
- Turning head fully when crossing the road or tilting head when watching TV
- Moving wallet or purse to the pocket where it can be most easily reached
- Using car roof rails to assist in getting in and out of a car
- Using transport such as a taxi or the train when you are no longer able to use the bus
- Doing shopping online rather than going to the shops or supermarket
- Using a bike as a way of independent transport when no longer able to drive



SOC theoretical definitions and examples

Selection

Selection involves an individual focusing on areas of life, goals and activities which they determine are most important to them. Typically in older age, this involves restricting involvement in certain goals, activities or particular areas of life, as a consequence of changing available resources. Selection can involve avoiding one particular area of life altogether or restricting the activities performed within several different areas of life. Selection can also involve new or changed goals or activities.

Examples:

- Focusing on most important goals/areas of life
- Committing to a goal
- Forming new goals
- Restricting or limiting an activity
- Performing an activity less often
- Giving up/avoiding an activity

Optimisation

Optimisation involves ways in which an individual enriches, enhances or refines their resources, therefore optimising their performance in their desired activities and areas of life. Optimisation strategies will depend on the goal in question and can vary from exercise to ways of increasing confidence in ability.

Examples:

- Acquiring new skills or resources
- Practicing skills or activities
- Investing time or effort in a task
- Focusing attention
- Planning activities

Compensation

Compensation involves substituting or compensating in order to continue functioning when resources or abilities become critically low. The use of alternative ways to achieve a goal can include modifying an activity or technological aids, such as a walking stick.

Examples:

- Modifying activities
- Receipt of help from others
- Use of assistive devices or gadget



Examining the adaptation strategies of stroke survivors within a theoretical framework

Thank you for agreeing to take part in this study. The aim of the study is to examine the adaptation strategies of stroke survivors by matching them to theoretical constructs. We have previously interviewed stroke survivors about their difficulties and the various ways in which they cope with or adapt to these difficulties. We now wish to determine if the strategies they have told us about match the theoretical constructs of a framework known as the 'Selection, Optimisation and Compensation' model (Baltes & Baltes, 1990). We will do this using a task known as a Discriminant Content Validation task.

Please complete the initial questions and then read the study instructions carefully before beginning the task. The task may take around two hours to complete. Please post the completed worksheet to the research team, using the stamped envelope, within one month.

Initial questions:

Age:

Gender:

Job title:

Area of research/work:

Experience of working with stroke survivors (please circle one answer):

A great deal Quite a lot Some A little None

Experience of working with the Selection, Optimisation and Compensation model (please circle one answer):

A great deal Quite a lot Some A little None

Introduction

We are interested in whether the following strategies match the theoretical constructs of a framework known as the 'Selection, Optimisation and Compensation' model (Baltes & Baltes, 1990). The model describes three different types of strategy that people can use to overcome a loss in ability or resources. These resources could be internal or external, personal, social or environmental. For example a stroke survivor may experience loss in mobility or memory capacity after a stroke. They may also experience a loss of internal resources such as decreased confidence in their abilities.

These strategy types are named **Selection**, **Optimisation** and **Compensation**. As a consequence of loss we have to identify those activities we want to continue to engage in, i.e. we **Select** activities. We then have to work to optimise our ability to perform those activities (**optimisation**), for example, after a stroke an individual may need to perform repeated exercises to improve musculoskeletal function. Finally, it may become necessary to adopt **compensation** strategies to enable those selected and valued activities to be performed, e.g. walking is supported by the use of a foot orthoses or a walking stick.

Theoretical definitions and examples of the three strategy types are presented on a separate information sheet included in this pack². Please read these carefully before beginning the task.

Task instructions

On the next page is a list of 149 strategies which stroke survivors have told us they use to help them manage after having a stroke. We are interested in your opinion on whether each strategy is an example of selection, optimisation or compensation. We have provided definitions and examples of each of the strategies on a separate sheet so that you can refer to them throughout.

Your task is to decide whether each strategy matches any of the theoretical definitions. You may feel that a strategy matches more than one theoretical definition. Please indicate your decision by circling whether you think each strategy is, or is not, an example of selection, optimisation or compensation.

You are also asked to indicate how confident you are in each judgment you make. Your confidence will be rated on a scale that ranges from 0%, i.e. not at all confident to 100%, i.e. completely confident. We are interested in your opinion therefore there are no right or wrong answers to this task.

² Definitions and examples were formed from the following publications:

Baltes, P. B., & Baltes, M. M. (1990). Psychological perspectives on successful aging: The model of selective optimization with compensation. In P. B. Baltes & M. M. Baltes (Eds.), *Successful aging: Perspectives from the behavioral sciences* (pp. 1–34). New York: Cambridge University Press

Freund, A. M., & Baltes, P. B. (1998). Selection, optimization, and compensation as strategies of life management: correlations with subjective indicators of successful aging. *Psychology & Aging, 13*(4), 531-543.

Gignac, M. A., Cott, C., & Badley, E. M. (2002). Adaptation to disability: applying selective optimization with compensation to the behaviors of older adults with osteoarthritis. *Psychology & Aging, 17*(3), 520-524.

Your task is to decide whether each strategy matches any of the theoretical definitions. You may feel that a strategy matches more than one theoretical definition. Please indicate your decision by circling whether you think each strategy is, or is not, an example of selection, optimisation or compensation. Please also indicate how confident you are about each decision.

An example of completed judgements of 2 hypothetical strategies

Strategy: "Giving up volunteering to concentrate on rehabilitation and improving fitness through weekly exercise classes"		
Theoretical Definition	Strategy matches Definition?	How confident are you in each of your judgments?
Selection	<input checked="" type="radio"/> YES / NO	0% 10% 20% 30% 40% 50% 60% <input checked="" type="radio"/> 70% 80% 90% 100%
Optimisation	<input checked="" type="radio"/> YES / NO	0% 10% 20% 30% 40% 50% 60% 70% <input checked="" type="radio"/> 80% 90% 100%
Compensation	YES <input checked="" type="radio"/> NO	0% 10% 20% 30% 40% 50% 60% <input checked="" type="radio"/> 70% 80% 90% 100%

Strategy: "Having a cleaner that comes weekly now and does the housework"		
Theoretical Definition	Strategy matches Definition?	How confident are you in each of your judgments?
Selection	YES <input checked="" type="radio"/> NO	0% 10% 20% 30% 40% 50% <input checked="" type="radio"/> 60% 70% 80% 90% 100%
Optimisation	YES <input checked="" type="radio"/> NO	0% 10% 20% 30% 40% 50% 60% 70% 80% 90% <input checked="" type="radio"/> 100%
Compensation	<input checked="" type="radio"/> YES / NO	0% 10% 20% 30% 40% 50% 60% 70% 80% 90% <input checked="" type="radio"/> 100%

Appendix 4.3: DCV University Ethics Committee approval

From: Laura Clark
Sent: 15 September 2014 10:47
To: Diane Dixon; Jennifer Dryden; Madeleine Grealy
Cc: James Baxter
Subject: Type 1 Ethics Application - Approval

Follow Up Flag: Follow up
Flag Status: Completed

Type 1 Ethics Application - Approval

Our ref: 453 11-Sep-14

Dear All

Validation of the Selection, Optimisation and Compensation model in describing post-stroke adaptation

CI Diane Dixon Other Investigator Jennifer Dryden, Madeliene Grealy

I can now confirm full ethical and sponsorship approval for the above study.

Regards

Laura



SCHOOL OF PSYCHOLOGICAL SCIENCES & HEALTH

Participant Information Sheet

Title of the study: Examining the adaptation strategies of stroke survivors within a theoretical framework

Introduction

My name is Jennifer Dryden and I am a 2nd year PhD student and trainee health psychologist at the University of Strathclyde. I am working with Dr Diane Dixon and Professor Madeleine Grealy in the School of Psychological Sciences and Health. You are being invited to take part in a research study. Before you decide whether to take part, it is important for you to understand why the research is being carried out and what it will involve. Please take the time to read this information sheet carefully. You will find further information about the nature of the study and what is expected from participants below. If, after reading, you have any questions please contact a member of the research team who will be happy to answer them for you. Thank you for taking the time to consider participating in the study.

What is the purpose of this investigation?

The aim of this study is to further examine the various strategies used by stroke survivors to adjust to life after stroke. Through previous interviews we have identified 149 different strategies and now wish to compare them to some theoretical definitions.

Do you have to take part?

No, you do not have to take part. Participation in this study is voluntary. You may withdraw from this study at any time without giving a reason. You may also withdraw your data from the study without providing a reason any time up until the 15th December 2014. After this date, however, data will be analysed anonymously therefore it will not be possible to remove your data.

What will you do in the project?

You are invited to take part in one task known as a Discriminant Content Validation task. This can be completed in your own time at home. Through previous interviews we have identified strategies used by stroke survivors to adjust to life after stroke and now wish to compare these to some theoretical definitions. We will therefore provide you with a list of these strategies and some theoretical definitions. We will ask you to decide whether each individual strategy matches any

of the theoretical definitions. We will also ask you to indicate how confident you are about your decision.

We will ask that you return the completed task within one month, using the stamped envelope provided. If you do not return the task within this time, we will send you one e-mail requesting that you do so. As we will ask you to review 149 different strategies, the task may take around two hours to complete.

You will receive no payment or reimbursement for your participation in this study.

Why have you been invited to take part?

We are looking for researchers or healthcare professionals who have experience of working in the fields of psychology and/or stroke research or care. You do not have to be familiar with stroke rehabilitation to take part in this study.

What happens to the information in the project?

The information you supply will remain confidential, and will be securely stored on a password protected computer. Your data will not be stored directly with your name, but with a code so that if you wish to withdraw your data, the researcher may identify your data.

The University of Strathclyde is registered with the Information Commissioner's Office who implements the Data Protection Act 1998. All personal data on participants will be processed in accordance with the provisions of the Data Protection Act 1998.

What happens next?

If you wish to take part, please complete the attached consent form and return it to the researcher. The study task will then be posted to you. If you do not wish to take part, thank you for your time.

This investigation was granted ethical approval by the School of Psychological Sciences and Health Ethics Committee.

Researcher Contact Details:

Jennifer Dryden
School of Psychological Sciences and Health
University of Strathclyde
Graham Hills Building
40 George Street, Glasgow, G1 1QE
Telephone: 0141 548 4284, Email: jennifer.dryden@strath.ac.uk

Chief Investigator Details:

Dr Diane Dixon
School of Psychological Sciences and Health
University of Strathclyde
Graham Hills Building
40 George Street, Glasgow, G1 1QE
Telephone: 0141 548 2571, Email: diane.dixon@strath.ac.uk

If you have any questions/concerns, during or after the investigation, or wish to contact an independent person to whom any questions may be directed or further information may be sought from, please contact:

Dr James Baxter
School of Psychological Sciences and Health
University of Strathclyde
Graham Hills Building
40 George Street, Glasgow, G1 1QE
Telephone: 0141 548 2242, Email: j.baxter@strath.ac.uk

Appendix 4.5: DCV consent form

SCHOOL OF PSYCHOLOGICAL SCIENCES & HEALTH



Consent form

Title of the study: Examining the adaptation strategies of stroke survivors within a theoretical framework

Name of Researcher: Jennifer Dryden

- I confirm that I have read and understood the information sheet for the above project and the researcher has answered any queries to my satisfaction.
- I understand that my participation is voluntary and that I am free to withdraw from the project at any time, without having to give a reason and without any consequences.
- I understand that I can withdraw my data from the study at any time up until the 15th December 2014.
- I understand that after the above date, my data will be analysed anonymously therefore it will not be possible to remove it from the analysis.
- I understand that any information recorded in the investigation will remain confidential and no information that identifies me will be made publicly available.
- I consent to being a participant in the project

(NAME)	
	Date:

Address to which you wish the study to be posted (please print):



Participant Debrief Sheet

Title of the study: Examining the adaptation strategies of stroke survivors within a theoretical framework

Thank you for taking part in this study on the various strategies that can be used to help stroke survivors adjust to life post-stroke. As you know, stroke survivors often find that their body has changed since having a stroke and that these changes can make life more difficult. We have already spoken to stroke survivors about the techniques which they find helpful and this task will help us to match them to the theoretical constructs described by the 'Selection, Optimisation and Compensation model (Baltes & Baltes, 1990).

If we find that the Selection, Optimisation and Compensation model is a useful framework for describing post-stroke adaption, we will integrate these strategies into a guided interview intervention. The aim of this intervention will be to help stroke survivors choose from and try out a range of strategies which might be useful in helping them to adjust to life post-stroke.

You may withdraw your data from the study without providing a reason, any time up until the 15th December 2014. After this date, however, data will be analysed anonymously therefore it will not be possible to remove your data. If you wish to withdraw your data please contact the research team quoting the participant code you were provided with at the start of the study.

Thank you once again for taking part in this study. If you have any further questions, please contact the research team below.

Researcher Contact Details:

Jennifer Dryden
School of Psychological Sciences and Health
University of Strathclyde
Graham Hills Building
40 George Street, Glasgow, G1 1QE
Telephone: 0141 548 4284, Email: jennifer.dryden@strath.ac.uk

Chief Investigator Details:

Dr Diane Dixon
School of Psychological Sciences and Health
University of Strathclyde
Graham Hills Building
40 George Street, Glasgow, G1 1QE
Telephone: 0141 548 2571, Email: diane.dixon@strath.ac.uk

If you have any questions/concerns, during or after the investigation, or wish to contact an independent person to whom any questions may be directed or further information may be sought from, please contact:

Dr James Baxter
School of Psychological Sciences and Health
University of Strathclyde
Graham Hills Building
40 George Street, Glasgow, G1 1QE
Telephone: 0141 548 2242, Email: j.baxter@strath.ac.uk

Life after stroke



Choosing goals or activities

It may help to change your goals so that you can focus on the most important ones. Here are some ways other stroke survivors have told us they have done this:

- Spending less time at work and more time with family
- Only doing social activities that you enjoy and that are important to you, for example, going to bed and reading rather than going out socialising
- Reducing the number of activities you take part in to try and cope with fatigue
- Avoiding situations that might negatively affect your health, e.g. where you might fall
- Continuing preferred social activities but spending less time on them, for example, playing fewer games of bowls or playing 9 holes on the golf course rather than 18
- Avoiding people who make you stressed or anxious
- Giving up doing chores and tasks for other people

- Giving up activities that are too tiring, for example, doing the gardening

Working towards goals or activities.

You may have to work towards a certain goal or activity. Here are some ways other stroke survivors have told us they have done this:

By practising:

- Repeatedly practising tasks such as getting in and out of the shower
- Training your concentration with mental tasks such as crosswords and jigsaws
- Repeating certain movements frequently, for example, hand exercises
- Practising using your senses, for example reaching for objects in a bucket of sand to help feeling in your hands

By planning:

- Thinking about things and planning in advance, for example planning what to take into the shower to avoid having to come in and out more than once
- Planning your day for when you'll be at your best, for example if you are most awake and alert in the mornings then plan to have important meetings at this time

- Making sure you get the right balance between activities and resting

By learning something new:

- Learning new ways to relax, such as walking or meditation
- Developing your own memory reminders, for example, sticking reminders to the fridge or the mantelpiece

By exercising and moving:

- Doing exercise when you have spare time, for example, physiotherapy exercises when watching TV at night
- Practising balance and movement using Wii Fit and other computer games
- Choosing a new exercise, for example, an exercise class designed for stroke survivors
- Exercising more to improve strength, fitness or for rehabilitation

By giving more effort or attention:

- Continuing to do things for yourself by allowing yourself more time to do them
- Continuing to use your weaker hand rather than giving up using it altogether

Choosing other ways of doing activities or getting to goals.

You may have to find another way of doing something. Here are some ways other stroke survivors have told us they have done this:

- Using speech and language therapy aids such as pencil grips and conversation booklets
- Using aids to help you with everyday activities, from walking aids, handrails and raised beds to reading aids such as clip lights and magnifying glasses
- Using gadgets to help with everyday activities, from trolleys to transport items about indoors, to kitchen gadgets such as a potato peeler or a slow cooker
- Seeking assistance from family, friends or carers with tasks such as eating, dressing, bathing and looking after body parts, e.g. getting a chiropodist to cut your nails, going to the hairdresser for a blow dry or hiring a care assistant
- Seeking help to understand documents and official letters
- Cutting up food into small pieces before starting to eat
- Doing tasks using the unaffected side of your body when you are no longer able to use the affected side at all

- Changing the way you do everyday tasks, for example, hanging washing inside or in a greenhouse rather than on the washing line, or sticking nail clippers to a work surface in order to cut nails
- Choosing an alternative way of doing an activity, for example having a shower or using a basin to wash when you are unable to get in and out of the bath
- Learning and practising new ways of doing things, such as special dressing techniques taught by occupational therapists
- Lifting lighter items with your affected hand and heavier items with your unaffected hand



Dear Sir/Madam

My name is Jennifer Dryden and I am a PhD student at the University of Strathclyde. I would like to invite you to take part in a research study which I have organised as part of my PhD research called 'Examining a 'life after stroke' helpsheet for stroke survivors'.

You are receiving this study invite because you are a stroke survivor and your treating clinical team has given you this information pack on behalf of myself.

If you are interested in reading more about the study and how to get involved then please read the rest of this information sheet for further information. Otherwise, there is no need to do anything further. Please feel free to contact me if you have any questions about the study.

Yours sincerely,

Jennifer Dryden (PhD student)
School of Psychological Sciences and Health
University of Strathclyde
Graham Hills Building
40 George Street
Glasgow, G1 1QE
Telephone: 0141 548 2571
Email: jennifer.dryden@strath.ac.uk

Information about the research:

Examining a 'life after stroke' helpsheet for stroke survivors

We would like to invite you to take part in our research study. Before you decide, we would like you to read over this information sheet. It will help you to understand:

- why we are doing this research.
- what it will involve.

Please take some time to read over this information and talk to others about the study if you wish. You can contact myself, Jennifer Dryden, if you have any questions about the study. My contact details are listed at the end.

If after reading this information, you wish to take part in the study, please fill in the attached slip and post it back to us in the prepaid envelope provided.

What is the purpose of this study?

Stroke survivors often find that their life has changed since having a stroke and that they may face new problems, such as difficulty doing housework or taking part in social activities. At the moment we do not know how to best help people adjust to these difficulties.

We have spoken to stroke survivors and asked them to tell us how they cope with life after stroke. They have told us about some ways that have helped them and we would like to share these with you, using a helpsheet. If you want, you can pick some of these ways to try yourself. You can tell us what you like and what you don't like about the helpsheet. This will help us make it better for stroke survivors in the future.

Why have I been invited to take part?

You have been invited to take part because you are a stroke survivor.

Do I have to take part?

No, you don't have to take part. Participation in this study is voluntary. Take some time to read this information sheet and consider if you wish to take part in the study. If you do wish to take part, please fill in the attached slip and post it back in the prepaid envelope provided.

You may withdraw from this study at any time without giving a reason and without any consequences.

What will happen to me if I take part

You will be asked to take part in 2 discussions with myself. Each will last a maximum of 1 hour. I will come to your house for these visits, or we can arrange for them to take place somewhere convenient for you. You can choose to have a friend, family member or carer present during the visits.

During the first visit we will discuss ways in which other stroke survivors have adjusted to life after stroke. This will include talking about how they have changed their goals or priorities since having a stroke. We will also talk about ways in which other stroke survivors have worked towards certain goals and what they have done if they haven't been able to do the same things they used to.

We will show you a helpsheet with examples of things other stroke survivors have done. An example is "reducing the number of household tasks you do in a day". We will ask if you would like to pick some of these and try doing them.

We will visit again 2 weeks later and ask you about how you felt doing these things. We are interested in whether you had the chance to use them and whether you found them easy/hard.

The visits will be recorded using a small digital recorder.

We will also ask your clinical team to share some information from your medical records with us. The information we will ask for is your stroke diagnosis, known as Oxfordshire Community Stroke Project Classification. We will not have access to your medical records nor will your clinical team share any additional medical information with us.

As part of the study we will also ask you to complete 7 paper questionnaires. These are short questionnaires, which take about 5 minutes each to fill in. These will help us to get a picture of your life since having a stroke. We will also ask you to tell us some basic information about yourself, such as your age, education and living arrangements.

With your consent, we will inform your GP that you are taking part in this study. This is for their information only – taking part in the study will not affect the care you receive from your GP or hospital.

What are the possible disadvantages and risks of taking part?

There are very few risks associated with taking part in this study. You might, however, want to try out some of the things on the helpsheet. We will need to make sure you are capable of trying these things safely and that they don't cause you any psychological or physical problems. We will encourage you to discuss them with your family, carer or healthcare team before doing them. We may also discuss them with your healthcare team to make sure they are right for you. This will only happen with your permission. Anything your healthcare team tells you to do should always be listened to.

You do not have to answer any questions that make you feel uncomfortable. You are also free to stop the discussions and leave the study at any time without giving a reason. There will be no consequences if you decide to withdraw from the study.

What are the possible benefits of taking part?

You may benefit from learning about the ways other stroke survivors manage their life after stroke. We cannot promise the study will help you but the information you give us could help improve the helpsheet for future stroke survivors.

What happens when the research study stops?

After completing the study you will be given information explaining the ideas behind this research. If you would like further information you can contact any of the research team.

Once the study is complete we will analyse the information and will submit the results of the study for publication in a scientific journal. No information will be published that can identify you personally.

What if there is a problem?

If you have any questions or concerns, during or after the study, you can contact any of the research team. If you wish to contact an independent person with questions or concerns you can contact:

Secretary to the University Ethics Committee
Research & Knowledge Exchange Services
University of Strathclyde
Graham Hills Building
50 George Street
Glasgow
G11 6NT
Telephone: 0141 548 3707
Email: ethics@strath.ac.uk

Will my taking part in the study be kept confidential?

Yes. We will follow ethical and legal practice and all information about you will be handled in confidence. If, however, you tell us that you are having quite a lot of problems with life after stroke, we may ask you if you want us to share this information with your clinical team so that you may receive further support. If we feel there are serious concerns about your health and wellbeing, we may have to talk to others to allow you to get help. We will always talk to you about this first.

Our discussions will be recorded using audio recording equipment and will be securely stored on a password protected computer. Only the research team will have access to identifiable data, which will be destroyed after 12 months. The information that we get will be made anonymous so you cannot be identified. The anonymised discussions will be transcribed into text and will be stored securely for a period of 3 years and then destroyed.

The University of Strathclyde is registered with the Information Commissioner's Office who implements the Data Protection Act 1998. All personal data on participants will be processed in accordance with the provisions of the Data Protection Act 1998.

What happens if I don't want to carry on with the study?

You may leave the study at any time without having to give a reason. You can do so by contacting any member of the research team. The contact details are listed below.

What will happen to the results of the research study?

We plan to submit the results for publication in a scientific journal.

Who is organising and funding the research?

The research is being organised by the chief investigator Jennifer Dryden. Jennifer is undertaking this study as part of her PhD training. The research is funded jointly by the University of Strathclyde and Chest Heart & Stroke Scotland.

Who has reviewed the study?

All research in the NHS is looked at by an independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed and given favourable opinion by the NHS Research ethics committee and The University of Strathclyde ethics committee.

What happens next?

If you want to take part in the study, please complete the attached slip and post it back to us in the prepaid envelope provided. Once we receive this form we will contact you with further information. We will also answer any questions you may have about the study and please ask us if there is anything that is not clear.

If you do not want to be involved, thank you very much for your time – there is nothing more that will be asked of you.

Contact details

Chief Investigator:

Jennifer Dryden

School of Psychological Sciences and Health

University of Strathclyde

Graham Hills Building

40 George Street

Glasgow, G1 1QE

Telephone: 0141 548 2571

Email: jennifer.dryden@strath.ac.uk

Supervisory Team:

Dr Diane Dixon

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University of Strathclyde

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40 George Street

Glasgow, G1 1QE

Telephone: 0141 548 2571

Email: diane.dixon@strath.ac.uk

Professor Madeleine Grealy

School of Psychological Sciences and Health

University of Strathclyde

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40 George Street

Glasgow, G1 1QE

Telephone: 0141 548 4885

Email: madeleine.grealy@strath.ac.uk

Dr Terry Quinn
Institute of Cardiovascular and Medical Sciences
Walton Building
Glasgow Royal Infirmary
Glasgow, G4 0SF
Telephone: 01412114976
E-mail: terry.quinn@glasgow.ac.uk

If you wish further information about this study or to take part, please fill in your details below. A member of the research team will contact you to discuss the research. You can still decide not to take part at any time.

Name –

Address –

Contact telephone number –

Please post this back to us in the stamped, addressed envelope provided.

Thank you

Appendix 5.3: SOC intervention participant consent form (NHS)



Participant identification number:

CONSENT FORM

Title of Project: Examining a 'life after stroke' helpsheet for stroke survivors.

Name of Researcher: Jennifer Dryden

**Please
initial
boxes**

1. I confirm that I have read and understand the information sheet dated 14/03/15 (version 2) for the above study. I have had time to think about the information, ask questions and have had any questions answered to my satisfaction.

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 being affected.

3. I understand that data collected during the study may be looked at by individuals from the research team, from regulatory authorities or from the NHS Trust. I understand that this data will be made anonymous so that I cannot be identified from or linked to the data.

4. I understand that the results of some standard stroke assessment measures will be passed to the research team by my treating clinical team. I consent to this sharing of information and understand that the research team will not have access to any additional medical information.

5. I consent to the visits being recorded using audio recording equipment.

6. I understand that anonymised quotes from the visits may be used for presentations and publications.

7. I consent to my GP being told about me taking part in the study

8. I agree to take part in the above study.

Name (please print) Date Signature

Name of Person taking consent Date
Signature

Appendix 5.4: SOC intervention Participant Information Sheet (other)



Dear Sir/Madam

My name is Jennifer Dryden and I am a PhD student at the University of Strathclyde. I would like to invite you to take part in a research study which I have organised as part of my PhD research called 'Examining a 'life after stroke' helpsheet for stroke survivors'.

You are receiving this study invite because you are a stroke survivor, previously took part in research at the University of Strathclyde and stated that you would be willing to be contacted about future research.

If you are interested in reading more about the study and how to get involved then please read the rest of this information sheet for further information. Otherwise, there is no need to do anything further. You will not be contacted again by me about any other research projects.

Yours sincerely,

Jennifer Dryden (PhD student)

School of Psychological Sciences and Health
University of Strathclyde
Graham Hills Building
40 George Street
Glasgow, G1 1QE
Telephone: 07725915309
Email: jennifer.dryden@strath.ac.uk



Information about the research: Examining a 'life after stroke' helpsheet for stroke survivors

We would like to invite you to take part in our research study. Before you decide, we would like you to read over this information sheet. It will help you to understand:

- why we are doing this research.
- what it will involve.

Please take some time to read over this information and talk to others about the study if you wish. You can contact myself, Jennifer Dryden, if you have any questions about the study. My contact details are listed at the end.

If after reading this information, you wish to take part in the study, please fill in the attached slip and post it back to us in the prepaid envelope provided.

What is the purpose of this study?

Stroke survivors often find that their life has changed since having a stroke and that they may face new problems, such as difficulty doing housework or taking part in social activities. At the moment we do not know how to best help people adjust to these difficulties.

We have spoken to stroke survivors and asked them to tell us how they cope with life after stroke. They have told us about some ways that have helped them and we would like to share these with you, using a helpsheet. If you want, you can pick some of these ways to try yourself. You can tell us what you like and what you don't like about the helpsheet. This will help us make it better for stroke survivors in the future.

Why have I been invited to take part?

You have been invited to take part because you are a stroke survivor.

Do I have to take part?

No, you don't have to take part. Participation in this study is voluntary. Take some time to read this information sheet and consider if you wish to take part in the study. If you do wish to take part, please fill in the attached slip and post it back in the prepaid envelope provided.

You may withdraw from this study at any time without giving a reason and without any consequences.

What will happen to me if I take part

You will be asked to take part in 2 discussions with myself. Each will last a maximum of 1 hour. I will come to your house for these visits, or we can arrange for them to take place somewhere convenient for you. You can choose to have a friend, family member or carer present during the visits.

During the first visit we will discuss ways in which other stroke survivors have adjusted to life after stroke. This will include talking about how they have changed their goals or priorities since having a stroke. We will also talk about ways in which other stroke survivors have worked towards certain goals and what they have done if they haven't been able to do the same things they used to.

We will show you a helpsheet with examples of things other stroke survivors have done. An example is "reducing the number of household tasks you do in a day". We will ask if you would like to pick some of these and try doing them.

We will visit again 2 weeks later and ask you about how you felt doing these things. We are interested in whether you had the chance to use them and whether you found them easy/hard.

The visits will be recorded using a small digital recorder.

As part of the study we will also ask you to complete 7 paper questionnaires. These are short questionnaires, which take about 5 minutes each to fill in. These will help us to get a picture of your life since having a stroke. We will also ask you to tell us some basic information about yourself, such as your age, education and living arrangements.

With your consent, we will inform your GP that you are taking part in this study. This is for their information only – taking part in the study will not affect the care you receive from your GP or hospital.

What are the possible disadvantages and risks of taking part?

There are very few risks associated with taking part in this study. You might, however, want to try out some of the things on the helpsheet. We will need to make sure you are capable of trying these things safely and that they don't cause you any psychological or physical problems. We will encourage you to discuss them with your family, carer or healthcare team before doing them. We may also discuss them with your healthcare team to make sure they are right for you. This will only happen with your permission. Anything your healthcare team tells you to do should always be listened to.

You do not have to answer any questions that make you feel uncomfortable. You are also free to stop the discussions and leave the study at any time without giving a reason. There will be no consequences if you decide to withdraw from the study.

What are the possible benefits of taking part?

You may benefit from learning about the ways other stroke survivors manage their life after stroke. We cannot promise the study will help you but the information you give us could help improve the helpsheet for future stroke survivors.

What happens when the research study stops?

After completing the study you will be given information explaining the ideas behind this research. If you would like further information you can contact any of the research team.

Once the study is complete we will analyse the information and will submit the results of the study for publication in a scientific journal. No information will be published that can identify you personally.

What if there is a problem?

If you have any questions or concerns, during or after the study, you can contact any of the research team. If you wish to contact an independent person with questions or concerns you can contact:

Secretary to the University Ethics Committee

Research & Knowledge Exchange Services

University of Strathclyde

Graham Hills Building

50 George Street

Glasgow

G11 6NT

Telephone: 0141 548 3707

Email: ethics@strath.ac.uk

Will my taking part in the study be kept confidential?

Yes. We will follow ethical and legal practice and all information about you will be handled in confidence. If, however, you tell us that you are having quite a lot of problems with life after stroke, we may ask you if you want us to share this information with your clinical team so that you may receive further support. If we feel there are serious concerns about your health and wellbeing, we may have to talk to others to allow you to get help. We will always talk to you about this first.

Our discussions will be recorded using audio recording equipment and will be securely stored on a password protected computer. Only the research team will have access to identifiable data, which will be destroyed after 12 months. The information that we get will be made anonymous so you cannot be identified. The anonymised discussions will be transcribed into text and will be stored securely for a period of 3 years and then destroyed.

The University of Strathclyde is registered with the Information Commissioner's Office who implements the Data Protection Act 1998. All personal data on participants will be processed in accordance with the provisions of the Data Protection Act 1998.

What happens if I don't want to carry on with the study?

You may leave the study at any time without having to give a reason. You can do so by contacting any member of the research team. The contact details are listed below.

What will happen to the results of the research study?

We plan to submit the results for publication in a scientific journal.

Who is organising and funding the research?

The research is being organised by the chief investigator Jennifer Dryden. Jennifer is undertaking this study as part of her PhD training. The research is funded jointly by the University of Strathclyde and Chest Heart & Stroke Scotland.

Who has reviewed the study?

All research in the NHS is looked at by an independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed and given favourable opinion by the NHS Research ethics committee and The University of Strathclyde ethics committee.

What happens next?

If you want to take part in the study, please complete the attached slip and post it back to us in the prepaid envelope provided. Once we receive this form we will contact you with further information. We will also answer any questions you may have about the study and please ask us if there is anything that is not clear.

If you do not want to be involved, thank you very much for your time – there is nothing more that will be asked of you.

Contact details

Chief Investigator:

Jennifer Dryden

School of Psychological Sciences and Health

University of Strathclyde

Graham Hills Building

40 George Street

Glasgow, G1 1QE

Telephone: 0141 548 2571

Email: jennifer.dryden@strath.ac.uk

Supervisory Team:

Dr Diane Dixon

School of Psychological Sciences and Health

University of Strathclyde

Graham Hills Building

40 George Street

Glasgow, G1 1QE

Telephone: 0141 548 2571

Email: diane.dixon@strath.ac.uk

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University of Strathclyde

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Institute of Cardiovascular and Medical Sciences
Walton Building
Glasgow Royal Infirmary
Glasgow, G4 0SF
Telephone: 01412114976
E-mail: terry.quinn@glasgow.ac.uk

If you wish further information about this study or to take part, please fill in your details below. A member of the research team will contact you to discuss the research. You can still decide not to take part at any time.

Name –

Address –

Contact telephone number –

Please post this back to us in the stamped, addressed envelope provided.

Thank you

Appendix 5.5: SOC intervention participant consent form (other)



Participant identification number:

CONSENT FORM

Title of Project: Examining a 'life after stroke' helpsheet for stroke survivors.

Name of Researcher: Jennifer Dryden

**Please
initial
boxes**

1. I confirm that I have read and understand the information sheet dated 18/09/15 (version 3) for the above study. I have had time to think about the information, ask questions and have had any questions answered to my satisfaction.

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 being affected.

3. I understand that data collected during the study may be looked at by individuals from the research team, from regulatory authorities or from the NHS Trust. I understand that this data will be made anonymous so that I cannot be identified from or linked to the data.
4. I consent to the visits being recorded using audio recording equipment.
5. I understand that anonymised quotes from the visits may be used for presentations and publications.
6. I consent to my GP being told about me taking part in the study
7. I agree to take part in the above study.

Name (please print)

Date

Signature

Name of Person taking consent

Date

Signature

Appendix 5.6: SOC short-form measure, used with permission¹

(B) Domain-general Instruction: Life-management

We are very interested in learning about how you decide which things in life are important for you and how you go about accomplishing what you want in life.

In the following, we present examples of two different ways people might behave. Imagine there are two people talking about what they would do in a particular situation. We would like you to decide which person is most similar to you -- in other words, which one behaves most like the way you probably would.

Now, think about your life overall, including how things are going, think about your goals -- that is, both things that you want to improve and things that you are satisfied with and want to maintain.

I. Elective Selection

item	Target	Distractor
S1	I concentrate all my energy on few things.	I divide my energy among many things.
S2	I always focus on the one most important goal at a given time.	I am always working on several goals at once.
S3	When I think about what I want in life, I commit myself to one or two important goals.	Even when I really consider what I want in life, I wait and see what happens instead of committing myself to just one or two particular goals.

II. Loss-based Selection

item	Target	Distractor
LBS1	When things don't go as well as before, I choose one or two important goals.	When things don't go as well as before, I still try to keep all my goals.
LBS2	When I can't do something important the way I did before, I look for a new goal.	When I can't do something important the way I did before, I distribute my time and energy among many other things.
LBS3	When I can't do something as well as I used to, I think about what exactly is important to me.	When I can't do something as well as I used to, I wait and see what comes.

III. Optimization

item	Target	Distractor
O1	I keep working on what I have planned until I succeed.	When I do not succeed right away at what I want to do, I don't try other possibilities for very long.
O2	I make every effort to achieve a given goal.	I prefer to wait for a while and see if things will work out by themselves.
O3	If something matters to me, I devote myself fully and completely to it.	Even if when something matters to me, I still have a hard time devoting myself fully and completely to it.

IV. Compensation

item	Target	Distractor
C1	When things don't go as well as they used to, I keep trying other ways until I can achieve the same result I used to.	When things don't go as well as they used to, I accept it.
C2	When something in my life isn't working as well as it used to, I ask others for advice or help.	When something in my life isn't working as well as it used to, I decide what to do about it myself, without involving other people.
C3	When it becomes harder for me to get the same results, I keep trying harder until I can do it as well as before.	When it becomes harder for me to get the same results as I used to, it is time to let go of that expectation.

¹ SOC items were presented to participants in an alternative order, such that items were not grouped into strategy types.

Appendix 5.7: NHS REC Notice of Favourable Opinion

WoSRES
West of Scotland Research Ethics Service



West of Scotland REC 3
Ground Floor – The Tennent Institute
Western Infirmary
38 Church Street
Glasgow G11 6NT
www.nhsggc.org.uk

Miss Jennifer Dryden
PhD student
Psychological Sciences and Health
Department
Graham Hills building, 40 George Street
Glasgow
G1 1QE

Date 26th March 2015
Your Ref
Our Ref
Direct line 0141 211 2123
Fax 0141 211 1847
E-mail WOSREC3@ggc.scot.nhs.uk

Dear Miss Dryden

Study title: Examining the process, feasibility and acceptability of the 'Selection, Optimisation and Compensation (SOC)' helpsheet intervention for stroke survivors
REC reference: 15/WS/0035
IRAS project ID: 162803

Thank you for responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information was considered in correspondence by a Sub-Committee of the REC. A list of the Sub-Committee members is attached.

The Sub Committee discussed item 4 in your response letter and noted your reasons for wishing to recruit patients who were already part of an NHS Rehabilitation Programme. After discussion the Sub-Committee decided that you had adequately justified the reasons for wishing to do this and agreed that patients already part of an NHS Rehabilitation Programme could be recruited to the study.

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 favourable opinion letter. The expectation is that this information will be published for all studies that receive an ethical opinion but should you wish to provide a substitute contact point, wish to make a request to defer, or require further information, please contact the REC Manager, Mrs Liz Jamieson, wosrec3@ggc.scot.nhs.uk. Under very limited circumstances (e.g. for student research which has received an unfavourable opinion), it may be possible to grant an exemption to the publication of the study.

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 favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission ("R&D approval") should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements.

Guidance on applying for NHS permission for research is available in the Integrated Research Application System 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 approvals from host organisations

Ethical review of research 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
Copies of advertisement materials for research participants	1	21 November 2014
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only)		04 February 2015
Interview schedules or topic guides for participants [Visit 1]	1	21 November 2014
Interview schedules or topic guides for participants	1	21 November 2014
Letter from funder	1	19 February 2013
Letter from sponsor		04 February 2015
Non-validated questionnaire [Intervention acceptability Questionnaire]	1	21 November 2014
Other [Debrief Information Sheet]	1	21 November 2014
Other [Life after stroke helpsheet]	1	21 November 2014
Other [CV local collaborator Terry Quinn]	1	16 February 2013

Other [CV academic supervisor (2) M Grealy]	1	15 February 2013
Other [Appendix 19 GP information letter]	1	14 March 2015
Other [Provisional opinion response letter]	1	17 March 2015
Participant consent form [NHS]	2	14 March 2015
Participant information sheet (PIS)	2	14 March 2015
REC Application Form [REC_Form_09022015]		09 February 2015
Research protocol or project proposal [Appendix 18 Protocol - Examining a 'life after stroke' helpsheet for stroke survivors]	2	14 March 2015
Summary CV for Chief Investigator (CI) [CV Jennifer Dryden]	1	04 February 2015
Summary CV for supervisor (student research) [CV Diane Dixon]	1	22 February 2013
Validated questionnaire [SOC - Technical Report]	1	21 November 2014
Validated questionnaire [BDI]	1	21 November 2014
Validated questionnaire [MoCA]	1	21 November 2014
Validated questionnaire [Barthel Index]	1	21 November 2014
Validated questionnaire [Frenchay Activities Index]	1	21 November 2014
Validated questionnaire [Self efficacy]	1	21 November 2014
Validated questionnaire [EQ-5D]	1	21 November 2014

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/>

15/WS/0035	Please quote this number on all correspondence
-------------------	---

With the Committee's best wishes for the success of this project.

Yours sincerely



Liz Jamieson
REC Manager
On behalf of Eoin MacGillivray, Vice Chair

Enclosures: List of names and professions of members who were present at the meeting
"After ethical review – guidance for researchers"

Copy to: Ms Louise McKean
Mrs Lorraine Reid, NHS Greater Glasgow & Clyde

Appendix 5.8: NHS REC Approval of substantial amendment 1

WoSRES
West of Scotland Research Ethics Service



West of Scotland REC 3
Ground Floor – The Tennent Institute
Western Infirmary
38 Church Street
Glasgow G11 6NT
www.nhsggc.org.uk

Miss Jennifer Dryden
PhD student
Psychological Sciences and Health
Department
Graham Hills building,
40 George Street
Glasgow
G1 1QE

Date 1st October 2015
Your Ref
Our Ref
Direct line 0141 211 2123
Fax 0141 211 1847
E-mail WOSREC3@ggc.scot.nhs.uk

Dear Miss Dryden

Study title:	Examining the process, feasibility and acceptability of the 'Selection, Optimisation and Compensation (SOC)' help sheet intervention for stroke survivors
REC reference:	15/WS/0035
Amendment number:	AM01
Amendment date:	18 September 2015
IRAS project ID:	162803

The above amendment was reviewed by the Sub-Committee in correspondence.

Ethical opinion

The members of the Committee taking part in the review gave a favourable ethical opinion of the amendment on the basis described in the notice of amendment form and supporting documentation.

Summary of Amendment

A request for a second recruitment process, i.e. to approach those who had previously taken part in a research study and had given consent to be contacted about future studies.

Approved documents

The documents reviewed and approved at the meeting were:

<i>Document</i>	<i>Version</i>	<i>Date</i>
Notice of Substantial Amendment (non-CTIMP)	AM01	18 September 2015
Participant consent form	3	18 September 2015
Participant information sheet (PIS)	3	18 September 2015
Research protocol or project proposal	3	18 September 2015

Membership of the Committee

The members of the Committee who took part in the review are listed on the attached sheet.

R&D approval

All investigators and research collaborators in the NHS should notify the R&D office for the relevant NHS care organisation of this amendment and check whether it affects R&D approval of the research.

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.

We are pleased to welcome researchers and R & D staff at our NRES committee members' training days – see details at <http://www.hra.nhs.uk/hra-training/>

15/WS/0035:	Please quote this number on all correspondence
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Yours sincerely



Liz Jamieson
REC Manager
On behalf of Dr Adam Burnel, Chair

Enclosures: List of names and professions of members who took part in the review

Copy to: Mrs Lorraine Reid, NHS Greater Glasgow and Clyde
Ms Louise McKean

Appendix 5.9: SOC intervention GP information letter

FOR INFORMATION ONLY

(Insert Date)

Dear Dr (insert name)

I am writing to inform you that (patient name) of (address) is taking part in the research study 'Examining a 'life after stroke' helpsheet for stroke survivors'. This study is being organised by the University of Strathclyde. The helpsheet is based on interviews with other stroke survivors and has been designed to help stroke survivors adjust to their post-stroke difficulties.

The study will involve asking (patient name) their views on the newly developed helpsheet and allowing them to the chance to try some of the strategies listed on the helpsheet if they wish. The study is not designed to replace rehabilitation programmes and will not interfere with any current treatment.

I have included an information sheet with full details of the study. Please get in touch with me or any member of the research team if you have any questions.

Yours sincerely,

Jennifer Dryden

PhD researcher
School of Psychological Sciences and Health
University of Strathclyde
40 George Street
Glasgow, G11QE
Tel: 07725915309 or 01415484756

Appendix 5.10: SOC intervention visit 1 schedule

Selection

Some stroke survivors experience difficulty following a stroke and because of this they might have to give up some activities, focus on their most important ones or choose new goals or activities.

- Do you think this is something that you have done/might do since having a stroke?
- Can you tell me more about how you feel about doing this?
- Have you had/can you think of any difficulties doing this?

Here are some ways that other stroke survivors have told us they have done this.
(Introduce helpsheet)

- Do you think you might like to try and of these/do they interest you?
- Can you pick one of these and see if you can try it over the next two weeks?

Optimisation

The next thing I would like to talk about is how stroke survivors work towards achieving goals and activities. There can be many different ways of doing this.

- Is there anything you do to enable you to achieve your goals or activities?
- Do you think this is something you might do since having a stroke?
- Can you tell me more about how you feel about doing this?
- Have you had/can you think of any difficulties doing this?

Here are some ways that other stroke survivors have told us they have done this.
(Introduce helpsheet)

- Do you think you might like to try and of these/do they interest you?
- Can you pick one of these and see if you can try it over the next two weeks?

Compensation

Sometimes stroke survivors find they are no longer able to do things the way they used to, so they either change the way they do it or accept some form of help.

- Do you think this is something that you have done/might do since having a stroke?
- Can you tell me more about how you feel about doing this?
- Have you had/can you think of any difficulties doing this?

Here are some ways that other stroke survivors have told us they have done this.
(Introduce helpsheet)

- Do you think you might like to try and of these/do they interest you?
- Can you pick one of these and see if you can try it over the next two weeks?

Appendix 5.11: SOC intervention visit 2 schedule

Selection

Last time we met we spoke about some ways that stroke survivors have changed the way they do things since having a stroke. Some stroke survivors experience difficulty following a stroke and because of this they might have to give up some activities, focus on their most important ones or choose new goals or activities. You chose to try doing this.

- Did you try doing this?
- Were there times when it came in useful?
- What were the outcomes of doing this?
- Do you feel you benefited from doing this?
- Did you have any difficulty doing this?
- Were there any things that made it difficult for you to do this?
- Did doing this make you feel more confident in adjusting to your stroke?
- Would you like to say anything else about it?

Optimisation

We also spoke about how stroke survivors work towards achieving goals and activities. You chose to try doing this.

- Did you try doing this?
- Were there times when it came in useful?
- What were the outcomes of doing this?
- Do you feel you benefited from doing this?
- Did you have any difficulty doing this?
- Were there any things that made it difficult for you to do this?
- Did doing this make you feel more confident in adjusting to your stroke?
- Would you like to say anything else about it?

Compensation

We also spoke about when stroke survivors find they are no longer able to do things the way they used to and so they either change the way they do it or accept some form of help. You chose to try doing this.

- Did you try doing this?
- Were there times when it came in useful?
- What were the outcomes of doing this?
- Do you feel you benefited from doing this?
- Did you have any difficulty doing this?
- Were there any things that made it difficult for you to do this?

- Did doing this make you feel more confident in adjusting to your stroke?
Would you like to say anything else about it?

Appendix 5.12: SOC intervention acceptability questionnaire

We are interesting in your opinions about the study so that we can make this helpsheet better for other stroke survivors in the future. We would be very grateful if you could answer some questions about how you found the experience. There are no right or wrong answer so please give your honest opinions. You can post this questionnaire back to us anonymously using the stamped envelope provided.

During the first visit, we spoke about how other stroke survivors have adjusted to life after a stroke.

1. Did you understand this?

2. Did you find this helpful?

We also looked at a helpsheet with examples.

1. Did you understand this?

2. Did you find this helpful?

You tried out some of the examples for two weeks.

1. Did you find this helpful?

You filled in 7 forms during each visit.

1. What did you think about filling in these forms?

Overall,

- 1. Did the visits and helpsheet change the way you acted?**
- 2. Did the visit and helpsheet make you feel more confident in adjusting to life after a stroke?**
- 3. Did you find the experience tiring?**
- 4. Did the visits and helpsheet change the way you thought about life after a stroke?**

Please tell us any other comments you have about the experience:

Thank you very much for your participation in this study

Summary information about the research: Examining a ‘life after stroke’ helpsheet for stroke survivors

Thank you for taking part in this study, which examined whether a ‘life after stroke’ helpsheet could be useful in helping stroke survivors. Stroke survivors often find that their body has changed since having a stroke and that these changes can make life more difficult.

Often people have to rearrange their priorities, work harder to meet their goals, or work out a different way of doing something. This study was interested in telling you about some of the ways other stroke survivors have done these things. You might also have chosen to try some of these out yourself. We have asked you about how you found this experience. This information is important because we want to make this helpsheet as useful as possible.

We plan to make this helpsheet better based on the information you have given us. We then hope to test this helpsheet with a larger number of stroke survivors in the future.

Feel free to contact me or any of the research team if you have any questions. The contact details for all the research team members are on the back of this page.

Thank you very much for taking part.

Contact details

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