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"Rip that whole book up – I've changed": Life and work narratives of mental illness

By

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Copyright Statement

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Abstract

Women with enduring mental illness are little considered in research and there is a dearth of occupational therapy literature concerning mental illness, although a third of therapists work in this speciality. This study explored two groups of women within a Scottish context. Phase One involved five women who lived with enduring mental illness, and Phase Two included sixteen occupational therapists who worked in mental health settings with similar women. Qualitative methodology, specifically, life history and focus group interviews, were used to give voice to the women's life and therapists' work experiences.

The data from the women's life history interviews was analysed using narrative analysis. This produced a unique, powerful narrative for each illustrating their complex, individualised experiences, allowing insight into and understanding of effects within their lives. This data was then analysed using constant comparative analysis. Six themes portrayed their lives. The findings highlighted the women's experiences as victims and importantly, as agents for themselves and others. Related to their personal agency was the need for future goals and hopes to be recognised and nurtured by health professionals. Furthermore, the significance of the women's experiences along the continuum of motherhood adds to our understanding of the long-term impact of continuing mental illness on women, their children and families. Overall, the women identified that they were experts in their own lives.

The focus group material was also subjected to constant comparative analysis. Five themes encapsulated the processes that underpinned therapists' interventions and the inter-dependency of their actions within specific work contexts. Comparison across the two groups of women revealed three common issues: their need for safe environments, their feelings of powerlessness and the importance of being heard. These findings have implications for occupational therapy practice, education and research specifically, as well as conveying important lessons to other professionals.

INTRODUCTION

My question is, “How did I get here?” What has influenced my knowledge and practice to take my work in a direction that culminated in this specific doctoral thesis? It is a thesis that I hope may make a difference that in some way may enable actions to be taken to make occupational therapy practice better, both for those who receive the service and for those who deliver it. This aim has required me to reconsider my beliefs and values, to re-examine what I held dear, and to understand how these have shaped my life and practice so far, and given my life meaning. In short, I had to examine and interpret my life to understand my own personal story and my resulting actions.

I grew up in a working class family living in a large Glasgow housing estate. My father worked and my mother kept the house. I was the eldest daughter with two older brothers and two younger sisters. It was an interesting position to inhabit. It was not until I was in my teens that my mother felt able to return to work. I am sure this was because I was now deemed able to take on board some of the household tasks that she left behind, for example, preparing evening meals. It did strike me at the time that my elder brothers were as capable as I was of cooking and serving up the tea but the task became mine. We were, after all, a traditional working class household with easily identifiable women’s tasks and men’s jobs. It took me a long while to realise things could be different.

I also grew up a stone’s throw away from one of Glasgow’s largest psychiatric hospitals. This meant that I had knowledge of psychiatry from a young age. Initially at nothing more than at a superficial level, I was aware that the patients I often saw at my local shops looked different in their dress and general presentation. I had further opportunities to observe the inside of the psychiatric hospital on my visits at different times of the year with the Sunday School and the Girls’ Brigade to celebrate the main

Christian festivities of Christmas and Easter. These visits were always interesting: I had a close-up view of the environment and of the patients, who seemed surprisingly ordinary. We were of course reminded on these occasions to be on our best behaviour. I later returned to this same hospital as I prepared for my interview at the Glasgow School of Occupational Therapy. On that occasion, I was allowed access to the patients within occupational therapy settings. Although my interest was stimulated, at this stage, I had decided my career in occupational therapy would be within physical settings. Perhaps I was drawn to the status and the inherent power.

However, this decision changed on my first placement. I found myself, in 1983, in another psychiatric hospital, this time in Dundee. This hospital upheld the Victorian ideal of asylum, being well away from the town; indeed, special transport arrangements existed to get staff to and from their work. I began to read around mental illness, not about the psychiatric conditions I witnessed, but from a sociological perspective. I realised that psychiatry was an area that was little understood and that society preferred to be out of sight. Nonetheless, during this placement, I was fortunate to be working in a setting that provided treatment to a range of patients who had acute and enduring mental health problems. I was fascinated by the lives of the people I met there. I was intrigued by the turns in their lives that had brought them into the psychiatric system. Some patients were on their first, frightening admission and others had spent a lifetime (or so it seemed to me) in this hospital. I tried to understand the pressures and the inequalities that had resulted in people having mental illness.

It was against this background that I decided psychiatry would be my future career. In my first post as an occupational therapist I worked in the long-stay psychiatric wards of the Royal Edinburgh Hospital. Here were women who had been admitted to the psychiatric services for not adhering to society's norms, for example having an illegitimate child. The result was a lifetime spent in an institution. I often wondered about these women, their experiences, and the child from whom they had been separated. Similarly, within acute psychiatric wards, I found that women were often labelled manipulative or attention-seeking, and that their roles as main carers of children and others was little considered. The focus was on stabilising the woman's mental status and on discharging her back to her community, with little or no follow-up. The development of my interest in women with enduring mental illness grew from these experiences. How was it that women found themselves in these situations? How did the profession in which I worked, which was and continues to be predominantly female, contribute to the maintenance of the system?

It was not until I began to study women with enduring mental illness for my doctoral thesis, to read of women's own experiences, and to explore women writing about women that I became interested in the women's movement and feminism. I came to this body of literature rather late in the day: it certainly was not part of my occupational therapy education, nor had it been an aspect of my other educational activities. This literature helped me to reconsider and gain understanding of my own experiences and to further consider the role of women in society and, specifically, the inequalities and oppression experienced by women with mental illness. This summary I hope makes the influences on my life and practice more transparent, and helps provide a context in which the research that follows can be more clearly understood.

This study then, explored the life stories of women with enduring mental illness. Though it concentrated on their personal experiences, it also examined the perspectives of a group of health professionals, namely, occupational therapists who worked with this client group. As this study involved women from Scotland it offered a distinctly Scottish view.

Women's general health has gained much from the feminist movement, with raised levels of awareness and more women-orientated services. The groundbreaking work of Chesler (1972), Women and Madness, is now considered a seminal text; so too, is Showalter's (1987) The Female Malady. Both of these texts are feminist, both consider the 'equivalence of madness and femininity'. However, women with severe mental illness were not focused on.

In addition, it is argued that feminist work has omitted two important groups: older women and disabled women (Morris, 1993). Therefore, it is proposed that women with severe mental illness are doubly neglected. First, they have no visible disability. Second, they are likely to be older and ageing. For both reasons they may be overlooked. Morris claims these groups of woman have little opportunity to portray their own experiences within the general culture. Their experience is often one of isolation and marginalisation. As issues for women with enduring mental illness have been little debated or indeed studied (Ritsher, Coursey, & Farrell, 1997), this research aimed to redress the balance by exploring the experiences of women who have lived with enduring mental illness. The aim is to strengthen knowledge and understanding of their lives.

Within the UK occupational therapy literature generally, there is a dearth of mental health research and there is no occupational therapy literature which deals specifically with women with enduring mental illness. Craik (1998) emphasises the lack of publications (p. 188) and notes that this publication pattern does not reflect the current practice situation where there are a large number of occupational therapists working with this client group. Therefore, the second purpose of this study was to explore the perspectives of occupational therapists who worked in a range of mental health settings with women with enduring mental illness.

Defining enduring mental illness

The size of the enduring mentally ill population is difficult to ascertain (The Sainsbury Centre for Mental Health, 1998). People with mental health problems have contact with a range of services including hospital and primary care settings. Figures are imprecise, vary nationally and are associated with levels of deprivation. It is considered that people with enduring mental illness form 2,000 - 4,000 per 100,000 of the general population. People with severe and enduring mental illness are believed to constitute 300-1,500 per 100,000 of the general population. The prevalence of severe mental illness most likely varies between 0.3–1.5% of the adult population.

In Scotland, it has been estimated that around 60,000 people have a sufficiently serious mental illness to be in contact with specialist psychiatric services. Twenty percent of these have a diagnosis of psychosis, schizophrenia and manic depressive illness. It is estimated that 60% of the mentally ill population are women. However, there is no significant difference in distribution for those individuals with severe mental illness. It is believed that they may form 50% of this population. (SWSI, 1995)

Bachrach (1985) described three elements used to distinguish people with enduring mental illness: diagnosis, duration and disability. However, the Department of Health (1994a) holds there is no consensus of definition regarding enduring mental illness. In a recent report dealing with people with severe mental illness, the 'Keys to Engagement', the Sainsbury Centre for Mental Health (1998) defined severe mental illness as:

> A mental disorder (i.e. psychotic disorders including schizophrenia, manic depression, severe depression or severe neurotic conditions and personality disorders) of such intensity that it disables people, preventing them, from functioning adequately as determined on the basis of their culture and background (p. 12).

This definition concurs with that of Bachrach in that it includes diagnosis and disability (or reduced functioning). However duration is not included. For the purpose of this study, Bachrach's three elements - namely diagnosis, duration and disability will form an element of the inclusion criteria for this study.

The literature that deals with an individual's experience of chronic illness in the main seems only to consider physical illness, with little reference to the experience of chronic mental illness. Chronic mental illness is now referred to as severe and/ or enduring mental illness; both terms severe and enduring are used interchangeably throughout this text. When the two are compared, there are no striking differences. The following table demonstrates the similarities.

Table 1. Similarities between chronic physical illness and enduring mental illness

Consequences of chronic physical illness. Charmaz (1983)	Consequences of enduring mental illness. Sainsbury Centre (1998)
Loss of productive function.	Loss of productive function.
Symptoms of the illness – physical pain and psychological distress, treatment and medical procedures used. Little energy.	Symptoms which may be intense and frightening. Depressive feelings and suicidal ideas. Energy levels will be low. Medication and side effects
Financial crises.	Financial situation - may not claim benefits.
Family strain.	Family strain
Stigma.	Stigma may lead to social exclusion
Restricted existence.	Restricted existence (Physically and by law)
Dependent and immobilised over time	Not fully independent/dependent on others
Loss of control over their lives and their futures	Loss of control over their lives and their futures
Not only low self-esteem but also self-identity.	Not only low self-esteem but also self-identity.

Women with enduring mental illness

Despite the fact that figures indicate that women and men are equally represented within the enduring mentally ill population, women with enduring mental illness are little studied. Wahl & Hunter (1992) concluded that this situation left a gap in knowledge. In the case of people with enduring mental illness, the most dominant group is perceived to be men who suffer from schizophrenia. Women's invisibility is increased as a result of being overshadowed by this dominant group. This is in part explained by Payne (1995) who discusses the difficulties of the visibility of this particular population, arguing that the specific needs of individuals and sub-groups become organised around the most dominant group.

The invisibility of this group of women within feminist literature has already been highlighted. However, this invisibility is also reflected across other spheres, in particular the literature of psychiatry, and occupational therapy. Psychiatric literature in the UK has been much slower than that in the USA to acknowledge women's mental health issues. When these are considered, the literature tends to concentrate on certain facets of women's experiences: for example, their representation within the homeless or prison population or health issues, such as family planning (Adams et al., 1996; Maden, Swinton, & Gunn, 1994; Marshall & Reed, 1992). While such studies add to the body of knowledge on women and mental health, they originate from a reductionist biomedical model and deny the woman and her life experiences. Nonetheless, there is some evidence of change in UK psychiatry Pilowsky et al. (1991), introducing a selection of papers from the 1st International Conference on Women and Mental Health, argued that women's special needs require to be understood and that mental health service planning should take these needs into account.

Of the medical and health literature, that relating to nursing appears to have given these women the greatest coverage. In their article, Harlene & Bernhard (1994), two American nurses, stress the need to value and validate the personal experiences of these women. As they put it, "By learning about a woman's personal experience the uniqueness of her situation can be appreciated" (p. 85).

Nursing literature, too, has acknowledged the feminist perspective. As the majority of health carers are women, and this is indeed true of occupational therapy in the UK, feminism may act as a method of making connections between the woman as client and the woman as therapist. However, Faugier (1992) argues that the debate must be integrated into the education of mental health practitioners, proposing that the feminist discussion must "find a way into clinical work with clients and our teaching of students" (p. 63).

As little research addresses in-depth the experiences of women with enduring mental illness, one way to supplement this lack of research is to examine complementary forms of literature. These texts, often autobiographical, exist in the public domain and offer a way to explore women's experiences of severe mental illness (Frame, 1990; Hart, 1995; Jamison, 1996; Pagett & Swanell, 1997). These authors present their unique experience: they deal with the varied aspects of being a woman living with mental illness, including the impact on relationships, hospital admissions, attempted suicide, employment and stigma. Geller (1985) suggests that women's writings can provide "insight into the relationship between mental illness, its treatment and their roles" (p. 1056). This alternative resource allows a rich source of personal experience to be discussed within research, educational and clinical contexts, offering recognition and understanding of the women's lived experience as narrated by them. Ussher (1991), a clinical psychologist, argues that "the woman herself is real, as is her pain - we must not deny that. So we must listen to women" (p. 306). Ussher urges us to 'listen to women', to hear their stories and to make changes. This study will take up Ussher's challenge and explore a group of women whose 'voices' are often unheard and neglected.

The need for research with regard to women with enduring mental illness has been established. This study aims to address some of the identified issues by investigating the life histories of women with enduring mental illness. Integral to this will be their occupational functioning throughout their life. Furthermore, the study will explore the perspectives of women occupational therapists who work with women. This brief introduction has set out the broad context and the themes which guided this research. In the following chapter, the literature review will explore the themes, relevant research and theoretical contexts.

CHAPTER ONE

Literature Review

Introduction

This literature review will provide the background to the study. In particular, it will discuss women with severe mental illness and their lack of recognition, arguing that they have been widely neglected. This results in their specific needs being unknown and therefore not met. It will argue that the issue of gender has never been fully addressed and that this in turn has been detrimental to women. Doyal (1995) emphasises "that gender differences are especially significant for women as they usually lead to inequality and discrimination" (p. 1). This study is about women: women who have lived with enduring mental illness and women who work with this group of women. This is not to say that men are treated differently or better in all cases, but it remains true that men in many societies are valued more and that they are still prominent in the distribution of resources for health.

The literature review will chart three distinct areas. The first presents an overview of women in psychiatry. Two perspectives will be reviewed: the psychiatric tradition and the feminist perspective. These present different and alternative views of women and their experiences of mental illness and psychiatry. Section Two will focus on occupational therapy highlighting, its close links with psychiatry and demonstrating that they share a common philosophy and history. Within the field of mental health, occupational therapy has played an integral part in service provision for the majority of this century. Occupational therapy continues to be a predominantly female profession, the significance of which may not be appreciated in working with women. Similarly, changes in psychiatry have impacted on occupational therapy practice. The knowledge and research base of the profession in relation to women with enduring mental illness will be explored.

Section Three concludes the review. This section will examine narratives, exploring the use of personal narratives to give voice to women. The case will be made that use of narrative inquiry, specifically life history, is an approach that enables women whose voice is not generally heard to tell their story and let their lived experiences take centre stage. The lives of women with severe mental illness will be presented from a range of sources. These narratives illuminate the many meanings that can be attributed to an individual's story. It will be argued that health professionals need to understand and take account of the lived experience of the women with whom they work.

Literature Search Strategy

In searching for relevant literature a variety of databases have been utilised to access the widest range of resources. These databases included Cumulative Index to Nursing and Allied Health Literature (CINAHL), Medline, Psychinfo (formerly Pscyhlit) and Applied Social Sciences Index and Abstract (ASSIA). Literature has been drawn from many fields to present a broad perspective of the subject. These fields include psychiatry, nursing, occupational therapy, psychology and anthropology. Literature has been drawn from the USA, Canada, New Zealand, Australia, South Africa and Europe. The literature covers a wide time frame to capture relevant material.

Section One: An overview of women and psychiatry

Women hold a particular place in the story of psychiatry. From the earliest times women regarded as 'different' by their society have been labelled as many things, from witches to insane (Roffe & Roffe, 1995; Chesler, 1996). As the 18th century started, the formalisation of psychiatric care within the UK was beginning. Women quickly became the main recipients of this budding specialism, often not at their own choice, and it could be argued they have been over-represented as patients ever since. Women outnumber men in mental health services as a whole (OPCS, 1994). One of the explanations of this figure includes the idea that women by nature seek more help than men. An alternative view, especially in the 19th and 20th centuries, was that women were oppressed by men, in male dominated institutions, within a similarly male dominated society: this patriarchal view of psychiatry is well-documented (Chesler, 1972; Showalter, 1985; Ussher, 1991).

A third perspective is the notion of gender bias in the diagnosis and care of women with mental illness. Busfield (1996) maintains that the official psychiatric classifications, namely International Classification of Diseases (ICD10) and the Diagnostic and Statistical Manual (DSM-1V), were developed to be gender neutral. However, she argues that the "formal, surface, gendered-neutrality does not mean that the categories themselves are constructed independently of gender" (p. 103). She highlighted that occasionally gender specific symptoms were included as well as statements that flag up the likely gender balance of the disorder. For example, within ICD10 anorexia nervosa is highlighted as a disorder more likely found in women.

Laurence & Weinhouse (1994) argue that sex role stereotypes are still found in the main diagnostic criteria for psychiatric illness. Depression is a case in point, because depression is considered more congruent with the female experience, women are more commonly diagnosed as such. However, Russell (1995) acknowledges that there is a move away from the diagnosis of depression as applied primarily to women. She argues that the diagnosis of Premenstrual Syndrome (PMS) may well replace it in the coming years. PMS offers

> the appearance of being quite specific. It is said to apply to a very large percentage of women and it seems perverse to say that the cause is biological. The reality is that it is totally non-specific and has not been shown to be biological (p. 70).

She goes on to warn that, "the promotion of the psychiatric diagnosis of PMS must be seen as a tool in the discipline of women" (p. 71).

Another factor which needs to be highlighted is the way in which criteria are interpreted. Individuals read the diagnostic criteria differently, which creates concern regarding their reliability. Such perceived bias can call into question the validity of the use of such criteria by mental health professionals.

Thompson defines gender as a "fundamental dimension of human experience. revealing an ever-present set of differences between men and women" (p. 37). Until fairly recently, gender issues in the psychiatric literature were rather neglected. Indeed, until the 1970s severe mental illness was portrayed as genderless. However, since then a range of factors have brought about some changes to this situation. These factors include the growth of the women's liberation movement, the impact of the feminist movement, and the move away from traditional female roles. These factors have led to heightened awareness that gender is a significant aspect that requires to be addressed. Here it will be discussed in relation to women with severe mental illness.

Identifying the issues

One group of women who are included in the general population of women, but whose experiences are rarely reflected in the literature, are women with enduring mental illness (Repper et al., 1996; Harlene & Bernhard, 1994). As a specific group, women with enduring mental illness have received little coverage in the literature over the last 30 years.

A factor that must be taken into account when considering mental illness is the definition used. A narrow definition has been favoured for enduring mental illness with a concentration on the diagnosis of schizophrenia (Perkins & Repper, 1996). This has resulted in research which has focused on schizophrenia, with little attention being paid to the broader category of enduring mental illness (Seeman, 1982). Perkins & Repper (1996) stated that this "has been a mistake" (p. 9), arguing that there are many who have enduring mental health problems with different diagnoses. A broader definition would recognise and include the diagnostic groups of manic depression, depression and substance misuse or abuse. The Sainsbury Centre for Mental Health (1998) a leading mental health research unit, reflects this broader perspective with its definition (see page 5).

There has been much discussion and debate over the definition of enduring mental illness (Bachrach, 1985). However, it is recognised that three aspects, namely, diagnosis, duration, and disability are significant. These aspects are inter-related but require to be viewed with caution. As indicated earlier, the research focus on schizophrenia has led to the development and delivery of services for people with schizophrenia. These may not be the most effective for others who are included in an expanded definition. When considering duration, this has traditionally referred to the time an individual spent in hospital. This needs to be expanded to include the length of time people have been involved with community services. However, even this has some difficulties. First, it would still exclude those who have never had contact but who would benefit from service. Secondly, it excludes those who have had contact with services but do not sustain contact. This group may actively avoid contact as a result of previous experience. It has been further suggested that duration should concentrate on the 'duration of the problems' rather on the duration of contact with service (Perkins & Repper, 1996). Disability too, has to be viewed not only as those factors that arise from the primary diagnosis, but also those disabilities that result from social attitudes, stigma, unemployment and poverty.

People with enduring mental illness may have experienced a range of contact with services. For example, individuals may have had repeated brief admissions to hospital over many years, the 'revolving door' syndrome. Others may have spent long periods of time in hospital: they may have been homeless or have had repeated changes of address. Some may have problems with substance abuse or be at risk from self-harm or neglect. Many will have experienced problems since adolescence and as a result may have received care from other agencies such as Social Services.

The Sainsbury Centre for Mental Health recognises the problems of this group to be complex. They include the social, psychological and practical consequences of having a mental illness. Symptoms of mental illness may be intense and frightening, including the experiencing of suicidal ideas. Some people with enduring mental illness may suffer from memories of abuse. Others may not accept the professional's view of their position and may not accept help. In addition, social disabilities may complicate and impact on their lives in other ways. They may be unable to enter the workforce, as a result of societal attitudes, resulting in unemployment. They may be unable to hold down a job for any length of time and they may not take up all their benefits. Children may be looked after by social services, resulting in distress and dislocation for both the parents and the children. Many sufferers may also have physical problems that remain untreated. Generally, poor social functioning may lead to isolated living in the community, where they may be vulnerable to others, this can lead to social exclusion (The Sainsbury Centre for Mental Health, 1998, p. 26).

However, people with severe mental illness are not all the same. This is also true of women with severe mental illness. These women are not a homogenous group. They span a wide range of diagnoses, and life experiences and they require a variety of services and support. The research that has considered these women's specific experiences will now be considered.

Perspectives on women with severe mental illness

Although there is more research related to women, for women with enduring mental illness, it is clear that there is still a paucity of information. It was not until the early 1980s that this group began to receive attention and not until the 1990s that an attempt to address the lack of research was begun. Literature which deals generally with women is included where relevant.

The literature falls into two main categories. First, there is the literature which highlights evidence that women have been discriminated against within mental health services (Test & Berlin, 1981; Carmen, Russo & Miller, 1981; Repper, Perkins, & Owen, 1998; Ritsher, Coursey & Farrell, 1997). Second, there is a body of literature which offers different perspectives on, or proposes alternatives for working with women (Harlene and Bernhard, 1994; Nahmias & Froelich, 1993; Cowan, 1996).

In 1981, two articles were published which reinforced the need for more research. Both articles formed part of special editions focused on women's issues, the first appearing in Professional Psychology and the second in the American Journal of Psychiatry. Both were reviews of relevant literature drawn from a variety of sources.

The first paper, which appeared in Professional Psychology, argued that women with enduring mental illness were considered as almost genderless by clinicians and researchers. It highlighted that even when these groups considered gender their response often followed the stereotypic route, which placed women in traditional roles and contexts. Women were offered treatment options which did not meet their needs but which were seen as being socially appropriate. This often resulted in a simple, wrong response to women's complex problems (Test & Berlin, 1981).

These authors also proposed that women's longevity may mean that they are most disadvantaged and neglected in terms of care over time. They hypothesise that although the homemaker role may offer flexibility, it also offers a high tolerance for unusual behaviour. It is accompanied by a low profile in the community that leads to isolation and possible social exclusion. Nonetheless, there are also disadvantages such as stress, and economic pressures with little reward, which may result in low self-esteem and status. Test & Berlin (1981) also identified that such women may incur serious limitations across a spectrum of areas, including their social, living and work contexts. They argued that little was known of this group in relation to their lives and their experiences as women, mothers, wives, lovers and carers. Their sexuality, sexual health, exploitation and abuse were rarely discussed. Test and Berlin called for 'responsible' research to explore the many facets of these women's lives, to advance the understanding of their experiences and to create appropriate services.

The same year saw the second of the review articles published, in this case by the American Journal of Psychiatry (AJP). Carmen, Miller and Russo (1981) explicitly discussed inequality and women's mental health. Although not specifically geared to women with enduring mental illness, many of the issues discussed are relevant. The authors strongly present the case that mental health workers need to address the social institutions which affect women with mental health problems. Some of the inequalities which women face, they argue, are increased by women's participation in the workforce, pay issues, types of occupations and financial issues. They re-iterate Test and Berlin's call for more research in relation to women with enduring mental illness.

In another review article for a special issue of Hospital and Community Psychiatry, the position of women with enduring mental illness is explored against the background of increasing interest in women's health and mental health (Bachrach, 1985). She highlights that these women need special attention and that in the past they have been reduced to general statements and therefore 'desexed' or made genderless. As the author puts it,

> Heightened awareness of - and responsiveness to - women's gender specific treatment needs requires more than knowledge of objective circumstances; it requires social endorsement as well (p. 1064).

Bachrach acknowledges that some of the endorsement has come for the women's movement. She further identifies those areas which should be included when planning for this specific group: homelessness, skills training, family planning and social networks. She, too, supports Test and Berlin's view that gender stereotyping results in lower expectations for woman than for men, and therefore reduced opportunities for women. Later, Bachrach & Nadelson (1988) re-iterate this point, describing how services for women are based on lower performance expectations.

The above literature is all from an American perspective. It was not until 1991 that the UK literature begins to discuss some of these issues in another special edition, this time of the British Journal of Psychiatry. One of the articles in this special supplement highlighted issues for women in the development of mental health services (Subotsky, 1991). She described how in Camberwell, London, there have developed services that follow a woman's cycle approach. She discusses the need to listen to the patient's experience and the importance of the role of the consumer, both as a patient and a carer. She adds a note of caution when she points out that 'these women-orientated services may not automatically follow, unless specifically fostered' (p. 21). She could be arguing for the social endorsement (as called for by Bachrach) to make changes to mental health services for women, as well as arguing for changes in how women and mental illness are viewed.

The question of women and mental health begins to surface in other professions other than psychiatry and psychology throughout the 1990s. From a UK nursing perspective, Faugier (1992) notes that while it may not be fashionable, and may not wish to be acknowledged by service providers and developers, there is a substantial body of evidence which points to the many differences between the mental health of men and that of women. The majority of mental health problems excluding schizophrenia and addictions are more commonly diagnosed in women. The author also criticises psychiatry for ignoring the differences in the rates of mental illness between the sexes and for tending to adhere to a gender-neutral view of mental illness. Faugier further argues that we need to attempt to understand and analyse the nature of such differences. She is critical of nursing as a profession for not doing enough to address gender issues. She highlights the need for the education of all health professionals, not only nurses, and for this education to place gender issues centrally in our work and our curricula. The Health Department of the Commonwealth Secretariat has recently endorsed this view of incorporating gender and health issues into health professional education (Harding & Sills, 1999).

It was not until 1993 that occupational therapy addressed the question of women and mental health, again in a review article. Nahmias and Froelich (1993), American occupational therapists, focus on gender role stereotypes and the implications of these for occupational therapists. They argue that it is essential that occupational therapists fully understand social cultural contexts and the theories specific to women's psychological development. They draw heavily on some of the articles above, acknowledging that "gender-related issues are virtually absent in the occupational therapy literature" (p. 40). These authors advocate an essentially feminist approach to enhance interventions. They consider occupational therapy, as a profession, to have been slow to respond to the changing climate. Insofar as this is the case, they call for occupational therapists to explore their attitudes and beliefs and how these translate into ways of knowing and working with women. Interestingly, this paper has recently been included in a mental health journal for British occupational therapists, perhaps re-emphasising the notion that occupational therapy has been slow to integrate these concepts both in their practice and education.

An article from an American nursing viewpoint offers a feminist perspective of the literature regarding women with enduring mental illness (Harlene & Bernhard, 1994). The authors confirm the voicelessness of these women, stating that the limited information about them narrows our thinking and that as a result there is not only missing knowledge but also a range of distortions. They assert that three factors dominate the situation. First, women are regarded as 'other' in a male-normed society. Second, enduring mental illness is viewed differently from physical illness. Lastly, healthcare personnel are educated in the dichotomy of mind and body split. The authors argue that these factors affect both the healthcare of women with enduring mental illness and their status as a population at risk. They reviewed the existing literature, much of which has been discussed previously, using five categories:

1. The genderless phenomenon - healthcare issues were identified but gender not included.
2. Healthcare for women focused on reproductive health.
3. Women's health perspectives do not include serious mental illness as an illness which affects women.
4. The bodiless phenomenon - issues for the mentally ill that do not include healthcare.
5. Writings that include a holistic view of health and a feminist perspective.

They conclude that feminist literature on health and mental health has avoided severe mental illness. They further suggest that the literature concentrates on issues relevant to white, educated and middle class women, such as career, relationships and topics which have previously received little attention, for example cancer. A third aspect of this literature is the abuse of women, including battering, rape and the overprescribing of drugs. The authors found that schizophrenia and bipolar disorders were not mentioned, whereas depression was consistently identified. They conclude that risks for women with enduring mental illness can be described as behaviour patterns, psychiatric disorders, accessibility and invisibility. They assert that "invisibility enhances vulnerability" (p. 83). The invisibility of these women is increased by the gap in the research literature that has failed to include the standpoint of women with severe mental illness. Finally, they advocate that the valuing and validating of personal experience is an aspect of quality feminist work "women's lived experience should be the starting point for all health efforts" (p. 85).

Another view of the field of women's mental health issues was presented from a Canadian perspective by Cowan (1996). She presented a psychiatric timeline, asserting that over several eras there has been a predominant way of viewing women. She draws on Showalter's The Female Malady (1987) which discusses the era of psychiatric Victorianism. Here women were seen as being more vulnerable because of the inherent instability that supposedly was linked to their reproductive organs. This belief held women in subordinate positions for generations, and acted as a barrier to professional and political aspirations. It kept them firmly in the control of the male whether in the family or in the workplace. At the same time, male behaviours were seen as the norm and therefore women who did not fit the societal view were seen as 'other'.

This debate was heightened during the era of psychiatric Darwinism when biological determinism was the main feature. During this period it was believed that women attempting to move beyond their narrowly defined roles would succumb to mental illness. The period of psychiatric modernism 1920-1970 was dominated by Freudian ideology. Although Freud, initially had recognised that women's place in society might well be a reason for mental illness, this was quickly forgotten in an attempt to get his theories more widely accepted in what was a highly male dominated arena (Showalter, 1987). These theories, it could be argued have continued to have a negative impact on the status of women. Cowan argues that it is only over the past two decades that women's mental health has been brought into the wider societal context. She advocates a woman-centred therapeutic approach but adds that deep-seated bias and oppressive ways of working have to be acknowledged and changed.

She supports Faugier in calling for staff to address these issues both in their practice and in their education.

This call for these issues to be addressed in both practice and education has been supported by various campaigns from the early 1990s onwards. The MIND (1992) policy paper expressed the belief that "women's experience in society, from birth until old age, generally exposes them to greater stress than men" (p. 7). MIND advocated that the way forward lies in providing women with the service options they wish including choice of woman-only space, women workers, adequate childcare and the chance to explore the causes of their distress. The policy document emphasised the need for training in gender and race issues. These calls have been supported by other organisations and professions: see, for example Good Practices in Mental Health (GPMH) (1994) and the Royal College of Nursing (RCN) (1994).

It has been shown that the literature highlights several major themes in relation to women and mental illness. These include the reliability of diagnostic criteria, the lack of gender recognition, limited and stereotypic treatment opportunities, raising awareness of the needs of women with mental illness, increased sensitivity to meet women's needs and the application of feminist thinking in practitioners' ways of working. However, the literature acknowledges the lack of relevant research.

The research perspective

In an attempt to bridge the identified gap in knowledge three major studies have been found that deal specifically with women and severe mental illness: one is American (Ritsher et al., 1997) and two are British (Repper, Perkins & Owen, 1998; Owen et al., 1998).

The American study was the first to take up the challenge to compensate for the limited research literature. This study conducted in Maryland involved a sample of 107 women and 59 men completing a 76-item questionnaire which aimed to explore the issues in living with severe mental illness (Ritsher et al., 1997). The authors developed the questionnaire on the basis of their work with three focus groups, two of them consisting of women with severe mental illness and the third made up of mental health practitioners. The sample population reflected a range of environments: urban, suburban and rural psychiatric rehabilitation centres. It is not clear whether all attendees at these centres were asked to be included or how, if any, attempts were made to refine the sample.

The study set out to address three main areas: issues arising from living with severe mental illness; interpersonal relationships; and relationships with healthcare providers. In addressing living with severe mental illness, the researchers examined whether men and women gave different explanations for their symptoms. They also explored how living with severe mental illness affected women's sense of themselves and their satisfaction with their life. A further aspect centred on their formative experiences and their current goals. Under the heading of 'Interpersonal relationships,' the four main areas included were; friendships and social supports, abuse, romantic and sexual relationships and parenting. The final heading investigated professional relationships and aspects of physical health care.

The results demonstrated that more women were diagnosed as having affective disorders, whereas men were more likely to have schizophrenia. There was a significant difference in the distribution of these two types of illness, as has been noticed before. The woman in the sample were on the whole slightly older and similarly their onset of illness was later than for men. Women viewed their illness in several ways, with one third of the sample believing that they did not have a mental illness. A significant proportion described their problems in terms that matched their diagnosis. When asked about the causes of their problems, women more than men cited "bad things in the past" or "the result of the way I was raised". Only one third attributed their problems to a chemical imbalance in the brain.

When addressing the impact of the illness on their lives, most women reported being moderately affected. About half of both men and women felt that the illness had forced them to give up or change life goals, such as jobs, college or having children. With regards to everyday concerns, respondents were asked to state in their own words the issues that most frequently occupied their minds. Three categories emerged: the idea of "normal", the notion of "ever getting better" and a third category related to "life within the mental health system". In addition, practical issues were significantly higher for women than for men.

With regard to personal relationships and support, women were much more likely to say they had a best friend, a mutual relationship or a pet. More women had pets than did men. Regarding membership of organisations, about half of both groups attended church. Men were more likely to attend self-help groups, and more men had involvement with clubs than women. Women were more likely to say that helping others was important to them. However, both groups agreed that helping others made them feel good.

In the area of romantic and sexual relationships, women were more likely than men to report having a partner. Fifty-five per cent of the sexually active women reported that they used birth control. One third of both men and women reported that their mental health medication impaired their sex life in some way. Being gay in this population was identified as a source of alienation. Of the nineteen percent of women who identified themselves as lesbian or bisexual, seventy-nine per cent felt unable to confide in anyone about issues related to sexuality.

With regard to parenting, women were more likely to have had at least one child. Eighty-two percent of the mothers reported that they were able to raise or help raise at least one of their children. Twenty-nine per cent of the women and eleven per cent of the men identified that the illness had made it harder for them to be good parents. Women in this study reported widespread abuse of many kinds, including physical abuse; the most common abusers were parents. More than half the women reported at least one incident of sexual abuse; this was significantly lower in the male group. Nineteen per cent of the women reported sexual abuse by a parent or relative with only two per cent of men reporting abuse.

Responding to questions about their physical health, about a third of the women reported not receiving regular breast or pelvic exams, birth control care or menopause care. Psychotropic medication was an important factor in relation to pregnancy. More than half of the women reported that if they fell pregnant they would have to stop taking medication and as a result might relapse. Similarly, the same number were worried that the medication might affect the child before birth or during breast-feeding.

An issue raised by the focus group in devising the questionnaire was that physicians did not take the mental health users' complaints seriously. However, this was not supported by resulting survey. Responding to questions about their relationships with healthcare providers, the majority of women indicated that staff members made them feel respected and that they had good relationships with staff.

In an attempt to tease out the effects of gender, the researchers established matched sub-samples on the basis of age, diagnosis, race, education and employment, and repeated the analysis. No major differences were reported. The researchers suggested that the findings were due to gender effects rather than diagnosis or marital status. Noting that women tended to refer to formative experiences before the onset of illness, they suggested that this supports the notion of "a gender-specific socialisation process operating on this population" (p. 1280).

This important study concluded that for women with severe mental illness, "the illness is not the center of these women's identities" (p. 1280). Although most women felt that the illness had adversely impacted on their lives the survey did not explore whether this was caused by the illness or secondary consequences. The findings highlighted the importance of relationships and social supports for women: most women managed to maintain some mutual relationships, in spite of their severe mental illness. The amount of abuse identified should alert clinicians to ask for this routinely in assessment of new clients. Overall, the authors concluded that women's experience of living with severe mental illness is considerably different from that of men.

The questionnaire and survey method adopted for this work, although useful in accessing the experience of relatively large numbers of subjects, loses the individual's unique perspective. The use of a multiple-choice questionnaire may result in people selecting the nearest option, as their own perspective is not represented, thereby affecting the reliability of the responses.

The above study illustrates that severe mental illness can be seen as complex with many effects on the lives of the women, each of whom has unique experiences, abilities, disabilities and specific needs. It expands the existing literature (Test, 1981; Bachrach & Nadelson, 1988).

A recent British study also placed women with severe mental illness at its core (Repper et al., 1996). This study used feminist methodology to explore the experiences of women, to build a framework for understanding the sex differences and to generate findings, which would be beneficial for women. The aim of the study was to investigate the acceptability and adequacy of mental health services for women with serious and ongoing mental health problems. The study was based in Nottingham, identified in the article, as a useful site as staff were interested in research and had a developed awareness of women's issues. A variety of research methods were used to describe the service and to compare men and women's experiences and views as service users. Methods included in-depth interviews, a questionnaire and focus groups. Two research papers have been published to date which are pertinent to this work (Repper et al., 1998; Owen et al., 1998).

The Owen et al. (1998) study aimed to evaluate the adequacy, accessibility and responsiveness of the services provided for women users. The study compared men and women who used the Nottingham services. Differences found included that there were fewer women (34%) than men in the service (66%). Women were more likely to be divorced or widowed and they were also more likely to have children. Men were more inclined to have a history of violence and to have spent time in prison or in a special hospital. The women tended to be living with a spouse or partner, or to be living alone with children.

Women user's views were sought through the use of focus groups. To gain representation across the service five separate groups were conducted in a range of areas: in total fourteen women took part in these groups. The focus groups aimed to gain an understanding of the impact of serious mental illness on the lives of the women; to explore the aspirations of these women; to discuss their views on the services they experience and to generate suggestions for better meeting their needs. Fourteen women participated in the focus groups (Repper et al., 1998). These group discussions were tape-recorded and transcribed. Analysis of the data revealed two main themes namely: loss and hope.

The findings revealed that women had an overwhelming sense of loss throughout their lives, which had been exacerbated since the onset of their mental illness. These losses were considered under three main headings. 'Loss in present lives' women reported experiencing loss of past relationships, partners, children, independence and work. Second, women included under 'loss as a result of symptoms' their lost ability to cope, their reduced energy, and their lack of control over symptoms and the side effects of medication. The final loss concerned 'opportunities in the mental health services'. Women reported that they had lost meaningful activity, contact with other women, and the ability to have a say in decisions, for example, in the choice of their key worker.

The other major finding, however, was that these women continued to nurture hopes. These were "very ordinary aspirations: they wanted to get married, have friends, a job, a house and something to do with their time" (p. 287). However, they needed help and support for these hopes to be realised.

As for suggestions and recommendations for improving services, the study found that the participants had very low expectations of the services. An important finding was the emergence of a sense of powerlessness on the part of women across all aspects of their lives. As Owen et al. (1998) highlight, "their experiences have been marked by events and relationships which have systematically reduced their independence, choices, dignity, self-respect and ultimately their power" (p. 288). The authors proposed that as this study had 'got close' to the participants, it was in a position to make clear recommendations about how the women's wishes and needs could be met. They suggested that services utilise approaches that increase the actual power of these women. They should be empowered to make choices and be supported in their choices. Mental health workers should bring women together to share their experiences, hopes and possible future actions. Services must work to reduce women's sense of loss and to support their future aspirations.

This study provided valuable information from the focus groups about the women's experiences of mental illness. It is well worth noting that focus group results are not generalised to the population but reflect a specific context. It is unclear if the women were consulted with regards to the final findings. However, they provided a sound baseline for further investigation.

The second study (Repper et al., 1998) utilises the same data but treats it differently, judging that in the data analysis of the first study the women's actual experiences were not reflected. As the authors put it, "by breaking up their stories their impact was lost" (p. 507). They argued that analysis which creates themes and categories, although useful, can reduce the individual to a list of words, which totally decontextualises the woman from her own story.

In an attempt to represent the women's perspectives more completely these authors reconstructed the focus group transcripts to discover that eight of the participants had told their 'life story' in the course of the groups. They reported that through this process similar themes and categories emerged, although they had been placed under different headings. Their stories told of social disadvantages predating their mental health problems, including sexual abuse, divorce and poverty. Loss of children, loss of relationships, loss of home and work and a lack of understanding about what had happened to them were all raised. These themes were consistent features across the narratives. The reconstruction also identified different stories between the older and younger women. Women's hopes and aspirations, as highlighted in the previous work, were tempered with staff attitudes, which did not support them or deemed their wishes unrealistic. This research concluded that the effects of such negativity on women with reduced self-confidence could only be detrimental to their well-being in the long-term.

The range of women's experiences reflecting loss across the social, personal and material spheres echoes the Sainsbury Report (1998). In relation to Ritsher et al. (1997), the women in this study similarly reported experiences that predated their mental health problems. Although some of these, for example, poverty can be the same for men, others were more often considered women's experiences: the lone parent raising children on a low income, sexual abuse and caring for others. There are clear links between adverse childhood experiences and adult disorders (CRAG. 1995).

Women in this study spoke of their significant relationships with staff members; these staff members were always women. The women here wanted to work with other women, whether staff or other service users. They disliked the higher number of men using the services, feeling vulnerable, isolated and lonely. The authors call for initiatives such as women workers and increased women-only treatments to be extended to this population, where men outnumber women.

This study raises one major ethical problem. The women in the study were originally participating in focus groups to address four specific topic areas. However, the authors have used that data to reconstruct life histories. It is acknowledged that the reconstruction is valid, but did the participants understand fully how their contribution would be used, and was their consent sought? Had they been asked to give their life histories, other factors would undoubtedly have been included in their narratives, or indeed they may have refused to take part.

The three studies cited above all found that women experience a range of difficult and tragic circumstances with resulting losses in all aspects of their lives, including control and choices. They further highlighted that their experiences of mental illness and mental health services can be at best neutral and at worst highly negative.

Repper et al. (1998) indicated that the life stories found in this study can be a way to represent the depth and breadth of these women's lives.

The feminist perspective

Feminism underpins much of the above literature. At its simplest it is concerned with women. However, feminism is often not defined and therefore assumptions and misconceptions can easily arise. Beaseley (1999) suggests that the meaning of feminism "is almost invariably assumed or evaded" (p. xi). She argues that the problem with defining feminism is that there many kinds of feminism and that one overarching definition can not capture the range.

Geiger (1986) proposed that feminism could be understood as the theory of women's points of view and she defines "the feminist method as the collective critical reconstitution of the meaning of women's social experience, as women live through it" (p. 335). This definition is a useful starting point. It places women centre stage and it individualises women's experience, recognising it to be unique to them. Women are diverse and their experiences are contextually bound. This acknowledging of difference, together with a move away from universalism continued through the 1990s as women from different backgrounds; working-class, lesbians, black women, women with disabilities and women from the developing world challenged the white, Western middle-class domination of feminist theory and practice (Doyal, 1995). These groups were critical of feminists who prioritised gender over all other social factors, "representing all women as members of the same oppressed group all unified by their experience of male domination and their uniquely female emotionality" (Ibid., p. 4). Doyal argues that the move towards a post-modernist feminist view, which is wary of the dangers of generalisation, is important. So too, is the validation of women's differences in relation to race, class and gender.

It is important to hear many voices and consider many interpretations. Feminist post-modern research facilitates the capturing of these diverse stories against the background of ever-changing cultural and societal contexts (Lyon, 1994; Mauthner, 1998). It has been proposed that the critique and the rejection of the grand narrative of empirical science has opened the way for the occupational therapy profession to revise its position in relation to medicine and its positivist reductionism model (Whiteford, Townsend & Hocking, 2000). Importantly, this shift in thinking both in and beyond occupational therapy has enabled a move to interpretative sciences that recognise power, diversity and contexts.

Feminism is important to this research in several ways. It is research about women by a woman within a Scottish context. The focus of this research is twofold. First, it explores the lives of Scottish women with enduring mental illness. Breitenbach, Brown & Myers (1998) judge that "there is a lack of research and serious study of the experience of women in Scotland, either in general or of the experience of particular groups of women"(p. 49). They go on to argue, "women may experience an added level of discrimination because of their age, class, race, disability, sexuality or religion and are further disadvantaged" (p. 59). Women and their discrimination by psychiatry has been at the forefront of debate (Chesler, 1972; Showalter, 1987; Ussher, 1991). The second strand of the research focuses on women occupational therapists, working with women in a Scottish mental health context.

Occupational therapy is a predominantly female profession (Yates, 1996). In 1998, Brown reported that men formed around 5% of the British Association of Occupational Therapists register. However, Creek (1998) reminds us that occupational therapists in the UK, whether in clinical or academic settings, "work in masculine environments"(p. 136). Hamlin et al. (1992) highlighted a lack of feminist occupational therapy literature. They proposed that this indicated an uneasiness with feminism that may be due to negative stereotypes. Historically, occupational therapy, like nursing, grew out of and developed its modern forms in "the patriarchal society of the 19th century" (Primeau, 1996, p. 64). Yet, nursing, and for that matter, social work have both addressed feminism earlier in their development, than occupational therapy. This may be because occupational therapy as a profession has traditionally had more autonomy than nursing, therefore nursing has had to challenge the medical profession's status and feminism offered a way to review their position. Similarly, it could be considered in the case of social work that social and cultural issues have driven the profession: leading to its early engagement with feminist thinking in both its practice and theory. An alternative suggestion may be the class composition of occupational therapy in the USA and UK, which until recently was mainly women from the middle and upper classes and therefore feminist issues were omitted or not perceived as a priority (Frank, 1992).

As will be discussed later, a male psychiatrist is credited with the foundation of occupational therapy. From their earliest days, occupational therapists were directed in their work environments by men. Within these environments, two aspects require to be considered. The first concerns communication within largely masculine organisations and the gendered nature of language. The second concerns women, working with women.

Language shapes our interpretations of the world we live in. Feminist theory maintains that language itself is male-defined (Franklin, 1985, p.2). Male communication styles are viewed as the norm and women's style as subordinate. For occupational therapists who work in multi-disciplinary teams, often led by a male consultant, this may mean that their voice is not heard. Furthermore, they may come to believe that their voice is not valued in these team settings. Fear of being scapegoated was a reason given by occupational therapists and others for their reluctance to share their professional opinions, according to recent research exploring the workings of multi-disciplinary teams (Atwal, 1999).

In considering women working with women, as highlighted above, feminist perspectives of health care delivery have not been at the forefront of thinking for occupational therapy. It could be argued that as the profession places the individual as its focus through the concept of client-centred practice, issues such as gender, race and class are implicitly factored into their treatment interventions. That said, this makes these factors less visible in practice contexts. Furthermore, if we look to the nursing profession, a debate about feminist principles impacting on practice and education is taking place in their professional journals and in their professional body. The same cannot be said for occupational therapy (Pollard & Walsh, 2000).

Although this is not evident in occupational therapy literature, feminism has a long history. It has had several rebirths, the most recently from the 1960s onwards in Britain and America (Lewin & Olsen, 1985). Feminism has emphasised particular areas of concern including women as full equal participants in society. A change, however, was the concern for women as recipients of health care and their work as providers within health care settings. This change is particularly evident in nursing literature (Gary, 1998; Henderson, 1998). This field has continued to grow and its influences are still evolving in these spheres. It does appear that in occupational therapy literature there is some growing recognition and debate, if perhaps not yet consistently, in any mainstream forum. For occupational therapists, a feminist perspective facilitates a questioning of women's traditional roles and an examination of occupational therapy practice. Occupational therapy's development as a profession will now be briefly considered.

Section Two: The development of occupational therapy in the United Kingdom

This section of the literature review will consider the growth of occupational therapy and its unique relationship with the early development of psychiatry. It will briefly examine the parallel historical development of both psychiatry and occupational therapy in the United Kingdom. It will also demonstrate that occupational therapy's development in Scotland, and the UK was significantly influenced by American and Canadian ideals. It will conclude by examining contemporary occupational therapy theory and research.

In Britain, from medieval times until the 18th century, mentally ill people relied on the charity of the church. In the 18th century, the affluent mentally ill could be looked after in a variety of ways, "in the homes of physicians or clergymen, or they could be confined to private madhouses" (Hume & Pullen, 1986, p. 3). However, for the poor, these choices were not available. It was not until the latter half of the 18th century and throughout the 19th, that changes began to take place in the psychiatric field.

At this time, Busfield asserts that "value was placed on reason, and unreason in all its forms - madness, crime and poverty was banished in a great confinement" (1996, p. 70). As a result, from the 1760s onwards institutions such as workhouses, prisons and hospitals were purpose-built, but few hospitals were opened for the mentally ill. The eventual overcrowding and abuse of these individuals led to the first legislation for the mentally ill in 1774 (Hume & Pullen, 1986). The mad, it was felt, needed to be cared for in special places. The result was the creation of the asylums: this was to be the mainstay of managing the mentally ill. This legislation introduced "certification, no person could be detained without the signature of a physician, a surgeon or an apothecary" (p. 5). In the field of mental illness, this resulted in the power of the medical profession, a male domain, being enshrined in law.

The impact of moral treatment

The emerging philosophy of this time was influenced by moral treatment; this approach to the mentally ill drew on the humanistic principles of the age of enlightenment. It proposed that 'all men were made equal and governed by universal laws"(Kielhofner, 1983, p. 11). There was an emphasis on the humanity of individuals and the importance of the arts to humanity. Moral treatment led Philippe Pinel to introduce work to the Bicetre Asylum for the Insane, Paris. He prescribed physical exercise and manual occupations, with the aim of the reducing the use of external physical coercion. This regime led to the freeing of inmates from their restraints in 1793. His reforms were widely recognised and followed across Europe and North America (Paterson, 1997).

In the United Kingdom, William and Samuel Tuke, Quakers, founded and developed the York Retreat, a private hospital based on moral treatment. Tuke believed that by treating the individual as rational, one could re-educate the patient. Re-education was hoped for, by structuring the environment physically, socially and temporally. Engagement in normal daily activities, work-related activities and play created a total daily programme of organised occupations which minimised the disorganised behaviour of the mentally ill. Occupation as therapy was created, the forerunner of occupational therapy (Wilcock, 2001a).

Although, Pinel and the Tukes were held in esteem as the liberators of the mentally ill there are some dissenters, notably Foucault (1967), the French philosopher, who argued that the constraints of the new moral treatment were just as tight as the chains that had held the people before.

Nonetheless, there was a growing emphasis in the 19th century on the use of occupations concentrated within the mental health field (Paterson, 1997). Examples exist from a variety of locations in Scotland. At the Montrose Asylum and later at the Crichton Institution, Dr W. A. F. Browne, was the "foremost of the moral psychiatrists in Scotland" (Paterson, 1997, p. 181). He understood the role of motivation in the therapeutic use of occupation. Moral treatment was seen to be a success.

The early proponents of moral treatment in the United States of America were also psychiatrists. They include in their number Rush, Dutton and Meyer, all of whom played a significant role in the formation of the profession of occupational therapy (Hopkins & Smith, 1993). Benjamin Rush, considered to be the father of American psychiatry, was the first to use the concepts of moral treatment and occupation. He, like the Tukes, was a Quaker. Towards the end of the century Meyer re-iterated the importance of occupation and treatment. His work has had a significant impact on the development of the philosophy of occupational therapy in the USA (Meyer, 1997). He would later employ Eleanor Clarke Slagle as the Director of Occupational Therapy at his hospital. She set up the first professional school for occupational therapists in Chicago in 1915.

Rush's nephew, William Rush Dutton, another psychiatrist, also advocated the use of occupations. In 1911, he conducted a series of classes on the use of recreation and occupation for nurses at his hospital. In 1915, Dutton published the first complete text on occupational therapy. He later became editor of the *Archives of Occupational Therapy* that eventually became the *American Journal of Occupational Therapy* in 1947.

At the start of the 20th century in the UK, asylum standards had fallen, as staff shortages and overcrowding grew and maltreatment persisted. Moral treatment could not be sustained against this background, with the result that most asylums provided only custodial care (Paterson, 1997). However, work activities were still used with patients but more for the maintenance of the institution rather than for the benefit of the mentally ill. Exploitation was rife. Notwithstanding, some smaller institutions did manage to continue to provide treatment regimes which held true to the value of occupation, both for the individual's own productivity and for their personal satisfaction (Jackson, 1993). What is clear is that the reforming moral psychiatrists shared with the new profession of occupational therapy a belief in the efficacy of meaningful occupation as useful treatment in psychiatry. However, other world events also influenced the development of the profession.

20th Century Developments

A significant factor in the development of occupational therapy was the First World War. This saw rehabilitation centres set up throughout the UK to treat both physically and mentally injured soldiers, through the use of occupation. Following the war, occupation was introduced into the (then) modern psychiatric hospital of Gartnavel Royal Mental Hospital, which opened in Glasgow in 1919. Dr D. K. Henderson headed this hospital. In 1924, he presented a paper on occupational therapy to a meeting of the Royal Medico-Psychological Society of Mental Science. Dr Elizabeth Casson, the first woman doctor to graduate from Bristol University, heard him speak. She specialised in psychiatry and this meeting prompted her to visit the USA and to introduce occupational therapy to her psychiatric nursing home, Dorset House. She later sponsored the education of Constance Tebbit at the

Philadelphia School of Occupational Therapy. Tebbit with Casson in 1930 founded Dorset House, the first occupational therapy school in the UK (Creek, 1990, p. 10). Elizabeth Casson today still influences contemporary occupational therapy through the provision of her trust fund, which supports education for occupational therapists and the Casson Lecture, which is the keynote address of the College of Occupational Therapists' annual conference.

Other factors were also impacting on the mental health field in 1920s. A Royal Commission (1924-26) recommended that a special officer be appointed to each psychiatric hospital to direct patients' activities. In 1925, the first trained occupational therapist, Margaret Fulton, was employed at the Royal Cornhill Hospital, Aberdeen, Scotland. She, too, had been educated in Philadelphia, America. In Scotland, the first school at the Astley Ainslie Hospital in Edinburgh was staffed by Canadian occupational therapists. In 1932, a group of eleven Scottish occupational therapists, mostly from psychiatric hospitals, formed the Scottish Association of Occupational Therapists. This became the first professional association in the UK. The influence of moral treatment, the growth of psychiatry as a medical specialism, and both American and Canadian ideals have all influenced occupational therapy and these aspects cannot be understated when reviewing the profession's development in Scotland and the UK (Schemm, 1993).

There are many milestones in the development of psychiatric care from the 1930s onwards, including legislation, the founding of the National Health Service (1948), the development of new drug treatments – especially major tranquillisers, and the move towards community care (Paterson, 1998). Barton (1959) and Goffman (1961) added considerable weight to the demand for community based services. Their work highlighted the dehumanising ways in which patients were treated in institutions, resulting in dependent and passive individuals.

Mental health legislation and policy documents, for example the Mental Treatment Act (1930), Hospital Services for the Mentally Ill (1971), the Mental Health Act (1983), and Caring for People(1989a), show how consecutive Governments aimed to improve mental health services. Most recently, governments, have reinforced the refocusing of care to the community. The NHS Plan (DH, 2000), the National Service Framework (NSF) for Mental Health (DH, 1999), and the Scottish equivalent the Framework for Mental Health Services (The Scottish Office, 1997), all advocate the further development of community care. Integration of health and social care agencies to provide effective care for people with enduring mental illness is embedded in these policies. Feaver (2000) stresses that to meet the aims of the NSF there must be a drive towards collaborative continued professional development.

The combined effects of these external factors have had a lasting impact on the shape of occupational therapy. Occupational therapists continue to work with individuals with a range of mental health problems and in many contexts. The closure of hospitals and the reduction in bed numbers has resulted in many individuals with enduring mental health problems living in the community. A range of work areas and employers has emerged from these changes. Some therapists work in in-patient areas, some bridge the gap between hospital and community and others work solely in the - community. Some are employed by the NHS, others by the Social Services and still others by non-statutory organisations.

Internal pressures within the profession have also contributed to changing practice. The 1960s and 1970s saw the influence of a range of theories impacting on occupational therapy practice in mental health, including analytical psychotherapy, behaviourism and cognitive theories (Kielhofner, 1983). The profession was in a time of crisis. The integration of such theories led to the loss of professional confidence and commitment to occupation. Reitz (1992) found that occupational therapy abandoned its earlier philosophy of occupation and health. Therapists had lost their appreciation of the importance of occupation and its significance to human life (Kielhofner, 1983; Whiteford, 2000).

These pressures were experienced not only in the United Kingdom but also in North America, and Australia. The profession identified a growing need among therapists for a unifying concept. In the 1980s the refocus on humans as occupational beings with occupation and occupational performance being identified as core concepts of the profession led to the development of practice models: for example, Reed & Sanderson (1980), Model of Human Occupation, (Kielhofner, 1985), The Canadian Model of Occupational Performance (CAOT, 1997). These models have strengthened therapists' belief in their profession. They have enabled most therapists to find the words to describe the complexity of the person-environment-occupation relationship.

Occupational therapy in mental health is still significant, with approximately one third of therapists being employed within this area in the UK (Walker and Lynham, 1999). However, there is an ongoing debate about the uniqueness of occupational therapy and its specific contribution within mental health. In an attempt to address these issues the College of Occupational Therapists established a Mental Health Project Working Group to produce a position paper on the way ahead for research, education and practice in mental health. It identified little research literature relating to the practice and management of occupational therapy in mental health (Craik, 1998; Craik, Austin & Schell, 1999). As a result, two surveys were undertaken to profil practitioners and managers working in mental health.

The first survey, by Craik, Chacksfield & Richards (1998), explored the views of practitioners. This work identified that issues existed around role definition, the need for a unifying theory and research, and the value of the profession. Nevertheless, the respondents were committed and enthusiastic about occupational therapy in mental health. Although few of the respondents had no direct involvement in research, most were aware of the need for research and evidence-based practice. The second survey examined occupational therapy managers in mental health. It revealed that the majority of mangers were female. In the main, similar findings to the practitioners' survey were found. These findings included the need for clarification of the core skills, roles and approaches of occupational therapists (Craik et al., 1999).

Building on the work by Craik et al., (1999), Fowler-Davis & Bannigan (2000) explored the priorities for mental health research. They identified the three areas most needing research to be occupation, groupwork and occupational performance skills. They further identified the core skills of the profession; professional status, effectiveness issues and finally, client-centredness were all worthy of further research. The message of these surveys was clear: occupational therapists were still questioning their contribution and their status within mental health services.

Duncan (1999) emphasises that one way to silence the continued call for clarification of the profession's contribution is for research into the efficacy of occupational therapy and occupation. Wilcock (1999) takes this further advocating for research and intervention at policy and population levels focusing on enabling occupation, health and well-being. Whatever form the research takes it requires to involve service users in its development, implementation and evaluation. Only such collaborative research can create a firm evidence base for occupational therapy to provide effective services to its users in both health and social care settings.

Recently, there has been some movement towards bridging the research gap in British mental health practice. Work has been conducted across a range of topics, including:

- The role of primary care in meeting the needs of people with enduring mental health problems (Cook, 1997).
- The quality of life priorities for people with enduring mental health problems (Mayers, 2000).
- Support groups for people who have experienced psychosis (Hyde, 2001).
- Clinical effectiveness and the Canadian Occupational Performance Measure (Chesworth et al., 2002).

This work is to be welcomed; it certainly adds to the knowledge base of the profession. However, none of this work addresses the mental health user's perspectives of the meanings they ascribe to their occupations and their life.

Most recently, occupational science has been developed as an academic discipline to generate knowledge about the form, function and meaning of human occupation. (Zemke & Clarke, 1996). Occupational science is a multi-professional discipline, initially developed at the University of Southern California. It built on the work of Meyer, Riley, Ayres and others and the ideas put forward have generated worldwide interest and research (Yerxa et al., 1989). It is argued that occupational therapy's unique contribution to health lies in the relationship between health and occupation (Wilcock, 1998a). Wilcock and others have argued that there is a human biological need for occupation (Wilcock, 1993; Wood, 1998b)

Wilcock (1998a) stressed that occupational therapy has latterly concentrated on ill health and that the profession has negated the potential of occupation to influence the public health agenda. She has worked to explore the public health perspective, in the process repositioning occupational therapy beyond its traditional health and social care borders. Occupational science as a theory has offered occupational therapists' new ways of thinking and new ideas to consider to broaden the profession's horizon (Wilcock, 2001a).

Occupational science proposes that individuals should be studied in their interactions with their occupations and environment in everyday situations (Yerxa et al., 1989). It draws upon a multi-professional background and recognises the need for a diversity of research methods that enable the illumination of our understanding of how people ascribe meaning to occupation and their lives. Methods to achieve these aims embrace the use of qualitative methods including narrative inquiry to access and present diverse accounts (Frank, 1996; Polkinghorne, 1995). These methods are consistent with the central tenets of post modernism, with its emphasis on diverse perspectives, situatedness, temporality and contexts.

Several authors in the UK have responded to the call for research exploring the relationship between health and engagement in occupation with users of mental health services (Mee & Sumsion, 2001; Chugg & Craik, 2002; Fieldhouse, 2001)

The first study considers the value of occupation from the perspective of people with enduring mental illness (Mee & Sumsion, 2001). This qualitative study utilised semi-structured interviews with six users of mental health day settings: a workshop and a drop-in facility. Four women and two men were interviewed. Participant observation within both the settings was also undertaken to increase the researchers' understanding of each of the environments and their specific cultures. The resulting data was analysed using categories and systematic coding strategies.

Three main themes emerged "generating motivation, building competence, developing self-identity" (p.124). Engagement in occupation, defined by Wilcock (1998a) as "all purposeful human activity" (p. 22), was identified as a means for increasing intrinsic motivation through reinforcing an individual's sense of purpose and by organising their time. Environmental factors were also identified as being important. The participants highlighted the importance of a welcoming and sociable atmosphere, one that was free from pressure and facilitated people making their own decisions. The second theme, building competence, described what the participants gained through occupation; they acquired skills, learned to cope with challenge and had opportunities to experience success. The final theme, developing self-identity, provided evidence of the respondents' creativity through occupation they felt useful leading to increased self-esteem and an improved sense of self. Although a small study it makes a valuable contribution through revealing the participants' experiences and offers occupational therapists advice on developing supportive and safe environments that allow people to make their own choices, and importantly enabling them to take control. Gender differences were not to the fore.

In a similar vein, Chugg & Craik (2002) explored the influences on occupational engagement for people with a diagnosis of schizophrenia living in the community. Eight participants, four women and four men, took part in the study via semi-structured interviews. Four main themes were identified: health, routines, external factors and internal factors. In relation to health, the results highlighted that the participants were able to describe the influence of either their mental or physical health on their occupational engagement. They felt restricted in what they were able to do and found that factors such as medication and its side effects impacted on their performance. This study identified factors that may be poorly understood or not consistently addressed by mental health practitioners. In addition the work called for therapists "to allow their clients to tell their own story to build up a picture of the influences on what they do" (p. 72).

Fieldhouse (2001) examined the impact of an allotment group on the lives of people with enduring mental illness. Qualitative methods using semi-structured interviews and a focus group were undertaken with participants who were actively attending the group or who had attended the group previously. He found that the participants described a sense of meaningfulness related to the dimensions of the environment, the social milieu and the occupational form, horticulture. The inter-relationship of these three factors seemed to underpin the participants' enhanced performance in goal-setting and social networking. The positive aspect of "doing with being" experiences increased the clients' sense of self and their skill acquisition.

These studies show the importance of occupation to people with mental health problems. Although all are based on relatively small samples, they contribute to a growing body of literature that explores the perspectives of mental health users. None of the studies have addressed possible differences between women and men or indeed looked for any gender implications. That said, they do begin to address the significance of occupation to maintaining mental health and they further explore in some depth the meaning that individuals' ascribe to their lives through occupation.

This section has reviewed the development of occupational therapy, examining its close links with psychiatry. It has provided an overview of current theories impacting on the field. It has emphasised the need for a feminist perspective of occupational therapy to be undertaken. Furthermore, it has highlighted the need to address service users' perspectives generally, whilst specifically identifying the need for research to explore women's lives and experiences of enduring mental illness.

Section Three: Narrative inquiry and life history – A means to understand women's worlds.

This section will highlight the use and growth of narrative inquiry as a way of accessing the meaning of an individual's life. It will consider how the written word and the oral tradition have been endowed with different attributes by society. Until fairly recently, the oral tradition, specifically the use of narrative, was deemed to be less valid as a research method although highly valued in some disciplines. Nonetheless, it has also been proposed that narrative is the primary form by which human experience is made meaningful (Polkinghorne, 1988). Narrative will be defined. The case will be put that personal stories or narratives are a valid means to explore and derive meaning of others' experience. Narrative and its uses specifically within occupational therapy practice and research will be discussed. The section will conclude by reviewing those personal narratives that illuminate the lived experience of women with enduring mental illness. To date a few "ordinary" women's stories have reached a public audience. It will be argued that narrative inquiry offers a way for these women's narratives to be heard and the complexity, and the possible meanings of their lives understood.

Writing is an advanced skill in terms of human evolution and development (Jewell, 1999). Most of us talk before we write. The written word for many is often seen as a communication form reserved for formal situations. It is not necessarily the first choice of communication for many people. This shying away from the written form may be a result of several factors and may relate to an individual's past experiences of writing. Some, when faced with a writing task, may be negatively reminded of school and related assessment memories, of feelings of inadequacy, even of actual failure. Many people may have had only limited experience of writing and written tasks since leaving formal education. As a result, expression through writing is acknowledged as an ability, which is highly regarded by particular social groups. As Geiger (1986) reminds us, "the act of writing is class and culture bound" (p. 335). In addition to being a skill, the product of writing is considered to be more accurate, a less subjective record of any given situation. In contrast, the spoken word is deemed to be less reliable, both in the transmission and in the interpretation of the message. The spoken word can be misheard or misrepresented to a greater extent. The speaker and the listener may hear the same message yet interpret it differently: there is more room for ambiguity.

This valuing of the written word is mirrored in the research world. Here, the spoken word has been seen as a less reliable form of depiction. However, in the last few years, there has been a significant growth in the use of narratives, especially oral and life history, as research methods which place the individual narrator and their story centre stage (Huberman, 1995, p. 129). Narrative can be approached from a range of perspectives: sociological and sociolinguistic, psychological, literary study and anthropological. Each of these disciplines focuses on different aspects of narrative, with resulting differences in its use and its analysis (Cortazzi, 1993).

As narrative has a range of meanings, it is necessary to define narrative and to do so from a variety of perspectives. A dictionary definition of narrative is simply "giving an account of any series of occurrences: story-telling" (Kirkpatrick, 1983, p. 841). Polkinghorne (1995) states that narrative has been extended to refer to 'any data that are in the form of natural discourse or speech' (p. 6). The narrative is seen as having a beginning, a middle and an end. It implicitly carries meanings, both for the storyteller and for the listener. The telling of a narrative assumes a narrator and a listener whose different stances affect how the story is told and how the story is heard.

Sarbin (1986), an American psychologist, expands this definition. He states,

> A story is a symbolised account of actions of human beings that has a temporal dimension. The story is held together by recognisable patterns of events called plots. Central to the plot structure are human predicaments and attempted resolutions (p. 3).

Sarbin emphasises the humanness of narratives. It is through narratives that the qualities of humanness are expressed (Goodfellow, 1998). It is considered that human lives are presented in a story form, and the storyteller creates the content, the structure and the purpose of the story. The American sociologist Riessman (1993) proposes that "individuals construct past events and actions in personal narratives to claim identities and construct lives" (p. 2). The narrative becomes the method for an individual to construct, reconstruct and present their lives. Charmaz (1999) reminds us that this is a dynamic process "that the self is always in process and never a static final product" (p. 367). Drawing upon social constructionist theories, Charmaz argued that people make themselves whilst simultaneously being shaped by the society in which they live. Furthermore, people are both active and passive in the construction of their own life histories (Connell, 1987).

Wetherell (1996) considers life history to be "the narratives of an individual life" (p. 300). Such narratives present a person's life, chronologically or topically or both, making sense of it in a social context. As Schempp (1995) states, "the person's life is seen as being lived in a time, place, under particular social circumstances rather than a simple collection of events" (p. 115). The individual's life reflects cultural, societal, personal, and institutional themes.

Importantly, the life history is constructed from a variety of standpoints and it is multi-dimensional. These standpoints include gender, sexuality, race, ethnicity, and class; all contribute to the story but may not be the sole driver of the life plot. The French philosopher, Barthes (1977) believed that as a result there were many stories to be told about individuals and not just one, reflecting the post-modernist view of multiple perspectives and realities. When we view personal narratives, the diversity and differences of each should be observed and the variety of meanings considered. At all costs these narratives should not be reduced to a homogenised tale. The uniqueness of each narrative must be preserved.

To illustrate life history, examples from beyond occupational therapy research are presented. Bloom and Munro (1995) explored the life histories of women teachers who become administrators. Walmsley (1998) and Rolph (1998) explored aspects of life history interviews with people with learning disability.

Bloom and Munro (1995) argue that to undertake feminist life history is to enter into conflicted landscapes. They highlight that women's positions are typically represented as objects rather than subjects of knowledge. They presented the life stories of four women educators who choose to become administrators, thereby entering into a male-dominated and defined environment. Three recurrent themes from these narratives are examined: contradictory gender discourses, resistance to patriarchy and stories of the body.

The first theme, contradictory gender discourses, described how these women experienced their transition from educators to administrators. They found it difficult not only because of "the barriers that kept women out" (p. 102) but also because of their own conflicted feelings about their new position as administrators. The second theme dealt with power and authority and the need for these to be redefined. These four women administrators found themselves in positions of power. Their struggles to be recognised as competent managers without having to silence their female inner voices is discussed. Bloom and Munro highlight that each achieved this in a variety of different ways, depending on themselves as individuals, their particular contexts and their everyday experiences. The final theme explored how these women experienced "the regulation of their bodies as a site of gender identity at work" (p. 107). To succeed in such an environment the women needed to be professional. However, being professional often meant conforming to male norms. The women had to deal with conflicts and tensions, and were constantly reconstructing their meanings and their place in their workplaces.

During the research, the researchers discovered that their own personal interpretations of the women's narratives at times blocked their understanding of the women's positions. They stressed that the subjectivity of the researcher is paramount and this must not be discounted or limited. However, they also recognised that multiple understandings were powerful and affirming, and that these women's conflicts and negotiations within their workplace could have positive results, leading to growth and change.

Life history research offers a way to be open to the conflicts and tensions of the self and the self in the world. Bloom and Munro (1995) pose some important questions for life history researchers. What does it mean to engage in work where there are no fixed meanings? How can authors resist authoritative final interpretations? How can researchers represent the intersubjective process of such collaborative work? Bearing these questions in mind, they advance life history method as a way to reveal the complexity, ambiguity and contradictions of lived experience which can interrupt the commonly held story.

Walmsley (1997) employed life history methodology with people with learning disabilities living in the UK. Her work, too, raises important issues. The aim of the research was "to discover what experiences people with learning disabilities have and have had of caring and being cared for" (p. 126). Twenty-two people were involved in the study. All interviews were recorded and transcribed. Walmsley identified several considerations in using life history with individuals with learning disability. These included explaining the research, power and involvement in the interview, the interview process and, finally, negotiating meanings.

Her first difficulty concerned identifying participants for the study and explaining the research. As she worked through intermediaries with varying understandings of the project, problems arose. Her use of an information sheet also raised issues: it seemed to place power with the researcher rather than with the researched. Walmsley acknowledged that tension existed as to how well the potential participants understood the notion of consent and what their involvement in the study meant to them.

In developing a rapport and relationship with the participants, Walmsley identified the need for time to build trust. A further issue was the involvement of others at the request and choice of the interviewees. Power is an aspect that raised more questions. Interviewees, she explained, did exert power in small ways. One example was asking for tape recorders to be switched off and on.

The third issue was the reliance on the spoken word implied by life history methods. For individuals with a learning disability who may have both reduced verbal and reading skills, a different approach to eliciting the life history was required. To overcome reliance on the spoken word an illustrated prompt sheet was developed. Data was collected using this prompt sheet; this formed the basis for the first interview, providing a loose structure for the interview.

The first level of analysis identified key points in the individual's biography. For this study, these were developed into a pictorial "life map." A second level of analysis identified the individual's social networks. Again these were pictorially represented. Some degree of reciprocity was indicated, using arrows between the participant and the elements of their social network. The data analysis is not clearly defined although it does follow the traditional route of chronological details and identification of themes, in this case related to social networks. What is not clear is how the final life histories were utilised. For example, did they stand alone? Or were they then compared and contrasted across the stories?

Both the "life map" and the "network diagram" formed a basis for the follow-up interview. The interviewer attempted to identify any omissions, ambiguities or contradictions. Clarification was sought and any corrections to the data were made. The onus was very much on the researcher to make her explanations understandable for the participants. Walmsley asked participants to bring photographs to the second interview as these proved a positive way of supporting the data previously gathered. A brief life story was presented to each participant as a means of closure, at the end of the process.

The final aspect considered how meaning was negotiated. Walmsley recognised the importance of leaving the "ownership of the research with the participants" (p. 136). This is often achieved by giving a draft report to participants and asking for comments on its validity. However, Walmsley opted not to do this although she did leave a tape with each individual. She argued that individuals can only comment on their co-authored own account, and that the overall, the final story must be held by the researcher. Co-authorship therefore cannot be easily developed with participants who, although they may share a common interest, do not form a close physical community.

Walmsley's work makes a useful contribution beyond learning disability. She rightly identified that while interviewees may be used to answering assessment questions about their life, they may not be familiar with research questions or situations. There is a responsibility on interviewers to explain and clarify the research interview and the researcher's role to the interviewee. Walmsley also stressed the need to consider participants' possible understanding of the research process. She endorsed Bloom's and Munro's (1995) opinion that this is a crucial way of ensuring that the researcher does not portray a version of the truth that is incomplete or influenced by particular assumptions.

Once again working with people with learning disability, Rolph (1998) identified both similar and different issues. Access to the individual as highlighted by Walmsley, was also raised by Rolph. However, she described negotiating layers of authority, including the Local Ethics Committee before she could access one particular woman. This raised issues of the woman's rights and ownership of her own story, and contrasted with the experience of others living in community settings who had more control over their own decisions. She raised an important point concerning the wish for participants in her study to have their own names used in the research. This caused concern for the Ethics Committee. The right to confidentiality and anonymity is of course paramount. However, a non-negotiable stance around name use could result in further compounding the "hidden" life experiences of individuals. A resolution to this situation can be made by joint agreement between the participants, their advocates and the researcher.

Rolph also dealt with issues relating to eliciting sensitive information from participants. In an empowered research design participants would monitor their own feelings and choose whether or not to raise the sensitive issue; furthermore they may decide to stop at any stage. For individuals with learning disability, support systems can be put into place to allow the participant both the opportunity and the right to tell their story. However, the process is problematic. Atkinson (1997) decided to take a safe route and avoid direct questioning, allowing the participants to share childhood and home memories. She discovered that she could not protect individuals from their own pasts, and concluded that she should not have tried to avoid such recollections.

These examples of life history applications give some indication of the issues and questions raised by this method. The method can be successfully used to understand people's narratives of their life. However, strategies for addressing these aspects require to be incorporated into the design and process of the research.

As personal meaning is offered through the individual's narrative, Mattingly (1998) considers the narrative form particularly appropriate for addressing illness and healing experiences. In narrative terms, the 'illness or disability' is considered as an episode within the larger context of the individual's life history. She regards narratives as being "event and experience-centred, which create experiences for the listener or audience" (p. 8). Williams (1984) posits that during certain times of crisis, of which illness could be considered an example, the life story is lost. The routine narrative can become confused, resulting in some reworking of the narrative to account for the disruption. This reconstruction is necessary "in order to understand the illness in terms of past social experience and to reaffirm that life has a course and the self a purpose" (p. 179). Such stories hold our experiences together, allowing links to the past, present and crucially, the future.

There has recently been a growth in personal illness stories reaching a public audience (Bloom, 1997). Some of these narratives are autobiographical, and some are biographical. The growth and prominence of this body of literature, may result from the legitimisation of the genre as a result of contemporary social and political movements in which people feel empowered to tell their story. These movements have given voice to those unheard before, or to taboo subjects such cancer, death and dying (Bloom, 1997).

Another factor that may be at play is these narratives let readers look at life though another's eyes. These personal narratives often deal with life-threatening illness experiences: they are dramatic and full of emotion. As Critchley (1998) puts it, "It seems that the dying have taken up their pens to take us through their agonies"(p. 35). People's narratives of cancer highlight this trend (Picardie, 1998; Diamond, 1998). Picardie and Diamond significantly were both journalists. Picardie, a 32-year-old journalist, married with twins, was diagnosed with breast cancer, which spread rapidly resulting in her death within a year. Her narrative provides the reader with an understanding of what cancer meant to her, emphasising how the illness was unique to her. It brought together her own copy from her newspaper column with other people's responses and her husband's perspective. A common theme throughout the text is her anger at her life being cut short and her loss of her future. She recognises that her narrative is coming to an end, stating "I think life will continue just fine. It's just that I'll miss it so"(Picardie, 1998, p. 59).

In a variety of ways these personal narratives resonate with us. They afford the opportunity to encounter some aspects of a given situation without the reality of the experience. These illuminations of chronic illness take on specific meanings that can be understood through the narratives of the storyteller (Kleinman, 1988). It is suggested that these illness narratives may serve different purposes. They act to transform the illness events and construct a world of illness. Similarly, the narrative reconstructs one's life history in the event of chronic illness allowing for explanation and understanding of the illness. The narrative may be a strategy in order to justify an individual's behaviour and to reassert their identity. Lastly, narratives transform individual illness into a collective phenomenon (Hyden, 1997). Sharing the story enables the storyteller to understand themselves and the meaning of their world better, whilst at the same time sharing their world and life experiences with others.

It could also be argued that the explosion of this genre of personal stories also reflects the move within research to focus on, and attend to, other's stories. The personal narrative is being "resuscitated as an important source of experiential data" (Holstein & Gubrium, 1999, p. 103). The increased use of narratives as a valuable research method within fields such as history, sociology and anthropology is reflected currently in occupational therapy's research and practice (Frank, 1996).

The growth of narratives in Occupational Therapy

One major reason for the recognition and growth of the use of narratives within occupational therapy, are the findings from a Clinical Reasoning Study funded by the American Association of Occupational Therapy and the American Occupational Therapy Foundation. This study addressed the question how and in what ways, do occupational therapists reason? Mattingly and Fleming (1994) proposed that occupational therapists used narratives in their everyday practice to enhance their understanding of their own and their client's understanding of their situation. Mattingly (1991a) defined the therapist's thinking through story telling as 'narrative reasoning'.

Narratives enable therapists to gain insight into current clinical problems, and to create stories of a different possible future for the client. Mattingly (1998) considered that therapists used narrative in two distinct ways. Firstly, they retold their clients' stories either as related general pathology 'chart talk' or by relating specific experiences of the person. The telling of such stories is always retrospective. The other use of narrative was in 'story making' in which therapists created a possible and desirable future for the person, envisaging how the therapist and the client could work towards that future image. These types of stories are always prospective. These stories are shared implicitly, as the therapist and the client work together. The use of narrative was highlighted as a practical reasoning strategy, enabling therapists to make sense of their work with clients (Hughes, 2002).

Kielhofner and Mallinson (1995) described stories as "interpretive vehicles through which one's life is made coherent and takes on meaning" (p. 63). To date, narratives have been used in occupational therapy to explore a range of issues. The body of literature encompasses work which illuminates clients' narratives (Clark, 1993; Price-Lackey & Cashman, 1996; Fanchiang, 1996; Mostert, Zacharkiewicz & Fossey et al., 1996); student and educational issues (McKay & Ryan, 1995; Ryan & McKay, 1999; Fortune, 1999); therapeutic potential (Polkinghorne, 1996; Hughes, 2002) and as a research method (Mallinson, Kielhofner & Mattingly, 1996; Frank, 1996; Frank, 2000).

Work illuminating a client's narrative was best illustrated by Clark's (1993) seminal paper, whereby she used narrative to present the story of Penny, a stroke survivor. This work portrayed Penny's life from an occupational perspective. It told her story, reconstructing her life though childhood to adulthood, to before the stroke the occurred: the story-telling dimension. The narrative then described how Penny and Clark worked together, as Penny rebuilt a new life and identity: the story making dimension.

A further example was offered by Price-Lackey and Cashman (1996). They used a life history interview to discover how one woman, Jenny, experienced a traumatic head injury and recovery. Two open interviews were conducted a year apart. Both interviews were audiotaped and transcribed verbatim. The first interview explored the woman's level of satisfaction in her occupations since her head injury. The second interview focused on gaining details of her life history and on her adaptation regarding major life events throughout her life including the head injury. The analysis was shaped by the authors' interest in the occupation and by their interest in rehabilitation of the head-injured individual.

They used narrative analysis to create a coherent story of Jenny's journey from head injured to recovery. Price-Lackey and Cashman used the constructs of occupation and narrative configuration to give meaning and coherence to Jenny's lived experience. Credibility was increased by involving Jenny in the interpretation and representation of the versions throughout the process. The outcome is a detailed portrait of Jenny that reflects her life before the head injury and her choices following her recovery. Large sections of the narrative are told in Jenny's words. The authors acknowledge that while one story cannot be generalised, it can serve as a vignette which can be referred to to gain insight and understanding when working with individuals in similar circumstances.

Similarly, Fanchiang (1996) explored the life history of Dale, a 25-year-old man with "learning disability". Here, a narrative approach was used to examine the process of adaptation. Dale's occupational history, personal and cultural viewpoints were all considered. The procedure involved the participant in six interviews, and four telephone interviews, plus a follow-up interview to look at occupational changes. All interviews were audiotaped and transcribed. The analysis used a modified life history approach. Each paragraph of the transcript that contained meanings, plots or occupations was coded and life events were arranged chronologically. Key words were inspected to determine similarities between them and from this process three themes emerged. A second analysis focusing on occupational changes was also conducted. This process resulted in a chronological life history which had Dale's occupational history embedded in it. The themes and occupational changes demonstrated how Dale adapted to his learning disability.

These three papers produced similar, yet different outcomes. The first two produced two narratives of the women's lives with coherence organised through the use of section headings corresponding to particular life-events or life stages. On the other hand, the latter produced a chronological story that is further explored by the main three themes drawn from the analysis. This results in a less flowing account of the person's life. However, the authors of each had different aims and these were reflected in the presentation of the findings.

These studies reflect how narrative has become established within occupational therapy, although it is not without its critics with some arguing that it is not adequate enough as a research method (Duchek & Thessing, 1996). These are several criticisms of narrative methodology that require further consideration.

The Popular Memory Group (1982) articulated some of the criticisms involved in creating life history in the present, drawing particularly on the field of oral history. They raise the issue of the historian's or the interviewer's dilemma in relation to oral research. On one hand oral sources can be used as a legitimate scholarly activity, grounded traditionally in empirical thinking. On the other hand oral history can be used as a method to address social transformation. They argue that oral history demands a different way of working that focuses on the power relationships inherent at every stage of the process and that draw out and explore the cultural implications at both the individual and social level.

They highlighted that oral history reflects current and past knowledge of an individual's everyday life and are often "held at the level of private remembrance (p. 210). Furthermore, tensions were associated with making this private knowledge, public.

Tensions derive from the ways in which the raw data or interview is revealed and include the position of the interviewee and the interviewer, their interactions and the context of the event. The individual's remembered past, at the time of telling, is influenced by the present context and conditions. Individuals involved in telling their history can only tell it from their own perspective. The meanings that they have attached to events and happenings are their representations. Their memories and their resultant narratives may have changed over time and in the telling and re-telling; they are therefore subjective accounts. These accounts require to be considered as social and cultural constructions of knowledge, not as truth statements. Furthermore, the participant's contribution highlights the question: what is significant in understanding the individual's experience with larger social changes? These issues require researchers to examine and share their understandings with the participants at all stages of the research process.

Other criticisms concern the interviewer/interviewee relationship, where issues of power and inequality are evident in the creation, the interpretation and the recreation of the history. The interviewer's use of their data can be problematic and may be exploitative, with all the benefits being experienced by the interviewer. In contrast, the interviewee is divided from the final product and remains mostly unchanged by their involvement in the process. Consideration requires to be given to how this division can be reduced and in what ways the process of creating history can be transformed into a more equal partnership so that the shared authority of the final product can be achieved.

Taking these issues into consideration within the research process and the use of life history research in other disciplines has sustained oral history as a valid tool that has a place in the research repertoire of the profession.

Narratives of Mental Illness

It is acknowledged that there is a growth in narratives within occupational therapy. Personal illness narratives are also on the increase, especially in relation to physical illness. By comparison, the field of mental illness and the stories of sufferers of mental illness have not been so readily presented to the public or in the professional literature. There have been some famous examples. For example, Gilman's The Yellow Wallpaper (1973) highlights her experiences of the "rest cure" where she was forbidden to participate in any activities including reading and writing. Plath's The Bell Jar (1971) depicts her experiences of depression and ECT. More recently, the actor, William Styron (1990) in "Darkness visible" portrayed his descent into depression and offered insights into this commonly misunderstood disorder and the usefulness of the treatments he received. In the same year, Millet's The Loony-bin trip (1990) highlighted her experiences of psychiatry in Ireland. These present unique accounts of mental illness from the insider's perspective.

Moreover, recent work has explored narratives and mental illness. For example, Jones (1997) reviews literature concerned with narratives of mental illness, not only as a way of understanding individual experiences of mental illness and distress, but, also as a method to highlight the conditions and the abuse people have faced in psychiatric institutions over time. Furthermore, Jones identifies that these narratives can inform the readers of the therapies available and the changes to these treatments that have occurred over time. She advocates that such narratives can offer clinicians alternative perspectives on treatment, including successes and failures. She concludes that there is a need for successful recovery narratives to offer hope to patients and their families. She reminds clinicians that individuals experience illness differently and therefore the individualisation of treatment is paramount.

The telling of personal accounts of mental illness is growing and is increasingly accessible. For example, Speaking our minds (Read & Reynolds, 1996) is an anthology of stand-alone personal experiences of mental distress and its consequences. These personal narratives explored a range of differing topics from the individual's perspective. These included the causes of emotional distress, the psychiatric treatments available, the in-patient experience, the move to community care, therapy, self-help and finally, the narratives of working for change.

Canadian nurses, Hayne and Yonge (1997) took a different tack, using personal accounts to illuminate the lifeworld of the chronic mentally ill. They reviewed personal accounts published in a range of mental health journals to access the experience of chronic mental illness. The journals covered the period 1986-1996. They identified 40 personal accounts; 30 were first hand accounts, and the rest were written by immediate family members. There is no mention of gender representation among the included narratives. This paper draws on phenomenology to analyse the accounts, therefore the 'lifeworld' is represented as four existentials, namely, corporeality (lived body), relationality (lived human relation) spatiality (lived space) and temporalilty (lived time). The authors argue that these existentials allow for a deeper understanding of the nature and meaning of severe mental illness (Hayne & Yonge, 1997).

The findings indicate that mental illness is experienced bodily in a variety of ways. Pain is experienced. Feelings that the body is unreal and no longer controlled by the self are common. Examining spatiality, the narratives spoke of being confined, of being swallowed, of being somewhere unpleasant. Relationality revealed the theme of a division between the self and the mind. The self is threatened. Another theme was that of marginalisation and exclusion; the accounts told of people living out of the mainstream of life, living in poor housing with little or no work. However, reconstructing the self and recovery from illness were identified as being important sources of strength. The final existential temporality explored the experience of time in relation to the happenings of life. With the onset of illness, time was experienced as awareness of illness, of being sick. Time was described as unfolding into "sick cycles, a chronology of sick episodes with intervals of elusive wellness interspersed with mounting illness" (p. 320). The authors proposed that by listening closely to the voices of those experiencing chronic mental illness, nurses could become more enlightened and benevolent in their care, developing both a greater understanding of and a greater respect for, their patients.

Hayne and Yonge illustrate one way in which personal accounts can be used to gain access to very personal experiences through the written word. This article does not address any differences in experience as a result of gender, class or race and it generalises the experience for all. However, it does utilise the narratives as a way of making meaning explicit.

Another recent study used patient's accounts to view the history of mental illness (Davies, 2001). Individual experiences were viewed as a means to reflect the wider changes that had taken place in psychiatry, including social, medical and cultural shifts. This work forms part of a larger study examining the history of psychiatry from the introduction of the National Health Service in 1948 to the present day. Davies interviewed twenty-one people about their first experiences of mental illness or distress from 1955 to 1998. The interviews were subjected to in-depth analysis and three key frames emerged as central to the shaping of individual's accounts. These were narratives of loss, survival stories and the self as patient.

Davies (2001) identified that loss acts as a means of expressing specific experiences and as a way of structuring and understanding people's narratives. Survival stories emphasised "the individual surviving the illness, the mental health system or treatment" (p. 281). The final frame considered the "self as patient", the explicit way in which the interviewees understood their mental illness. Throughout this paper, Davies uses rich examples from the participants, both women and men, to illustrate these key frames. Nonetheless, the analysis of these narratives into three frames forces the individual's perspective into these specific areas and thereby loses the unique narrative of the individual.

Individual personal accounts do exist. However, they tend to come from people who are well used to the written word as an expressive form, such as authors, poets and representatives of other professional groups. Other examples of women with mental illness who have used their writing ability to tell their own stories include Janet Frame, a New Zealand author, Kay Jamison, an American psychologist, and Nicola Pagett, a British actress (Frame, 1990; Jamison, 1996; Pagett & Swanell, 1997). It could be considered that they have an already established base from which they can present their narratives.

This established base from which to tell your story is not the case for those women who suffer from severe mental illness, whose lives are not in the limelight or are dramatic, extraordinary though they may be. The written form is not necessarily something they would utilise to communicate their experiences to others. Furthermore, they may not perceive their lives to be of interest to others. As a result it could be debated that few of these women's stories have come to the public's attention. By enabling such women to tell their story, we may be able to begin to understand what they experience, "to make sense of their lives and to comprehend how they come to terms with their altered existence" (Charmaz, 1999, p. 374).

That said, some examples do exist, for example the insightful text by Hart (1995), Phone at nine just to say you're alive. This book chronicles the author's experiences during a period of hospitalisation as a result of schizophrenia. As she recounts her time in hospital, she describes her experiences of her mental illness, her time as a patient and her steps to recovery, set within the broader context of her life history. The book takes the form of a diary written while she was an inpatient in an UK psychiatric hospital. Her story is frightening, painful at times but illuminating of her struggle with schizophrenia, giving important insights into the mental health system and its impact on her. She identifies a range of issues which although particular to her situation may be reflected to some extent in others' life histories or narratives: for example relationships, conflicts and stigma.

The British Library Mental Health Media Testimony Archive holds a unique source of personal, mental illness narratives. This video collection records the accounts of fifty people who had experienced living in psychiatric institutions during the period 1925-1985. The National Sound Archive supports the project initiated by Mental Health Media with funding from the Department of Health. Interviews were carried out during 1999-2000 and included those who lived in psychiatric asylums (long-stay patients), as well as 'revolving door' patients and those with a mental illness diagnosis in the second half of the twentieth century in England and Wales. Up to four hours of life history interviews were collected for each individual, following their lives from their childhood to the present. The collection contains a mixture of good and bad experiences and some of the accounts are distressing. In total, two hundred hours of life history interviews were collected and record the scope and depth of users' experiences. Project interviewers had themselves experienced mental health problems and had first-hand knowledge of the system. The use of users as interviewers had two advantages: interviewers were accepted by the interviewees, and they were also perceived as being receptive to subtleties in the interviewees' accounts. These accounts consider aspects such as admission to hospital, institutional life, treatments and resistance. This permanent collection is free to access and the British Library is committed to enhancing access and to disseminating the collection.

An innovative text by Leibrich (1999) further explores individual's own stories. This book is the culmination of work by the New Zealand Mental Health Commission to counter discrimination against people with mental illness; the aim was to produce a book of stories about how people deal successfully with mental illness. Leibrich interviewed people from New Zealand over a two-year period. The interviews were taped. Leibrich then drafted each story. The draft and the full transcript were returned to each participant for them to make changes. Within one week she met each person and together they worked on the final draft. This collaborative process has produced a range of individual stories that challenge some traditional views of mental illness.

An important aspect of this text was the inclusion of personal pictures that accompany each story, emphasising the uniqueness of each person's experience. As a New Zealand Government document this book it is radically different however; it stresses the need for new ideas and new ways to bring about change. As Leibrich comments, "to make a difference, we need to act differently" (p. 190).

This book presents twenty-one narratives, thirteen from women and eight from men, including Leibrich's own story of her life with depression. The stories highlight many aspects: stigma, lack of understanding, few safe places, access to services, the importance of friends, work, effects of medication, the need for care and compassion. It also emphasises the aspects that have helped people to survive and succeed, the creativity of the individuals, the unexpected outcomes of mental breakdown, the rediscovery of people who have lives to live and who have shared their lives with others.

Conclusion

This literature review has given consideration to the issues influencing this study. It has examined the place of women in psychiatry, both from the traditional perspective and from a feminist's standpoint. This highlighted that women with enduring mental illness were a group who received little attention. Furthermore, the relationship was explored between psychiatry and occupational therapy, emphasising that psychiatry has had a profound impact on occupation therapy's development. Attention was given to recent occupational therapy research involving mental health users.

The literature suggests that occupational therapy as a predominantly female profession in the UK, has failed for the most part to engage in feminist debate as a way to explore its place and status within the healthcare arena. Similarly, the significance of women as therapists providing care for women as users of mental health services has not been addressed.

The final section defined and discussed the growth of narrative, specifically illness narratives, in the public arena and the research field. It stressed that changes have encouraged the acceptance of such experiential data as a valid means to make sense of people's lives. The lack of research concerning women with enduring mental illness may be addressed by the use of narrative to facilitate hearing these women's life histories.

Narratives can "illuminate the course of the life over time and allow for its interpretation in its historical and cultural context" (The Personal Narratives Group, 1989, p. 4). This group was established in 1983 to facilitate feminist scholarship. It developed the use of personal narratives, as a means of interpreting women's lives. Its work has raised several issues in relation to the use of personal narratives. These include context, both time and situation, 'Who's voice?' in regard to the narrator and the interpreter, and the relationship between the two. Research has emphasised that factors including power, production, control and use of women's narratives need to be considered. Another issue concerns the interpretive framework that is followed to understand how people make sense of their life experiences. The methodology the group suggested reflects a move towards a post-modernist stance. There is a small body of research on which to build, what is clear is the need for further research which is sensitive to the needs of the women and which offers an opportunity for their experiences to be heard.

Two research questions have arisen from the literature review, namely:
1. What is the lived experience of women with enduring mental illness?
2. How do occupational therapists' work with women users of mental health services?

The aims of this research are twofold:
1. to explore and describe the experiences of women with enduring mental illness across their life-span.
2. to identify the factors that influence women occupational therapists working with women with enduring mental illness.

The following chapter will address the methodology and methods chosen to achieve the research aims. Furthermore, consideration will be given to the concerns highlighted above as well as to ethical and analysis issues.

CHAPTER TWO

The Research Design

Section One: Introduction

This study has two main foci: first, the exploration of the lived experiences of women with severe mental illness; second, the identification of the perspectives of occupational therapists, working with such women. In addressing these foci, I held several beliefs. A cornerstone belief was that the research process should be a collaborative venture between the participants and myself, with trust between each being paramount; therefore, the process undertaken should be as transparent as possible. Finally, the product created should represent the women's and therapists' voices in a credible manner.

The chosen methods will be introduced here and considered in more depth later in this chapter. However, it is first necessary to give some consideration to the nature of the philosophic assumptions underpinning this qualitative study. An essential aspect concerns the origin of knowledge; in other words, the epistemological question considers the nature of knowing and the construction of knowledge. Therefore, it is useful to attend to the relationship between the researcher and the knowledge created. This relationship is considered as interrelated: the relationship is one of closeness (Cresswell, 1998; p. 253). Depoy and Gitlin (1998) ascertain that qualitative inquiry is based on the "assumption that it is not possible to separate the outside world from an individual's ideas and perceptions of that world" (p. 27). The researcher's values, preferences and how they view the world must be made clear if the findings created are to be credible. In this work, my personal stance reflects the social constructionist position that considers that individuals are shaped by the worlds in which they live and that they adapt and reframe their lives accordingly. In developing the research, these beliefs influenced the ensuing research methodology and the implementation of the research methods through the processes of data collection, interpretation and representation. I considered methods that would address the research aims and facilitate my gaining insight into, and understanding of, the participants. In the case of women with severe mental illness, life history interviews through narrative inquiry seemed a potential way to bring to the fore these womens' past, present and future lives (Bateson, 1990; Frank, 1996; Walmsley, 1998). When considering therapists' perspectives, the focus group method offered a qualitative method that explored shared experiences and meanings of the participants in a dynamic encounter (Kitzinger, 1995).

These identified methods are firmly located within the construct of qualitative research. Patton (1990) suggests that qualitative inquiry "cultivates the most useful of all human capacities — the capacity to learn from others" (p. 7). Qualitative research is characterised by Creswell (1998) as

> An inquiry process of understanding based on distinct methodological traditions of inquiry that explore a social or human problem. The researcher builds a complex, holistic picture, analyses words, reports detailed views of informant, and conducts the study in a natural setting. (p. 15)

Therefore the goal of qualitative research is the development of concepts which aid our understanding of the meanings and experiences of the people involved in the study. These methods offer ways to discover how people adapt and how they view what has happened to them. Qualitative methods are particularly useful in healthcare where this focus on people enables the complexity of their lives and their interactions with others to be explored and interpreted (Pope and Mays, 1995). As Morse (2000) highlights: "We study the lives of those who are in the process of change, of becoming healthy or ill. Qualitative methodologies are ideally suited for documenting such changes" (p. 579).

Qualitative interviewing, begins with the assumption that the perspective of others is meaningful and knowable (Patton, 1990). Both life history interviews and focus group interviews can be encompassed within the broad category of qualitative interviewing which can be considered as cultural. Rubin and Rubin (1995) define "cultural interviews as having a focus on norms, values and understanding of a group or a society" (p. 28). These methods allow for context to be appreciated and potentially rich data to be collected from the participants.

Life History Method

Life history is a form of biographical research and is drawn from anthropological and social science research (Creswell, 1998, p. 48). Frank (1996) defined life history as "a narrative approach in which empirical methods are used to reconstruct and interpret the lives of ordinary persons" (p. 252). As was discussed in the previous chapter, life history can be used to increase our understanding of how particular people experience and adapt to major life events. Rubin and Rubin (1995) argue that life histories "tell us about life's passages whilst they can also provide a window on social change by exploring what factors have impacted on an individual's life" (p. 27). This type of research is considered as ideographic, defined by Denzin (1989) as "research that assumes each individual case is unique" (p. 20). As it deals with the particular rather than the general, this research design is essentially emic in nature, as opposed to etic research with its focus on the general (Denzin, 1989). This method emphasises the complexity of an individual's unique life across time and contexts. It highlights what may be specific and what may be common, while remaining true to the real life experience of the individual and thereby valuing their perspective. In addition, it recognises that the life is socially constructed and that it changes over time and through the telling and retelling. This approach to qualitative research recognises that the individual's responses depend on when we ask the question, reinforcing that knowledge is situational and conditional.

The focus for the first phase of this inquiry was to ascertain the lived experience of women with enduring mental illness, to explore not only, their illness narratives but also their whole life story, with an emphasis on their occupational functioning. The nature of this work meant that the participants would describe their meanings and understanding of their lived experiences. Narrative here was considered as a social construct: individuals telling their narratives at a particular time and in their own way.

This method involved interviewing women in their own homes on two occasions, so the setting was considered as naturalistic. The first interview used life history, specifically, an unstructured format to encourage the women to describe in their own words, events and experiences from their world. This strategy was chosen to provide the participants with an interview process that was led by them and to their advantage, enabling them to discuss topics in their preferred order and depth. The second interview used a semi-structured format to gain further insight. It allowed for a detailed perspective, enabling the unique diversity of each woman's life to be understood and represented.

Focus Group Method

The second phase utilised another qualitative method the focus group, to explore and identify occupational therapists' perspectives of working with women with severe mental illness. The focus group is a "form of group interview that capitalises on communication between the research participants in order to generate data" (Kitzinger, 1995, p. 299). Focus groups developed originally as a marketing tool. However, their use as a research method has grown over the last decade. Focus groups offer the opportunity to collect multiple perspectives from the individuals who form the group, facilitating the collection of data during one session and thereby maximising both time and resources. For the focus group interviews, some of the data from the first phase of the research were incorporated as stimulus material presented to each participant in a pack, during the group, to gain new perspectives on the meaning and implications of the findings (Morgan, 1997).

For this study, with women and occupational therapists, the researcher adopted a collaborative and empowering design. Stewart (1994) presented empowerment as "the process of supporting individuals and providing them with opportunities to take control for themselves" (p. 248). Four aspects of empowerment; giving choice, control, enabling participation and consultation were integrated into this research design. The aim was to encourage the participants, both women and therapists, to voice their views in their own language. Hooks (1989) proposed that this is one way of giving a voice to those who are silent in society.

The identified methods were chosen as they enabled participants to express in their own words, their experiences and their understanding of their lives, or their practice as occupational therapists working with women with enduring mental illness. For both phases of the study, key informants were required to bring the researcher into the area being studied.

Alternative Research Methods

Before selecting these methods, consideration was given to the alternatives available. In relation to women with severe mental illness, several alternatives were considered. These ranged from a quantitative survey or questionnaire to a more structured interview. Both the survey and questionnaire were rejected early on the grounds that women with severe mental illness have been little researched and an in-depth perspective of their experiences was preferred. Survey and questionnaires have some advantages in that many individuals could be included in a study; therefore the data set could be sizeable, and speed of data collection and in some cases speed of analysis could be facilitated through the use of these research methods (Depoy & Gitlin, 1998).

The design of both survey and questionnaires demands questions that are clear and responses that reflect a range of alternatives. However, depth of response is limited by the nature of the responses, in the attempt to give a range of selected items. Individuals may find that their own situation is not reflected in the category, or indeed that they are forced to select the nearest category, thereby diminishing the accuracy of the tool. Other disadvantages include the inability of participants to check what is required or to seek clarification. An additional drawback is the poor return from postal surveys and questionnaires.

A more structured interview could have been utilised. This would have overcome some of the difficulties traditionally found with surveys. However, because of the nature of the work, which explored "lived experience" this was felt to be inappropriate, as it would have required that pre-selected questions were designed. Here too, this would have limited participants' responses. For these reasons, an unstructured life history interview was chosen for the first phase of interviewing. Marshall and Rossman (1999) point out that the primary advantage of interviewing is the focus "on the deep, lived meanings that events have for the individual, assuming that these meanings guide actions and interactions" (p.113). The second semi-structured interview allowed for further exploration of issues identified from the first round as well as facilitating new topic areas.

With regard to the focus group, alternatives could have included the nominal group technique or the Delphi method. With both these methods key informants are necessary. However, their purpose differs from that of focus groups. Both these methods aim to produce a consensus, or agree a plan, or make decisions with regard to a course of action. As Krueger (1994) states: "focus groups have a rather narrow purpose for which they work particularly well — that is to determine the perceptions, feelings, and manner of thinking of consumers regarding products, services or opportunities" (p. 19). As this study was explorative, consensus or problem solutions were not issues. Focus groups offered a means to explore occupational therapists' perspectives of working with women with severe mental illness, revealing their views and opinions generated from discussion with others.

Access

The first phase of the study researched the lived experience of women with severe mental illness living in the community; therefore, a way had to be found to contact the specific target group. Denzin (1989) said that in addressing the research question it is necessary to go to the place where people with the experience are to be found (p. 51). This was achieved by gaining access to a mental health resource facility in a Scottish city. This centre, run by a major mental health charity, is a community-based resource for those affected by mental illness or serious mental health problems. The centre offered a range of services including "drop-in", counselling, a café, a selection of groups both educational and health orientated, benefits advice, support and carers' support. Services were provided from Monday to Friday. As with other facilities of this type, there was a tendency for women to be the minority group within the total population. The ratio of men and women at the centre at the time of the initial contact was estimated to be 25% women, against 75% men (personal communication, 1998).

To gain access to this setting contact was made with the manager by telephone and letter (August 1998). A meeting was then organised which enabled me to visit the centre and discuss the study and its aims with the manager. Following consultation with users of the centre, access was approved. The decision was taken that I would be permitted to inform women in the centre of the study, on the proviso that I undertook a series of group sessions within the centre. This allowed me to make personal contact with possible study volunteers. It also enabled the women to feel secure, as the centre had validated the study. Another important aspect, for the women participants and myself, was that support in the form of counselling was available from the centre staff, if needed. The sessions ran from October 1998 till January 1999. Additionally, an advertisement regarding the study was also placed in the centre's newsletter, giving those not attending the centre information on the study (Appendix A).

To gain access to the therapists, the manager of a large primary care trust was contacted. She was willing for me to approach the relevant staff group and supplied a list of staff names for me to make contact with them individually. Staff volunteered for the focus groups.

Ethical Considerations

As this research involves people, ethical issues were an integral part of the research process. This research falls into the category of non-therapeutic research; that is to say it is not designed to give direct gains to the research participant. However, it is acknowledged that taking part in this type of research could be a difficult process; therefore a support system for participants as identified previously was deemed necessary. That said, some positive effects for the individuals involved may arise. For example, as the interviews were related to an individual's personal history there might be an inherent therapeutic aspect to the process, as it gave an opportunity for the participant to review and revise their life to date (Brannen, 1993). This personal reflection could be empowering, enabling participants to re-evaluate their experience and gain personal insight. Yet, it is important to acknowledge that the interview may become a therapeutic opportunity, and so the researcher should have a plan of action to hand if required. This may include, for example, identifying relevant forms of support or professional help for the participant (Birch & Miller, 2000).

Sieber (1992) highlights three main ethical principles that need to be reflected in the research process: respect for persons, beneficence and justice (p. 18).
Several ethical issues relating to "respect for persons" were identified: informed consent, confidentially and data protection. Informed consent placed the onus on me to supply possible participants with sufficient knowledge of the research to enable them to understand and make a knowledge-based decision. All participants in this study were given an information sheet that outlined the study (Appendix B), its purpose and participants' possible involvement. Express consent was sought from the participants; that is to say, they actively agreed to take part in the study and this was confirmed by their signing a consent form. These documents form Appendix C.

Participants were given assurances about confidentially and anonymity. No aspects that could identify the participant would be published. Participants in phase one were encouraged to select their own pseudonym for use in the study and for publication. One participant wished her real name to be used; her request has been met, although all other names in her narrative have been changed. In relation to data protection issues, all information was held securely in a locked filing cabinet at the researcher's home. Tapes were destroyed on completion of the research. No one other than the researcher or the external auditor had access to the data.

Beneficence means maximising the benefits of the research and minimising harm to participants. For this study volunteers who met the criteria were sought. Individuals were under no obligation to volunteer. They were made aware that they could withdraw from the study at any point without giving an explanation to the researcher.

Justice relates to the principle that there is an ethical obligation to treat each person in accordance with what is morally right and proper and to give each the respect they are due. Although for this study it is acknowledged that the participants for phase one could be considered as a "vulnerable" group, namely, women with severe mental illness, the women were able to give their informed consent. The research goal could not be met by using other women, as it was the purpose of the research to gain knowledge of the particular life histories of women who had lived with severe mental illness. Similarly, occupational therapists working with women were the key informants each was treated with due respect.

Finch (1984) raises issues specifically related to interviewing women. She suggests that if you are a woman researcher reasonably skilled in interviewing, it is "the easiest thing in the world to get women to talk to you" (p. 70). The ethical difficulties that arise from this situation include power in the relationship, identification with the researcher as a woman, and trust. These need to be considered explicitly and reflexively by the researcher and strategies to acknowledge them must be articulated. The researcher must explain the motives behind the research to the participants. The development of a non-hierarchical, collaborative relationship can go some way to levelling any power dynamics. Finally, trust relates to the researcher's handling of the participants' data, so that this is not exploited. Opportunities for participants to have access to the findings, and to share their reactions, are some of the ways in which trust is maintained.

It was identified that possible ethical difficulties could occur when using the focus group method. For example, in groups where members had previous relationships, for instance a manager and their staff, this dynamic could impact on the members within the group, perhaps resulting in participants withholding information. As Smith (1995) states, this could be an issue "as group members reveal their thoughts not only to the researcher but also to the rest of the group" (p. 482). Two strategies were employed to lessen this possible ethical dilemma. First, confidentiality was firmly located as a topic within the introduction for each focus group. Members were asked not to share with outsiders what occurred in the group. This was restated at the end of each focus group. The second strategy involved constructing the group membership in such a way that the groups reflected the different levels of staff grades, in an attempt to lessen the possibility of previously established roles influencing the process.

As with the individual interviews, a debriefing component was built into the focus group, with participants being able to discuss their reactions to the process.

The Trustworthiness of the Research Design

A central issue for qualitative inquiry is obtaining an in-depth, rich description of the particular context under study. The final representation must be a credible account. Drawing on the guidance of (Lincoln & Guba, 1985) and (Krefting, 1991), the following strategies were used in this study to ensure the trustworthiness of the research process from data collection, to analysis and representation.

Table 2. Strategies for Trustworthiness

The role of the researcher
Reflection and reflexivity
Triangulation
Member checking strategies (return of transcripts, narratives and focus groups transcripts and findings)
Observer and external auditor
Prolonged contact

These methods were used to attempt to produce findings that were credible representations of the individuals and the focus group members. These strategies and their implementation within this study are described below.

The Role of the Researcher

Boud and Walker (1991) advocate that reflection to enable effective learning is required before, during and after an event. The "event" can be considered as the distinct phases of this study. The "before" activities involve the researcher in identifying and focussing on their knowledge and skill prior to the event. The "during" activities place importance on the central activities, here the individual and focus group interviews. There is a need to be aware of and notice what is occurring within these interactions. "After the event" is a way of reviewing by examining the experience; the main strategy for this was the reflective journal.

This method was used to place myself firmly in the research process. My acknowledged background as an educated woman from a working class Scottish family has influenced my position, and may affect what I 'find' (Reay, 1996). Similarly, my personal journey of working as an occupational therapist in a variety of mental health contexts, and more recent experiences of researching in mental health have also shaped my perspectives. I therefore needed to be vigilant about my own ideas, assumptions and influences. The development of this research originates from my experience as a practitioner, my continuing interest in women's mental health issues and my desire to effect change.

These factors influenced the research role I undertook for the study. The Concise Oxford Dictionary (1999) defines role as "a person's or thing's function in a particular situation" (Pearsall, p.1240). Goffman (1961) and Merton (1968) have defined and developed the concept of role. They have made much of role as performance, arguing that each of us plays a number of roles in different situations. The role played by myself was structured in relation to the participants and aimed for me to be seen as a researcher rather than an occupational therapist.

As I wished to be able to negotiate a collaborative relationship with possible participants it was advantageous to be open about my background and my interests. As a result, possible participants attended a meeting held in the mental health resource centre, the purpose of which was to get to know me and for my research to be introduced. The women were informed that I had experience of working in mental health settings as an occupational therapist, although not in their region. They were also aware that I worked as an occupational therapy lecturer in England. In addition, the research information sheets made available to possible participants explained the purpose and the aims of the study and possible involvement if they agreed to take part (Atkinson, 1998). All contacts were directed to my academic address, reinforcing my role as an educator involved in research.

Having identified my background, I was keen to keep my role as researcher to the fore. However individuals may place you in a "role" of their own so it has to be borne in mind that how I was perceived may have influenced what people said. It is my belief that the women for the most part saw me as a researcher; there was little discussion in any of the interviews about either occupational therapy or myself.

A similar situation arose with the focus groups. I was known to a few members of the focus group as a past colleague, eight years previously. However, to the majority I was a researcher. Strategies were employed to lessen my past worker role. I attempted to keep my researcher's persona to the fore. In addition, I tried to greet all the participants in a similar way, treating each as an equal.

Reflexivity

Reflexivity is considered to be highly desirable in qualitative research (Mauthner, 1998). Reflexivity demands that the researcher demonstrate sensitivity and understanding of how they influence the research participants, the research process and the research findings. Ruby (1980) refers to reflexivity as the assessment of the researcher's personal history, their background, perceptions and interests on the qualitative research process. For qualitative research it is necessary to acknowledge and make explicit who the researcher is and where the researcher is placed, as these are understood to be significant to the research process and the findings produced. The aim to be separate and objective, although worthwhile, is not possible within the qualitative sphere, nor desirable within this study. As this was the case, Opie (1992) stressed the need for reflexivity in the research paradigm. In my study, a strategy was devised for dealing with my influences on the study and making those explicit and open to others. Lincoln and Guba (1985) discussed the practice of writing notes to themselves as being central to the research process. In the case of my study, to aid reflexivity, the notes took several forms including the use of a journal and notes in the margin of the transcriptions. Here my thoughts on the research as it proceeded are shown in a box at the end of following chapters.

I maintained a reflective journal for the duration of the study. Initially, the journal recorded my immediate thoughts following individual interviews and focus groups sessions. It was then continued during the analysis and interpretation phases of the study. I used the journal to describe and explore my thoughts and feelings in relation to the research process. It offered a way to acknowledge my biases and the preconceived ideas and feelings I brought to the field of study throughout the research process. This enabled reflection on my own behaviour and experiences and consideration of how these influenced my data gathering, analysis, and interpretation. Raising awareness of these allowed for biases and potential conflicts to be acknowledged as influencing factors on the research process. Miles and Huberman (1994) assert that the use of reflective remarks are worthy of analysis and can add substantial meaning to the research, "pointing to deeper or underlying issues" (p. 66).

Reflexivity was also supported by the use of "supervision". As I was interviewing women about their lived experience, I was very aware that I would hear painful and emotional material. Therefore, prior to commencing data collection professional supervision was built into the research process. This was to be used if I felt the need to discuss this material confidentially. A fellow lecturer, who was an experienced counsellor, offered the supervision. This was a valuable support structure which I did make use of following one of the first phase interviews. This supervision process enabled me to talk through and reflect on a particular event and allowed me to review my actions and responses during the interview.

In addition, research supervision offered further opportunities for reflexivity allowing for concepts to be clarified and developed and for interpretations to be shared and discussed within the supervision process. Further opportunities for reflection have also developed as the process was shared through formal and informal presentations. Questions raised have been recorded and used by myself to think through the many facets of the research.

Triangulation

Triangulation is a basic aspect of data gathering. Hammersley and Atkinson (1995) state that triangulation involves the checking of inferences drawn from one set of data sources by collecting data from other sources. Knafl and Breitmayer (1989) state that a number of types of triangulation exist. The types that related to this study will be considered. The most common is the triangulation of data methods. Lever (1981) stresses that what is involved in triangulation is a matter not of checking whether data are valid but of discovering which interpretations from those data are valid.

This study involved a combination of techniques that made it possible to review the trustworthiness of the researcher's interpretations. Methods included in-depth interviewing, follow-up interviews, use of reflexivity and reflective journal, member checking and a comparison of the findings from the interviews with a review of literature.

Member Checking

At the core of qualitative research is the ability of the informant to recognise their experiences in the researcher's findings. Lincoln and Guba (1985) emphasise that member checking is a technique that allows the researcher to test interpretations and findings with their informants. Member checking involves the participants and the researcher in a collaborative relationship and is achieved through several means. In the case of my study, after the first interview participants were sent two verbatim transcripts of their interview. Each participant was asked to read and amend their interview transcripts, returning the amended copy to myself while retaining the other for their own records. The amended transcripts were returned and any identified alterations were corrected in the data files held on the computer. This contact also afforded an opportunity for further communication with the women at this point. Two of the women sent letters with their returned transcripts. Amendments on the whole were concerned with dates and places. Three women made minor alterations to their transcripts, while the remaining two were returned with no alterations.

The Phase Two interviews offered a further opportunity for participants to add their voice to the process and for data collected to be verified. This process took two distinct forms: a biographical overview and the discussion of a concept map. First, a biographical representation of the person's life history was formed from the interview data and discussed with the participant. This proved a useful tool. At the start of the second interview I shared this biography with each participant. It served as a way of tuning the participant back to the previous interview. It also identified some errors not previously identified by the participants. The second form; the concept map, presented my initial interpretations of their story: this map of the individual's story was shared with the participant. Maykut and Morehouse (1994) discuss that the use of concept mapping to enable convergence on a topic of interest. In this case the topic was the woman's life story. This method allowed for the story to be explored from a different perspective and offered an opportunity for questions to be asked or for previous information to be expanded or altered.

The final member checking strategy with the women involved the return of the completed narratives to each participant. This offered an opportunity for the women to review their narrative, affirming that this reflected their life experiences and that they could recognise themselves within the narrative. In addition the participants were asked to answer the following questions and return their answers to me.

1 Having read your story, what were your reactions to it?
2 Do you feel the main influences on your life have been included?
3 Any other comments.

Member checking with the focus group took a similar form. Each group transcript was returned to the individual group members for checking. This again provided an opportunity for group members to amend or add further information. The findings from the analysis were also returned to each of the group members for additional comments.

External Auditor

A further strategy for ensuring trustworthiness was the use of an external auditor at various stages of this work. An auditor was used to give me an opportunity to reflect on other possible interpretations that could be drawn from the data. Two different individuals acted as auditors, one for phase one of the study, with another involved at phase two. Both were occupational therapists with mental health backgrounds. This strategy aimed to strengthen the legitimacy of the final interpretation (Depoy & Gitlin, 1998).

Prolonged contact with participants

Prolonged engagement in a field of study is highlighted as an essential characteristic of qualitative research methodology. An important strategy for my research was to develop a collaborative relationship that enabled contact with participants over a prolonged period. This prolonged contact with the participants allowed me to check perspectives and for the informant to become accustomed to me. This extended time period proved significant. As the relationship developed, participants volunteered different or more sensitive information than they had done at the outset of the study. Importantly, prolonged engagement can assist in detecting whether the participants' responses are consistent over time (Krefting, 1991).

During phase one of this study, engagement took the form of face-to-face contact, letters, telephone calls and, with one participant, email correspondence. In phase two contact with the therapists was maintained across one year. A limitation of this strategy could have been over involvement of the researcher with the participants, which could paradoxically bias the findings. Here the use of reflexive strategies such as the journal were essential to ensure that such biases were noted and considered.

To conclude, this section has outlined the research design, identifying issues that were central to the study: the research methods selected or rejected, access, ethical considerations and strategies for trustworthiness. It provides the background for the discussion of the research methods which follows.

Section Two: Research Methods and Procedures

This section presents an overview of the participants, the main methods of data collection and how they were operationalised to meet the study aims.

Life history participants

This study examined the life histories of women with enduring mental illness. Women were sought as volunteers for the study. People may choose to volunteer because of their desire to help others through making their experience open. Opie (1992) discussed the idea that by taking part in the research they were able to "lift the veil of invisibility"(p. 64). Facilitating individuals to share their everyday lives and their experience of marginality can reveal their particular unseen or indeed unknown experience to a wider public forum. The inclusion criteria compiled were:

1. Women with one of the following diagnoses: manic depression, depression and schizophrenia.
2. Severe mental illness for a period of at least five years.
3. Women living in the community, not currently hospital in-patients.

These criteria follow the definition of severe mental illness discussed in the introduction. The decision to concentrate on women living in the community was taken, as these women often become invisible within their community, following discharge from hospital. Participants were sought through a strategic sampling technique and participation was voluntary. Participants either responded to an advert, "Tell me about your life" placed in the mental health resource centre's newsletter, (Appendix A) or they had met me at the centre when the study and its aims had been discussed. Convenience sampling was also adopted, as one participant was included because she became aware via a mutual contact, that the research was being conducted.

Following contact with possible participants, their informed consent was sought via a signed consent form which was returned to the researcher (Appendix C). I then made telephone contact with the women and agreed times for their interviews to take place at their convenience. All interviews took place in the participants' homes and were tape-recorded. The first round interviews ranged from 90 minutes to 2 hours 15 minutes with second interviews ranging from 90 minutes to 2 hours. The average time gap between the first and second interview was 15 months. During this period, contact was maintained through letter, return of transcripts and responses to them. In addition, telephone calls were used to arrange and confirm second round interviews.

Focus Group Sample

Volunteers were sought from the occupational therapy staff of a large primary care trust. As highlighted previously, occupational therapists who met the following criteria were contacted by letter to invite their participation. The inclusion criteria included were:

1. Having worked with women with severe mental illness for more than two years.
2. Being women.
3. Having an interest in the topic.
4. Senior 11 Grades and above.

The preferred focus group size was four to six therapists. Focus groups that have similar members, for example same professional level, are less likely to have conflict or members that refuse to contribute (Holloway & Wheeler, 1996). It was felt beneficial to run a series of focus groups allowing for staff from different grades to be placed in the most homogenous group. Therapists volunteering for the study were given information about their participation and their role in the groups (Appendix D). Their informed consent was sought, with all participants signing consent forms prior to the focus groups taking place. All the focus group sessions were video-recorded. All participants were sent times and location details for their particular group (Appendix E).

Data collection Procedures

Two main types of data collection methods were used for the two different spheres of the study. The first method was life history interviews. Importantly, pilot interviews were conducted before the main data collection phase. These are discussed below.

The second data collection method was a focus group. In addition, a journal was maintained; this too, contributed to the data set.

Pilot Interviews

The importance of pilot interviews cannot be underestimated. The pilot enables the researcher, the research tool and the equipment to be tested. As Kvale (1996) states "conducting several pilot interviews will increase the researcher's ability to create safe and stimulating interactions" (p. 147). If possible, the pilot interviewees should be as similar to the intended study participants.

For this study, two interviews were undertaken in respect of the life history interview. The first pilot interview undertaken was with a woman who was similar to the final participants as she had a long history of mental illness. She volunteered to take part as a pilot via a colleague. The "grand tour" question (Spradley, 1979, p. 86) was used. Although much relevant data was shared, this interview focused mainly on the participant's illness experiences. It lasted for 40 minutes. It was felt following this experience that more time should be spent introducing the topic to the participants, to underline my interest in the women's lifetime of experience. Therefore, a second interview was completed, again using the grand tour question but with a longer introduction by myself. This seemed to work more effectively. The second pilot interview was undertaken with a colleague. The need to seek clarification at times was highlighted. This interview lasted 90 minutes and produced greater breadth than the previous pilot. Some difficulties were experienced with equipment during this pilot, highlighting the need for familiarity with the equipment and to carry a spare microphone and a back-up tape recorder (Easton, McComish & Greenberg, 2000). The need to plan in advance was also reinforced.

Life History Interviews

The purpose of interviews is to discover what is in, and on, someone's mind. Interviewing aims to access the perspective of the person being interviewed (Patton, 1990 p. 278). Maykut and Morehouse (1994) stress that the use of interviews to illuminate salient features of culture and human experience has a long and established history (p. 80). Kvale (1996) agrees. However, he proposes that the significant change is that qualitative interviews are being seen as research methodologies in their own right.

Life history can be used to increase our understanding of how particular people experience and adapt to major life events (Clark, Carson & Polkinghorne, 1997). The life history interview was judged to be a valid tool for data collection for this study, as it explored women's lives. Geiger (1986) identified life history research as a "method for the broader deeper understanding of women's consciousness, historically and in the present" (p. 335). She argued that the method provides an outstanding resource for studying the life of women in their own contexts, cultures and across their life stages. Similarly, Denzin (1989) acknowledged that research demands that the voices of women speak through the interpretative text (p. 27). Opie (1992) stressed the need for the researcher to recognise her own process of appropriation and not to treat women as a homogenous group. These issues were kept to the fore to encourage participants' voices to remain central to the study.

Atkinson (1998) states that "the less structure a life story interview has, the more effective it will be in achieving the goal of getting the person's own story in the way, form and style that the individual wants to tell it in" (p. 41). Opie, too, suggests that the use of interviews free of rigid interview schedules can benefit the individual. The unstructured interview can result in greater breadth than other types of interviews. It was used in the first instance "to understand the complex behaviour of members of society without imposing any a priori categorisation that may limit the field of inquiry" (Fontana & Frey, 1998, p. 56). This mode of unstructured and responsive interviewing, if used reflexively, can enable socially marginalised people to be empowered, as it assumes they can contribute in a significant manner to the description and analysis of a social issue.

Women in this study were considered to belong to such a group. However, following the strategy of an unstructured interview can raise some thorny issues. Participants' narratives may reflect their past experiences of being asked to tell their story within psychiatric contexts. This can result in the dominant themes being repeated and little new information being revealed. Similarly, participants may actively select what they reveal to the interviewer. However, this is also the case for semi-structured and structured questions. In the case of my research, it was judged that the strength of the unstructured interview outweighed these concerns.

The first interview asked a "grand tour" question (Spradley, 1979): "Tell me your life history." During the first interview, the researcher sought clarification by using probes where necessary, for example asking, "When was that?" No other questions were asked. This allowed the participant to tell their story in their own way, in their own words.

Following transcription of the first interview a copy was forwarded to each participant. This offered an opportunity for member checking and for each to add to or alter their transcript. For the most part the participants altered little. Two participants returned letters with their transcripts with additional thoughts on the process and what it had meant to them. These letters were added to their data set.

Second round Interviews

The second, follow-up interview was semi-structured in format. It covered three main aspects: a review of the participants' biographical details, the presentation of the initial themes via the concept map and, lastly, questions of a retrospective nature and questions with a future orientation. These questions (found in Appendix F) were included to address more specific questions. The concluding questions asked participants to review how being in the study had impacted on them, and offered them an opportunity to add any additional information. Importantly, the final question asked if they felt the researcher's presentation of their life was recognisable to them. The content of several of these questions acted as a form of triangulation with the first round data. The opportunity to ask follow-up questions was available at the second interview. However, with each of the participants, follow-up questioning was individually geared and shaped by the women's responses and openness to further questioning.

The biographical details were derived by searching the first interview transcript for named chronological information. This included any mention of the respondent's age, as well as particular dates and specific time periods they identified. The data elements were arranged chronologically and the event or experience described from the transcripts. This chronological review was used at the start of interview two as a way of re-orientating the participant to their previous information.

The second aspect presented was an initial analysis of the themes arising from interview one. A concept map was developed for each participant. This aimed to enable convergence on the person's life story. The process was used to identify which elements of the life history were contributing to the individual's story. Copies of both the chronological overview and the concept map were given to each participant. (An example of a concept map forms Appendix G). The third component of the follow-up interview asked a range of questions of each of the participants. These questions were retrospective and future looking in nature, allowing the participants both to look back and to think forward.

In both the interview situations, when a natural end to the interview was reached, participants were asked for their final thoughts or whether they had anything they wished to add. Following the formal closure of the interview, time was always built in for the researcher to spend with the participants to wind down from the emotional intensity of the interview (Rubin & Rubin, 1995). Verbatim transcripts were also completed following the second interview. These were added to the data set, which consisted of interview transcripts, biographical data, the concept map and relevant reflective journal entries and letters.

The Focus Group Method

Focus groups have become an increasingly used research method within health and social contexts since the 1990s,"focus group" being a 1990s term (Then, 1996). The group interview, however, has a much longer history with a recorded use dating back to 1920s. It received little attention until the 1940s and then was used as a market research tool to gain group members' thoughts and feelings regarding a specific product (Holloway & Wheeler, 1996).

More recently, the focus group has become a research method used in a variety of ways. Initially it was used as an adjunct to other research methods as a way to explain the "why" behind the numbers produced in quantitative research. Nyamathi and Shuler (1990) support this view, suggesting that the focus group generates "detailed narrative data as opposed to numerical data" (p. 1282). The focus group method is currently used to explore poorly understood areas: to generate constructs and hypothesis, to explore the meaning of behaviour and to develop research instruments. Examples of focus group research have included aspects of consumer satisfaction and quality assurance within health care. It has also been used extensively in health promotion (Sim & Snell, 1986).

Recently, focus groups have been advocated as a suitable method for occupational therapy research (Hollis, Openshaw & Goble, 2002). Some examples of the field are briefly reviewed. Toomey, Nicholson, and Carswell (1995) made use of focus groups to investigate the clinical utility of an assessment, namely, the Canadian Occupational Performance Measure (COPM). Nineteen therapists participated in four focus groups to examine why some of the therapists used the assessment and others did not. Within this study, each group generated themes for discussion by the group that followed, thereby allowing for confirmation, refutation or expansion. Analysis, then, was ongoing throughout the data collection phase. A further plenary session was held with all focus group participants as a feedback session. The authors found the method successful, but felt that the time allocated for each group, one hour, was a restriction on the depth and breadth of discussion within the groups.

Corring and Cook (1999), occupational therapy educators, provide another example, again from Canada. They utilised the method to discuss with mental health service users their meaning of client-centred practice. Three focus groups were conducted with 17 participants taking part. The groups were audiotaped, transcribed verbatim and then open coded. Following analysis, the emergent analytic categories and sub-categories were presented to participants as a form of member checking. The authors felt that the focus group method had been useful in eliciting a depth of understanding from the clients' perspectives that had not been found previously.

Hollis (1997), in an UK example, made use of focus groups as a means of elaborating the variables associated with the clinical performance of occupational therapists. Three focus groups were conducted over a two-month period. The total number of participants involved is not specified. The focus groups' proceedings were all transcribed. Analysis initially concentrated on answering the main questions before moving to a more interpretative approach. Hollis found the method enabled the focus of her study to be addressed, with insights gained into the variables that constitute clinical ability. She did express concern that within the focus group members were susceptible to peer persuasion, but felt this would have been more of a problem if only one group had been conducted.

Gray-Vickrey (1993) believes that "focus groups are best suited for exploratory studies in which a researcher is learning more about a specific phenomenon" (p. 21). Asbury (1995) agrees, but adds that it is a way of gaining understanding from the perspective of a specific population. In the case of my study, both these elements the specific population and the specific phenomenon were essential. The focus group explored occupational therapists' (specific population) perceptions of the women with severe mental illness (specific phenomenon). Reiskin (1992) supports the notion of using focus groups to get in-depth explanations of data previously collected, as in this study. Morgan (1997) concurs, indicating that individual interviews can "help generate group guidelines" (p. 22).

Basch (1987) defined the focus group method as "a qualitative approach to learning about population subgroups with respect to conscious, semi-conscious and unconscious psychological and socio-cultural characteristics and processes" (p. 411). Kitzinger (1994) describes it as "focused in the sense that it involves some kind of collective activity...debating a particular set of questions" (p. 103). The strength of the focus group is the production of data that presents more than one voice. The focus group members, it is hoped, will develop the subject under discussion. This can lead to new perspectives or the development of concepts as a result of group interaction and group processes. Holloway and Wheeler (1996) stressed that the production of data is through the social interaction, as informants build on each other's views. This is the prime advantage of focus groups, as they explicitly utilise the group interaction to "produce data and insights that would be less accessible without the interaction found in a group" (Morgan, 1997, p. 2).

In this study, video recording was used to capture the group dynamics demonstrated. Other advantages of the focus group include the fact that informants' perspectives can be validated and clarified during the process, allowing development of the topic and spontaneous discussion (Butler, 1996). In addition, transcripts were returned to focus group members for each to confirm that the transcript was a valid record of the session. This process also provided an opportunity for participants to add any additional information. The method is relatively cost-effective, compared, with say dyadic interviews, as respondents are in a group. The focus group is also generally seen as a safe forum for the expression of views (Vaughn, Schumm, & Sinagub, 1996).

On the other hand, this method is less easily controlled than dyadic interviews. Groups may digress from the topic, the groups may vary, and the data can be difficult to analyse, particularly if informants speak over each other (Then, 1996). Ideally, two or more groups need to be conducted. Morgan (1977) advocated that two groups provide "much safer ground than one group in concluding that the group dynamics were not responsible for the content" (p. 44). Kitzinger (2000, personal communication) recommended four or more groups, although, this may increase the expense in terms of both time and money. Kitzinger (1994) has raised a significant criticism: that focus group research often fails to capture the different voices and the interactions among the participants. She advocates that rich quotations in the findings, and where possible dialogue between the participants, be included in order to illustrate the dynamics of the group.

Groups should generally be from 4 to 12 members; the smaller size is recommended as it allows for more individual talk time, especially when the participants are interested in the topic and respectful of each other (Tang & Davis, 1998). The group members should have equal status. Kingry, Tiedje, and Friedman (1990) argue that the key principle in forming a focus group is homogeneity, with members also being unknown to each other beforehand. However, Holloway and Wheeler (1996) propose that this is not necessarily the case noting that "familiarity between participants can be useful" (p. 147), as it reduces the need for warm-up time and allows a more immediate focus on the topic. For this study, the group members were all occupational therapists from a specific NHS Trust. This common professional background provided a shared foundation from which all participants started. Nonetheless, it was possible that beforehand participants only knew group members as names on a staff list.

For this study, four focus groups with women occupational therapists were conducted in order to enable different grades of staff to be accommodated and to ensure the equality of all members. This was felt to be necessary as less senior staff members might have felt "unsafe" sharing their views with immediate supervisors. The single sex group has been found to have a greater diversity of ideas than mixed sex groups, which often result in conformity to traditional social roles among the members (Holloway & Wheeler, 1996). Informed consent was sought for all participants and anonymity assured both in the transcript and in future publications (Appendix D). Twenty-eight occupational therapists who met the criteria were contacted with a view to taking part in the focus groups. Three therapists indicated they would be unavailable at the time of the study. Nineteen therapists agreed to take part. There were six non-respondents. Participants indicated their availability for either a morning or an afternoon session of two hours maximum. A final confirmation letter was sent to the participants with location and timings (Appendix E). Four groups were held over a two-day period. In total, 16 staff participated in the groups. One therapist withdrew before the groups took place. During recording, two therapists were unable to attend because of personal commitments. The final groups consisted of two groups with five therapists and two groups with three therapists. All were conducted in December 2000.

The role of the facilitator or moderator is important in creating a safe environment and facilitating interaction. Ideally the facilitator should have group leadership experience and be able to draw more reticent members into the discussion. The aim is to encourage discussion between group members, not just between the facilitator and the members. A balance needs to be struck by the facilitator between active and passive roles. Morgan (1997) warns that the researcher's interests must not lead the participants to "reinforce or confirm a prior hypothesis" (p. 347).

In addition to the facilitator, this study made use of an observer for the first two focus groups. The primary observer role was to review the role of the facilitator and to take notes on the facilitator's performance and adherence to the questioning route. The observer was experienced with group dynamics. With the first two groups the observer was also able to contribute to the post-group debriefing. Krueger (1994) recognises that this contribution can be "extremely helpful" (p. 104).

Practical issues were considered such as location were carefully considered. A comfortable and neutral setting was preferred and accessible studios met these criteria. Timing was considered to allow maximum participation by the members. Two-hour morning or afternoon sessions were decided upon, with participants selecting the most convenient time for them. Refreshments for the participants were made available on their arrival at the studio.

The type of recording equipment used was also considered. Although video equipment can be seen as being intrusive, it has a distinct advantage over audio recording as you can see who is talking, and it becomes possible to capture the non-verbal as well as verbal communication. In audio recording, the facilitator must make a record of who speaks, which can distract from the group process. Video recording was the preferred option for this study, as it enabled the non-verbal communication and group interactions to be analysed in addition to the text. The format used was a "u- shape". This enabled a camera to be placed behind the facilitator, giving a full view of the group members.

Before the focus groups, were conducted the following protocol was completed (Appendix H). At the beginning of each group, members were welcomed and introduced to each other. The group's purpose and ground rules were set out. The importance of confidentiality was restated. The ground rules indicated that

- members' perceptions and views were important
- each participant's views were valid
- knowledge was not the issue.
- there were no 'right' or 'wrong' answers.

Structuring the focus group questions

Krueger's (1994) "questioning route" (p. 54) was used as a guide to structure the group. This comprises opening, introductory, transitional, key and ending questions. This route is advocated for researchers new to focus group research as it provides a planned framework for the sessions and allows a sequence to be followed, moving from general questions to specific questions dealing with the core of the study (Appendix I). In determining the questions, Asbury (1995) suggests that an initial, opening question should be put to the group to allow all members to respond. It is designed to be answered quickly: seeking known information about the participant, for example "Can each of you tell the group where you currently working with women with enduring mental illness and how long have you been in that post?" This opening question was designed to introduce the topic of women with severe mental illness in a non-threatening manner. The introductory question aimed to acquaint the participants with the topic for discussion (Kingray et al, 1990). In this study, "What interventions do you utilise in working with women with severe mental illness?" This gave the participants an opportunity to begin to draw on their own practice and to interact with each other.

The transitional questions sought to move the conversation toward the focus of the study. They served to link the introductory with the key questions. These were introduced to the group members as exploratory questions around gender issues. These enabled participants to become aware of others' experiences and views.

Krueger (1994) suggests using two to five key questions directly related to the aims of the study. This study used data derived from the phase one findings, the women's life histories, as stimulus material (Appendix J), thereby enabling participants to consider and explore women's lived experience of enduring mental illness and services. These questions covered several areas, including occupation, women's roles, meeting needs, safety issues and finally, educational issues.

The closing questions were vital to the study as they helped group members reflect on what had gone before. Krueger (1994) identified three closing questions: the summary, all things considered, and the final question. For this study the order of these questions was altered. Following a verbal summary of the key questions and responses, the group was asked, "Is this an adequate summary of the session?" This question was the last opportunity for the facilitator to put an overview of the study to the members. Following this, the all things considered question asked, "Have we missed anything?" This is an important question, particularly at the start of a series of groups. It can identify gaps or test the structure, for example, to determine if it is logical and complete. The final question allowed participants to put forward their own view by asking them "What for you was the most important aspect raised in this group's discussion?" Importantly, as with the individual interviews, follow-up questions could be asked within the course of the focus groups. Follow-up questioning was stimulated from the therapists' responses within the focus group.

The group session was concluded with a restatement of confidentially and anonymity issues. In addition, members were informed that transcripts would be forwarded to them for member checking and that the findings would be shared with them in due course.

Reflective Journal

A reflexive approach was central to this study of qualitative data and should not be considered as separate from it. Researchers must strive to be aware of, and recognise, their own influence on the process. One way of addressing this is the use of a journal. Lincoln and Guba (1985) suggest that the journal should be kept throughout the research process and should include three components: a daily schedule, practical issues, and personal components.

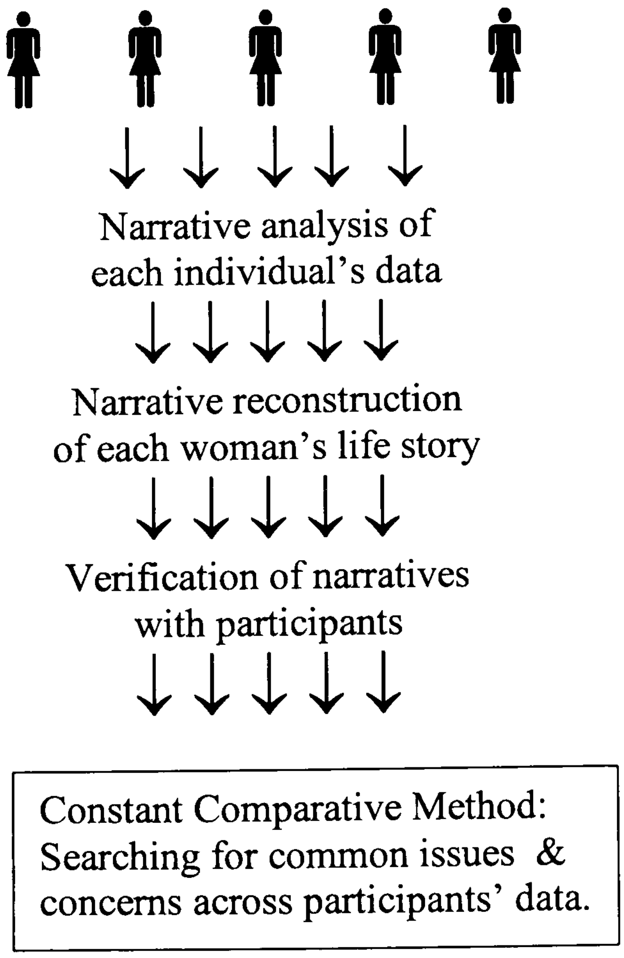
The third is similar to a personal diary, reflecting the researcher's thoughts and feelings as generated by their involvement with the participants. It also included questions that arise, difficulties or any dissonance experiences as the research progresses. Moments of frustration should also be included. This strategy aims to keep the researcher alert to bias and preconceived assumptions that may impact on the work. The recording of these personal insights should allow the researcher to walk through their own research journey, making the process transparent to others. Such awareness leads to changes in behaviour or style that can have the effect of opening up the research process.

This section has reviewed the main data collection methods and outlined the procedures utilised. The following section will discuss data analysis procedures for the two distinct studies within this research.

Section Three: Data Analysis Procedures

This section presents the data analysis procedures related to Phase 1 and 2 of the study. There were two distinct analysis strategies employed for the Phase I data. The first phase looked at the data vertically, with the focus on each woman's unique life (Figure 1). The narrative analysis method was used as a means of analysing the data from the women's transcripts, which led to the creation of a narrative representation for each participant. The next phase utilised the Constant Comparative Method to discover common themes and concerns horizontally across the participants' narratives. This method was chosen as it offered a clear path for engaging in analysis of significant quantities of data. Glaser and Strauss (1967) devised the method, while Lincoln and Guba (1985) later adapted it. The method facilitates an inductive approach to data analysis, allowing for important themes to emerge from the data through inductive reasoning. This method was also used in relationship to the focus group's findings. The narrative analysis method will be considered first, followed by an overview of the constant comparative method and its use within this study.

Figure 1. **Analysis Procedures for women's data**



Narrative analysis

The literature shows two distinct approaches to the interpretation of narratives: analysis of narratives and narrative analysis. Polkinghorne (1995) explains the difference between them thus he builds on the concept put forward by Bruner (1985) that there are two ways of knowing: cognition and narrative. Cognition is seen as recognising the data elements as members of a category, whereas narrative is considered as the organisation of elements into an emplotted story. The cognition approach, most often used in qualitative research, uses analytic procedures which produce categories of stories similar to the work of Davies (2001). Her work, highlighted previously, utilised three distinct frames to shape the participants' experiences. Narrative analysis, on the other hand, uses analytic procedures to produce explanatory stories from the data, stories which consist of actions, events and happenings. The resulting story is temporally organised.

Polkinghorne discussed how analysis of narratives in qualitative research was seen to be the norm. He argued that this need not be the case. He believes that the schematic representation of data as advocated by Miles and Huberman (1994) leads to decontextualisation of the data. He stressed that the story was the most suitable manner to represent the linguistic form in which human experience, as lived experience, can be expressed. He is concerned with narrative as story and story usage in qualitative research. Plot is seen as being the key narrative structure, enabling understanding and relationships to be described. The paradigm of cognition is good at addressing the question, "What is common?" The similarities among participants are revealed. Narrative, in contrast, focuses on the particular and unique characteristics of each participant. Polkinghorne advocates narrative analysis as opposed to analysis of narrative; however, he does recognise that there has been less attention given to the procedures for analysing the collected data. He suggests that the following questions be asked of the data "How did this happen? Why did this come about?"

Polkinghorne presents an adaptation of seven criteria for life history originally developed by (Dollard, 1935): these criteria are culture, embodied nature of the protagonist, significant others, central character, history, generation of the story and the production of a plausible and understandable plot. The final plot must be reflected in the original data. Polkinghorne (1995) identifies steps for the completion of the narrative analysis. This involves placing the data elements into time order (time line) and identifying the elements which contribute to the outcome, the emplotment.

In relation to this study, narrative analysis as described above should produce a unique and distinct story of each woman's life. The task initially was for me to discover a plot that linked the data elements. These elements would then become parts of the unfolding temporal narrative that moved the story towards its conclusion. Therefore, narrative analysis was decided upon as the way ahead for the first level of analysis as it would create unique, individual and contextualised life stories. Before this process was conducted data had to be formed into a data set. The data set included transcripts, my reflective journal, and any additional women's comments.

Organisation of data for analysis

To form the data set all interviews were transcribed into verbatim transcripts. All transcripts were word-processed by myself. It is acknowledged that in any study, however complete the text, some deformation occurs, thus emphasising the selectivity and incompleteness of any account (Reissman, 1993). Therefore, the researcher must be reflexive, and seek to challenge their own position in relation to the data. The journal entries related to each participant were photocopied. This process is displayed in Figure 3. All data was coded, enabling identification of the following.

1. The type of data: transcripts, reflective journal.
2. The data set: which participant it related to.
3. The source where it would be found.

For example, T1M1 identifies the data as being Transcript one (T1); the data set is concerned with participant (M), the source is page one (1). Once the data was coded it was photocopied in a different colour. The original data set for each participant was stored securely. This process preserved the original data intact, enabling data units to be examined in context throughout the process of analysis and interpretation.

Figure 2. Building the data set

First interview
↓
Verbatim transcripts
↓
Returned to participant
↓
Initial analysis

Chronological Order
↓
Outcome
Biographical Review

Initial elements identified
↓
Outcome
Concept Map

Second Interview
↓
Transcribed
Data Set formed

Narrative Analysis Procedures

Interpretation of the data set is seen as a process of exploration. As Denzin (1995) puts it, “elements and essential structures are uncovered, defined and analysed” (p. 57). It is important to acknowledge that in reality the process of analysis begins much earlier in the research process than the formal analysis procedure; that is to say, analysis is ongoing from the first interview and this informs what follows. Data analysis can take considerably longer than data collection. From transcription, to the analysis of each participant’s data, to the reconfiguration of the narrative took me on average four weeks to achieve. Data collection, including both interviews, took on average for each woman 3.5 hours for each woman involved in the project.

Dollard (1935) developed a set of criteria for constructing a life history. Although there is some tension in utilising criteria developed in an earlier period and for different purposes, the revisions identified by Polkinghorne (1995) and Frank (1996) produced a useful template to generate the life history of each woman. The seven guidelines outlined by Polkinghorne (1995) are:

1. **Cultural context:** The contextual features that give specific meanings to events. These include: value; roles; meaning systems; accepted and expected personal goals and strategies for achieving these goals
2. **Embodied nature of the protagonist**: including bodily dimensions; height and physique; emotion as body; temporal limits and recognition of end.
3. **Significant others**: Relationships with parents, siblings; spouse; friends, personal antagonists; actions concerned with others' well-being
4. **Central character**: The interaction between the person and the setting. This category encapsulates choices including occupational choices; actions, the person's meanings and understanding; vision of the world; plans and purposes; motivations and interests, and goals.
5. **Historical continuity**: The events which the protagonist has lived through; past and previous experiences; habits; act the same/act differently
6. **The generation of the story**: The power of a narrative outcome is the distinct individual. The temporal period; beginning, point of denouement, specific context, unique individual and particular situations.
7. **Provision of the plot**: A story-line that serves to compose the elements into a meaningful explanation of the protagonist's response and actions. The story is a reconstruction of events that produce a particular outcome. The story ending locates the point from which to select data elements for producing the conclusion.

I took the decision to work with each woman's data individually. Keeping my focus on one person's life history was a way to become immersed in their world and gain understanding of their experiences. Therefore, the process of analysis followed the order of the interviews. Once this was completed I moved to the analysis phase. Listening and re-listening to the interviews during and after the transcription process was an extremely useful way of placing myself back into the participant's story. This, along with reading and re-reading each participant's data, allowed me to gain a sense of the complexity of their lives as well as to start identifying significant happenings. Immersion also included making marginal notes on the transcripts, and giving thought to each of their life experiences; for example, asking myself, "What must that have been like?"

When I was familiar with the person's data and felt I had a "feel" for them, the data set for each individual were systemically read and searched for data elements that matched criteria 1 to 5 above. These data elements were considered as units of data, which were meaningful when separated from the body of the text, such as sentences and paragraphs. When found and identified these data units were marked in the text. Computer files were created for each of the women and for each of the five criteria. A process of "cut and paste" was conducted, placing the identified data units into the appropriate location heading within the computer files. This process was continued until the data set had been completed. This process of identification took place over a two/three day period. Once regrouped under the five headings, the data were searched for important or significant events or periods. These were noted.

During this first analysis, an independent person not related to the study audited part of the data set. The auditor was provided with the full transcript of the first person interviewed, the life history criteria, and the analysis of that data using the criteria. She was asked to review the documents and to consider whether the analysis was appropriate. This form of checking adds a level of credibility to the process of analysis (Cresswell, 1998). On this occasion, the auditor reported that the data and the resultant analysis were consistent with the criteria.

This process created the data into a structure that allowed for the remaining two stages to be addressed. It highlighted the temporal period of each woman's life: the beginning, the specific contexts, and her unique situations. The important aspect of Criterion 6 was the unravelling of the person's story and the search for the dénouement, plot or sub plots that underpinned her life. The data was searched for a statement that seemed to capture the essence of each story. This quote became the title of their story, the use of the interviewee's own words seemed an important way of making the final narrative theirs, and acted as a way of lessening my presence.

The final stage, Criterion 7, involved the re-ordering of the data units into a coherent whole. Polkinghorne (1995) advocates that, "the storied product is a temporal gestalt in which the meaning of each part is given through its reciprocal relationships with the plotted whole and other parts" (p. 19). Having identified the main plot, my analysis then integrated those elements into a narrative with a distinct beginning, middle and end. This process of synthesis, integrating the data elements with the main plot, led to the creation of the particular narratives. This interpretation must be recognisable to the person. They must be able to see themselves in the finished product. Therefore the final narrative was shared with the participant and their reflection on it was included. Emihovich (1995) stressed that collaboration and a constant testing of our meaning against that of others builds a consensus around the shared meanings. Phase One Analysis produced five individual life stories; these and each participant's reflections from Chapter Three. Figure 3 outlines this process.

Figure 3. **Schemata of the Data Analysis Process**

Data Set
↓
Searched for data units
↓
Units placed under life history criteria
↓
Narrative constructed
↓
Narrative returned to participant
↓
Outcome: narrative and participant's reflection

The Constant Comparative Method

The second analysis strategy employed the Constant Comparative method to explore participants' narratives. The data set for each individual was open coded: "the researcher forms initial categories of information regarding the topic by segmenting information" (Cresswell, 1998, p. 57). An account of the constant comparative approach adopted in this study is described below.

Unitising the Data

All data sheets for each participant were searched for units of meanings. These are chunks or units of meaning that stand-alone; that is, the units are understandable without the need for additional information. For this study, units were considered as a paragraph or several paragraphs: these units were constructed by me from the text. Each unit was then assigned a phrase or a sentence that indicated the essence of the unit. Where possible, this phrase or sentence was drawn from the unit, using the *in-vivo* language of the participants in order to maintain the participants' perspective (Strauss & Corbin, 1990). This also served as a strategy to prevent the researcher moving to abstract concepts too quickly. Once identified, these units were separated by drawing lines across the data sheet: an example from Marguerite's transcript forms Appendix K. (This process was assisted by using the word processing package of Windows 98). Richards and Richards (1998) acknowledge "the modern word processor as a flexible and full-featured tool for document exploration and the construction of analysis documents" (p. 222). A file was set up that allowed the units of meaning for each of the women to be recorded; noting whom it concerned, where in the text it was located and the unit of meaning — for example: Marguerite, Page 1: Earliest childhood memory. This process enabled a relatively accessible system of coding and retrieval to be established, allowing for the future location of data in relation to the original data set (Appendix L).

Discovery

The data having been prepared for analysis, the next step was to identify themes that had occurred throughout data collection. These were issues and ideas that had appeared often in the journal and data sheets. Taylor and Bogdan (1984) identified the discovery process as an important first step in data analysis. Eighteen issues and ideas were identified at the discovery stage. This initial coding forms Appendix M.

These topics may or may not have been reflected in the final outcomes of the study. However, they provided a useful starting point for analysis. These were recorded and the data was searched for matches. This resulted in an overview of the strength of a topic across all of the women's data. For example, "survival" — one of the discovery topics, was upheld as a category, as all the women had ideas of survival. However, using this system showed that survival was a particularly strong aspect for two participants, both had several entries under this heading. During the data analysis, some topics were upheld: others were discarded or subsumed. For example, "stigma" and "discrimination" were initially identified as separate aspects, but both eventually became part of the final category "Everybody can understand pain." Matches were separated from the main data and a new file created, recording the text and the participant. For example, the following were initially coded as poor treatment experiences:

Poor Treatment

Helen	I mean you are treated dreadfully with mental illness You were treated abominably you know and I wanted out of that and yet I could not leave.
Pam	It was hellish, I hated it because for that two/three days I didn't feel like I belonged anywhere. You could cry your heart out over there and none of them would bother coming near you. I saw a patient being hit and all the rest of it.
Pat	"Don't bother us we're busy". They weren't doing anything they were just sitting drinking tea..."We're busy". You could stand there for hours waiting, then they would shut the door on you. You'd knock on the door and get, "For goodness sake stop bothering us, go away we're busy".
Marg.	Sometimes your not treated very well. It is difficult to sort of specify. There's other ones I maybe don't want to remember. I don't think I could say I was ever physically struck, but they way some people spoke to you, it's like you were a second class citizen.

The next step was to identify the themes that were central to the analysis. What factors were common to all? What differences between the women's experiences emerged? This process aimed to clarify meanings and explore the relationships with other categories that arose. The adapted Glaser and Strauss (1967) Constant Comparative Method was used to guide this process (Figure 4). This model combines inductive category coding while noting comparison across all units of meaning.

This process, adapted by Lincoln and Guba (1985), required the researcher to examine each item of data and then code the data into specific categories. From this process, similarities and differences between the data were highlighted, patterns and structures were refined, and the data units were then categorised into look-alike/feel-alike categories. The above example was coded into the category "You could cry your heart out over there," emphasising the women's negative treatment in hospital.

Figure 4. Constant Comparative Method of Data Analysis

Inductive category coding and
Simultaneous comparing of units of meaning across categories
↓
Refinement of Categories
↓
Exploration of relationship and patterns across categories
↓
Integration of data yielding an understanding
of the lived experience of enduring mental illness.

Having grouped the units using the look-alike/feel-alike criteria, these were examined to identify similar characteristics from within these clustered groups. A rule for inclusion was then written to portray the meaning found in these groups of data. Rules for inclusion were written as propositional statements. Taylor and Bogdan (1984) state "a proposition is a general statement of fact grounded in the data" (p. 134). These rules aided clarification of what information was included in or excluded from the categories. Data analysis continued until all the data had been placed in a category with a rule for inclusion. For example, the inclusion rule for "You could cry your heart out over there!" represented data that covered the participant's experiences of care, both negative and positive.

This process resulted initially in the development of 27 categories and rules for inclusion (Appendix N). As the analysis progressed, three of these categories (5, 7,14) were subsumed into other categories because of their similar content. Again these were located in a Word file for ease of access.

To increase the credibility of the process at this stage, the coding and results were viewed and cross-checked by an external reader — a researcher, not directly involved in this research. There was agreement that the resulting categories and rules for inclusion were derived from the data. Further interpretation of these categories resulted in 11 main themes being established. These themes were explored and relationships established, resulting in the major findings being identified. Further refinement led to six key dimensions being identified into which the 11 themes were incorporated. The category "You could cry your heart out over there!" became part of the sub-theme *Talking Back*, which became part of the theme *Illness Transitions.* These themes, together with supporting narrative extracts, will be presented in Chapter Four.

Focus Group Analysis Procedures

When considering which methods to employ to analyse focus group data Krueger (1997) proposed that any analysis should be systematic and should have two dimensions. The first considers how data are collected and subsequently handled. The second deals with the process the researcher adopts. He acknowledged that the process might vary from study to study. Both dimensions require the researcher to "follow a prescribed sequential process" (p. 127). It is important to note that focus group procedures produce a large amount of data including the focus group data and fieldnotes.

The first step in the analysis sequence was the recording of fieldnotes: these were made following each group. This procedure acted as a form of analysis directly after data collection. To aid this debriefing, the researcher considered the following questions as suggested by Krueger (1997):

1 Usefulness of the questions – any revisions
2 Most important themes
3 Most noteworthy quotes
4 Comparison and contrast of the group with previous groups.

As an observer was involved for the first two groups, this individual was also involved in the two debriefing sessions immediately following the first two focus groups. Following the first debrief session, an additional question was added to the final question area regarding education. This question was then asked in Groups Two, Three and Four. No other revisions were made to the questioning route.

The decision was taken early on to use transcript-based analysis. Although it is the most time-consuming approach, it "offers the most rigorous approach" (Krueger, 1997, p.143). In this study, transcripts produced 70 pages of data plus field-notes. The transcribing process for the four groups took 40–45 hours. As people do not speak in tidy sentences, the transcripts were often "messy". The decision was taken and shared with the participants that if the transcript were "messy" some minor editing would occur as long as it did not change the meaning. In addition, the transcripts were returned to all group members for clarification with a clear instruction — if they wished to include thoughts occurring after the end of the groups, then these comments could be attached to their returned transcripts. Any amendments noted by participants were corrected on return to the researcher. Any additional comments from group members were acknowledged as such in the final report.

To begin the analysis, the four group transcripts were photocopied on to a range of coloured paper to assist in identification during the cut and paste stage of the process: Green Group I; Blue Group 2; Pink Group 3; White Group Four. In dealing with a large amount of data it was necessary to focus the analysis on the transitional and key questions, as these were the areas of primary concern. These four transcripts were now separated and collated under the transitional and key question areas. The process suggested by Krueger was now used to guide the analysis process. The collated transcripts were initially read one question at a time, to look for recurring issues. This process involved reading the pasted transcripts and noting any observations in the margin, a method described as "editing" by Crabtree and Miller (1992, p. 94). This procedure was aided by use of a Word file to store and locate the codes arising from each question area. These observations were then re-organised into categories that were further interpreted to produce the main findings in relation to a specific question.

Krueger (1997) recommended that the data set should be subjected to a procedure to examine the total data set for themes. The constant comparative analysis process described previously was used for the examination of the data set. This process used as its starting point the overall findings from the exploration of the individual focus group questions, which form Appendix O.

Some of these topics may be eliminated from the final outcomes of the study. Five other headings were added to this initial discovery list as they either appeared in my reflective diary or were recurring topics in the data. The five were: education, personal safety, resources, loss of roles and the medical model. The previously coded data was searched for units of meaning that matched the above areas. Any such matches were separated from the main data and a new file created.

Following this process, the next step was to examine the provisional categories. This process aimed to clarify meanings and explore the relationships within and between categories. As this process continued, the categories were reviewed using the look-alike/feel-alike criteria. This led to categories being differentiated. Categories with similar characteristics were then clustered into groups. A rule for inclusion was then written to portray the meaning found in these groups of data. Rules for inclusion integrate the categories and present possible hypotheses, for understanding the findings. Data analysis continued until all the data had been formed into a category with a rule for inclusion. This resulted in the development of 19 categories and rules for inclusion (Appendix P). These were located in a Word file for ease of access.

Further interpretation of these categories, resulted in 5 main themes being established. These themes sought to capture the perspectives of occupational therapists working with women with enduring mental illness. These themes, supported by quotations and, where necessary, longer excerpts and dialogue, will be presented in Chapter Five.

Following data analysis, an external audit of the focus group data was undertaken. The individual who was the observer acted as an auditor for this phase of the research. It is acknowledged that someone with no connection to the study would be an ideal auditor (Cresswell, 1998). However, it was felt that in this instance the individual's involvement as an observer would be beneficial in understanding the focus group process. The role, this person was asked to undertake was an amalgam of an external auditor and peer reviewer; their responsibility was to keep the research 'honest'. The reviewer was sent all the raw data pertaining to the focus group research, including the four videotapes, the transcripts, the phases of the data analysis and the initial draft of the focus group findings. The auditor's task was to assess the findings, interpretations and conclusions, ensuring that all were supported by the data. This process allowed for inter-rater reliability to be enhanced (Cresswell, 1998). The auditor was provided with a set of instructions and asked to address related questions (Appendix Q). This auditor who was selected on the basis of her familiarity with the field contributed positively to the review process in a variety of ways. She identified a range of issues, she confirmed the analysis and interpretation, and in addition, she also posed further questions. She identified aspects that I had failed to highlight across the data set. For example, with Group Four members she highlighted that they "felt" protective and responsible for women in their care, and this had not been included in the summary of their group. With the categories created, the auditor made additional links: for example, within "Power Issues" she identified that "things done to people" should be included in this category. She also confirmed findings. Commenting on the lack of recognition of gender by therapists, she found this to be "amazing and quite shocking." She raised the possibility that the results might stem from the particular "setting" and queried whether this result would be the same if conducted in other UK cities. She questioned the therapists' lack of responses to issues in their practice in working with women. Why was this the case? The auditor's contribution to the process was very useful.

The final findings from the focus groups were forwarded to all the therapists for their information and with some additional questions for comment (Appendix R). Six of the sixteen therapists returned comments.

Conclusion

This section has reviewed the data collection and analysis procedures employed for both phases of the research. The results of the analysis and interpretation will now be presented. Chapter Three presents the individual narratives of the women from phase one of the study. Chapter Four considers the themes across the women's lived experience of enduring mental illness. Finally, Chapter Five presents the findings from the focus groups.

CHAPTER THREE

The Findings – The Narratives

Introduction

> "It is hard when looking at the pasts of other people to understand the finer points to their lives. It is difficult to know the exact shadings of dates which were never written down and to know the intricacies of events we have not lived though ourselves but only viewed from the distances of time and space." (MacLeod, 1999, p. 62)

It is acknowledged that the recollection of one's life history, is as identified by MacLeod (1999), a process that may lose detail in the retelling. Indeed, it could be argued that no version constructed by another could truly represent an individual's experience. Notwithstanding this, the task for the researcher is to glean the essence of the significant events and relationships that shaped the narrator's being. In so far as this is the case, what follows is my interpretation of each participant's life history. I have through the use of the life history criteria, created a narrative that synthesises my understanding of the important events and turning points in each of the women's lives, using their words to capture the core and substance of their experiences and memories.

The narratives were constructed by using the life history criteria as a template, as described previously. The process for the development of each narrative followed the same procedure and took on average four weeks to complete. This time period commenced with the transcription of second interviews; it included the re-organisation of the raw data into the life history criteria, the consideration of the elements within each of the criteria, the outlining of the plot and the final production of the narrative.

The narratives that follow do not present first person accounts of the women's lives. As a model this might appear to be an ideal but the data collected required processing to enable a coherent account to emerge. In reality, even a first hand account involves selection and refinement by the teller. Nor are the womens' lives presented as a collection of quotations. It could be argued that a selection of freestanding quotations could represent the women's perspectives; however, I believe that such an approach would be fundamentally reductionist and the selection of the quotations from outside the context of the individual would be highly reliant on my personal stance and perspective. An alternative approach would have been to present the women's transcripts in full. This option was rejected at the outset because it was not felt to be a suitable method for an academic dissertation. Therefore a collaborative methodology was employed; this ensured the involvement of the participants throughout the research process. Their views, concerns and in some cases amendments have been sought at all stages and their personal reflections on my representation of their narratives conclude each of their stories. These are presented as boxed text to highlight their perspective.

This chapter will present the five narratives of the participants in the study. Each narrative consists of three elements: an outlined plot, a biographical overview, followed by the narrative. All of the participants' narratives are included, as a cornerstone of the study was to explore and present each woman as a unique individual. The wider socio-cultural and historical perspectives are embedded in each of the women's narratives. You may feel that this representation does not provide enough context; however, this is a way to see the woman's own story, a strategy to bring her to the fore without the backdrop obscuring her life. Table 3 gives an overview of some characteristics of the participants at the time of interview.

Table 3. Characteristics of the participants

Number of Women	(n=5)		
Living with	**Marital status**	**Employment**	**Diagnosis**
Partner 1	Single 1	Voluntary work 3	Manic depression 2
Alone 3	Divorced 3	Part time work 2	Depression 2
Other relatives 1	Widowed 1	Full time work 0	Post traumatic Stress 1

The narratives are presented in chronological order; in other words, the first person interviewed is presented first. The chapter concludes with my own reflections on this process. All the names have been changed except in the case of one woman who wished her story to bear her name. However, all other names have been changed. Quotes included are supported by a location key, for example:

T1M3 denotes Transcript One, Marguerite: Page Three,

L1M1 denotes Letter One Marguerite Page One.

Marguerite's Story

"I've had a few blips…but I'm still here"

Beginning: A peaceful beginning?

WW11 finishes M born

Her earliest memory

School days

First breakdown

Transition from school to work

First admission

Linda's birth

Leaving it all behind

Middle – A different life: Storms and calms

Moving to parents

Picking up the pieces

Maintaining contact with Linda

Working/illness

Life's dilemmas

Caring for Parents

End – Peace of Sorts

Retirement

Developing relationships

New beginnings

Marguerite's

Biographical Data

1945	*Birth*
1949	*(4/5)* *Earliest memory, living in town*
1950	*(5-8)* *Moved house* *New school remembers the opening. Lice at school.*
1953	*(8)* *Joined the Girls Guildry*
1955/56	*(10/11)* *Sister had a breakdown*
1958	*(13)* *Just started periods, was 'misbehaving'. Doctor prescribed medication.*
1961	*(16)* *Stopped attending secondary school – mum found – out given a choice go back to school or get a job.*
1961	*Two job choices: Civil Service/City Corporation. Picked Civil Service. Joined the Inland Revenue.*
1962	*(17)* *First admission to hospital, had ECT. Went to Germany with a friend on holiday in July. Made permanent at work*
1963	*(18)* *Met future husband at dance.*
1964	*(19)* *Got engaged*
1965	*(20)* *Got married*
1968	*(22)* *Birth of daughter. Home a week then admitted to hospital*

1968/69	*(22-24)* *In hospital for nearly two years. Only home at weekends. Mother-in-law cared for daughter. Did not seek custody of daughter.*
1969	*(24)* *Left hospital, moved back to stay with mum and dad. Got a shop job. High dose of medication. Window Incident - seriously ill*
1972	*(24-28)* *Spent long time recovering at home with parents.*
1972	*Job in head office of a shop chain, clerical work – made a friend in this workplace.*
1975/76	*Job at an accountant's office. Met chap, got pregnant* *Brother offered to help, got a termination via NHS* *Left that place of work.* *Driving by this time. Spell of not working.*
1976	*(31)* *Job in corporation. The manager knew of her illness but not on application form.*
1977	*(32)* *One year there, interview for new job within the corporation.* *Ill - Back in hospital - off work again.*
1978	*Parents moved house. Promotion an issue. Ill again - On return to work, moved to a different department.*
1979	*Moved to new area. Promotion, bit more responsibility, there till 1991.*
1982	*Dad died in January, Further breakdown in September/October. Last hospital admission. Still on lithium.*
1993	*Mum died (92)*
1996	*Retired at 50*
1996-99	*Still working, some temping, I year course-studying business technology. Some after-school care work.* *Back to hospital every six months. Medication an issue.*
2000	*(55)* *Living in Glasgow, new job, feeling content.*

Marguerite's Story

"I've had a few blips...but I'm still here"

A peaceful beginning?

Marguerite was born on the 30 May 1945, just three weeks after the end of the war in Europe. Although the country was at peace Marguerite's life would not be peaceful. Mum came from Aberdeen and her dad from Kirkcaldy and they lived in inner city Glasgow. Her mum was in her forties when she gave birth to Marguerite. who was the youngest of five children. She had three elder sisters and a brother. Another brother had previously died of diphtheria. She described her parents. "Mother was kind of highly strung, my dad, we think he suffered from severe depression which was never diagnosed"(T1M5). This insight into her parents may explain this family's unique experience of mental illness. "Out of the five of us, four of us have got a problem, not all exactly the same, it's a pretty high ratio"(T1M5). That there is a genetic predisposition in the family is undeniable. Nonetheless, her core and extended family have played and continued to play a major part in her life. She described "a close, family, quite family orientated. We keep together if anyone is not well, we always keep in touch"(T2M10).

Marguerite spent her early years in a tenement room and kitchen in Glasgow, before moving to one of the new housing schemes on the outskirts of the city. She recalls her earliest memory at around the age of four: "I was getting lifted upstairs from the dentist's (laughs) up to the house. I don't remember anything before that "(TIM1). While she recalls the move to a housing estate, Marguerite has little memory of her early life and activities. More information arises from her school days. She recalls the official opening of her primary school by a Canadian. She was part of the choir for this event. A recurrent problem with head lice figured prominently in her school memories. Church activities, such as Sunday school and the Girls Guildry, which she joined at eight, were her main activities. She enjoyed and still enjoys being part of a group; her choir singing begun at primary school, continues today.

At school, Marguerite enjoyed team games and sports, playing in the hockey and netball teams. She preferred these types of activities to, for example, climbing the wall bars. She liked languages, maths and geography. She recalls whilst at secondary school wishing to take geography but not doing so because she would be the only girl in the class. "Just as you were at that time, you just don't want to be in a class of boys"(T1M2).

As a child, Marguerite witnessed her sister's problems: "I shared a room, I was only about ten, she had a breakdown and I'm not saying that that necessarily caused me to have one but it would have had some sort of effect. Because like in the middle of the night she would be sitting banging her head off the headboard" (T1M5). When the male General Practitioner (GP) was called to her elder sister, "the doctor said there was nothing wrong with her – a good skelp on the backside was all she needed" (T1M5). Here the GP negated her sister's experience of mental illness. This episode is one of the earliest of her family's dealings with their male GP and they experienced a paternalistic attitude.

Marguerite had her first incident of mental illness aged thirteen. She recalls, "I had just taken my periods and I can remember at the end of the year, it was like into wintertime. I don't know I was obviously having problems, misbehaving, and not being right. My mother took me to the doctor. He prescribed something, I can't remember what it was. But it was sitting in a bottle and I was in bed, obviously depressed, or whatever. I took the whole bottle. And my friend, across the back, came over I can remember her walking me up and down the hall"(T1M22). This first episode could be linked to hormonal changes and indeed over the years, including her twenty-year history of admissions, hormonal change could be a significant factor. Marguerite believed that the GP let the family down not realising the significance of the pattern of illness beginning to be evidenced in the family: "I mean, you think if he knows it's in the same family that there's something!" (T1M22).

At sixteen, Marguerite began to skip school. It had started as avoidance of a French test but developed into full-blown truancy. At the same time, Marguerite had a

Saturday job as a cashier in a shop. Following an outburst with a customer she lost her job. She also remembers an incident with her friend where she sprayed hair-spray into her face. She believes that these incidents were symptoms of her developing illness.

Meanwhile, her mother, on discovering her truancy presented her with an ultimatum: either she returned to school or she found a job. She chose to take up a position with the Civil Service in the Inland Revenue. This job involved her working as part of a team. Working in office settings as part of a team would be a pattern of employment throughout her working life. As she was still sixteen, she was able to attend college, on a day release basis, to take the ordinary grade examinations that had just been introduced. She was successful in gaining three passes.

At age sixteen, she had her first admission to the local psychiatric hospital, in 1962. This was the start of a twenty-year history of admissions, with her last in 1982. Her behaviour had become increasingly bizarre: "my sister found me I had no clothes on, ...I wasn't standing at the window or anything. They must have got the doctor who came out. They whipped me up the road" (T2M9).

Marguerite has concerns about her first admission when she was treated with electro-convulsive therapy (ECT) and prescribed "liquid cosh" (the nickname for a major tranquilliser). She continues to wonder if the ECT had long-term effects. Her memories are unclear of this time, perhaps as a result of her illness or the drug treatment or the ECT.

Following her discharge, she went on holiday with a friend to Germany. She remembers being very drowsy, probably as a result of over-medication. She did, however, return to work after the holiday.

This first psychiatric admission interfered with the process of gaining permanent status at the Inland Revenue. She feels it blighted her working life from then on: "I'm sure it had taken me two years, normally it would have been a year before you were made permanent" (T1M6). Since then, Marguerite has experienced many episodes of discrimination, especially in relation to her working life.

Her social life at this time involved the youth club and the "dancing". It was at a dance in Glasgow that Marguerite then aged 18 met her future husband. They got engaged the following year and were married in March 1965, when she was only nineteen. She did inform her future husband of her psychiatric history. She feels now that she was "rather too young at nineteen, I think really I had a lot of growing up to do" (T1M7).

She had another breakdown and in September 1965, during her first year of married life, she was again admitted to hospital. "Again I took some pills and my brother and my husband, I can vaguely remember, I must have been loaded up with them, cause they had to carry me to the hospital" (T2M7). She remembers that symptoms of these early episodes of her illness affected her physically. "I can vividly remember, I was on the cross, I was on the cross… and I was convinced I was Joan of Arc. I had this blue trouser suit, the top was white and flowery but, this was my chain mail" (T2M9).

In 1968, Marguerite's daughter Linda was born. Immediately there were problems as Marguerite states: "the poor wean never got fed cause there was not enough milk for her" (T1M9). These words set the scene for what can only be described as a difficult relationship over the years. Marguerite experienced a severe breakdown immediately after giving birth, resulting in her spending well over a year and half in hospital.

There were no specialist services available to her and Linda, as 'Mother and Baby Units' were not routinely found in psychiatric hospitals at this time. Therefore, her opportunity to develop a relationship with her baby was restricted to short, weekend visits home, when these were feasible. She believes that she did not have the opportunity to bond with her daughter over this crucial period. Following her breakdown, her husband and her mother-in-law cared for the baby. The mother-in-law "more or less took over and basically brought her up from then and practically right up till she left the house"(T1M8).

She recalls some of her experiences of this time, for example, being in occupational therapy making a teddy for her daughter. She was aware that the ward was not a good place to be all the time. She enjoyed and benefited from occupational therapy. However, she was frightened that she was "going to end up permanently in the hospital" (T1M8). She decided to leave the hospital.

Following this long hospitalisation, she decided to leave the family home and return to live with her parents. She chose to leave her daughter in the care of her husband and mother-in-law, a decision she often reviews. She did have options: for example, she could have taken her daughter to live with her parents. "I went back to stay with them. They would have taken the wee one as well, but my mother was forty-odds when she had me so they were getting on and I thought it might have been quite a lot for them but the offer was there"(T1M8). It is evident that Marguerite was making life-changing decisions around this time when it could be argued she was not best able to do so.

Another major decision involved the custody of Linda. Her husband by this time wanted a divorce. Marguerite was advised that she should not seek custody of her daughter. "The lawyer said because of my history there would be very little chance of me getting custody and it would be very traumatic to go up there and be asked all those questions and all this to come out in court. And the only reason I would have defended the divorce would have been on those grounds, but that was his advice and I took it" (T1M8). This is another decision that Marguerite often revisits. She felt unable to take on the legal system and received little encouragement to do so. In fact, the opposite was true; the threat of exposure of her mental health history is explicit in the above statement. The lawyer may have felt this advice was in Marguerite's best interest. As a result, Marguerite did not challenge or fight for custody of her daughter. However, a consequence of this action was that her relationship with her daughter was dislocated from this point onwards.

The decision to leave the family home, return to her parents and not to challenge for custody of Linda finishes this phase of her story. Her life would now take a different turn.

A different life: Storms and calms

Following her return to her parents' home, Marguerite tried to re-establish her life. Not long afterwards she had a new job, this time in a city department store. She had only been in the job two days when she was involved in an incident at her parents' tenement flat that would be with her from then on. As she recalls, "I had stood on the window-sill, I remember thinking: Do I want to do this? Do I want to do anything? But I looked down and I lost my balance and I came down all on one side"(T1M9). This fall continues to be a source of ambiguity: did Marguerite fall or did she jump from the window? "I had serious problems at that time, I think I thought I've no husband, I've no daughter, I've nothing, what is there?"(T1M9). Today, Marguerite believes that the fall was not a suicide attempt, believing that had she meant to kill herself she would have done so. What is clear is that she was very distressed, dealing with a burden of loss and functioning on large amounts of medication.

The injuries that resulted from the fall were very serious and Marguerite remembers being in the hospital ward. "A girl who was in the bed across from me said. 'We didn't think you were going to survive.' I didn't realise how bad it was" (T1M9). This fall resulted in Marguerite having a range of operations over a period of years. The constant pain in her leg resulted in her over-using her painkillers. "I was getting to the stage, I was just eating them like sweeties. When I remembered that I had forgot to take them, suddenly I had the pain. So it must have been a wee bit up here [head]"(T1M16). The result was an extended stay in a general hospital and then transfer to the psychiatric hospital. She recalls how one psychiatric nurse "took away my crutches – I had to crawl to the loo – and then said, 'You do have a fractured femur' – no apology or anything"(T2M14). In 1972, to reduce the pain she experienced, she had an operation to fuse her hip; this resulted in her having a quarter of an inch difference in her leg length and therefore a noticeable limp.

Marguerite's body bears witness to her psychiatric illness. She carries a range of physical signs that can be ascribed to various episodes of her mental illness. These physical reminders include her shortened leg, and a scar on her hand from putting it through a hospital window. A hidden consequence of the fall was the resultant damage to Marguerite's pelvis. These overt signs are more obvious but unseen emotional aspects are just as significant. Today, Marguerite presents as a small woman, who wears glasses, has a hearing aid and walks with an obvious limp. Marguerite feels that her physical condition generally doesn't really bother her until someone comments "but you just get used to it" (T1M16).

She had a long period at home with her parents recovering from this incident. However, she did not allow her physical difficulties to interfere with her continued contact with her daughter. "I went down with two sticks, I went down with one stick" (T1M26). It was to be several years before she could consider finding a new job. In the meantime, she decided to return to the Girl's Brigade. "I went because I needed something to do...I thought if I go back it's something for me. It got an interest back". (T1M29). Going back to the organisation offered her an opportunity to work with girls aged eight and upwards, slightly older than her own daughter. It also offered her the opportunity to work as part of a team of leaders and to take on responsibilities involved with the organisation of this type of group. This work involved one night every week, plus attendance at meetings or events, as necessary. It gave structure to her week. She remains committed to, and involved with this organisation.

In 1972, she returned to work. She got a job in the city, again doing clerical work. Whilst working she met and developed a friendship with another woman whom she still sees today. She worked in this job for three years and then moved to a new position in an accountant's office. She enjoyed this job and was there for a year until 1976: "I was only there for a year and then another, something happened, wait to I think...I don't know whether to tell you about this, it's really, really personal...very few people know about it...We went to some dancing. I met a chap and I went out with him a few times and one thing led to another and I got pregnant"(T1M10). As

Marguerite recalled this story she became very quiet: "Half my family knew and half my family didn't"(T1M11). Importantly, she elected not to tell the father.

The pregnancy and the time leading up to Marguerite's decision to terminate it was undoubtedly stressful. At this time, she turned to her brother as her confidante. "I went to meet him wherever he was working... and I told him about it. He said he would give me the money to go and get it done. It wasn't even the money, just that I didn't know what to do" (T1M11). She went to the GP. "The first one I saw was a Catholic doctor. She wasn't entertaining anything. Anyway I saw one of the other doctors and I went and got the termination" (T1M11).

This was a traumatic time in which she had contradictory thoughts. Here was the opportunity to be a mother, to replace, if you like, the missing daughter. But it was also an opportunity fraught with complexity. How would she be able to care for the child? What kind of life would she have been able to offer him/her? Would the same mental illness affecting her at the birth of her daughter be repeated? If so, who would care for the child given the fact that her parents were ageing? The pregnancy also brought to the fore her pelvic injuries from the fall: "I wouldn't have been able to deliver, I think physically or mentally"(T1M12). Her decision to terminate the pregnancy was not taken lightly. "I didn't just do it willy-nilly. I had to sort of weigh it up and this was a very difficult decision to make"(T1M11). She acknowledges, "Every so often you think, oh dear, you know what I mean. He would have been twenty-one, twenty-two now. However, that's life"(T1M12).

As a result of this situation, Marguerite left her job and was unemployed. The stigma she experienced from her first post shaped her actions in the world of work. This was particularly evident when applying for jobs. The decision to tell or not to tell about mental health problems continues to be considered as a Catch 22 situation. She explains. "As soon as you put it down, when you put it down, some people don't consider you. If you don't put it down they consider you and if it comes out you could be fired" (T1M14). Against this background, in 1976, she applied for a new job; "Funnily enough, the man that interviewed me, the manager, I told him, I had never put it on the form but I told him I'd had a mental illness but he was quite willing to take me on"(T1M12).

She was there for a year. Then she applied for and was successful in getting an internal post within the organisation. Importantly, her decision not to record her mental illness on the application form would have consequences when she was next ill. She was working in the new department when "I remember being off, and of course I hadn't put down that I had any mental illness. The woman who was in charge of the office phoned and spoke to my mum. 'When did Marguerite last have an episode like this?' My mother never thought for a minute. So when I went back, this same person, she moved me out of her department...she moved me because she just didn't want anybody like that in her section. She could have had me fired"(T1M14). Marguerite believes the stigma surrounding mental illness affected her working life in several ways. For example, it limited her scope for promotion: "I mean, I didn't have a great chance. I got that one wee promotion. I'm sure that was then put on my record and I never got promotion until I went to the union and complained very strongly about various other things"(T1M14). Failure to do so, she believes stemmed both from her mental illness history and from her gender. She felt both to be barriers to promotion. "I tried for a few promotions but if you weren't male you didn't get anywhere. I went for an interview before and there was two guys so there was no way I was going to get it, or else my face didn't fit or whatever"(T1M15).

Marguerite has always worked when she has been able to do so and her working life was, and is, important to her both financially and socially. Although she had many admissions to hospital over the years, generally these were around six to eight weeks in duration. Once she received treatment, her recovery was quite quick. She identified how her illness affected her in the workplace. Sometimes she had so much energy at work she could get thorough masses of work and at other times she could barely do anything. She has been fortunate to be able to return to her work and pick up her working life. Perhaps the type of jobs and work environments have in some way facilitated her re-engagement into the workforce following episodes of illness.

But, she felt she was perceived as "always ...off work, because you have it [sick leave] all together, suddenly you know, you're a risk to their figures"(T1M17). In a different vein, she recalls how moved she felt on returning to her work on one occasion. She explained. "I always remember going back to work. Often if you've had a nervous breakdown, people don't think about it as a physical thing. But I went back and I remember this woman, she says 'My, you've had a real shake'. So she could see, and that meant more to me than all the ones not saying anything" (T1M17). For Marguerite, this acknowledgement of her health difficulties is a validation both of herself and of her mental illness. Generally, people in her workplace were unsure how to react and therefore chose to do or say nothing on her return from a period of ill health.

Marguerite advocates for more education about mental illness in order to reduce the stigma surrounding it. Marguerite feels very strongly that there is a need for greater openness, that mental illness should be acknowledged and discussed more and that the public should have access to education to increase their knowledge and understanding, particularly as so many people are affected with mental health problems. She acknowledges that mental illness "is very difficult to understand if you've never had it, but once you've had it you can empathise with people...any time I get a chance I try and get rid of it [stigma]"(T2M12).

Her experience of psychiatric hospitals includes having ECT on several occasions including her first admission, receiving "liquid cosh" (Largactil), being detained in locked wards, being escorted as she was a runaway risk, and attending occupational therapy. I asked her in the second interview why there were so few stories from her time in hospital. She replied: "It's difficult to sort of specify, there's ones I don't want to remember. I don't think I could say I was ever physically struck but the way some people spoke to you, it's like you were a second class citizen" (T2M12). In some respects her time in hospital is in her past and she clearly wished much of it to remain there.

Her last admission was in 1982, since then she has been maintained on her medication. "I've had a couple of blips since then"(T1M21). But she has not been re-admitted. Medication, specifically lithium, has played a key role in keeping her out of hospital over the past years. She discussed her need to take the medication and the effects on her. "I mean, I've still got to take them, fair enough. I am always thirsty, well, I still drink a lot of irn bru"(T2M6). Currently, she is on a smaller dose than previously and is coping well.

Nevertheless, within this pattern of illness, admission and being well, Marguerite continued to maintain contact with her daughter. Following the divorce, from when Linda was "five till sixteen technically I got to see her as agreed and I should have had her weekends but that never really worked out. I went every Saturday"(T1M25). Visiting was obviously not at all easy and at times there was animosity between Marguerite and her ex-husband. However, she felt she was going to see her daughter not her ex-husband and persevered: "I used to feel that when I saw her, I was trying to buy her affection because I was bringing stuff, but it was the only time I saw her" (T2M8). In her relationship with her daughter, she was on the periphery: she did not want to intrude but she wished some involvement, some role. As if to reinforce the distance, she remembers that one of her doctors said. "I didn't even know you had a daughter" (T1M25). When her daughter was 14, Marguerite bought a car giving her greater mobility and freedom. The car also enabled her to do different things with her daughter, and importantly, away from the family home.

As her daughter grew up, Marguerite attempted to clarify what had occurred between herself and Linda's father but her daughter did not want to know. When her daughter became sixteen the legal proviso for contact to be maintained lapsed. Marguerite recalls, "I just tried to keep going to see her, making contact"(T1M27). In her twenties, Linda sent a letter to Marguerite telling her she "wanted to be part of an ordinary family, her stepmother, as far as she was concerned, nobody knew that she wasn't her mother" (T1M26). This obviously affected Marguerite, and today, she still has the letter.

Marguerite feels that she has missed out on family life and that she did not meet society's expectations of her. " My friends when they talk about their daughters and son and they've had them all those years...Maybe it's silly but you feel you're missing out on something (T2M11)". She admits that when her friends discuss their children "I feel quite jealous of that" (T2M11).

In contrast, Marguerite developed a very positive relationship with her niece. "She was the one I was most close to...she has been more like a daughter, see that relationship I've never been able to develop with Linda (T1M27). This relationship was in some way a compensation for Marguerite.

It was in relation to her daughter that final confirmation of her diagnosis was given. Previously, she felt she was not given sufficient information about her condition and at times felt that health professionals obstructed her quest to find out more. She recalls how one doctor side-stepped the diagnosis issue by responding, "If I gave it a name would you feel any better?" (T1M27). It may be that she had in fact been given the diagnosis before but not in a way that she was able to understand. Furthermore, no one approached her to check out her understanding of her condition and its implications. At one point, however, Linda's stepmother "asked me about what were the chances of Linda getting the illness. Well I had thought about it but I had never done anything about it. So when I spoke to the doctor this was the first time I had ever been given a ticket, or a label as they say. He said, 'One in a hundred have manic depression' and I kind of went (facial expression)"(T1M27).

Throughout, Marguerite lived with her parents. She willingly took on the role as carer for her parents. In 1978, they moved to a new house, as her parents were finding the stairs to the flat difficult to manage. Her father had a long spell of illness, becoming progressively worse. He was finally diagnosed as having lung cancer. He telephoned home from the hospital the night before he died and her mum was unable to get to the hospital. Marguerite regrets that she was working at the time. If she had been told she would have gone to see him as she says. But as she points out, "It was just one of those things...there's not anything you can do about it" (T1M19). He died in January 1982. Later on that year, she had her final admission to the hospital. She said, "I don't know whether it was a delayed reaction, but everyone had said I kept it up for my mum, I just wanted to be alright for my mum"(T2M4).

Her mum's final years were spent at home with Marguerite. Following her mother's stroke, aged 89, and a long period of 18 weeks in hospital, Marguerite felt that taking on the role of her mother's carer was only natural: "The doctor said, 'This is a wonderful thing you are doing, taking her home'. I said, but that's what you do, is it not?" (T1M24). As a result of her willingness to care for her mother, her mum lived another three years at home. As Marguerite recalls, "She was restricted to the house...but she was as sharp as a tack right up to the end" (T1M24). Marguerite reflected that during this time at home their roles often reversed, with Marguerite checking on her mother's whereabouts and her mum acting as her social organiser.

This situation changed when her mother was hospitalised following a fall at home during the night. Marguerite on this occasion had not got up to check on her mother, as she had done, on so many other occasions. She states, "the thing was, the time she did fall, I'll never forgive myself for that...all those times you got up ...and the time you should have..." (T1M24). Although she knew that in reality it made little difference it still causes her some feelings of guilt. "I just knew when she went in to hospital that she wasn't coming out...she wouldn't have been able to come home the way she was ... she wouldn't have wanted to be a burden on anybody" (T1M25). Her mum died at the hospital, aged 92, in 1993. Marguerite expected that her mum's death would be a time of relapse but she coped with additional medication and by support from family and friends. Marguerite's relationship with her mother is highly significant. It provided a vehicle for Marguerite to care for someone, and latterly she was the "mother" in the relationship.

The death of her mum ends this phase of her story. It reflects turbulent periods in which she strove to maintain contact with her daughter, to continue to work, to maintain a balance in her life between illness and health. Latterly, her focus was as main carer for her parents. Their deaths meant that for the first time ever she would be living on her own, without her parents to support her.

Peace of sorts

Following her mother's death in 1993, Marguerite continued to live in the same home. She returned to her work and to her everyday routine. At work, the opportunity to take early retirement arose. She got the information but on this occasion she decided against it. However, when she turned fifty, in 1995, a better deal was on offer. This meant "I would be getting a lump sum and a pension so I thought, do I need to stay here and get all this hassle? No. So I left"(T1M15). She took her retirement in January 1996.

Since retiring, she has continued to seek new opportunities. She has completed a computer course, and has done some secretarial temping and after-school care. At the time of the second interview (April 2000) she had recently started a new part-time job in the office of a plumbers' merchants, working in the mornings. She explains, "I'm happy with the new job, it gives me a wee bit extra, it gives me an interest, and it gets me out in winter" (T2M12). She continues to maintain her other interests, too.

The most significant change in the last few years has been Marguerite's relationship with her daughter. This has recently developed into an easier alliance, mainly due to her granddaughter, who was born in 1998. This growing involvement with her granddaughter is an opportunity for both mother and daughter to develop their relationship further. Her granddaughter offers a way for Marguerite to have an active role in their lives in both a supportive and financial way. This child in some way bridges the gap and provides a focus for both Marguerite and her daughter. Additionally, her involvement with her granddaughter enables her to experience many of the milestones she missed when her own daughter was growing up. She explains "all those things I missed out on...you see I'm reliving what I missed out on with Linda through my granddaughter. It's like a second chance" (T2M11).

Through her role as grandmother too she has experienced situations similar to those of her peers and is able to contribute and identify herself as a grandmother.
Today, Marguerite sees herself as content. “I’m happy with my lot at the moment. I think I’m quite pleased, I’m taking care of myself”(T2M12). She has a new job, and she is developing positive relationships with her granddaughter and daughter. She is pleased that a little of her will continue through her granddaughter. She considers the important things in her life to be people, not possessions. She has been able to maintain and develop friendships throughout the years. Her family, especially her brother, continue to play a major part in her life. Today however, she is able to support them with their own mental health problems. Her brother in particular has not been well since his wife died. This is a great concern for Marguerite.

She continues to have strong attitudes about the need for mental illness to be more widely acknowledged and for appropriate education to be available to the public. She has also increased her own knowledge base by attending Manic Depression Fellowship meetings in the past, and she finds their literature very good and informative. She gets angry with those who display little sensitivity to mental illness or who do not know how it affects people. However, recently a family member, one of her nieces has developed a mental health problem. “It’s kind of worrying. That’s the sister that it missed, so it’s kind of jumped a generation” (T2M5). She is dismayed by the family’s handling of it: “She (my sister) is very secretive about it…I think that is totally wrong, if you keep doing that, it is going to keep treating it like something you are ashamed of” (T2M12). Marguerite’s experience brings home the fact that there is still a great deal of stigma surrounding mental illness.

In trying to make sense of why and how it happened to her, Marguerite identifies times of stress such as starting new jobs, studying, major change, and times of family crisis, like her father’s death, as factors. Nonetheless, she feels that there is more than one factor involved, that it is too simple to say, for example, it was studying. Furthermore, she considers that her family’s experience of mental illness is exceptional, with four out of five siblings experiencing severe mental illness.

Reflecting on her life so far, she comments: "It's the loss of your life, the time you're ill, you're losing your life"(T1M). But she states positively, "I think not overcoming but living with manic depression for thirty years and coping with it, I think that is an achievement, not letting it beat you" (T2M11). Perhaps in Marguerite's case she lost some battles, but ultimately she has won a type of peace.

Taking part in this research has enabled her to look back on her life and in a letter states: "It lets you put some things in perspective i.e. some things you thought were awful, don't seem so awful when you confront them"(L1M1). She felt the process was "quite cathartic, it was good, saying it – was like – that is it and everything has gone (T2M14). She pronounces "I've managed to cope with a lot and I'm still here (T2M14)" and she is!

Marguerite's reflections

When I read it on the morning it arrived I actually cried reading some parts of it, but when I finished it off, I was not so emotional. To see your story as perceived by someone else was quite something as it makes you rethink some of your feelings about what has transpired.

Helen's Story

"I'm living with my feelings"

Introduction

Beginning – " I lived in a mental stour" [1]

London breakdown

Back to Glasgow

Seeking help - pills and more pills

TB – a year of my life

Back home – nothing's changed.

Crying out for help

Supporting others

Admission

Getting help: 40 years on.

Middle – Making sense of my life

Child of the Depression

Happy for 6 – the war years

Meeting, marriage and sex.

Julie

Mother again

Pals

End – Painful acceptance of my life

Looking forward.

Planning for death

Helping Grandson

Message for others.

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[1] Stour: muddle, confused state

Helen's

Biographical Data

1924	*Birth* *Father a tradesman and mother worked. Poor, lived in Glasgow. Had diphtheria as child. First communion.*
1934	*(10)* *Ran away to Ireland.*
1936	*Left school*
1939	*(15)* *War started – worked lots of jobs – happy times*
1941	*(17)* *Involved in war work – lived in Cambridge*
1945	*(21)* *Met future husband – got married*
1946	*(22)* *Gave birth to baby daughter*
1946/52	*Living in London: Pain and depression*
1952/62	*Back in Glasgow working hard – as a waitress in a club. Attending support group ran by a psychiatrist. Admitted to hospital with TB. Daughter (15) - first job.*
1963	*(39)* *Discharged from hospital after one year*
1968	*Daughter married*
1970/89	*Shoplifting – got caught – case dismissed – next week back shoplifting. Worked as a carer for an elderly woman, money was not a problem. Daughter was married and living abroad. Depressed. Involved with voluntary mental health services in Glasgow. Looking after grandsons.*
1989	*(65)* *Suicidal feelings. Admitted to hospital for five months.*

1997	*Husband diagnosed with cancer – wanted to be supportive to husband. Organised respite care for self so that she could care for her husband*
1998	*Whilst in the day hospital collapsed – diagnosed with an ulcer.*
1999	*(75)* *Living at home, had problems with mobility, due to arthritis, finds it difficult to go out.*
2000	*(76)* *Long admission to hospital for hip operation very frail – found it very difficult to cope, carers attending. Putting her affairs in order with youngest grandson main beneficiary.*

Helen's Story
"I'm living with my feelings"

Introduction

On meeting Helen on the first occasion I was confronted by a small, determined woman, in Glasgow parlance a "bachle". She came towards me along the corridor to her flat, walking assuredly with a stick that firmly struck the concrete. She had been out that morning buying her cigarettes. She welcomed me with a powerful, confident voice.

During our first meeting, her narrative centred on her mental illness experiences. At the time I wrote in my diary how little there was of anyone else in the story. There were fleeting mentions of her daughter and of her husband. They were necessary asides but in no way central to her narrative.

On my second meeting with Helen, I was struck by the change time had made on her. When she opened the door to her flat, she had shrunk physically, and she walked slowly with a zimmer frame, her steps slow and hesitant. She looked a shadow of her former self. Her recent hospitalisation for her hip operation had indeed taken its toll. On my first visit, she had made the tea. On this occasion, I helped her to make her breakfast. In her living room, Helen's chair had become the command centre of her existence. All her daily necessities were arranged around her chair: a large supply of cigarettes; the phone within easy reach; the coffee table, displaying a range of medication. These were placed to maximise her functioning in this corner of her home. Her existence had indeed been reduced.

As we settled down to the second interview, it became apparent quickly that things would not go to my plan. Helen had her own story to enlarge on and in her own way. I soon abandoned my scheduled activities and followed her lead. Certainly the data I had expected to collect was different from what I now heard. There was some repetition of previous data, but the detail of her story this time was richer. Several reasons may account for this: her poor physical health, perhaps her own realisation that she had things to say and time was running out. She was not going to be shaped by my format. The sense that, for her, time was running out was palpable in the room. What follows may lack specificity of dates but the feelings and her depth of her emotions are evident.

"I lived in a mental stour"

"It's pain, that's what I call it. I was twenty-eight years of age living in London. I had never been ill before, I didn't know what had hit me. It was too hard to explain how I felt, but it started with pain. Pain in my mouth and I thought oh my God. I went to the doctor; he sent me to the dentist. I had all my teeth out" (T1H1). Pain, emotional pain was to characterise Helen's experience of depression. At this time, 1952, Helen was living in London with her husband and six year old daughter. She recalls, "When I had that breakdown in London I spoke to a doctor. She asked me if I had any problems. I've never had a house. I've had to live with Tom, Dick and Harry. There was a war on and I wouldn't get a house for ten years. I had to live that way, I had to plan my life their way: don't make a noise, keep the baby quiet. It was tense and worrying, you know. So they couldn't give me a house. I say to this day they couldn't give me a house so they gave me pills"(T1H4).

As Helen's pain and depression continued she felt increasingly unable to care for her daughter, so the family decided to return to Helen's home, Glasgow. Helen felt that her family would be able to help her in care for her daughter. On returning to Glasgow, Helen soon became immersed in her extended family's lives. She felt that one sister in particular needed her help. Her husband had returned to the USA leaving her with five young children. Helen took it upon herself to become actively involved in caring for the family. She felt this "was the bad start to my being a housewife and mother" (T210). She also re-established relationships with past friends, soon discovering, that a close friend had also had a nervous breakdown. The two friends over the coming years would be a support for each other.

Throughout this time she continued to feel depressed. She sought help, but she felt that her doctor did not take her illness seriously. She recalls how on one occasion when she called the doctor out for her daughter, Julie. "He came in saying, 'What is it this time'? He lifted my daughter's hand and said, 'At least this is a real illness'. You were condemned for being ill. That's what it felt like (T1H2).

Help for her depression through the fifties and early sixties took the form of pills. One of her medications was Dexedrine, a psycho-stimulant. "I went to the doctor just to get my prescriptions, I had lost all hope in them, what with them saying you're mental" (T1H2). At this time, she also gained support through various outpatient groups but she describes the 'emotional pain' as always being there.

She returned to work, securing a job as a silver service waitress in a club in the city centre. She felt work helped her. It gave structure to her day, providing a social outlet away from home and some financial independence. She was often called upon to do extra shifts. "I was the only one that lived in town then. All the others had moved to the schemes" (T1H1).

At the start of the 1960s, life for Helen continued much the same. By now, she was attending an outpatient group in the city run by a psychiatrist. The group was useful and she was a vocal member of it. Others approached Helen to discuss their problems and worries, outside of the group. She felt she was viewed positively: "I was a coper" (T1H6). She was someone who could express what others found difficult to articulate.

By 1962, Helen had been suffering from depression for 10 years. She described at the start of the year working extremely hard. Indeed, she felt compelled to work hard, both at work and at home. She felt that something was dreadfully wrong. "I worked and worked and worked and worked and when I came home I even scrubbed the coalbunker. That's when I really thought I was fucking nuts. I mean I was scrubbing coalbunkers, especially when you're not even using them. It was as though you had to use this energy"(T1H2). She felt that no one noticed how ill she was, including her husband, her family and the psychiatrist who led the support group.

She remembers that it was a chance meeting with her Aunt, who thought she looked unwell, that got her to go for help. "If my Auntie hadn't found me (pause) I was dying, because I would have never went to a doctor"(T1H2). This fortunate meeting resulted in her going to the hospital where she was diagnosed as having tuberculosis (TB). When she was told that she would be in hospital for a year she said, "I can't stay now, I'll need to go home and change the curtains"(T1H3). She recalls she even had her cutlery in her bag for setting up at the club.

Both Helen's family and co-workers were amazed that she had TB and all of them had to be tested for it. She felt ashamed of having the disease. Helen was dismayed when the doctor mistook her sister as the patient, reinforcing her belief that people didn't recognise that she was ill. On admission, her medication for her depression was called into question. Helen told the admitting doctor that her medication was Dexedrine. She had received many repeat prescriptions and had not seen a doctor for some time. Sainsbury (1974) describes Dexedrine as a psycho-stimulant prescribed for "mild depression and states of fatigue" (p. 273). He adds that due to the rapid development of tolerance, larger doses are needed to produce mood-lifting effects, making the drug of little use in clinical depression. During Helen's time in hospital she withdrew from this medication. She spent a year in hospital. She felt it was just what she needed: "I just loved being in that hospital. I mean, I really did. I didn't even care if I died. It was the most peaceful thing that had ever happened"(T1H2).

The psychiatrist involved in the outpatient group was an early visitor. She apologised to Helen for not noticing that she was so ill. Helen felt that she had tried to tell the psychiatrist that she was unwell, but she had not been heard. Helen believed that an important lesson had been learned by the psychiatrist: the need to consider physical health as well as mental illness, and to consider what other unspoken needs people might have but do not raise in such a group.

Helen remained in hospital for a year. She says, "A year out of your life isn't easy to recapture" (T1H3). She felt that it was a difficult time for her to be away from home as her daughter, now 15, was just starting work and she felt that her daughter needed her at this important time of transition.

Following her discharge from the hospital in 1963, Helen spent a year at home. She continued to receive support form the district nurse, ‘the green lady”. At home, her relationship with her daughter was difficult. For example, Helen insisted that Julie should contribute part of her wages to the household. But her father had not taken any money from Julie whilst Helen had been away. Helen felt that she was placed in a difficult position, one in which she was seen as the enemy.

Within a year, Helen was back at work. She explains: “I still had this awful unreal feeling, it’s so hard to explain mental illness, I didn’t feel right”(T1H4). She began to develop, in her words, ‘silly things”. These included running away and petty theft. Running away consisted of two main courses of action. The first type of running away involved Helen leaving home. She would pack a bag and tell her husband she was off. She would get on the train, travel so far down line, often getting to Carstairs Junction, before returning to Glasgow. The second type of running away involved her renting a flat in another part of the city. She would just go and sit there. She recalls that her husband Albert would make a joke of it. “You’re only going for a message Helen, you’re not going into lodgings. Are you sure you’ve not got your case?” (T1H9).

Helen also began to steal from local shops. The items she stole were meaningless to her but she felt compelled to have them. They included items such as Christmas decorations, a baby doll, pens and food. It was no surprise to her that she was arrested in 1968, having been caught in the newly opened supermarket stealing streaky bacon. She was placed in the cells overnight. “I didn’t care, nothing mattered, I was searching for something. But I didn’t know what I was searching for”(T1H5).

Needless to say, Albert was very concerned about this turn of events and called on Helen’s brother to help out. Her brother was surprised by her situation. He knew that it was not due to his sister’s lack of money. Helen regularly lent him money. He recognised that something else was wrong with her. However, he did manage to calm her husband down. Helen recalls the outcome thus: "I went into court and they dismissed me, first time. So they never knew to this day, I was doing the same the very next week. I don't even know how it stopped. It was compulsive"(T1H7). Other family members, including her daughter, never found out about this episode. Julie was by now married and living in Singapore.

Helen continued to seek help for herself and joined a mental health organisation. She was glad that there was now an organisation for mental health users that was outside of health service provision. The users were active in running the association and in appointing its staff. Throughout the 1970s and 1980s, she actively worked with the organisation. She was one of a group who would share their experiences of mental illness with a variety of people and organisations, to promote good mental health practices. She continued to be supportive of others, often in an informal way. Others would phone her at home. She felt that she was able to assist or reassure them. However, she felt that she too needed to be helped.

She subsequently, left this organisation after becoming disillusioned, following the death of one of her friends. This woman, a regular at the association, felt that her mental health needs were not being heard. She contacted Helen, desperate for help. Helen first advised her to try the association again and make her needs known to the staff. However, this was not successful. Helen contacted another mental health organisation and arranged for someone to contact her. Before she had a chance to meet this person, her friend died at home of a heart attack. Her husband contacted Helen to tell her of his wife's death. He told Helen that his wife was very happy the night before she died because she was going to be seen by someone. She had hope.

In 1989, Helen felt increasingly depressed and described terrible pain in her back. She felt suicidal. "I got a taxi, I must have waited about five hours in that casualty for help but I was willing to stay there. The pain in my back was sore. Somebody saw me, they offered me pills. I said, please don't send me home. I do feel suicidal. I mean, I had to make it clear I went there for safety. I was afraid of what I would do"(T1H10).

On this occasion, Helen was admitted to the psychiatric department of a large general hospital. She describes the hopelessness of her situation; "There was no treatment in there, just the same wee bit of therapy. You spoke with other patients, I think they all knew there was no cure and they just accepted"(T1H11). Throughout her stay she felt that the staff and the organisation were uncaring and insensitive in their treatment of those with mental illness. For example, there was one night when Helen felt awful. The nurse on duty told her to take a pill. Helen knew that the pill she was offered was not something she would normally get. She recalls the nurse insisted that she should take the medication. Helen felt pressured to take the medication but continued to refuse and asked to see the doctor. It transpired, the following day, that her medication had indeed been written up incorrectly. She recalls "I mean, no fucking apologies, you know what I mean. I mean, you are abused"(T1H10/11).

She was very low in mood and her pain became increasingly unbearable. The depth of her depression was emphasised during a hospital trip to the Pantomime; she was in reality only a few yards from her home yet she was so depressed she was unable to go home, although she hated the hospital. As it was coming up to Christmas, people had the opportunity to go home. Helen took it. "I'm not going back there, whether I die. I am not going back there"(T1H12). She never returned to the psychiatric hospital.

In the 1990s, Helen's husband was diagnosed with cancer. Helen, whose mother had died of cancer, wanted to be strong for him and sought support to enable her to be strong. This support took two forms. First, she found out about a counselling service for those supporting people with cancer. Secondly, she arranged access to temporary accommodation away from her home. She believed that if she was to help Albert she needed some respite from home in order to cope. Through the counselling service, she was referred to another counselling service in the city. The counsellor, an older man, was a godsend for Helen. He helped her to cope with Albert's cancer but also with his death in 1997. He also helped Helen look at her own life and try to make sense of it. Helen stated, "Through the counsellor I could work through my feelings. I should have had that forty years ago"(T1H14). She no longer receives counselling, but she continues to seek the answers to her life, using writing to help her examine her life, her pain and her depression. She describes the energy she uses in her writing as "steam in your pen," and how it is a very important way for her to express herself: "Where do I put all the pain, it's in these books" (T2H10).

Helen believes that had she known in her late twenties, how long her illness would last, she would have taken her own life.

Making sense of her life

Helen was born in 1924. Her family lived in centre of Glasgow. She was one of eight children. The Depression was the major backdrop to her childhood. Times were hard and she believes this had a profound effect on her life and on those around her. Her parents, she believes, did their best through difficult times. "My father was a tradesman, he had great hands, he couldn't get the work. My mother had to do wee jobs to keep us alive. I never saw them leaving us for a night. They were there all the time. If I was hungry, they were more hungry"(T1H17).

Her parents were from different backgrounds, one being Catholic and the other Protestant. There were family feuds around religion, and relatives who would not talk to each other. Helen was brought up as a Roman Catholic.

Poverty had a significant impact on her life, not so much from being poor but from how one was treated for being poor, somehow seen by others as not worthy. She remembered clearly wearing clothes that were handouts; she recalled how they felt, the rough texture and the smell. She described her childhood as deprived. "I've been wearing designer labels since I was five year old. My gymslip had a stamp in it, my pants, my shoes, my knickers. That was in case your mother pawned your shoes. So all the people I mixed with all my life, even round here now, they were all the same. So maybe I just thought it was normal to be poor"(T1H17).

Such poverty affected every aspect of her life. Attendance at her local Roman Catholic chapel was limited because her mother would not send the family if they were not able to wear "respectable clothes". School life was affected because non-attendance at chapel led to punishment on Monday at school. The simple act of borrowing a book from the library became an issue. If a member of the family had an overdue book, others were unable to borrow from the library. She recalls feeling hungry and physically unwell most of the time.

However, as everyone was in the same boat, there was a communal sense of all being there together. Now, "when we are all here, we can all talk about the same things, we laughed at it, because we didn't laugh at the time, it was brutal"(T1H17).

Helen was seen as being the brightest of her siblings, but also the weakest, health wise. She had diphtheria when she eight and she lost three friends with TB. Her diphtheria meant that she missed a significant part of her schooling. She had only three days to prepare for her first communion and was rushed through it. She was always two years behind everyone else. For example, she was the last of her peers to start her periods.

Aged ten, Helen recalls helping out at home doing the chores, getting messages for her mum. At this time, she undertook a trip that would follow her throughout her life. While her mum was in hospital, Helen was helping out at home and had an idea to go to Ireland. "I just wanted to go, to enjoy something"(T2H2). She could not let the idea go, so she began to plan a trip to Ireland to visit her grandmother's sister. This involved writing to her Gran's sister in Ireland. Letter writing was a task she always did for her Gran. In the letter, she wrote she was being sent over for a holiday and she organised her relatives to meet her. She stole money from her Gran to pay for the trip. She recalls, "In my mind I was going somewhere, but I knew I was coming back"(T1H3).

She had no idea of the pain and disruption she left behind her. The family did not realise she was missing, her parents thinking she was with her Gran, her Gran thinking she was with her family. The police were called. When she returned she didn't feel she had done anything wrong. Nonetheless, she was severely reprimanded by her parents, her relatives and the school. Her Gran was the most generous, realising that her ten-year old granddaughter must have the spirit and intelligence to plan such a trip. But the recriminations from this trip continued for many years. This episode of running away may have been a forerunner for her later 'trips". There was little joy in Helen's childhood. Her life was about surviving.

Helen effectively finished school at the age of twelve. Her mother was instrumental in securing her a post that would suit her health. She worked as a cashier and she enjoyed working. She recalls the years from 14 to 20 as being the happiest period of her life. "I was free to be myself and I remember having my friends around me and the laughs we had"(T2H8). This period coincided with the war. She continued working as a cashier and she spent part of the war in Cambridge, contributing to the war effort.

In the summer of 1945 on VE night, she met Albert, her future husband. He was in the navy, she was 21. "So after my good times I got married"(T2H5). She believes she married by default; she didn't know him. "I wasn't really in love with him, I didn't feel anything for him" (T2H16). He wrote to her mother asking if he could marry Helen. Her mother thought he was a 'nice smart boy'. Helen was due to go to London to meet his Albert's parents, but she sent a wire telling him that she was not coming. However, her mum convinced to her to go.

Albert and Helen were very different individuals. He was very quiet, "a loner". Helen was bright and enjoyed being in company. She met his parents. He asked her to marry him and she did. She recalls, "I actually got a man without thinking, I just done it to please him"(T2H16). They were married in London, in October 1945. Helen knew nothing about sex. She didn't know she was pregnant till she told her sister she had missed a period. Julie was born in July 1946.

Helen and her family lived in London for six years. During this time Helen was depressed. This culminated in a breakdown in 1952. The family then returned to Glasgow. Helen became involved with her extended family and began to question whether she was a good wife and mother. She felt increasing guilty and blamed herself for her impact on Albert and Julie's lives.

Helen did not like the sexual side of her relationship. She describes it as a fear, although she can think of no reason why she should have been frightened, other than ignorance. Helen believed that the difficulty with sex they had as a couple was her problem. She sought help from her doctor and later her psychiatrist. The doctor advised her to relax and go home to her husband. The psychiatrist tried hypnosis but it didn't help. Guilt about "not being a wife was making me more ill" (T2H11). She offered Albert a divorce, feeling that was the right think to do. However, he didn't want a divorce. Her wish to work and her financial independence was in part a result of their sexual difficulties. Helen explained, "See my sisters used to wonder, how is it that Albert was the best dressed out of all the brothers-in-law? I didn't tell them because I couldn't be a wife sexually to Albert. I felt I didn't deserve any money." (T2H13).

There are no happy references to her daughter, Julie, in Helen's narrative. Even when she found out that that she was pregnant she recalls, "I didn't even want the baby I was carrying, I know I had to have it"(T2H5). In some ways, especially when they returned to Glasgow, she seemed to handover the parenting of Julie to Albert. This may not have been deliberate, although she now says, "I was rejecting them without knowing it"(T2H7). She felt that Julie was fine, her father loved her and was there for her. He was a very quiet man, not often away from home. As an only child, Julie had luxuries that her cousins didn't. Helen began to devote her time and energies first to her sister and her five young children and secondly to her father. She felt that her 'mothering' skills were needed there. Her father did eventually tell Helen that she should return to her own family where she was needed.

Helen's admission to hospital in 1962 for TB did not help her relationship with Julie. She was not around to support her daughter at this key time. Julie did challenge her mother that she cared more for her sister's children than she did for her. Helen tried to make sure that Julie was well informed about sexual relationships, buying her books when she was fourteen, so that – unlike her mother – she would not frightened.

By 1968, Julie was married and living abroad. She had two sons in the early 1970s. Julie and her husband, now back in Glasgow, both had alcohol problems. This resulted in Helen becoming actively involved with her two grandsons. She says, "I may not have been the best mother to Julie, but I was her mother when she needed me. I was the one who did all the donkey work. I was the one who had to bring her home. I was the one who took her to the hospital. I was the one she near broke my jaw. I was the one who looked after her kids, I had them from they were that size. She's never put a nappy on"(T2H19). Helen joined Alanon, the organisation for family members of people with alcohol dependency. Julie later divorced and married again. Their relationship is still difficult. They had a further altercation following Albert's funeral, when Julie accused her mother of hiding her father's will. Helen was clear there was no will.

Helen has contact with only one of her grandsons. The eldest is married and lives in the USA. Since the confusion surrounding her husband's will, she has had no contact with him. She has a good relationship with her youngest grandson, Peter, who lives in London in a hostel. He left the family home to escape his parents' drinking. She speaks to him regularly on the phone. He last visited at Christmas 1999. Helen feels he has very little, and was affected adversely by his parents' addiction. She worries about him. Up until the year 2000, she always arranged for him and one of his friends to have a holiday with her. He is clearly the light of her life.

Another source of pleasure for Helen has been her friends, many of them from her schooldays, with whom she still maintains contact. This group acts to reaffirm Helen's as a person who had happy times and laughter in her life. They share a common heritage and common memories. The sex issue, which for Helen was highly significant, they helped put in perspective by sharing their tales of sex and marriage. Susan in particular shares a bond with Helen through their depressive illness. They have empathy for each other, each understanding the other's pain, and over the years they have supported each other.

In trying to understand how her life has turned out, Helen feels that others did not recognise her pain. They did not see how ill she was, either physically or mentally. She is angry that this happened to her and that she did not receive help when she needed it. She feels aggrieved that she was supportive of others but that there was little help for her until many years after her initial breakdown. She believes that because she was seen to cope she was not helped enough. Her involvement with her General Practitioner only served to reinforce her belief that her needs were not recognised and were not even valid. Her insensitive handling at hospital did not help. As in the case of many other women of her generation, married life thwarted her potential to be someone else. Her roles as wife and mother were unsatisfactory to her, leaving her feeling guilty. She tried to get a divorce but her husband did not agree.

Helen presents a paradox. Externally she was able, supportive, an active advocate for mental health issues. Internally, she was depressed, wanted help and wanted recognition of her pain.

Painfully acceptance of my life

In my last meeting with Helen, it was clear that she was planning for the future not her own her future, but her grandson, Peter. Helen said, "I don't know if I'm going to get better or if I'm going to die"(T2H1). She was at one stage considering giving up her home and moving to residential accommodation. However, "I would rather die here and let my grandson have it" (T2H18). She wants him to use the money so that he can get a flat and some furniture and make a home for himself in London. She has already taken steps towards this goal. Her will is written and in safe keeping with her brother. Like others of her age, she has money set aside for her funeral arrangements.

She feels that Julie and her husband have enough money and that her small estate would make a major difference to Peter's life.

Helen, reflecting on her life, felt that although she has blamed others for how things happened, the time has come when she has to take the responsibility. She feels that now "I'm living with my feelings"(T2H2), even though these are painful to her. She explains depression as "a horrible illness, you cannot blame anybody. The search I'm looking for is how do I forgive myself"(T2H13).

With regards to her relationship with Albert, she has this to say, "I think I needed him those 52 years 'cause he was calm and quiet you know, and he was always there" (T2H15). Julie continues to be a source of guilt, Helen wonders if she was responsible in some way for Julie's alcohol problem. Could she have done things differently? Her friends remind her that she was good to others, and that they like others, have benefited from her help over the years.

There were several messages throughout Helen's story. An important message for all mental health workers is that when dealing with people you need to be open so as to hear and see what may be impacting on their lives, especially if you are seeing people in the community. From her friend who died without getting help, she understood the importance of hope and believing that things may change. Helen also wanted her mental illness history, in particular her medical notes, to stop affecting her life: "I'd love somebody to go up there and just rip that whole book up because I've changed, I'm not that person"(T1H12). She wanted to go forward, not to be reminded of what had gone before. This type of stigma made her really angry. She recalls how after returning from a holiday, her flat had been flooded. When she went to her doctor he said, "of course, you suffer from anxiety" (T1H12). Helen informed him that if he had been in her position, he too would be suffering from anxiety. Her assertiveness did not allow him to get away with such a remark.

Helen's reflections

I just feel no one wants to understand how I feel. So I gave up hope. The hardest thing I feel is to die, as I feel that's all I have to look forward to. I just feel I am indoors alone with all these painful feelings without help from anyone.

Pam’s Story

“I am very much a person”

Beginning: Working towards her goal.

Planning ahead

Taste of freedom

Choices & consequences

A perfect mum?

Saved by work

Middle: Building up and letting go.

Building a career

Moveable homes

Exploring self

All Change

End: New foundations

Managing mental illness

Developing partnerships

Advocating actively

Pam’s

Biographical Data

1950	*Birth*
1957	*(7)* *Steering the tractor on the family farm*
1958	*(9)* *Granddad died. Father moved to new farm – Pam helped with the milking* *Wanted to be a teacher*
1960	*(10)* *Saved baby brother (18 months) from a drowning accident*
1962	*(12)* *Learned to drive the tractor*
1964	*(14)* *Drove the lorry* *Working hard at school*
1966	*(16)* *Driving lessons from dad to pass driving test*
1968	*(18)* *Met Andrew who worked on a farm* *Left home to go to teachers training college* *Enjoyed learning; wished she had gone to university. She felt she was not aware of the options available.*
1970	*(20)* *Fell pregnant; on medication* *Got married*
1971	*(21)* *Son born*
1972	*Professional qualification a year later* *Being at home with the baby drove her round the bend.*
1973	*Started work in a school part-time*
1974/84	*Worked for many years in a range of schools* *Full-time post from 1974*

1984	*(34)* *Psychiatric episode off work but not admitted – suicidal ideas.*
1985	*Back to work although felt it was too soon.*
1987	*Three years free of medication – first since she was 20. Back at work*
1990/92	*(40-42)* *Psychiatric problems* *Health and work problems - off sick*
1993	*(43)* *Officially left work (on grounds of ill health)*
1994	*First major admission to hospital* *Husband had an affair - left the marital home*
1995	*(45)* *Sold the marital home and moved to new area* *Admitted to different psychiatric hospital*
1996/2000	*(46-50)* *Third admission to hospital.* *Involved with MH forum and regional mental health group.* *Several episodes of ill health – managed at home.*
2000	*Has a new partner. Leads as active a life as possible enjoys the countryside. Still involved in several mental health projects. Church is a very important aspect of her life*

Pam's Story

"I am very much a person"

Working towards her goal

Pam was born in 1950. She began life on a farm in central Scotland, before her family finally settled on a farm in southern Scotland. Life was a struggle for the family as money was often short. She feels that her childhood was hard, as it was expected that she would contribute to the running of the farm from an early age. She recalls: "I always had to work on the farm, I remember steering a tractor when I was seven. I would come from school and help dad with the milking and things, I was just short of nine. I helped a lot" (T1P1).

Pam was the eldest child in the family, with a younger sister and two younger brothers. She feels, looking back that things were easier for her sister and that she resented this at the time. As the eldest, Pam recalls being responsible for her siblings but felt that at times it was too much for her. When her younger brother got into trouble, Pam saved her brother "from drowning...he was only eighteen months...I got the blame" (T1P1). She also was often at the receiving end for things they did, often being 'smacked" by both her parents. She believes her father set unrealistically high standards for her; "He expected 110% ... "it didn't seem to matter how hard I tried, no matter what I did it was never good enough" (T1P1). Nonetheless, she describes herself as a "Daddy's girl...I thought the world of him, trailed round after him"(T2P6).

At the age of nine, Pam decided that she was going to be a primary school teacher and she worked towards that goal. She recalls that she had little contact with friends except at school, and often felt isolated and lonely. Every fortnight, she was able to go to the local picture house to see a film. However, the timing of the last bus home meant that she never saw the main movie through to its conclusion. She recalled that "in the 1970's, I would say to myself: I know this, I don't remember this bit". It eventually dawned on me it was all those films I had started to see the first half hour of" (T1P2).

Pam had begun driving the farm vehicles at an early age. Her father was keen for her to get her driving licence to help around the farm more. When she turned sixteen, he purchased an old van and taught her to drive. She successfully passed her test and continued to help out on the farm. But for her driving was so much more – it was 'the very first time I had freedom" (TIP1). She was able to leave the farm independently and go out to see the full picture.

Pam's hard work throughout school paid off and she attained four "O" Grades and three Highers. In October 1968 she left home to go to teacher training college to train as a primary school teacher. She had considered going to university to do history, but changed her mind. She had met her boyfriend, Andrew, in February of the same year.

College was for Pam a time of freedom; "it was the first time I had ever been free" (T1P2). The college was only in its second year, the residencies were brand new and she enjoyed the opportunity to learn. Psychology was for her a revelation and she became interested in the subject, although she retained her love of history. She felt that, for her and her peers, college was more like an extension of school. Pam regrets that it was never made clear to her that she could have gone to university and then done a one-year postgraduate teaching course. She believes university would have offered her even greater freedom.

In 1970, she was doing well at college when she fell pregnant in the summer between her second year and third year. Andrew was the father. When the pregnancy was confirmed, she began to take medication for depression to help her cope with the situation. At this time, the principal at the college was very supportive: "He was the nicest of the lot. His attitude was 'that's fine, the desk and chairs move, so, just move them forwards as the bump gets bigger'" (T1P3).

At this time, she and Andrew got engaged. Her father was unhappy with this turn of events. Pam felt this was because they had not asked for his permission. She recalls, "Nothing ever seemed to be pleasurable in my life. Things that should have been good always seemed to be tarnished"(TIP3). Nonetheless, they were married. The decision was taken, by Andrew and her parents, for them all to live with her parents, as Andrew's work was nearby. In 1971, she had a son, Craig. She returned to college to finish her teaching qualification. This proved to be a difficult time. "I had to struggle very hard. I had gone down to well under 7 stone and the doctor at the college insisted that every spare minute I had I went to sick bay to lay down and have a rest" (T2P6). She achieved her award, just a year later than she would have done.

The new family were now living in a flat in a Lanarkshire town. She describes feeling guilty. "I was going to be the perfect mother. God, it drove me round the bend. I couldn't stand it being stuck in this flat with this child crying and too young to tell me what was wrong"(T1P3). By the September, she was back on medication. She recalls the pills "kept me going and then I would be fine" (T1P5).

Following a chance meeting with the head teacher of the school where she had her final placement, she was offered a work opportunity. She jumped at this offer. She organised a babyminder for Craig and took up the post. She worked part-time in the school from January to June, initially teaching Primary One children, then working as a remedial teacher.

This job proved to be a turning point. Her feelings of relief were evident. It was she said "great for me, it meant I was using the brain, I was getting some exercise" (TIP3). Craig too, benefited from his mother's job. "I had a great time in the afternoons with Craig, I always spoke a lot to him, spent a lot of time with him" (T1P3). However, this job finished and as the summer developed Pam was soon back to feeling unable to cope. She just couldn't take it staying at home. She felt trapped. "You know, these four walls clawing in" (T1P3). She actively sought a teaching post and took on a job as a remedial teacher in a primary school. Craig went back to his childminder. She did worry for Craig, as he was the only child with the childminder.

Nonetheless, she took up the job and it lasted a year. She began a full-time post in a local school and Craig went to nursery full-time, with other children.

Building up and letting go

From 1973 onwards, Pam had teaching posts in four schools. She loved teaching and enjoyed working with the children. Her early experience as a remedial teacher influenced her way of working, stressing to her the importance of working at the level of each individual child. She gained experience with most age ranges of primary schoolchildren. She undertook her Infant Teaching Qualification (ITQ), recalling it as "an accomplishment as I was working at the time" (T2P6). She did, however, find the increasing paperwork involved in education a chore. She worked at one school for six years. During this time she developed enduring friendships with three teachers amongst the staff group. However, following a "misunderstanding" with the head teacher she moved to a different school, within the same geographical area. Craig was now in full-time education.

Meanwhile, life at home with Andrew was difficult. As Pam says, 'the three years we went together it was always 'Pam do you want?' The minute he got the ring on the finger, he was the other way round. I was the chattel" (T2P6). She had to fight "to have a life of her own and become a person" (T2P6) However, things improved, "and I was allowed to go out and see my friends"(T2P9). In 1979, she did consider leaving Andrew, but in the event did not, deciding that Craig's need for his father outweighed her own.

The family bought a new house, which involved Pam in a 50-mile trip daily to and from work. She decided to move to a new school nearer home.

In August 1984, Pam went to her doctor feeling unwell. "I wasn't great, I knew things were hitting me sooner" (T1P5). Since her pregnancy in 1970, Pam had a period of time, around September or October every year, when she felt she required medication, either Valium or Librium, to help her cope. On this occasion, her doctor gave her a different medication. She felt it was "lighter" than her usual medication.

A few weeks later she accompanied her husband on a business trip to London. As the weekend progressed she became increasingly ill at ease and remembers spending a lot of the time just lying on the bed in her hotel room. She returned home and on the Monday went to work as usual. However, she was beginning to feel that something was amiss. When Andrew came home in the evening she met him on the stairs and told him "I'm going mad, I'm sure I'm going mad" (T1P5). The doctor was called but he was unable to make a housecall. An appointment was made for the next day. Pam recalls that it was a horrific night; she wonders how they both survived it. "My legs, my arms everything was going, talk about windmill" (T1P5). The following day she could not stop moving, she could not sit, she walked up and down the surgery, and when she saw the doctor she paced the consultation room while he asked her questions. During this session, the GP asked her if she had ever considered suicide. She replied, "yes". She recalls that her husband was upset by her response, Andrew had not known, and she had not told him that she was contemplating suicide.

On this occasion, her GP prescribed different medication. She recalls it "knocked me out for a few days" (T1P5). Due to Andrew's health insurance, she initially received private care with a psychiatrist visiting her at home. Later she travelled to his rooms. She found these sessions very helpful: "through talking to him, that made me begin to believe in myself as a person" (T1P6). In addition, she also had some relaxation training at this time. She was off work for the best part of the year.

In the August of 1985, she returned to work and the family moved to a farmhouse. Neither of these transitions were easy. She felt she returned to work too soon. She had discussed a later start date with her doctor but the early date was preferred. Work was difficult and she felt she was pushing herself too hard, but she didn't want the children to lose out. During the next two years she was on medication but she was able to continue teaching. From 1987 to 1990 she was completely medication free. She recalls this "drug-free"" period was "the only three years since I was twenty" (T1P6). During this time the family converted the farmhouse. Pam described this time as the happiest period of her marriage, as she and her husband had the same goal.

Unfortunately, in 1990 Pam began again to have mental health problems again. She had a very short admission (two days) to the psychiatric ward of a general hospital in 1991. In 1992, things became increasingly difficult, especially at school. At work, she was asked to take over as the teacher of a composite class, to help sort out some problems that had arisen. At the time, she felt she was given this job because of her track record in working with a range of children. However, it proved to be difficult for her. Pam recalls problems although she is unable to specify their nature. A further complication was her travel arrangements. By this time, Craig, now 20, was at university. He used her car and she relied on a friend for transport to and from school. She became more unwell. "It was absolute hell, a lot of the time I was completely zombified" (T1P6).

As her health deteriorated, Pam took early retirement from teaching in 1993 on the grounds of ill health. "I can never do that again, we are precluded from going back, once we have resigned on health grounds" (T2P7). This was a huge loss for Pam. As things deteriorated she was eventually admitted to the local psychiatric hospital. Her husband insisted on this hospital admission.

Initially, she was unsure of what was happening to her. During her admission Pam had a course of Electro-convulsive therapy (ECT). She found this to be very helpful. "It wasn't very nice but on the other hand I started to become a person again" (T1P7). However, it did have a major drawback. "My memory had gone and that was a shame, many of my memories had gone" (T2P2). This admission lasted three months, but she slowly got better and started to attend the day hospital. Once discharged home she continued to attend the day hospital. Reflecting, Pam found her time in this mental health service very useful for her. She felt that the staff were very understanding and supportive "I mean, you really were well cared for and you really did have your own occupational therapist and carer. You know, anything you needed, it was just like that (snapped her fingers). They made time for you" (T1P10). Pam, at this time, also received counselling sessions. She used this to address issues related to her husband and her father. Both men had a significant impact on her life. She says, "Andrew mentally abused me over twenty odd years. They (Andrew and father) spent their time telling me what to do...forty years of conditioning, it's difficult." She also attended a range of groups and these along with the counselling "helped me assert myself for the first time" (T2P6). Her relatives found it difficult to adapt to a new more assertive Pam. She still finds being assertive with her parents difficult although they now realise that "I'm a more dominant person than I was" (T2P6).

She was coming to terms with these changes in her status when Andrew had an affair with another woman and he left the marital home in 1994. Pam remembers that "it didn't come as an awful shock, really" (T1P6). He cited one of his reasons for leaving as Pam's mental health problems. Pam reflects, "Very few marriages stay together when there is mental health involved. Maybe they still stay as the carer but they are not together" (T1P12). Pam had now to rebuild a life for herself.

New foundations

Pam returned to live in the same town in Lanarkshire where she had begun her teaching career. She would have preferred to stay in the area where the family had been living, but she felt that with Craig at university she would be isolated and without transport to get out and about. Returning to Lanarkshire, in November 1994 had several advantages for Pam. She returned to a previous GP with whom she had a very good relationship. "He was the only doctor I found who had a real understanding of mental health...and he never dismissed anything physical"(T1P7). In addition, her three valued friends all lived in this area. They had stuck by me that's the important bit" (T1P7). The move to the new area was not easy. Pam felt isolated in her new community.

In April 1995, Pam " tried to commit suicide...I was on my own a lot and Craig was away at the weekends...What is the point of me being on this earth?... All I'm doing is causing my family a lot of bother" (TIP11). Pam was admitted to the local psychiatric hospital where she had her stomach pumped out.

Prior to this admission, Pam believed that her mental health problem was depression. She had read around the subject. "If you think you're depressed, you concentrate on the one which is talking about depression and just flip through others. I knew I wasn't schizophrenic" (T1P8). She recalls, "Nobody ever actually said I was manic. I just noticed my doctor was writing something out for me... he wrote one word... it said bipolar. It was only later that I discovered that bipolar was the fancy new name for manic depression" (T1P8). Indeed, prior to this admission, she had spent a lot of money, a common sign of mania. She believes if her new diagnosis had been identified earlier it would have made her life a lot simpler, explaining her behaviour and actions.

This admission lasted a month. She had a new psychiatrist whom she liked very much. Craig rarely visited her during this stay in the local hospital. She felt this was due to the stigma the hospital carried in the local community, as he had often visited her on during her previous admission. During this admission she met several people who would later become her friends. One of these individuals, Graham would play a significant part in her life.

Nearly a year to the day in April 1996, she was back in hospital. Again she had been spending money. In addition, "I didn't know it, but I was doing the weirdest things. I can't remember... at one point I was saying the opposite of what I thought I was saying" (T1P8). She is heartened by the fact that she does not always remember how strange her behaviour has been. "The brain is a nice organ in many ways it doesn't remind you of the worse things you have done ...I'd hate to know all the things I did when I was manic" (T1P12).

At the time of this admission, her psychiatrist was exploring different medications and introduced to her medication routine, Carbamezapine. This medication has had a good, stabilising effect on her episodes of mania, although she 'still gets very bad depressions ...but it has made a big difference" (T1P8).

This notwithstanding, her experiences in her local hospital were less than satisfactory. It compared badly to her first hospital admission. She felt unsupported and that some staff were uncaring. "You could cry your heart out over there and none of them (the staff) would bother coming near you. I saw a patient being hit" (T1P9). She recalled how "I had been shoved down into Ward Z. I came back after a weekend away at home, to discover that somebody was in my bed" (T1P9). She felt that this type of situation should not arise and it left her feeling abandoned with no feeling of belonging. For Pam, this incident also raised the issue of feeling safe. "In Ward Y at least I was checked every night...the important bit was that the staff were checking us through the night. Well, I was awake all night and not a soul came by on Ward Z" (T1P9). Pam decided that she would not be like the others who sat and complained about the service they were receiving. She took action, compiling a letter with the help of the local advocacy service. This led to an investigation being carried out and steps taken within the hospital to improve the service provided to patients.

Since the 1996 admission, Pam has been cared for and maintained at home. In 1997, she had several months of depression, similarly in 1998 and 1999. Her illness affects her in a variety of ways. "I can't work. I can only sustain anything for a certain length of time and then I've got to rest, I've got to work my day out right...if I don't I'm a wet rag the next day or the next several days" (T1P9). Her concentration is also affected. She found at one time she was unable to even read. With her last depressive episode, Pam was unable to drive because of her high dose of medication. She found this difficult as it meant her life was very restricted to her own local area. When unwell, Pam wants 'to go to bed I feel so much better in my bed, in the ward they want you to sit up and I feel more ill that way"(T2P4). On this last occasion, in November 1999, Pam was not admitted although her doctor wanted her to be, to sort out her medication. Pam sums it up: "the ward is so debilitating...you feel more ill on the ward than you'd feel at home. There is nothing to do" (T2P4).

To help her in the summer of 1999, Pam was awarded a Disabled Living Allowance (DLA). This allowance enables Pam to pay towards a service she prioritises. "I now have a home help, I can't stand housework, I just found it really got me down trying to do it... You know, it's this pushing of a vacuum cleaner, waving of the duster and one thing and another, I'm exhausted in no time...It leaves me free to go out and do things that I want and not be restricted" (T2P3).

Medication is still an issue for Pam. While trying to sort out her medication last year Pam experienced severe reductions in her blood pressure. Now, her regime has settled and she appears able to cope with the increased dosage. Pam is keen for this to work: "It would be great if they had got the medication right ... it would mean that I wouldn't have to go every month ... the aim is for every six months" (T2P4). In the long-term she hopes "that they will find a tablet, something that puts me on an even keel. It might even be early enough that I could do some work" (T2P7).

During her second hospital admission, Pam had met Graham. Their friendship grew. Her relationship with Graham has been mutually beneficial with each caring for the other. Graham has an anxiety depression disorder. Pam described how he helped her to be maintained at home. "He made sure I had my medication, he hauled me out of bed in the morning, shoved me in the shower...put food down my throat" (T1P12). With her last episode of illness, Graham's support enabled her to get out of the house and to visit places. "But for him I wouldn't have got out, just gone to bed like I usually do" (T2P3).

Her parents do not approve of their relationship, as it has resulted in Pam becoming a carer for Graham. Her parents still play a significant role in her life. This is especially true for her father who has Power of Attorney over her personal finances. This was set up to curtail Pam's spending ability should she have a manic episode. Pam seems unconcerned by this situation. "When I ask for money I get it, I don't even need to tell him why I need it"(T2P6). Her financial situation is a worry for Pam, especially as she feels that the value of her money has gone down in real terms. "I am pedalling backwards all the time"(T2P7). Pam hopes in the future, if she is well enough, to be able do take on paid work. Ideally, she would like to use her teaching experience. However, "if I tried to use it I would immediately be told that you are healthy enough so I would lose my pension"(T2P7). This would obviously have a serious impact on her personal circumstances.

She may in the short term take on some voluntary work, something like the 'kids club' at the church. She also worries about letting people down. "I had to have a big chunk of time out of the groups and things...last year (1999)"(T2P3). In the current organisations in which Pam is involved, people understand her needs. Although she would like to do different types of work, other workplaces may not be as understanding of her situation. Stigma and lack of knowledge are still evident. Pam has returned to the church in the last few years. She did join the church in her teens but stopped going during her marriage. She has found "the church a great source of help" (T2P7). She attends most Sundays and she is involved with the Women's Guild.

Currently, Graham and Pam spend a good deal of time together, even though Graham still maintains his own flat. She acknowledges that at times, because of her experience with her father and her ex-husband, she gets "snappy with Graham, I try so hard not to ... I know he is not actually telling me what to do. He's not the type" (T1P13). She expands: "With Graham, I am very much a person and we are very close" (T2P6). They share similar interests, for example history, walking and music. Both are keen on the countryside and make the most of special promotions to visit other areas within Scotland and further afield. These offers keep the costs to a minimum. They try to have a holiday each year, finances allowing. She emphasises how important Graham is in her life "it means all the difference to me between living and a living death" (T2P5).

Pam's initial step to complain about the hospital service proved to be highly significant for her. One of her friends was involved with the local mental health forum and she invited Pam to attend the group. Pam has now been the secretary of that group since 1996. This involvement has led Pam into several mental health related initiatives both at her local hospital, her community and at a regional level. There is now a liaison committee at the local hospital. Pam explains, "If anybody has a complaint they can come straight to the group, tell them and it can be taken straight away to the committee"(T1P10). Pam has been active in working on the local mental health framework strategy, regularly attending meetings. She has also been involved in the setting up of a drop-in centre in her community, a facility that was not available in her local community. Formerly, people had to go into Glasgow to access this type of service. In addition, Pam was involved in counselling and advocating for others with mental health problems.

Pam enjoys being active in these organisations. "I was driven crazy by not doing anything and at least when I'm doing this I feel like I'm doing something. I'm trying to make the lot of the people with mental health a better deal because it is not very good" (T1P11). She is committed to making change happen in her local psychiatric services. She would like mental health professionals "to listen to what is being said. The patients know themselves what is wrong with them...Everybody feels thing differently. Everyone needs to be dealt with differently. We are after all individuals, we are not a herd" (T2P8). She acknowledges that mental health work is frustrating and hard on the people involved. For her own part, it is like "knocking my head against a brick wall half of the time, nay change that to 99% of the time" (T2P5). She believes that her illness in 1998 was in part a response to her doing too much mental health orientated work.

Pam's narrative tells of someone who has adapted to the changes in her life and circumstances. Currently, she is contented with her life. There are some things she hopes to be able to achieve in the future, for instance a return to paid employment. She continues to be an active advocate for mental health and uses her previous teaching skills to support this role. She has a range of interests that she pursues independently or with Graham. She has a small, but supportive group of friends whom she values. She has regular contact with her son and his partner.

In telling her story she "hoped it would be of value, it would help others" (T2P8). She was also clear that she had been open and honest and that her parents did not know about the study and that she did not want them to know. Insofar as her life has turned out differently from what she imagined, her mental illness experiences, although difficult and painful, have facilitated Pam to discover who she is and to believe in herself once again as a valid person.

Pam's reflections

I have made a few changes...anything else I don't think would be that wrong. Have now found what appears to be the correct dosage of medication. Have been very stable since late 1999. Just a short blip recently, nothing like as depressed in the past.

Pat's Story

"It's left its mark on me"

Beginning: Home life - hard times

Life at home

Working life

Married life: short & bitter

Solo parenting

Middle - Giving it up - getting it back

Being admitted

Leaving the children

Hospital life

Rehabilitation to the Group home

End – Starting Over

New home – new life

Loss of physical health

Addressing the past

Family Connections

Working with others

Pat's

Biographical Data

1938	*Birth - a twin (two girls) – North East Scotland* *older brother*
1944	*Sister born.*
1948	*(10 - 15)* *Grandmother died* *Working hard at school and at home* *Enjoys working with animals* *Holidays at Aunt's farm*
1953	*(15)* *Twin sister left home to go to nursing college*
1954	*(16)* *Moved to first job in Edinburgh*
1954	*In hospital with appendicitis.*
1954	*Moved to job at the Kennels outside Glasgow*
1956	*(18)* *Went home to look after her mother*
1957	*(19)* *Placed an advert in the trade paper as a result went to work for a vet in England.*
1959-1964	*(21-25)* *Came back to Scotland - job in dog parlour, moved back home*
1964	*(26)* *Started pupil nurse training at Nursing College in North East.*
1966	*(28)* *Got married.*
1967	*Husband tried to kill her - First son born*
1968	*Daughter born* *Abuse continued.*

	(32)
1970	*Separated from husband – pregnant.*
1971	*Second son born*
1971-79	*Bringing up the children – mental health problems*
	(41)
1979	*Father died*
	(43)
1981	*Admitted voluntarily to psychiatric hospital. Children went into care*
	(47)
1985	*Moved to group home.*
1987	*Mum died, almost eighty two*
1989	*Youngest son moved in to group home.*
1990	*Operation in May.*
1991	*Moved to new house with son. Had a stroke.*
1992	*Admitted to hospital with thyroid problem*
1993-2000	*Enjoying home-life, Physical health a problem: poor mobility.* *Involved in ME Association* *Still attends mental health drop-in when able* *Supporting friends and family* *Writes poetry*

Pat's Story

"It's left its mark on me"

Home life – hard times

Pat was born in 1938, one of twin girls. She and her twin had an elder brother and a younger sister. They lived in a small town in the North East of Scotland. She described life at home as very difficult. Her father suffered from depression. "He was bothered with his nerves quite a bit. He had treatment every two or three years" (T1P1). In addition, his mother was considered by the family to be "a bit loopy" (T1P1).

Pat stated her mother "was never off father's back… she never stopped nagging him" (T1P1). Her mother ruled the household. She had strict guidelines that had to be observed. The children were involved in the general upkeep of the house, each with their own tasks. Pat described not being able to have friends over or to visit her friends out of school hours. Pat realised early on that she and her twin sister were treated differently from their eldest brother, who was clearly their mother's favourite child. "I've an older brother, his childhood was totally different from Jane's and mine" (T1P3).

Pat recalls of her mother, "We were terrified of her as children" (T1P1). Her mother was often critical. "You two will never be any good, you will never get anywhere. You are hopeless. She never ever gave a word of praise …Of course when you are a twin, this thing 'the terrible twins', I used to think I had done something bad though I couldn't think what it was. To be called that, it leaves its mark on you" (T1P1). The twins were also subjected to physical abuse. "She had a half-size walking stick she used to lay into us with" (T1P3), Pat recalls. "My mother couldn't knock her (youngest sister) around because they discovered she had a hole in her heart when she was 6… But she got it verbally" (T1P3). As Pat remembers, "I always used to wonder why the school never said anything. But of course in a small town, they must have wondered about the bruises on us and you had nobody to go to" (T1P3).

As a child, Pat loved animals. She had her own dog, a present from her father. She took great pride in training her West Highland terrier. She enjoyed holidays she spent with an aunt who had a farm. She loved working with the animals there. As the war progressed, she held hopes of joining the Women's Land Army and becoming a 'land-girl'. However, the war finished: "It got disbanded the year before I left school" (T1P3). A career change was called for.

The twins both wished to be nurses. However, at that time the admission policy to the nursing school in the North East stated that only one family member at any time could join the course. So Jane went off to the nursing college. Pat stayed another year at school. As school came to a close, she organised a job on a local farm, where she would live in. But her mother objected: 'She wouldn't let me do that" (TIP3). She had a different plan for Pat and had organised a job for her as an assistant in a nursing home in Edinburgh. This post paid minimal wages but it included board and lodgings.

At sixteen, Pat set off for Edinburgh. She missed her twin sister, her home, and the hills very much. However, she soon made friends with one of the other staff members. This girl's sister worked in kennels, near Glasgow, and Pat was intrigued. She enquired about the possibility of a job there. "I got this letter from the woman saying if I wanted to come and work for her it would be fine" (T1P4).

However, before she was able to take up this position, Pat was hospitalised with emergency appendicitis. Her mother had to give permission for the operation to take place because of Pat's age. Pat recalls that her mother was "most annoyed being phoned in the middle of the night for her permission to give me the anaesthetic" (T1P4). Whilst in hospital, she was offered a job by the woman from the kennels once she was fully recovered. Pat was delighted but very worried about handing in her notice. "I was so under the thumb right through my life... I wanted to go and work in this place. I was in panic stations actually doing something that I wanted to do" (T1P4). However, her new employer took care of this for her.

So Pat moved to the outskirts of Glasgow. She really enjoyed her work in the kennels and was very happy there for several years until her mother became unwell and Pat returned home to look after her. Once her mother had recovered, Pat, now 19, began to look for a new job. She placed an advert in a trade paper. As a result, she moved to Birmingham to work with a vet. She worked here again for several years before returning to Edinburgh, in the late 1950s to work in a dog parlour. Here she learned the skills of clipping and dressing dogs. After a few years she returned home to the Northeast, but she was unable to find a job that paid as well as her Edinburgh post. Pat, now 26, decided that she would pursue her earlier idea of nursing and she enrolled in 1964 on the pupil nurse training course.

In 1966, aged 28, Pat got married. She fell pregnant quickly and was unable to finish her nurse training, leaving at the end of her second year. She explained calmly, "My ex-husband tried to kill me when I was expecting my first child. He tried to strangle me" (T1P6). Pat left him and returned home to her parents. Her son was born in 1967 She had a difficult birth. Someone informed her husband that the baby had arrived. She remembers, "He got down on his knees and cried and promised...My marriage vows meant a lot to me, for better or worse. So we got back together"(T1P6). Pat's husband appears rarely in her narrative.

The family then moved to Glasgow where her husband had secured a new job. A second child was born, this time a girl. However, the marital relationship continued to be abusive. "I had to in the end get away and make a life for the children and myself...He had started turning on them as well as me"(T1P7).

In June 1970, she took the children and set up a new home in a council house in Glasgow. She recalls, "It was really quite bad. You just kind of plodded on from bit to bit. Sometimes it felt like from hour to hour"(T2P2). At this time, she was pregnant with her third child. Her second son was born in 1971. Pat was 33.

Life for Pat then was very arduous and her main concern was the children's welfare. She explained: "Well, you've got to pay the rent and at that time you paid full rent. It came in your money…All that is in your mind is you've got to pay the rent. You've got to pay the bills, you've got to put food in your children's stomachs and you've got to feed and clothe them and you've got to give them heat and light…That was the main thing on your mind...You dreamt about it" (T2P4).

Pat's life revolved around caring for the children. She had little time for herself. She recalls, "I was never out. I couldn't afford to go out" (T2P4). On one occasion, a friend convinced her to go out for the evening "to the dancing". Pat organised a babysitter for the children. However, on her return home the children were misbehaving. "They were making so much noise they never heard me come in the door…the three of them got the fright of their lives"(T2P4). The following day her eldest son announced, 'That it wasn't fair that mum had gone out" (T2P4). Pat explained, "He thought I had no right to be going out to do something I wanted to do…I said to myself, 'I'll never go out again until they are grown up.' In a way, I didn't go out again" (T2P5).

Lack of money was a real issue for the family. As Pat said, "You don't have enough for extra things…People say they can't manage on social security. You can, it is a struggle but you can do it" (T2P4). Pat explains, "You've got to try and survive and make sure that they get all they need. That was the one thing on my mind. That they had to have everything they needed"(T2P4).

As she continued to look after the family struggling to make ends meet her mental health began to suffer "I didn't realise. Now, I know it was a culmination of my childhood and everything. It caught up with me in my late thirties. The strain of trying to bring up three children on a limited income on my own. It just all caught up with me" (T2P18). Additionally, in 1979, Pat's father was killed in a car crash.

During this period, Pat felt that she did not receive any help although now she was attending a psychiatric day hospital in Glasgow. She remembers that she was asked by her general practitioner (GP) to consider giving up her children. "I gave birth to them and even when things are difficult at times, it's my job to bring them up"

(T1P11). She discovered from her GP that this possible solution to her difficulties had been suggested by her psychiatrist. As her mental health deteriorated she was admitted in 1981 to the local psychiatric hospital.

Giving it up - getting it back

Pat was admitted voluntarily to a Glasgow psychiatric hospital. She felt that she could no longer cope with her life and her situation. She was divorced, bringing up her three children with no support, in a council flat on a housing estate. She had suicidal thoughts. These thoughts were a prime motivation for her to seek admission. She recalls, “I was crying. I didn’t even know what I was crying about. I got frightened to go out. I started getting panic attacks” (TIP7). For Pat to seek an admission was not a decision she took lightly. However, she was fearful about the children, especially what would happen to them if she was not there. “I had nobody to look after the children…they went into care” (T1P6).

So began a long admission. Approximately three and a half years of Pat’s life were spent in a range of wards in the hospital. Her memories of that time are clear but her memory is less accurate with regard to precise timings of events. “I can’t remember…so many years have gone past” (T1P7). However, her difficulty with recalling exact dates is likely to have been affected by her mental state that precipitated the admission, as well as medication taken throughout this period.

Her time in psychiatric care was anything but uneventful and she believed not conducive to helping her progress. Her relationships with the staff, and especially her psychiatrist were strained at the best of times and at the worst times she experienced open conflict with him. She felt that her psychiatrist was unhelpful and, perhaps more importantly, she felt threatened by him. “He just wanted to fill you up with injections and pills until you were just a zombie. He didn’t want to know at all. I mean, if you’ve got somebody gazing at their shoes or gazing just over the top of your head, you get the message”(T1P8). She recalls. “He had me on this tablet. It didn’t even have a name”(T1P8). Pat remembers challenging her consultant about this during a ward round. “You are supposed to ask me if I am willing to take a drug that you're trying out for a drug company" (T1P9). She recalls, "He was near spluttering with rage, he couldn't speak" (T1P9). The tablet was not given to her at the next drug round and she was informed that she would no longer be receiving it.

Pat also remembers being put under pressure to give up the family home. "For three months it went on - nursing staff, by his learners (junior medical staff) at the time, by himself. 'Give up your house, Give up your house'" (T1P12). Eventually she agreed to put her house in her eldest son's name. With regards to her psychiatrist, Pat felt, "The feeling that came from him was this unspoken threat of what he would be able to do"(T2P24).

She considered that the nursing staff were generally unhelpful. For example, their behaviour when she had an item of clothing stolen. "I had a bra nicked out of my locker. I went to the duty room. They weren't doing anything, they were just sitting, drinking tea. You could stand there for hours waiting, then they would shut the door on you" (T1P9). The staff advised her to search the other patients' lockers. She insisted, " I'm not doing it. I want a nurse to go around and look at all the lockers" (T1P9).

One day, a member of the nursing team held Pat against her will. Pat had made arrangements to go to a review of one of the children and she informed the staff that she would be off the ward. She was told that she could not leave the ward as she was expected to attend a meeting with her consultant. She reminded the ward sister, "I'm a voluntary patient. I can go out when I want...At the main door of the admission unit the nurse put her back against it to keep me from going out. I couldn't remove her, lift her up and put her aside. That would have been assault"(TIP10).

Throughout her time in hospital, the children were in care. "I actually thought the children would have been better off without me because I felt I wasn't being a proper mother because I was in here"(T1P8). The boys had initially remained together in a children's home but her daughter had been placed in a different children's home. Pat did query this. " I thought social work policy was to keep children together, not separate them"(T1P8). Pat maintained contact with the children with regular visits. On one occasion, she recalled that one woman, a member of staff at the home the boys were in, called her an unfit mother and told her." I don't have to listen to you. You're a nutcase"(T1P8). Pat became increasingly aware that her youngest son in particular seemed ill at ease. "He was sort of closed off...he was so closed in on himself"(T1P8). Pat didn't want to make things difficult for the boys after she had left the home. "I had to shut my mouth a lot... I knew something was going on" (T1P8).

Her youngest son was later placed with foster parents, a decision that surprised Pat. "I never gave my consent to it and I hadn't given them up... I don't know how that was worked" (T1P8). Pat was keen to make sure her rights and others were upheld: "I mean, the number of people I gave the Mental Health Act and the Social Work Act...I felt I needed to have them. I needed to know my rights...I'm that kind of person I find out what's legal and everything like that before I make a move" (T1P12).

Pat's return to better mental health was slow. She did not have a confirmed diagnosis for several years. Much later, once discharged, she asked for her diagnosis to be clarified. Her consultant stated endogenous depression. Notwithstanding, a lack of diagnosis, the medication she was given caused difficulties for her, especially the side effects. "I felt like a zombie. I was massive with the tablets...I put on weight and weight and weight. I was nearly 14 stone. I was so slow"(T1P18). Pat developed angina during her admission.

As Pat's mental health improved she was involved in an active rehabilitation process. She was moved from the admission ward to the rehabilitation unit. She recalls this unit as being "quite good"(T1P18). She attended occupational therapy. On the whole she found the environment in the occupational therapy department beneficial for several reasons. "Patients feel that the occupational therapist is their ally. It's not so frightening there as it is on the wards and other departments... they (patients) would voice things a lot there that they wouldn't voice anywhere else". That said, Pat felt that for the most part occupational therapy didn't meet her needs. She recalled, "I used to walk in the occupational therapy (department) and out the other door. See, if I was asked if I'd been to occupational therapy, I wasn't lying when I said yes. I hadn't lied. I'd been in it and straight out again" (T1P18). Pat did have a good relationship with the head occupational therapist "I know I told her things I would never voice to him (her psychiatrist)...but I felt it was safe, it was alright to tell her" (T2P24).

Later, Pat worked in the wards as assistant, three mornings a week. This employment was considered as therapy, and so Pat was entitled to therapeutic earnings of £10 a week. She recalled that others often forgot that this work was intended to be therapeutic. For example, "One morning I had this bad angina...I had the tablet that you put under your tongue. It used to give me a shocking headache. It lasted for about 24 hours. The sister said 'Carry on, there is no need for you to sit.' I said, 'Wait a minute, this is work therapy ... If you're insisting this is a job then I want the going rate for it'"(T1P14).

At the end of her hospital admission, Pat and two other women were transferred from the hospital to a group home in the local community. One of the women, in Pat's opinion, could not deal with group living as she was both physically and mentally unable to care for herself in the this type of environment. She indeed only lasted a short time in the group home before finally returning to the hospital, where within a short period of time she died.

Pat and the other woman, Hazel, lived together in the house. They had support from both a community psychiatric nurse and a social worker. Pat felt that much of the responsibility for running the house and caring for Hazel fell heavily on her. She shopped and cooked for them both, in addition to general household work. Pat recalls, " I used to take her for walks and that kind of thing. I was very fond of her...You had to tell her to change her clothes...She couldn't manage it"(T1P16). They remained in the group home for six years. Pat believes that her physical health suffered because of her time in the group home. “A lot of it is to do with the strain of keeping that house going for six years”(T1P15).

Within this environment, Pat was concerned about confidentiality issues, particularly in relation to other people who had access to the house. Initially, these concerns were primarily focused on the community psychiatric nurse (CPN) and then later on the home help who assisted with Hazel’s share of the housework. Pat believed that the home help was asking the CPN about her history, this was unacceptable and unethical. In addition, the home help lived near the group home, so Pat felt that others locally might have been given information about her. Pat eventually confronted the home help: “You have no right asking the CPN about me... It is none of your business...If there is any more I will have your job”(T1P17).

Boundary issues were also a concern for Pat. She felt that the group house was her home, and therefore others should be respectful within this environment. She recalls. “The CPN arrived one day and I was just taking stuff out of the oven. She never told us when she was coming”(T1P16). This situation of the CPN turning up at all times of the day led Pat to negotiate convenient visiting times with the CPN. “If you tell us when you are coming we’ll try and make a point of being here for you coming” (T1P16). This issue, CPN visiting, was also highlighted for Pat when several years later in, 1990, she was admitted to the local general hospital for surgery. She did not wish the CPN to visit her at all. However, the CPN intimated that she would come and that she could visit at anytime because of her status. Pat felt that this was inappropriate and asked that she only visit at the designated visiting times, and “You don’t say who you are or what your job is”(T1P17).

Throughout these years, Pat still maintained communication with her children. Her youngest son Mark, now seventeen, had been housed in an independent living flat. fairly near to Pat. He decided that he would move into the group home to be with his mum. This situation of course was not sanctioned or indeed known to the hospital or the social work department. He lived with his mum for about 18 months before the situation was discovered during a routine social work visit. Meanwhile Pat had been trying to find alternative accommodation, and in March 1991 she and her son moved into their new home. This was to be a new beginning for Pat.

Starting Over

Pat had been in the group home for well over six years when she and her son moved to their new flat in March 1991.The flat is in a development with an active social programme. Pat set about establishing herself in her new community, taking part in the available activities. So did her son, who currently sits on the accommodation committee.

She did not tell people about her time in hospital or in the group home. "Nobody knows, by the way. My next door neighbour is one of those who thinks people in mental hospitals shouldn't get out" (T1P13). She banned her CPN from coming to her house. "I told her when I moved here, 'You're not coming near me at all at any point'"(T1P15). Pat maintains that the CPN would tell "everybody who she is and who she was coming to see" (T1P15). Pat was happy for other staff to visit her at home. However, her experiences with her CPN left her feeling angry. The CPN did attempt to visit Pat in her new home but Pat refused her entry.

Over the past 10 years Pat has had a range of different physical illnesses, a situation which she sees as ironic. "As my mental health got better my physical health decided to give up"(T2P7). In October 1991, she became unwell. "I had a bad stroke and I lost my speech…it gradually came back. (laughs) I've never shut up since then"(T1P2). In 1992, Pat was once again in hospital this time with a thyroid problem that required surgery. "I was actually dying on my feet"(T1P18). This condition affected her bones, especially her ankles. Pat believes this illness was due to medication that had been prescribed when she had been in hospital. However, it took a long time for the cause of the problem to be discovered. As a result, her ankles have been weakened. She now walks with the assistance of walking sticks and her ankles continue to cause problems.

Following this episode, Pat decided to change her GP. She had to negotiate terms with her proposed GP, who agreed to take Pat on to her list for a month's trial. If problems arose she would have to find another doctor. However, things worked out well for Pat. She was well pleased with her new GP. Pat explains. "I'll tell you what she did for me. I'm fed up with the stigma that there is if you have been in a mental hospital or attended one. I asked her to take all references out of my file… and she did" (T1P19). Today Pat has another GP with whom she has a good relationship. Her physical health remains poor. She regularly attends various hospital departments.

In recent years, Pat has suffered from Myalgic Encephalomyelitis (ME) and she has become an active member of a ME support group with meetings being held in her flat. Until fairly recently she was still attending the mental health drop-in, in the city. Here she met up with friends and attended the creative writing group. The women all support each other, not only in the centre but informally, especially over the phone. Attending the centre has become more difficult as her mobility problems have increased.

But what of the children? Nowadays, Pat's family is very significant to her. Pat has a good relationship with her daughter, who is married with her own son. Both her grandson and her daughter visit regularly. Pat feels that she is a useful sounding board for her. In the last year, Pat has been supporting her daughter through a family crisis. "I don't mind if she bends my ear for an hour. She is talking out any worries she has. She realises now that I have always been there"(T2P19).

However, her relationship with her eldest son is somewhat strained, with little contact between them. Pat finds this difficult especially because she is unable to see her three grandchildren, a boy and identical twin girls. Pat feels that her eldest son blames her for how his life has turned out. "He's still convinced that all of his troubles were me. I'm not going to feel guilty…I'm not going to dig myself into an early grave worrying about it. He is a grown man"(T2P27).

Over the past years, Pat has had to come to terms with the knowledge that both the boys were sexually abused while in care. She discovered the abuse only when the boys came out of care. "It nearly took me apart when I discovered it. It was only a chance remark from the oldest one that I discovered it. It nearly took me apart at the seams"(T1P6). She has asked her youngest son why he did not tell her what was going on when she visited. "He said he was frightened of what would happen once I'd left him. Pat reflects, "I was a voluntary patient. I wouldn't have gone back to the hospital. I would have taken him out of there straight away. He didn't know that and I didn't know"(T2P18). Pat says of the abuser, "I can't forgive him for what he did...He abused his position in the home, in a place they were meant to be safe"(T1P7).

As a result of this abuse and its effects, Pat worries about the future of her younger son, especially his future relationships. However, she really enjoys her relationship with her youngest son. He is a constant support to her, both emotionally and physically, often accompanying her to hospital appointments, shopping, and generally being active in her life.

Pat has started to write poetry. She has been a participant in the creative writing class run at the mental health centre. "Since my physical health went down hill this came...it's like as if some things were taking away you were given something else"(T1P24). She adds. "I did sort of write my life story when I lived up the road in the group home...I put it away for about two years and then looked at it. I thought it was total dross and tore it up"(T1P24). Now, Pat writes humorous stories about animals. She laughs, "Quite often I would be getting in the bath and the whole thing was there by the time I got out of it. There's not been so much poetry coming since I got my walk-in shower" (T1P24).

Today, Pat says, "I'm happy, I'm content, I'm a very much stronger person...I maybe can't do much physically but if I can do my wee bit, my writing or phoning or that for folks along the way, that is OK"(T2P24). Reflecting on her experience of this study, Pat felt, "Well, for a wee bit it opened hurts that I thought I had buried but it didn't have a lasting effect…It's not done me any harm. I feel it has been worthwhile. If I had been part of this 10 years ago I would have still been afraid to say that's how people feel in the mental health system"(T2P30). Looking to the future, Pat states, " I don't think a great deal about the future. I live fairly much in the present (laughs). I don't think ahead at all"(T2P28).

Pat's reflections

I am amazed that you got a story out of what I said on tape…I know I flit from one part of a topic onto another part. I feel the main influences have been included.

Sarah's Story

"When you feel that you are coming together
as a whole person it is amazing!"

Beginning: A less than perfect start

Lost childhood
Finding faith - A future path
Learning and earning
An unwelcome visitor
Working to the future

Middle: Growing Realisations

Campus life
Secret revealed
Silenced
Motivated to work
Missionary life

End: Wheelchair, ramps and freedom

"Her indoors"
Dramatic Change
Hopeless
Old friends
Sarah's "others"
Integration and beyond

Sarah's

Biographical Data

1952	*Born in Glasgow, one of nine children. Sister and brother died in early childhood.*
1952-1963	*Sarah did not speak directly of this time period. The time of her sexual abuse at home by her father.*
1963	*(11)* *Rushed to hospital at eleven, burst appendix. Became a Christian at 11.*
1964	*(12)* *Abused by a teacher in her first year at secondary school.*
1965	*(13)* *Moved house to new area.*
1966	*(14)* *Left school at end of her third year. Worked initially as office junior, later worked as secretary to the work's manager.*
1970	*(17)* *Attacked at work. Took an overdose a few months after this attack.*
1973/78	*(21–26)* *Went to Bible College in the USA.* *Problems with her periods. Sexual abuse revealed. Incident at college admitted to private psychiatric hospital. Mute for three weeks. Went back to college went to counselling.*
1978	*Graduated from Bible College.*
1979	*Home in Glasgow for the summer and friend took her life. Back in the States went into therapy began to deal with the real issues.*
1981	*(29)* *Commissioned to Northern Ireland. In the December, involved with a bomb scare incident after that started having 'turns' again. Back to Scotland for tests.*
1982/3	*(30-31)* *Having seizures, falling down stairs, too many accidents. Diagnosed as having epilepsy*

	(32 - 42)
1984	*New house in 1984. On anti-convulsant medication till 1994.*
	(42)
1994	*Neurologist retired, new neurologist, Taken off her medication in October - no support.*
	(43)
1995	*A friend came back into her life, met up with her at a missionary conference.*
	(44)
1996	*Attended a course on sexual abuse. September went to a learning styles seminar.*
	(46)
1998	*Mum died in the September*
1999	*Studying Greek, going to church, involved with the women's group.*
	(48)
2000	*Running women's group, working in office part time and childcare. Aiming to have her missionary status reactivated.*

Sarah's Story

"When you feel that you are coming together as a whole person...It is amazing!"

Sarah came to be involved in this study through the mental health drop-in centre. She attended one of the sessions I ran there and expressed a wish to take part in the study. She was a slim, small woman in her middle years, who was smartly dressed: indeed, her dress stood her apart from the others at the centre. A time was mutually agreed for the first interview.

On arrival outside Sarah's home, I was surprised to see a wheelchair ramp leading to the front door, a trademark sign of an occupational therapist's involvement in a case. However, as I approached the house, I saw that the ramp was in bad repair. Some side supports had sprung from the framework. It was not safe for a wheelchair user. I was somewhat surprised, as I was sure Sarah had said she lived on her own. However, all would be revealed!

A less than perfect start!

Sarah was born in 1952 into a large family the fifth child of nine children. She lived with her parents on a Glasgow housing estate. One sister died at nine months from a convulsion and a younger brother died of peritonitis, aged one year and eleven months. Sarah did not refer to her early childhood. Her story began when she was 11. This lack of reference to her early childhood was acknowledged by Sarah. She explained that during these years her father sexually abused her. She felt unable to discuss this period of her life, as she was still actively addressing the abuse in counselling.

At 11, Sarah was rushed to hospital with appendicitis. An incident she remembers as being quite frightening as she feared she would die. "Burst appendix is something which six of us suffered ...We were rushed into hospital...Of course, every one of us knew that we'd lost a wee brother and were terrified that we would die, too"(T1S4).

Fortunately, Sarah survived her operation.

Later, she went to a camp organised by the Baptist Church. This was to be a refuge for Sarah. She recalls, “I was there at camp at eleven, camp was like a haven to me”(T1S20). At this age, Sarah decided to become a Christian and to follow God. She believed she was called to be a missionary within the church. Her decision was not supported by her family. Indeed, they viewed it as something quite foreign. Nonetheless, Sarah was determined and she had a future goal to work towards.

At twelve, Sarah moved from primary to secondary school. In her first year at secondary school, she was abused by a teacher. “I know that I wasn’t the only kid in the school abused by that man”(T1S3). She felt betrayed by the older children believing they should have protected the younger children and warned them. Soon afterwards, Sarah’s family moved to a different part of Glasgow and Sarah, now 13, went to a new secondary school. “My grades improved a wee bit but it still wasn’t a real performance of my potential” (T1S3).

Whilst at school, Sarah had to choose whether to do domestic science or commercial subjects. She chose commercial subjects as she was still pursuing her goal of becoming a missionary and felt that office work would be useful to her. Throughout this time she continued to be involved in church activities.

She left school at the end of her third year and got a job straight away working in a nearby firm as an office junior. She did this for a year, and then got the opportunity to work with the personnel department. At seventeen, she became the work manager’s secretary. This promotion resulted in her having her own small office linked to her employer’s office.

Whilst at work in this office, an incident occurred that was to have a significant impact on Sarah’s life. “When I was seventeen a man came into that office and put me up against a wall and was about to rape me when my boss came into my office. It was really quite amazing...Mr N (her employer) never used my office door...He never would come in here and that day he came in...If he hadn't come in (sighs). My boss phoned my mum and told her. Do you know what she said to me? 'You've just got to pretend it didn't happen.' That's what I was doing with my whole life, I'm afraid, pretend it didn't happen"(T1S5). In addition, as 'nothing happened' this incident was not reported to the police. Sarah reflects, "That was back in 1970...it has ruined my life. Not just that I was abused as a child in my own home, all of it has ruined my life"(T1S6). Sarah's past experience of abuse as a child was reinforced at this time.

A few months following this incident, Sarah took an overdose of tablets. She explained, "I did that after that incident, I didn't do it right there when it happened it's like a month or two later when there is no reason...I didn't know why I did that thing"(T1S7).

Growing Realisations

Sarah was still working toward achieving her aim of becoming a missionary. She was successful in being accepted as a candidate for Bible College and in 1973, aged 21, she went to Bible College in America.

She enjoyed campus life and she had several friends. Although she was successful in her education she failed to recognise her achievements. "I worked hard to get my grades...I didn't have the academic side of intelligence. Practical, yes, and being organised were all in my favour"(T1S3).

She had chosen to stay on campus for the summer vacation, working on the campus. One of her friends was teaching her to sew. Therefore, in the evenings, she was busy sewing, making sundresses for a friend's children. Sarah had problems with her periods: specifically she was bleeding heavily. This resulted in her consulting a doctor. During this consultation the doctor, who was also one of Sarah's friends, asked her if she had been sexually abused. Sarah recalled this significant moment. "I just dropped my head, and I thought at that point that's me out of Bible College, that's me finished. I'll never be able to do anything"(T1S6). The doctor reassured Sarah that help was available and organised an appointment for her to see him the following week.

Sarah was obviously distressed by this situation. However, the revelation of the sexual abuse coincided with her friend going off to a wedding and Sarah felt unable to share her distress with her. She did however, indicate to this friend that she might not be there on her return from the wedding. The following evening, Sarah was working on her sewing when around midnight she was frightened by noises outside. She heard scraping noises outside her room and went to investigate. A fellow student jumped out at her as a prank. Sarah recalls, "I felt something in my head snapping. I don't even remember how I did it, I just ran all across campus. It was like I was running on air. I didn't feel the ground. I ran back to the dorm and took an overdose without stopping"(T1S7). Sarah called the doctor to tell him she would not be able to keep the appointment. "I went to my bed to die, that's what I really wanted...He (the doctor) came right over to the dorm and he took me to the hospital and had my stomach pumped"(T1S7).

Following this suicide attempt, Sarah was admitted to what she thought was a convalescence home. "The Dean of Women drove me to this convalescence place, forty-five minutes away from the college. To me, it was like in the wilderness, miles away from anybody that I knew. It was quite terrifying. I was silent. I didn't say a word for about three weeks"(T1S7). As a result of Sarah's silence, electro-convulsive therapy (ECT) was considered as a treatment option.

However, in the meantime another patient came to Sarah's attention. A young girl went berserk, she was picked up by the staff and locked in her room. Sarah slowly realised that her convalescence home was indeed a private psychiatric hospital. Sarah recognised her predicament and broke her silence. She also began to trust the staff and share her situation with them. However, "I was still minimising anything that had happened in my life. But I was willing, I really wanted to get back to college and they were glad I had the motivation to do that. I think when I look back on my life I never allowed myself to be depressed for very long…I would be doing other things. I would do what I could do to come out of it, but I wouldn't stay in the depression"(T1S8).

Shortly afterwards, during a visit home to Glasgow, Sarah found that a friend's mother was having psychiatric problems. This woman was very important to Sarah, - they belonged to the same church and Sarah considered this woman as her "spiritual mother"(T1S8). Sarah was increasingly aware that she had to work on her issues so that she could have some understanding of her own situation.

On her return to America, Sarah attended the hospital as an out-patient. "I did a lot of good work, I couldn't know my memory. I knew things had happened in my home. I was doing the work but I wasn't really believing that it was so wrong or a real issue"(T1S9). She explains further. "See, I didn't believe my memories. I remember my therapist wanting me to get angry, and getting angry because I wouldn't get angry. But, you see, I know now why I couldn't get angry; because I didn't believe that it was so wrong. You see I was wrong. I was wrong because I couldn't be normal and let people touch me in a sexual way, in any way. I let those things happen, it wasn't so wrong, that was normal actually and they didn't know that I was thinking, that's normal behaviour"(T1S9).

Sarah continued in her counselling and graduated from Bible College in 1978. She explained, "I graduated and I came back to Britain and did summer camps with the mission. I taught while I was doing that and I looked after children. I joined with them in their activities. I was studying more in the States. But, then I did deputation work where I was going to churches telling them what I would be doing when I came over here, raising my support"(T1S12).

In 1979, when Sarah was back home in Scotland, her friend's mother committed suicide. Sarah found this very difficult to accept, and she was unable to attend the funeral. However, it raised again for Sarah the importance of dealing with what had happened in her past. "I believe it is when I really began to deal with very real issues.

I was seeing them as real and not just (pause) not just doing it because I have to do it. This is something I have to do, I knew that it was very, very important it was necessary. But still not knowing the truth that it was so wrong. I think this is what we need to drum home to people, who have been abused, that it is a criminal offence" (T1S12/13).

In August 1981, aged 29, Sarah was commissioned as a missionary to Northern Ireland from the United States. Things proved difficult for Sarah here. The other missionaries were not happy with her work and she found one of her male colleagues very difficult to deal with, as he reminded her of her father. Nonetheless, Sarah continued her work. In December 1981, she was staying with a family across the road from a prison. Sarah recalls the events: "On my birthday, at 7am in the morning, a soldier came up to my room with a gun and ordered me out of my room, out of the house. Now, he was protecting me but the terror! We had an eight-day-old baby in the house and the lady I was staying with was the grandmother...We were all evacuated from this house because someone had left a bomb outside the entrance of the prison and if it had exploded our home would have been involved"(T1S14).

Following this frightening incident, Sarah had a recurrence of what she called her "funny turns". Describing her past experiences of these, she said: "What happened in America to trigger it, I think and I believe that really is what did it. I was changing a light bulb in a ladies house and there was a faulty wire and I was hit with electricity and fell off the table and hit my head on the floor"(T1S14). She continues, "Two months later, I had some kind of seizure outside and a couple of times when I was driving, I had to come off on the shoulder of the road because I was either going to pass out or vomit. I was feeling really nauseated but then I would waken up three hours later and I didn't know what was happening. (sighs) They put me on a small dose of Tegretol in America. In Ireland, the doctor wanted me to come over to Scotland to be tested...I was having seizures and falling downstairs or I was having too many accidents. But I was probably diagnosed in 1982/3 as having epilepsy. By 1984, I'm on all this anti-convulsant medication but that's what I shouldn't be on"(T1S14).

Wheelchair, ramps and freedom.

On her return to Scotland, Sarah lived with her parents for as long as she could. In July 1984, Sarah now aged 33, got her own house not far from her parents' home. On August 31, she was walking her puppy when she was mugged. She believes the mugging exacerbated her epilepsy. "This changed the seizures from petit mal, mild to aggressive"(T1S3). As a result, she was placed on increasing amounts of anti-convulsant medication.

Sarah continued to be involved in her church and to participate in a range of activities such as teaching Bible club. She recalls, "Even in my illness I taught deaf awareness, a social worker got me involved...I learned sign language. I did two grades and then I was given these notes to teach and I did"(T2S22). However, things deteriorated for Sarah. "The last seven years of my illness, I was in a wheelchair with a helmet on my head and totally oblivious to life around me. Literally, being lifted and laid and taken out in the chair. For some of the years, I worked in the garden it was the only place I could go out to. Probably that's what kept me alive, kept me focused"(T1S2).

Her situation was considered so serious that brain surgery was considered twice. Sarah remembers her minister advising her that she had a choice: she could say no to the surgery. Sarah did say no. However, she was having many seizures a day. As a result she was unable to physically care for herself and had carers with her 24 hours a day.

Sarah's situation changed dramatically when, in 1994, her neurologist retired and her new neurologist reviewed her case and decided to take her off all her medication. During the initial withdrawal, Sarah recalled, "It was as though I went through five days and five nights looking at my entire life in that sleep, like a coma state...It was almost like everything happened yesterday"(T1S3)."I woke up. It was as though I woke up in 1984 and it was actually 1994"(T1S2). At this time Sarah was 42. She continues, "I was suffering from flashbacks which I had never had in my life and I believe the drug withdrawal added to that because they stopped 14 years of drugs cold turkey. I've been angry with the medical profession for what they did to me" (T1S2). She continues, "Even taking me off the drugs, they were going to start me on Melleril (a major tranquilliser), because I was talking, I was aggressive, talking about the abuse and I wouldn't stop. I was standing on a platform and talking about it, broadcasting, it was so awful. I wasn't protected during it...If I had been a drug addict I would have been given more help. I got no help. They wanted me out of the hospital"(T1S15). She adds, "I haven't said a word about the hospital, the treatment I had in the hospital during those nine days of withdrawal. The staff were talking about my financial gain, that I had done this for the money. I was terrified to waken up. I could hear them"(T1S17).

However, Sarah's physical health did improve following the withdrawal of her medication and she went home with no support. She feels this was an extremely difficult time for her, she went from 24-hour care to no input at all. She was little prepared to run her own life: "No support, take responsibility, pay your bills, after fifteen years"(T1S16). She felt utterly abandoned.

In addition, Sarah had to come to terms with certain physical feelings she was now experiencing. "You see your body is important but it wasn't important to me. It was like I didn't feel anything from here down (points to waist) until I came through the drug withdrawal. Now part of it was probably because of the drugs that I had been on and I really didn't feel. But even before that, like when I was in Bible College I really had no feelings, I'd say from the waist down, it was like I knew I had feet and ankles but from up here to there or the waist maybe I didn't feel"(T1S13). Sarah continues, "I remember the first time feeling a sexual feeling. I got up out of my bed and I got ready and I went right into the centre and I asked to talk to my counsellor, because it was like I had never had that before"(T1S13).

A friend from the mission, in America organised for Sarah to come to the States for treatment with a specialist. This involved Sarah negotiating with the social work department that she would be out of the UK for four months. On her return home, Sarah had no financial support for nine weeks, and she was threatened with eviction from her home. She felt completely isolated. Even her church was not supportive of her. The revelation of her sexual abuse alienated her within the church. In addition, Sarah felt that her church was more supportive to her parents, even though they had no links to the church. This made things especially difficult for Sarah, as the church was such an important aspect of her life. Throughout her illness she was still part of the church and on the inactive list of missionaries.

At this time, Sarah had no contact with her parents or other family members. “My parents were just around the corner…I couldn’t go near them because I would say something and really hurt them. I know that I couldn’t go and be in their company, especially my dad. I know that my dad abused me, my own father, I couldn’t do it. I think it is right not to be there, not to see him. But it has taken a lot” (T1S9).

Sarah sought help for herself in Glasgow. This proved to be a difficult task. She found counselling services very poor, with little understanding of sexual abuse. Indeed, she found some of the counsellors unable to deal with their own issues let alone hers. She made contact with the mental health drop-in centre. “I wouldn’t trust anybody but the people at the centre…I belonged more to these people who had psychological or psychiatric problems”(T1S2). She was offered counselling. One counsellor was very significant to Sarah. “Tricia was marvellous with me. At first, I didn’t talk to her I signed. I just signed. I didn’t talk because I had been told that I didn’t talk properly when I was shouting about abuse. So, rather than speak I started signing (laughs)”(T1S17).

In April 1995, Sarah met up with an old woman friend, Chris, at a missionary conference in England. Chris spent time with Sarah at the conference and Sarah told her story from beginning to end. Since that time, Chris has been a constant support to Sarah, both practically and emotionally. Chris lives in the USA. To help their communication, Chris gave Sarah a computer so that they can maintain contact via email. Chris has played a significant part in enabling Sarah to address her abuse issues. So to has Petra, a friend from Finland. Both Chris and Petra have given much support to Sarah over the past six years.

In 1996, Chris accompanied Sarah to a weeklong course on sexual abuse. The course is an educational programme for Christian leaders, but on the course there were some people who were dealing with their experiences of abuse. Sarah described the course. "They run it for a week...They have an hour teaching and then they have an hour and a half of group work three times a day. It is highly intense"(T1S10).

This course proved to be a turning point for Sarah, now 44. She explains, "I came out of the small group and, oh boy, I was angry, I was angry. What had made me angry? We weren't working as a group and I didn't know what we were supposed to be doing here? And I heard this lady, she was twenty years my senior. She was dealing with the fact that her father had sexually abused her till she was twenty years of age. She was her in her sixties and still unable to get over it. Her dad had been dead for 10 years. So one of the leaders asked, 'How does everyone else feel?' And I said, 'I see the power of a dead man and how he is having power over her life, even dead.' It's frightening. In my mind, I was thinking about my own dad and I was thinking I don't want to be twenty years along the road still not dealing with this and I came out of there truly angry"(T1S10).

Chris helped Sarah to address her feelings of anger, to work out whom she was really angry with and to identify her real source of anger as her parents. Sarah reflects, "That night was a very big breakthrough for me because I had let that angry come and I had felt it. I had stayed with it"(T1S12). Sarah has made much progress since this first course.

Later in 1996, Sarah attended a course on learning styles. She found this course very beneficial to her. It gave her a model about how she thinks and how she learns. This course enabled Sarah to feel that she could learn successfully. She has been making the most of the opportunities open to her. She is now an avid reader. She has joined a

Greek class at the Bible College that she is enjoying very much. As her knowledge of Greek grows she is able to use her new learning to increase her study of the Bible.

Since January 1998, Sarah has been involved in leading a small group of woman who have all been abused. These are all Christian women active in their own churches. The group meets fortnightly and Sarah takes the lead in preparing teaching materials for these sessions. Sarah is keen to improve sexual abuse awareness, training and services within the church. She is eager to make sure that her own experiences of isolation and of having to find help for herself are not the same for others in a similar position.

In September 1998, Sarah's mum died. Sarah described her relationship with her mum "as non-existent". She continues that in redecorating her home, "part of that was erasing my mum from it"(T2S20). Her father, when I first met her, was unwell at home. On my second visit, he was in a nursing home, Sarah did not know where. She has little contact with her family, other than with one sister, who is also a Christian. However, that relationship is somewhat strained.

Early in the second interview, Sarah revealed that she considers that she has multiple personality disorder (MDP). The decision not to share this on my first visit was taken to safeguard Sarah. "Chris and I have said, definitely we won't tell anybody. This is only between us and my counsellor. It wasn't to keep it a secret, it was to keep me safe. So that's why I wouldn't have said it to you and because it is not even accepted here"(T2S6). Sarah explains, "It's like it is a very scary thing to admit and to expose. Probably since you interviewed me I have realised that this is vital to me to see what is going on inside and the different stages that were broken off'(T2S3).

In this interview, Sarah identified five "wee ones". All are young girls under 11 years old. Sarah is working to reintegrate these personalities into her being. Indeed, Sarah is the name of one her "wee ones", which was the pseudonym that she selected for the study. She recalled on receiving the transcript that she was surprised and shocked to see this name being used.

Both Chris and Petra are aware of Sarah's "wee ones". In fact, Petra has been very understanding of Sarah's situation, nurturing her towards re-integration. "Petra, she has been amazing, just like a mother"(T2S6). Sarah went on, "The wee ones are the ones who need to do the work. They need to do the talking, then I can come to know the integration...More and more I can see them in their place. That's an amazing sense when you feel you are coming together as a whole person"(T2S9).

Since our first interview in February 1999, Sarah has continued to make improvements in her life both emotionally and practically. She considers that her greatest achievement has been living at home independently. "I've come through, what I have come through to be at a place where my whole house is gutted, my garden is more or less in order and, my life is almost there"(T2S19). Sarah is currently going through the procedure to buy her house from the council.

Emotionally, Sarah has made many gains. She understands now that, "You learn as a child when you're abused you don't think, and you don't feel and nothing about you as a person is affirmed or validated"(T2S19). Now, "I am aware of myself. Even the weight gain has been a good thing in an amazing way. It's like, I'm feeling like the adult. I used to feel I had this wee tiny waist, and it made me feel empty. It was almost like as though I didn't grow. I couldn't feel like I could. I was just staying in this wee body. See gaining the weight, I love it. But the most important part was I felt like a woman. I'm feeling like an adult and I really don't want to be that way, skinny, personally I want to be a woman" (T2S14).

Sarah continues to lead the women's group. She is hoping to begin working with men. She still attends the day centre, where she is a regular player in the centre's pool team. She now has a part-time job, child-minding for people in her church. She really enjoys this work. In addition, she has been working voluntarily in an office. She still hopes that she will be able to return to full active service within the church. Both Chris and Petra are assisting her to work towards this goal.

Reflecting on her life and her experiences Sarah considers, "I think it so deeply affected me that it made me sick, and that made me unable to cope and to work and to know that I am of value or anything. It was the feelings, the depth of despair at being abused by your own father"(T2S8). Reviewing the past six years, Sarah has an awareness that at some level she perceives herself as a new person. "I'm only appreciating that now. At the very beginning there was something about feeling like a new birth, but I couldn't appreciate it" (T1S16). Now, "I think it matters more to allow myself to be who I am ...Just to be"(T2S20).

Looking to her future, Sarah wishes to fulfil her dream of being a missionary. She is still working towards returning as an active missionary. Although she now realises that this decision is not in her hands alone. But she has friends who are supporting her through this and helping her to confront some past events that occurred in the church. Ultimately, she feels she has survived her life and today she can see a future for herself as a valued member of her community, working with others and helping them to get to where she is now.

Sarah's Reflections

My story is like a gift, although it was difficult to see it so orderly and in black and white. As I became acquainted with it and used to the idea of its reality, I am being able to 'own it' and to know where I can fill in the blanks. One day I want to share with you the years I could not speak about.

Epilogue

In January 2001, Sarah was diagnosed with stage three ovarian cancer. She had a full hysterectomy on January 31 and then commenced chemotherapy. She continues on treatment.

Conclusion

Each of these five unique narratives portrays a variety of plots and subplots, providing evidence of lives altered by mental illness. The key frames utilised by Davies (2001) are found within these women's lives, namely loss, survival and patient experiences. However, there is also so much more to each of their complex, different and diverse lives. These narratives place the women at the centre, using their words to give voice to their meanings and stories. The narratives capture one possible representation of how they experienced their lives, enabling these to be understood.

Personal Reflections

As I set out on this project, I tried to envisage the experiences that the women would share and what the process of each telling their story would be like. Yet, as the research progressed, I still heard the unexpected, the unconsidered. Throughout, I was vigilant to being aware of my reactions, thoughts and feelings.

Initially, I was amazed by the openness of each of the women. I was struck by this sharing. I started my reflective journal with a sense of amazement at their candour. This feeling stayed with me throughout the study. I could not help wondering if I would have been so able to articulate my life, or indeed if I would have taken part in research such as this? I found myself wondering who I was to them? For the most part a total stranger, nonetheless, I was in their living rooms, with their objects, symbols and memories surrounding us. In their space, I listened as they freely spoke of the most intimate aspects of their lives. Perhaps, the stranger is indeed easier to talk to!

It is difficult in this type of human interaction not to be moved by the enormity of others' experiences and I was often touched by their lives. I also know that I had on several occasions to mentally remind myself that I was there as researcher not as a therapist and I had to refrain from action that within a therapeutic encounter would have been second nature to me. For instance, as Pat shared her distress about discovering her sons' abuse, I caught myself at that moment in time having to stop reaching out to comfort her as I would as a therapist. I did of course offer support but I felt it was not my natural response. Not withstanding, my journal recorded my discomfort of my forced reaction. It could be that I was working hard to maintain my novice researcher role and that this blocked my usual therapist's reactions. Now with more experience of working with people to research sensitive material I would be more able to deal with such an occurrence differently if it were to arise in the future.

The setting of the interview was a site for the construction of knowledge, not for truth-telling; the participants and myself created particular knowledge influenced by our stances and interdependency. The constructed story was created through listening and responding to each other. Therefore, the final narrative was a version of what had developed through the shared authority of the women and myself. The issue can lie with the situation the people think they are in, and what they which to convey and why.

Many types of feelings appear in my diary: surprise, anger, hate, irritation, sadness, disappointment and dismay. At times I was shocked by the treatment the women received from mental health professionals and I felt embarrassed that I was also a mental health professional. Following my first interview with Sarah I wrote 'I feel confused, angry and horrified at the life this woman has led'. Powerful emotions. I was aware, too, that I was only feeling these emotions vicariously. What must it have been like for each of the women in their particular situation?

Within the interview contexts I could have followed up each participant's story by further questioning, or by asking them for more examples. However, it was difficult at times for me to challenge what I was hearing. This difficulty, I think, occurred for several reasons. Primarily, I had placed the women as the drivers of their own story and this meant that I did not pursue aspects that they did not raise. The participants may have been happy to share other aspects but this would have resulted in my needs being to the fore. Had I raised such aspects with the participants they may or may not have addressed these issues. This may have had no significant impact on their narratives or the final findings. However, I acknowledge that in taking this stance the study may have been compromised to some degree.

A second difficulty arose when it was clear from the participants that they would not disclose, or did not wish to recall, past events. For example, Sarah was not willing to disclose or discuss her early years of abuse, nor did Marguerite wish to recall further stories from her many hospital admissions. A balance had to be struck that gave as credible a picture as possible but that also recognised that all the narratives were incomplete in some aspects.

Another peripheral issue was raised in relation to exploring an aspect that seemed to take the participant away from their story. For example, in the second interview, Pat shared her daughter's current family situation in some detail, although this clearly impacted on Pat's support of her daughter. This information was very detailed and of a sensitive nature. It was not necessarily information I should have been party to and I felt uncomfortable about hearing of others' personal circumstances who were not directly involved with this work. The paradox here was that I did not wish to alter the course of the narration in case something important was missed. These issues need to be considered when reading the narratives.

As I continued to work with the women's narratives to form a sense of them and their experiences I found myself becoming increasingly attuned to the richness of the data and the importance of treating their information well and with respect. In some way I had to offer in the treatment of the data a better experience than the women had received in their lives, a small thing but important to me. As it came to the time to forward their story to each of the women I was uneasy. I felt anxious - had I represented their lives well and realistically? Would they crucially recognise themselves and their experiences? Had I treated them well? I waited for their comments and their reaction like a nervous inventor. Would my (re) creations pass their inspection?

All of the women in the study commented to some extent on their narratives. They were recognisable representations. Some things they had expected to see were not included. For one of the women her sense of rage had not been strongly represented. In the case of another, a childhood friend had been omitted. However, on the whole there was a general agreement that I had met the task.

CHAPTER FOUR

Searching for the significant: Understanding the women's lived experience of enduring mental illness

Introduction

This chapter presents the findings following the completion of the data analysis using the constant comparative method. As the data analysis and interpretation proceeded, it was evident that the findings were neither linear nor separate entities. There existed many interconnections, and it was clear that within the women's lives these impacted significantly on themselves or on others. As I moved through the process from a descriptive stance to explanation through the narrative analysis, I sought a method to express this rich data, to bring to life the voices of the women.

From this interpretive process, I constructed six themes from the findings that seemed to encapsulate the lived experience of the participants. For clarity, a theme is derived and created from the patterns and topics present in the data (Depoy & Gitlin, 1998 p. 313). In this study, each theme represents a section of the women's lived experiences: a specific frame of the bigger picture of their lives. The six themes are presented in Table 4. The **Present Life** presents the current status of the women and their lives. **Life Roles** considers the women's past and current occupations. The **Relationships** theme highlights the importance and diversity of connections with others through the participants' lives. The theme **Illness Transitions** represents their progress through the many convoluted journeys of mental illness and treatment. Their personal coping strategies and areas that would improve care are considered within the theme of **Help**. Finally, the theme **Cultural Context** deals with the wider socio-cultural and historical perspectives that significantly influenced these women's lives.

The themes of lived experience are firmly grounded in the social constructionist perspective that the self is a dynamic creation, developing and changing in relation to the experienced world. These six themes describe, and allow further understanding of, these specific women's lives.

Table 4. The Six Themes of Lived Experience

Present Life	**Life Roles**
Relationships	**Illness Transitions**
Help	**Cultural Context**

Within each theme exists one or a number of sub-themes and categories. These act to further refine the theme. The title name of each sub-theme aims to reinforce the process of hearing the women's voices, while the essence of the phenomena, the similarities are found within the categories. In constructing the category names, attention was paid to the words used by the women to describe their world: their words are retained here to reflect their worldview. Categories bring together similar and related concepts. Where a difference exists within a category, this will be highlighted as the inclusion of such differences adds to the breadth of the study. The themes, sub-themes and categories are presented in Table 5. There is no hierarchical or horizontal significance across the themes.

Table 5. Themes, Sub-themes and Categories

THEME	SUB-THEME	CATEGORY
Present Life	Hear and Now	Still here with my funny walk. But mostly just to be. I phone her on a Tuesday
Life Roles	Voicing Volition	I always wanted to be a teacher
	Messages from Mothers	I was going to be a perfect mother
Relationships	Relatively Speaking	Because of my parents Brothers and sisters
	Silent Partners	For better or worse
Illness Transitions	Speaking our Minds	I discovered I was bipolar: it meant nothing to me I even scrubbed coalbunkers I still drink a lot of irn bru I hadn't discovered quantum physics or anything It's the loss of your life
	Talking Back	It's an unsaid you're the patient, you have no rights You could cry your heart out over there
Help	Amplifying Asylum	A place to walk into I went there for safety Listen to the patient
	Spreading the Word	I'm doing something about this! My sanity was my faith My friends were the ones who stuck by me
Cultural Contexts	Public Pronouncements & Personal Plights	Everybody can understand pain, mental pain they can't! Rip that book up: I've changed, I'm not that person
	Interference	You've had a real shake.

The themes, sub-themes and categories are presented and illustrated with narrative extracts from the data. These quotations add to the findings by providing sufficient detail to convey an individual's thoughts and situations. Patton (1990) advises that there must be "sufficient description to allow the reader to understand the basis for interpretation and sufficient interpretation to allow the reader to understand the description" (p. 430). Therefore, the data presented are intertwined with a commentary on the categories. The findings portrayed here reflect my interpretation of the data. Another researcher or a similar study at a different time would unfold alternative results. There are of course many different realities, and this is one of many. The starting place for this discussion will be "Present Life".

PRESENT LIFE

This theme represents the way the women expressed how they perceived their lives at the time of the study. The sub-theme **Hear and Now** describes how I heard and interpreted the way the women spoke of their lives. This encompassed for most of the women, feelings of "coming through" a range of life events to where they are now. At the time of the study, most perceived their lives as better than before. The sub-theme recognises what they have become and highlights their own ways of being. A major facet of their lives is being available to support others. This sub-theme incorporates three categories, namely: *"Still here with my funny walk"*, *"But mostly just to be"* and *"I phone her on a Tuesday"*.

In *"Still here with my funny walk*" what is highlighted is that most of the women feel they have survived their experiences of mental illness. For all, there is a sense of surviving the war, but not totally unscathed: indeed, some carry physical as well as psychological scars and memories. Surviving could have been a life and death experience, as in Marguerite's situation. But for most it was getting through particularly difficult periods of their lives. As Pat stated, "My twin sister will say to me 'I don't how you came through all that?' I said 'You just plod on from day to day, that is what you do'" (T2P18). This "plodding on" was Pat's way of getting through, of coping with her situation. It emphasised her struggle to move forward.

Pat and others expressed the feeling of being victims of their circumstances. At times they were unable to establish or assert control over their lives. However, at other times the women were able to actively seek opportunities for change. For example, both Helen and Pat took action to remove their psychiatric histories from their general medical records. They both felt that this act enabled them to be treated more objectively when in contact with NHS staff.

Surviving includes the notions of acceptance, self-responsibility and self-management. Acceptance means acknowledging that this current stage of their life may "be as good as it gets". Self-management and self-responsibility are evident within the women's approach to coping with their lives. As Marguerite explains, "It's how you manage the illness ...obviously there is maybe a certain amount of medication you have to take" (T1M29).

Here, Marguerite characterises what is true for her and the others: that to keep well, both physically and mentally, they recognise the need to take day-to-day control which may include life-long medication. In addition, it may involve planning their day to avoid fatigue, caring for themselves or having support at home, like Pam's home help.

Within the category, *But mostly just to be,* all but one of the women expressed the belief that they had in a sense "found" themselves. The majority felt happier with themselves and their lives now. As Sarah reflects, "I've come through what I've come through to be at a place where my whole house is gutted, my garden is more or less in order and my life is almost there" (T2SP9). This powerful imagery of Sarah physically clearing the house and garden parallels her ongoing psychological process of removing or dealing with her past. As a result she describes her life as vastly improved.

All the women reflected that their lives had turned out differently from how they were originally envisaged. There was a sense of movement in their stories, from "how I was to how I am now". For most, this sense of "being here" was positive.

Only one woman felt differently. Helen believed she had her time of "being content" prior to her marriage. "I only had five years, I can honestly say only five years of happiness" (T2H10). This time was seen as a fun and carefree period and it contrasted unfavourably with her current situation.

Most of the women spoke of possible futures, with some looking to some small changes, perhaps in their employment status or with relationships. Sarah envisaged her future as bringing closure to some of her past life events. From a different perspective, Helen stated, "I was only hanging on for my grandson as he gets everything I've got" (T1P18). Helen seemed to be looking to her future death and how this might provide some financial support for her grandson. She saw her future not about change but about ending.

One shared aspect of their current lives was that all were to some degree involved with others with mental health problems. This is explored in the final category of this sub-theme: "*I phone her on a Tuesday.*" The variety of ways in which the women were supporting others, both women and men, was highlighted. Pam's experience illustrated this variety well:

> One of the chaps who comes to the drop-in has OCD (Obsessive Compulsive Disorder) and he broke his shoulder in three places. I can work with him and help him with his OCD. I'm quite happy to stand with him at the tap for the sixth time as he washes his hands…We very much have a looking after ourselves network (T1P12).

Practical support as highlighted above was extremely important. But even more was the network of social support that Pam identified. Networks of support were evident in the other participants' narratives. All were involved in personally initiated informal communication routes such as regular telephone calls or a more organised emergency telephone tree where one person was responsible for making contact with named individuals. In addition, some of the women organised regular informal meetings in local cafes to meet with others. Some were involved in running or contributing to support groups, as in Sarah's women's group or Pat's ME group.

Pam was involved in the provision of voluntary community mental health services in a range of ways as a volunteer and as an active committee member. This involved her dealing with the successes and failures of community involvement. She reflected. "The drop-in was going so well and all of a sudden it has just gone down which is a great shame. So we were...trying to work out ways of building it up again" (T2P2). Pam has become a committed player in her community to improve mental health services. Helen, too, was once active in the development of non-statutory mental health services. Both had become personally involved in changing and shaping local mental health provision.

This frequency and range of support was a surprise finding. It seemed there was a good deal of support ongoing amongst this small group of women. These roots of support could indicate that the women had been enabled by services to support each other. However, the women in their narratives described services that were failing to meet the diversity of needs. It is evident that these support mechanisms offer reciprocal support for each of the participants.

The 'Present Life' theme has highlighted where the women consider themselves to be in their lives. This 'sense of being' incorporates their awareness of where they are in the world and that they have responsibility for their lives. It portrays their ability to adapt to their circumstances over time, to build supportive networks for themselves and others. Furthermore, they mostly recognised that their present lives were on the whole, better and more settled than previously. Their life roles, past and current, will be considered in the following theme.

LIFE ROLES

This theme considers the major roles and responsibilities identified by the participants as being significant through their lives. This theme consists of two sub-themes: **Voicing Volition** and **Messages from Mothers**.

The sub-theme **Voicing volition** highlights that for the women, meaningful engagement in occupation across the life span has been essential to them. It consists of the category *I always wanted to be a teacher.* This focuses on what the women have done in their pasts and what they currently do from an occupational perspective. Occupation was considered as a broad concept, including self-care, leisure, paid employment and voluntary work. Engagement in occupation was multifaceted and was experienced as unique by the individual. The women's experiences of doing and of engagement in a variety of occupations are considered from childhood through adulthood.

Childhood occupations were affected by parental influences, as well as environmental and financial constraints. Helen's experiences of poverty best illustrate the impact of financial constraints on her childhood, as she grew up during the Depression years in Glasgow's city centre. She recalls. "Everybody was poor, even the schoolteachers were poor" (T1H17). Poverty was experienced communally and in many ways, such as high unemployment and little money, leading to shortages of food and of other basic needs such as clothing. As a child, she and some of her friends fell victim to diseases associated with poverty, such as diphtheria. She survived but others died. Poverty did limit her opportunities. She missed out on her schooling. Her lack of shoes meant that at times she did not attend chapel. Her brother's library fine curtailed her use of this public resource. There is no sense from the other women of their childhood being financially secure. Indeed, Pam and Pat both recalled working hard on their family farms to contribute to the household. Helen perceived that her opportunities had been limited because of the level of poverty she experienced and that these early experiences contributed to her depression in later life.

Sometimes childhood occupations led to employment opportunities. For example, Pat, who as a child trained her dog, later became involved in working with dogs, first in a kennels and later in a dog parlour. For others, childhood ambitions were eventually achieved, with Sarah becoming a missionary and Pam a teacher.

All the women in this study worked after leaving school or, in Pam's case, teacher-training college. The jobs they had ranged from waitress to clerical administrator, secretary, nurse and teacher. Their range of jobs reflected the most common employment areas open to women. Only Pat gave up work following after marriage.

The participants all experienced occupational disruption in their working lives as a result of their mental illness. Marguerite reported that when she was depressed, she accomplished little work at her office. However, during manic phases, her production rate increased. Pam did not elaborate on how her bipolar disorder impacted on her role as a teacher. It may be that she took time out from the classroom, knowing that the classroom environment and the children were not tolerant of her behaviour, or it may be that being in the classroom exacerbated her mental health problem. The two women who were in full-time work had significant time periods away from their workplace. Importantly, both Pam and Marguerite managed to return to work following periods of time in hospital or at home recuperating, but the transition back into their workplace was not always easy. Marguerite recalled that her colleagues did not understand her illness. It seemed that people either did not understand or they underestimated the impact of mental illness on her general health: "The others thought nervous things, nothing you know" (T1M17).

Pam and Marguerite took early retirement from work, Pam as a result of her mental health and Marguerite because the opportunity arose in her workplace. Today, of the three women who are below retirement age (65), Marguerite and Sarah have paid part-time clerical jobs. The others have a range of occupations both within and outside their homes. They each recognised that absence of occupation had a negative impact on their mental health and general wellbeing. They actively sought meaningful occupations. Several are avid readers, some write, others are creative in other ways, for example, crafts, singing and gardening. Some are involved in local community activities. These range from church activities and youth programmes to active participation in local mental health facilities. As Sarah explained,

> I can be at the mental health centre and I know I'm respected... Did you know I'm on the pool team? There's a new captain and they are trying to get rid of me, so I'm going there and I'm beating those guys. (T2S23).

Sarah's quote illustrates the point that engagement in occupations, in this case the game of pool, provided her with a sense of self-efficacy and with a positive identity. For the women, engagement in occupations provided independence, financial security, skill maintenance and development, relationships and social networks, as well as mental stimulation and physical activity.

Several of the women identified that they had interests in, for example, environmental and ecological issues. They were not actively involved but maintained their interest through reading and television. To gain access to leisure activities such as places of interests and museums, or to go on trips or holidays, some of the women maximised opportunities for cheap travel and accommodation. As Pam explained, "What we do is we make use of the vouchers and things in the paper" (T1P14).

The issue of keeping down costs as they struggled to manage on limited budgets was a major issue for all the women. None were currently experiencing hardship, although all spoke of the need to be vigilant with their resources. Limited finance was a constraint on their opportunities to do certain things. For most, this was an area of concern as there was the likelihood of reduced funds in the future, as occupational pensions and state pensions might fail to rise with inflation costs. For some, limited finance in their later life was a reminder of the poverty experienced in their past.

Other barriers to engaging in occupation were mobility and access. As mobility for Helen and Pat has become more difficult their opportunities to engage in occupations beyond their own front door has become increasingly problematic, as neither are now able to use public transport. This has placed restrictions on what and where they could attend. Both had stopped attending the mental health centre because of travel problems: "I'm getting too tired and I need a taxi" (T2P20). Helen has used community transport to enable her to access her wider community. All the participants use the phone as a way of having contact with others and keeping up to date.

This sub-theme considered the current and past occupations that the women have experienced. It identifies some of their current occupations and the benefits of these. It also highlighted that engagement in meaningful occupations requires financial resources as well as accessible environments.

The sub-theme **Messages from mothers** reflects the fact that motherhood was felt to be a major life role for the four mothers in the study group. As such, it required to be explored separately. Motherhood is a longitudinal role with issues changing over time. This distance of time offered the women ways of viewing their experiences retrospectively from their current life stage. Three of the four women are now grandmothers: this specific role will also be explored. The category *I was going to be the perfect mother* represents the continuum of motherhood, from being pregnant to being a grandmother, as it was represented in the women's narratives. Pregnancy will be considered first.

For Helen and Pam, their pregnancies were unexpected. Helen was unaware that she was pregnant, and when it was confirmed, her reaction was one of fear. Helen stated, "I didn't want the baby I was carrying...I knew I had to have it" (T2H5). Helen was unprepared for motherhood. The result was she felt frightened and that she had no control over what was happening to her.

For Pam, becoming pregnant was also unplanned and it was an event that changed the direction of her life. Pat's experience of her first labour was difficult and problematic. However, by far the most traumatic was Marguerite's experience. The onset of a major psychotic breakdown following the birth of her daughter resulted in her feeling that she had failed to bond with her daughter. Her long hospitalisation at this significant time further compounded her feelings of inadequacy and loss. "My ex-mother-in-law watched her …she more or less took over" (T1M8). This quote emphasises Marguerite's situation: she was unable to be involved in caring for her new daughter in anything but a peripheral role.

Following the birth of their children, Helen and Pam felt unable to cope with their roles as mothers: feeling unable to look after their children. However, each took a different approach to their dilemma. Helen left London and returned home to Glasgow where her sisters and their families provided her daughter with care. Pam returned to teaching part-time. She recalled, "I was going to be the perfect mother. God, it drove me round the bend, I couldn't stand it" (T1P3). Her return to work enabled her to cope better with her new role as mother. Balancing this with her role as teacher provided much needed time away from the house: "It was brilliant. I came home I had a great time in the afternoons with my son" (T1P3). These strategies seemed to assist both of them to cope with their roles as mothers.

Guilt was a feeling expressed by each of the four mothers in this study: specifically, they felt guilty about being inadequate mothers. Marguerite felt guilty about her decision to return to live at her parents' home, leaving her daughter in the care of her husband and his family. Later she would feel guilt over her decision to have a termination.

Pat, following her separation from her husband, was solely responsible for the children. She spoke of putting the children's needs first and of never going out. However, as she became depressed, she was increasingly worried. She felt unable to care for her children and was concerned for their safety. Following her admission to hospital, her children were placed in local authority care. They would never live together again as a family. Her guilt at placing the children in care was further intensified by the revelation that her sons had been sexually abused while in care.

She continues to reflect that if she had not been ill the abuse would never have happened.

Another strong emotion evident in the women's narratives is blame. Here, the women blame themselves for things that occurred to them and their family members. For Pat, could she have prevented the abuse? Similarly, Helen continues to ponder her daughter's long-standing alcohol problem. Was her own illness a factor?

Marguerite almost immediately, and Pat sometime later, experienced motherhood from a distance. They felt that they worked hard to maintain contact with their children, although this was often in difficult circumstances. When in hospital, Pat maintained contact with her children: "I used to go to the reviews" (T1P10), even though, on occasions this was difficult. Pat recalled one such occasion, "Doctor, you know there is a review at the home where my children are. You knew that I'm going to that and yet you planned this morning! (for a case review) I'm a voluntary patient and I'm now leaving to go to the review. I walked out."(T1P12). Here, Pat had to assert herself and her status as a voluntary patient to be allowed to leave the hospital.

Pat's experience may highlight that when people are patients in hospital, the multi-disciplinary team may not recognise the importance of the roles people have, including the parenting role, especially in the case of women. As a result the team may be seen to be hindering rather than supporting the maintenance of the parental role.

For Marguerite, even though some level of regular contact was established for many years, nonetheless her daughter chose for a while to reject her and not to see her for a period of time. This was a rejection that Marguerite felt deeply. Her relationship with her niece did in some way compensate for this loss, as did her return to the Girls' Guildry. Here she was offered the perfect opportunity to be with children and to be involved in some small way in their lives. Her service to this organisation was in some small part a compensation for Marguerite.

The idea of being "a proper mother, a good mother or a perfect mother" recurs throughout the women's narratives, although they do not specifically articulate what this meant to them. It was unclear from them whether the expectation of being a perfect mother was a personal or a societal expectation, or a degree of both. It was evident, however, that they believed they fell short of the ideal in their relationships with their children. Marguerite's positive relationship with her niece emphasises the difference, "I've never been able to develop that with my daughter" (T1M27). Being seen as a good mother was, and remains, a powerful motivator for the participants. Most of the women, today, have stable relationships with their children, albeit these may be positive or negative relationships.

Pursuing the continuum of motherhood, three of the women in the study were grandmothers. This role has proved to be very important. Involvement as a grandmother is highly valued by the women, although their experiences as grandmothers are different. Helen became the legal guardian of her two grandsons as a result of her daughter's alcohol problem. Her younger grandson is her named beneficiary. Pat's role as grandmother is marred by her poor relationship with her eldest son. As a result, she rarely sees these particular grandchildren. However, she is actively involved with her daughter and her grandson. She has been able to support her daughter. For Marguerite, the opportunity to be involved with her granddaughter was like a second chance. "When I see her now…every so often I think I missed that with my daughter" (T2M11). She has experienced the developmental milestones she missed with her daughter, and she is a significant person in her granddaughter's life. Importantly for her, she is able to have a role that is sanctioned by society and one that she loves. In addition, like her peers she can share stories from her grandmother's perspective.

From the participants in this study, whose experiences spanned several decades of mental health care, the message is clear. They experienced little support or indeed little recognition of their unique roles as mothers. Not all mothers with mental illness will require support, but some will and all should be asked if they have unmet needs in respect of their capacity to mother. Assessment procedures concerned with maternal capacity should be supportive rather than punitive. In addition, such assessments should acknowledge mothers' strengths and not undermine their identity or confidence. Mothers must be partners in the process. They may have a range of strategies or developed solutions that will work for them if they are provided with the necessary information or support. There is a need for the development and provision of services across in-patient and community services. Importantly, these services should support not only new mothers but also those mothers who have recurrent episodes of mental illness and who therefore face a range of different issues as their children grow up and their caring demands change. There is also a need to work with mothers and families to include their insider perspective to change or design services.

This sub-theme has explored motherhood as experienced by the women in the study. For them, being a mother, seemed to encompass being there for the children, supporting them, protecting them, giving advice and moving them safely to adulthood. There is for each of them a sense of loss in relation to being a mother. In some ways they perceived their experiences were diminished or narrowed in comparison to other mothers. All the women experienced mothering to some degree as a life role that had been interrupted as a result of their mental illness.

Overall, the Life Roles theme has highlighted the range and significance of specific roles for the women. Motherhood was the most significant life role that emerged, although it was experienced differently by the participants. All recognised that engagement in meaningful occupations was important to them. However, factors such as finance and access impacted on their ability to participate fully in what they elected to do. This may continue to be the case as finances reduce and age increases. The next theme explores relationships and their impact on the participants.

RELATIONSHIPS

This theme recognises the significance of relationships for the participants. This theme has two sub-themes: **Relatively Speaking** and **Silent Partners.**

Relatively Speaking incorporates two categories, B*ecause of my parents* and *Brothers and sisters.* Parental relationships were recognised by the women as impacting on their lives. For some, these were constructive relationships; for others, these were viewed as destructive. *Because of my parents* explores these relationships further.

For Sarah, this category was highly significant. Her childhood was represented by a gap in her narrative. As her early years are absent, her story starts from when she was eleven. Sarah's parents appear rarely in her story but their impact is huge. Sarah's sexual abuse by her father has had many repercussions throughout her life. Her mother's part in her life is not discussed. It is evident that Sarah's relationship with her parents caused much grief. " When I got angry, I couldn't go near them because I would say something and really hurt them" (TIS9). Subsequently, she chose to have no contact with them. Her parents failed to protect her and indeed were primarily responsible for causing her harm. The impact of this abuse continues to influence her adult life. She was still working to bring some resolution to this period of her life. Sarah's experience was perhaps the most destructive example of parental influence in the study.

In contrast, Marguerite and Helen felt that their parents were supportive towards them and helped them when necessary. They viewed their parents as good parents. Marguerite returned to her parents' home following the breakdown of her marriage and remained with them as their main carer till their deaths. These positive parental roles contrasted with their own negative experiences of parenting.

For some, mothers were powerful figures in their lives, in either positive or negative ways. Marguerite's mother epitomised the strong, helpful figure, whereas Pat's mother was seen as powerful but with negative connotations. For example, she was very strict and seemed to favour her eldest son over the other children. Pam spoke of the significant influence her father played, and continues to play, in her life. She believed her father asserted control over her and that she failed to meet his expectations, never being quite good enough. Today, however, her father has Power of Attorney over her financial affairs and in this way he still has control over this aspect of her life. Despite this, Pam appears happy with the arrangement and does not see it as paradoxical.

One factor that emerged was parents' and grandparents' mental health histories. Marguerite and Pat both identified that there was mental illness, or at least mental stress, within their families. Interestingly, there are no clear diagnoses named in either of their narratives. This history may reinforce the genetic component of mental illness.

Not unsurprising, a mixed picture has emerged of the importance of parental influence. What is clear is that parents did have a significant influence on the development of their daughters' lives. Another important set of relationships that emerged was those with *Brothers and sisters*.

All of the women had siblings. One of the women, Pat, was a twin. Relationships with siblings raised both negative and positive feelings and attitudes, for example feeling resentful of siblings. In general, where siblings faced similar mental health issues, as in Marguerite's case, relationships were more positive, with a greater amount of understanding and flexibility between siblings. This is in contrast to those women whose siblings had no experience of mental illness. An important aspect for sibling relationships was the appearance of mental health problems within the next generation. For example, Pat and Marguerite have nieces who have developed mental health problems. However, they viewed these differently. Pat expressed frustration with her niece who suffered from anorexic nervosa: "She's had all the support going. Sometimes I think if it had been a bit harder for her, she might have taken a bit more thought to herself" (T2P7). In contrast, Marguerite, whose niece has a bipolar disorder, was supportive of her. However, this appearance of mental health difficulties in the next generation has acted to strengthen their sibling relationships, with each being active supporters of their sisters. Sarah's situation with her siblings is one of isolation, other than some minimal contact with one of her sisters. Overall, the picture is not clear cut, with some women having sibling relationships that offer support, and others where this is not the case.

The sub-theme **Silent partners** reviewed past and current relationships and their impact on the participants. The category *For better or worse* represents the impact of marriage and its consequences for the women in the study. Four of the women in the study were married. In the case of three of them, their marriages ended in divorce. Of the remaining women, Helen was widowed and Sarah was single. Current relationships will also be highlighted.

For the three women who were divorced, their ex-husbands were rarely included in their narratives. For Marguerite and Pat, their husbands were little more than bit players in their life stories. Marguerite's mental illness history predates her meeting her husband. However, she omitted him from her narrative till after she had described the birth of her daughter.

In Pat's story, her marriage was characterised by her husband's violence towards her and the children. There were few other references to him. In the main those that existed were negative. Pat's mental health problems came to the fore following her separation and subsequent divorce from her husband. Physical abuse was a feature of Pat's marital relationship. However, Pam described degrees of emotional abuse in her marriage. Pam's husband was included more in her narrative but not in great detail.

For all the married women, it could be argued that their relationships with their husbands compromised their mental health. In Helen's case, her sexual relationship with her husband clearly increased her levels of stress and feelings of inadequacy, although she reflected "He was calm and quiet and he was always there and he visited me a lot" (T2H15). Although there were problems, Helen still felt supported by her husband. The support offered by husbands was felt to be an important factor. There was a sense from some participants that if they had had more supportive husbands, perhaps things would have turned out differently.

Sarah did not discuss any current sexual relationships. Pam on the other hand was the only woman of the group who was in a relationship with someone: he, too, has a history of mental illness. As Pam states, "It is amazing how many people with mental health problems end up together" (T1P12). It may be that their shared knowledge and understanding of mental health difficulties is a positive factor in relationships. Perhaps there is a greater empathy for each other's situation and that being cared for and caring for your partner is an equaliser in relationships.

From this specific group, Pat sought a divorce from her abusive husband; Marguerite's husband filed for divorce and Pam divorced her husband. Helen remained married although she contemplated divorce on occasion. Marriage, they perceived, in their cases had been unsuccessful. It may have resulted in compromising their mental health.

To summarise, the Relationships theme has considered both familial and marital relationships for each of the participants. No overall pattern emerges. What is clear is that significant relationships may cause stress and that these, when combined with previous factors, may exacerbate mental health problems. The women have experienced differing levels of support and understanding from family and partners. The next theme explores the women's illness experiences.

ILLNESS TRANSITIONS

This theme portrays the women's representations of their illness experiences and their perspectives on the treatment they received. Two sub-themes, **Speaking our minds** and **Talking back,** constitute the theme. **Speaking our minds** was constructed from several categories including; *I even scrubbed coalbunkers, I discovered I was bipolar, it meant nothing to me, I still drink Irn Bru; I hadn't discovered quantum physics or anything* and finally *It's the loss of your life.* Together these categories illuminate the women's journeys through mental illness.

The category *I even scrubbed the coalbunkers* highlights how all the women in the study were able to identify behaviours that were unusual or out of character for them, either before or during illness episodes. As Pat explained, "I was crying, I didn't even know what I was crying about…I got frightened to go out"(T1P7). Pat was aware that something was amiss but felt unable to take action or indeed she was unsure what action to take. For the most part, the women were aware of changes in their feelings and behaviours, although they were perhaps unable to react to these or seek appropriate help.

I discovered I was bipolar, it meant nothing to me: this category explores the process of naming and framing diagnosis. This was problematic not only for the individual but also for their family: not knowing their diagnosis or not understanding it left them unable to make sense of what was happening to them or what could happen to them. Marguerite discusses her diagnosis:

> "I had been suffering from problems since I was sixteen, so I had it for years at that point…I don't suppose that giving it a name, but I mean you could go look up a book. But sometimes that's no use either because you end up reading too many things" (T1M4).

Marguerite's case of not knowing and not being able to seek correct information was a common experience reflected by the other participants: it left them unable to seek out further information that could have been beneficial. This lack of key information may have had the effect of making the women, on the whole, passive recipients of care. All of the women in the study experienced difficulty in getting to know and understand their diagnosis and the consequences of their diagnosis.

The impact of treatment is represented by *I still drink a lot of Irn Bru.* The women believed that the treatments they received, over time, had affected and continued to affect many aspects of their lives. Two of the women in the study, Marguerite and Pam, had experienced ECT, each recognised that the science behind the treatment method was an unknown. As Marguerite remembers, "They don't know how it works, basically. So I had the ECT and I was a bit better"(TIM4). Its ability to effect positive change in their condition was acknowledged by them. However, both identified loss of memory following this treatment.

With regards to the medication they received, the women expressed a range of negative responses. For some, medication was seen as a panacea. Helen summed it up: "They couldn't give me a house, I say to this day... so they give me pills." (T1P4). Another viewed the giving of medication as a way of silencing individuals. Several women identified the overuse of medication as being problematic at times. In Sarah's case, she was prescribed large amounts and this she believed caused her many problems; "By this time I was at my end, I couldn't take any more. I was going though 22 seizures a day. It was horrible"(T1P14). Sarah's negative experience of medication was compounded by her medication being stopped quickly without appropriate care and support being made available to her. Helen, too, suffered a similar experience after many of years of drug use.

The women identified a range of side effects from the treatments they used. These included lack of concentration and attention, tiredness, thirst (hence the Irn Bru), being oblivious to the world around you, being zombified, increased weight and slowing down. Medication impacted on their ability to function in all areas of their life, including self-care, productivity and leisure. A further issue for several of the women was perceived damage to their systems as a result of particular medications.

The continual monitoring of medication and the restrictions some medication placed on individuals were considered a necessary inconvenience. Some would prefer to stop taking medication but realise that it is necessary for them to continue being well. Others still hope for the perfect combination of medication, or of being medication-free, at some time in the future.

The category *I hadn't discovered quantum physics or anything* characterised the participants' encounters with suicidal behaviours due to their felt lack of self-worth. All the participants recognised that at some point in their lives - for some prior to contact with mental health services - they had contemplated or actively engaged in suicidal behaviours. Helen recalled her feelings following her husband's funeral: "I came home that night, it was awful hard work…I was going to commit suicide because I didn't know how to handle it" (T2H21). All the women had experienced suicidal ideas at many times throughout their lives and some had acted on these thoughts on several occasions. Ironically, the preferred method of this group was drug overdose: availability of drugs may have been a factor here. Three of the women had been hospitalised because of drug overdoses.

Suicidal ideas were often experienced as perceiving themselves to be worthless, of having lost what was important to them, and of having made no significant contribution or service to society. The women believed their lives were not valued and therefore should be ended. The presence of suicide as an element of the women's experiences was not surprising. However, what was surprising was the occurrence and frequency of suicide as such a strong feature in all the women's narratives.

The final category, *It's the loss of your life* is concerned with the overall impact of mental illness on the women. All viewed mental illness as a negative influence on their lives. Marguerite stated; "The time you are ill, you are losing your life" (T1M24). Some considered that mental illness had significantly limited their life choices and opportunities. A further perception was that there was no cure, that part of their lives had been lost through mental illness, and importantly, that this time could not be regained.

The second sub-theme is **Talking back**. Two categories represent the women's experiences of the care they received: *You're the patient, you have no rights* and *You could cry your heart out over there.*

The category, *You're the patient, you have no rights!* will be considered first. In their interactions with those involved in their care, the women for the most part felt powerless. They felt that they had few or no choices over their care. They felt disenfranchised and considered that they had little status in the treatment process. Pat viewed her consultant psychiatrist as someone who had power over her and of whom she felt afraid. She felt threatened by him describing him as "a total bastard"(T1P13). This was no foundation on which to build a therapeutic alliance; yet the women at times felt threatened by the power of staff. They were frightened at what could be done to them and of the possible repercussions on their future care. They experienced being patronised by staff, and significantly they felt they were not viewed as being unique individuals with specific needs, "...everyone needs to be treated differently after all, we are not a herd"(T2P8).

You could cry your heart over there! This second category characterised the participants' experiences of care, which at best was adequate and at times fell short of the expected levels of safety and care. It is worth noting that the women were treated in a range of locations over several different time periods. Individuals reported both positive and negative experiences of care. For example, Pam initially reported helpful and caring staff during her first contact with psychiatric services. However, her later experiences in a different environment contrasted badly. Her change of view may have reflected her increasing awareness and expectations of care, or the fact that the service was indeed poorer.

Within the women's narratives medical and nursing staff often featured more negatively, than other professionals did. This may have been due to the status and prolonged involvement of these staff with the women, in relation to other staff groups. For example, several participants reported that nursing staff ignored patients by talking amongst themselves and making patients wait for unreasonable periods of time for their needs to be addressed. Other aspects of poor treatment were also highlighted. Sarah, for instance, recalled a visit to the hospital and an encounter with a staff member: "She was shouting at me for wasting time I was totally distraught by her words to me" (T214). Staff attitudes and behaviours were identified as having a negative impact on the women. Whilst in care women experienced a diversity of feelings: insecurity, anger and terror. Some found the hospital environment to be a fundamentally sick environment that made people feel worse, not better. That said, at times the women were able to identify positive examples of care and caring behaviours.

What these findings show is that the women's journeys through mental illness, treatment and care were at times very difficult for them. They seemed to be further complicated by systems that, instead of working for them, perversely worked against them. Possible solutions from the women at both a personal level and a systemic level will be presented in the next theme.

HELP

The theme of **Help** considers aspects of the mental health services that could be improved and it presents personal strategies and resources for dealing with mental illness. Two sub-themes are present: **Amplifying asylum** will explore the improvement of mental health services and **Spreading the word** addresses personal coping strategies that the women have found helpful to their situation.

Amplifying asylum comprises three categories: *A place to walk into, I went there for safety* and *Listen to the patient. A place to walk into* considers that the women in the study felt that help and assistance were generally not available to meet their needs. Issues of accessibility, such as location or opening hours, the limited services that were available: and the existence of very few local centres, were all raised. Opening hours were confined to normal working hours i.e., 9-5. Pam summed up the situation she experienced: "There was no real care for people after 5 o'clock on a Friday and before Monday" (T2P10). The lack of services particularly over the weekend, was difficult for people as often this was when a crisis occurred. Pam sought to remedy this situation by helping to establish a local weekend drop-in service.

Where women sought help through non-statutory provision such as counselling services, they reported that these were often poor or indeed they were perceived as potentially harmful, perhaps, compounding their problems. Some found that counsellors were not skilled or lacked knowledge of issues. However, again individual experiences vary and Helen, described very good counselling support from a well-established service in Glasgow. The need for a range of services such as day centres and support groups was highlighted.

The category *I went there for safety* recognises the need for a "place of safety". For the majority, the hospital was identified as serving this function. However, of concern was the finding that the women felt unsafe and not cared for in the hospital environment. Polices that existed compounded these feelings. For example, Pam was moved to a different ward to sleep: "I hated it because for that two/three days I didn't feel like I belonged anywhere" (T1P9). Pam experienced a sense of not belonging and of not being cared for. Others, too, felt that more should be done to enable them to feel safe and protected in the hospital and importantly in their own homes.

Creating environments where women feel safe is of paramount importance. So too is the need to *Listen to the patient.* A recurring issue for the women was the need for health professionals to listen more and believe what individuals were telling them. Pat stated: "I think the staff, if they help the patient to realise they have been believed, they are actually starting that patient to get better" (T2P30). Listening was more than just hearing: it encompassed accepting the individual's perspective, believing them, and seeing the individual as the expert in their lives. Communicating with the person and allowing issues to be discussed openly was also felt to be beneficial.

Another important aspect to emerge though listening to the individual was the need for health professionals to offer hope to people. Hope was seen as a necessity for improvement, allowing the women to focus on the future. Pat summed it up: "They need that when they are in hospital ...especially if there is not much joy coming from the psychiatrist... even if it is only a little thing. It helps a person to feel a person again"(T2P31). Hope is future orientated: it opens the person to the possibility of change and links to a new possible future.

The other sub-theme to be explored is **Spreading the word**: this deals primarily with strategies that women used to maintain their health. Three categories are presented: *I'm doing something about this, My sanity was my faith,* and finally, *My friends were the ones who stuck by me.*

I'm doing something about this recognises that at times women spoke out or took action to alter the direction of their life and bring about change. There is evidence of women taking up the challenge of speaking out for themselves and advocating for others. In Helen's case she sought help for a friend: "I'll get help I fought for that centre. I said my friend is very ill and she needs someone to talk to"(TIH20). On this occasion, Helen's intervention brought some hope to her friend. The women said that while they were now able to speak out, at an earlier stage in their lives this would not have been possible for them; they had needed someone to speak for them, to be their supporter.

Other forms of asserting control included moving on or making changes in their care, for example, changing their general practitioner, doing something for themselves or getting involved in service development. These actions were often responses to a specific situation, with the result being a changed dynamic to a more favourable outcome for the women. Often these decisions were turning points or epiphanies in the women's lives.

A significant support mechanism for the majority of the women is highlighted in the sub-theme *My sanity was my faith.* Spirituality holds an important place in four of the women's lives; for some, this belief is related to a particular religion. Sarah explained: "God is very much a big part of my life" (T2S17). She drew both comfort and learning from her beliefs. The women's faith offered support, help and friendships. Three women are actively involved in a range of church activities, giving them identifiable roles, for example as the leader of a youth organisation. They feel they are valuable contributors to their local communities.

Other supports the women identified were friendships. Within the category, *My friends were the ones who stuck by me* all the participants valued the important roles their friendships had played throughout their lives. Some women had retained friends from their childhood, as Marguerite illustrated: “Talking of long-term relationships that’s the friend I was christened with she fell and broke her foot”(T2M10). These friends acted as supporters for each other through their various troubles. All the women identified friendships with people whom they had met as a result of their illness. These friendships offered the women contact with individuals who had had similar experiences and who were able to identify with their difficulties and share possible solutions.

Friends provided not only support but also a range of other functions; they were seen as motivators, as confirmers and as encouraging voices. Friends were valued as positive role models. Friendships were reciprocal relationships. Most of the women identified women as their significant friends. The loss of friends over time was acknowledged. The women especially felt the loss of significant friends who had died through suicide. Some identified that they lost contact with friends as a direct result of their mental health problems.

This theme has presented the systems and strategies that the women have utilised to maintain their health or improve their control over their lives. It has shown that the women found help from within themselves, to a greater or lesser extent, and that they were their own agents for change. It has highlighted the individual support systems that existed as well as identifying some aspects for improving service provision.

CULTURAL CONTEXTS

The final theme to be presented is Cultural Contexts: this deals with socio-cultural aspects that impact on the lived experience of mental illness. It incorporates two sub-themes, **Public pronouncements/personal plights** and **Interference**.

Public pronouncements/personal plights considers the lack of understanding of mental illness amongst the general public. This is represented by two categories *Everybody can understand pain, mental pain they can’t!* and *Rip that whole book up, I’ve changed. I’m not that person.*

Everybody can understand pain, mental pain they can’t! Within this category the women identified a lack of understanding of mental illness amongst their family, some friends and the public. They perceived a failure to appreciate the many and varied effects of mental illness and the difficulties that they faced. This was compounded for Sarah who felt that there was also little acknowledgement or understanding of sexual abuse.

The women believed the public understood physical illness more and were therefore more sympathetic and accepting of physical illness. This lack of understanding and the resulting consequences are explored in *Rip that whole book up, I've changed, I'm not that person*. This category characterised the ways the women have experienced stigma and discrimination as a result of their mental illness. Both of these concepts were felt at both a personal and a societal level.

At the individual level, stigma was felt and experienced in a variety of ways. The women perceived they were different and as a result they felt ashamed. This led to the women having dilemmas about whom to share with their mental illness history with. Marguerite elected not to inform her employers, while Pat tried to maintain her privacy in her community. She felt so strongly about this that she banned the community psychiatric nurse (CPN) from visiting her at home. Helen's earlier situation with TB offers a parallel experience where people were ashamed of an illness and its perceived consequences, not unlike the reaction to mental illness.

Discrimination, that is the act or process of being treated differently because of prejudice, was experienced in many forms. These are considered across a range of aspects including work, parenting, gaining access to services and lack of opportunities. Within the working environment, Marguerite believed that she had been discriminated against, for example being passed over for promotion. A more subtle discrimination was also at play with the implication that due to time away form the workplace through ill health, "you were a risk to their figures"(T1M17). As a result, Marguerite believed that others saw her as less competent. Sarah believed that her depressive illness and her history would stop her continuing her college career and that this would be an opportunity lost to her. Notwithstanding, her work as a missionary has been significantly disrupted over the years.

Marguerite and Pat believed their roles as mothers were affected by discrimination. Marguerite's decision not to seek custody for her daughter was adversely influenced by her history of mental illness and society's expectation of mothers. She had been advised that she would not succeed in fighting for custody, as her history would have to be declared in open court. Pat believed her interactions with Social Services to be negative because of her in-patient hospital status. Pam recalled that her son would not visit her whilst in hospital due to the stigma associated with the psychiatric hospital.

Access to services was also affected by having the diagnosis of mental illness. Both Pat and Helen felt so strongly that their mental illness history impacted on the service they received that they both removed their psychiatric case notes from the general practitioners' files, an entitlement that has been available only from the beginning of the 1990s.

What is evident is that the women identified that both stigma and discrimination were present and that lack of education and understanding only perpetuated this situation. The women understood that mental illness services received less resource than other areas of healthcare, thereby demonstrating discrimination at the policy and fiscal level.

The final sub-theme to be presented is **Interference,** with its category *You've had a real shake*. This considers that the physical effects of mental illness are not generally recognised by others and that physical illness is often negated in the presence of mental illness. Conversely, mental illness can interfere with the women's physical health. Most of the women believe that some of their current physical ailments were either directly or indirectly related to their mental illness and related treatments. As Helen stated, "I've had a lot of physical things I'm quite sure that the emotional illnesses I had was the cause of them"(T1P10). Overall, there was a consensus that more emphasis should be given to monitoring the physical health of people with mental health problems.

Conclusion

This chapter has, through six themes, portrayed the women's past, and current experiences of living, before and with enduring mental illness. It has demonstrated that many facets of the women's lives were significantly transformed by their mental illness, although to some extent this may not be unexpected. However, what is surprising is the range and diversity of the areas of their lives that have been affected and the far reaching, long-term implications, both for the women as individuals and for their families. The women come from different generations and their experiences cover a wide time span.

For example, the effects of stigma and discrimination remain evident. Mental illness and its consequences continue to be misunderstood within the general population and this impacts on individuals. The naming and framing of diagnosis was for all the participants difficult. It may be the case that the women were informed but not in a way that was meaningful to them. Other findings include the strategies the women used to maintain their well being; the importance of friends, and the development of local informal social networks to support themselves and others. The presence of suicidal ideas in the women's narratives was not surprising. However, what was disturbing was the frequency of suicidal ideation that was apparent, and for some it still remains as a shadow. Moving to their treatment within mental health services, at the very end of the twentieth century, the women experienced lack of power, threats, patronising staff, and a lack of understanding of their lives, roles and responsibilities. Importantly, their roles as mothers and carers were disregarded, with barriers to continuing these roles being placed in their way.

The individual themes, as specific frames, could be considered as contributing to a larger canvas, one canvas that portrays the landscape of living with enduring mental illness. The sub-themes and categories within each theme are layers that build, adding texture and depth. Overall, the six themes and the many inter related issues and patterns produce a final gestalt, offering one depiction of the women's lives and their diverse experiences of living with enduring mental illness. My purpose has been to produce an account of these women's lives that is credible and rooted in the data. This is only my representation. The findings from this chapter will be discussed in Chapter Six.

CHAPTER FIVE

“It’s not an area that we explore or talk about enough!”

Therapists’ thinking on working with women with enduring mental illness

Introduction

This chapter presents the findings from, and the analysis of, the focus group interviews. These interviews addressed the second aim of the study: to explore the perspectives of occupational therapists working with women with enduring mental illness in an attempt to gain insight and to identify factors that impact on occupational therapist’s ways of working with women with enduring mental illness.

The findings from the data analysis process described in Chapter Two will be presented in two sections. The first outlines the responses (in the order they were asked) to the transitional questions, the stimulus material, and the key and closing questions. The questions for the focus group interviews form Appendix E. The second section highlights the interpretation that emerged from the constant comparative analysis across the data. In presenting the responses, a variety of means will be used including bullet points, tables, and quotes or sections of dialogue (Krueger, 1997). My reflections on the focus group procedures conclude the chapter.

Section One: The Focus Group Findings

The participants

Sixteen woman occupational therapists, from the same Scottish NHS trust, took part in four focus groups, over a two-day period, in December 2000. The groups were video recorded in a neutral setting. The characteristics of the participants, as distributed across the four groups, are illustrated in Table 6. These characteristics were derived from the introductory questions.

Table 6. Focus Group Participants

Focus Group Participants	**Designation**	**Time in current post**	**Years as occupational therapists**	**Area of practice**
Group 1				
Participant A	Senior 11	3 months	12	In- patient
Participant B	Senior 1	5	11	Community
Participant C	Senior 11	15 months	5	Community
Group 2				
Participant D	Senior 11	2	4	Community
Participant E	Senior 11	1 month	2 .5	Community
Participant F	Senior 1	7.5	7.5	Community
Participant G	Senior 11	10 months	5	Community
Participant H	Senior 11	7/8 months	2.5 years	In-patient
Group 3				
Participant I	Senior 11	1	2.5	Community
Participant J	Senior 11	3	7	Community
Participant K	Senior 11	2	2	In-patient
Participant L	Senior 1	8	13	In-patient
Participant M	Senior 1	1 month	6	In-patient
Group 4				
Participant N	Head	8	15	In-patient
Participant O	Senior 1	6 months	5 .5	In-patient
Participant P	Head	8	16	In-patient

The therapists had an average of 7 years' experience. Of the sixteen therapists who participated, the majority were designated as senior 11 grades representing (56%), senior 1 therapists represented (31%) and head occupational therapists represented (13%) of the cohort. The range of clinical areas they represented included forensic, acute admission and rehabilitation wards, day hospital and community mental health teams. The majority of therapists (44%) worked in community mental health teams.

Acute admission wards represented (25%), with rehabilitation and forensic settings each representing (12.5%) and the day hospital making up the remaining (6%). To maintain the confidentiality of the participants, the broad descriptors of community or in-patient areas have been used above.

Findings from the transitional questions

The purpose of the transitional questions was to orientate the participants to the subject under discussion. The transitional questions in this study were used to explore issues in working with women and issues impacting on women.

a) What does it mean to you being a woman working with other women?

In each group, the participants cited a number of issues. However, across the groups, two main aspects were highlighted. These were the benefits of being a woman working with other women and the issues this raised for some of the participants. Table 7 presents these issues. The numbers in brackets represent how often the participants raised this aspect.

Table 7. The benefits and issues of working with women

Summary of Benefits	Summary of Issues
Identification (7)	Behavioural issues (5)
Empathy (3)	Challenging (3)
Similar experiences (3)	Lives so different (3)
Shared values/roles (2)	Hard work (2)
Broader understanding (2)	Making assumptions (1)
Advantage (2)	
Different connection (1)	

The following quotes are illustrative of the benefits of being a woman working with women and the issues involved.

> "You can identify perhaps with their roles as a wife or mother. Perhaps working with a man you can sympathise but you won't have the same empathy or you might not have been through similar experiences." Participant F (7 Dec.)
>
> "It's definitely an advantage in lots of situations." Participant A (7 Dec)
>
> "I maybe find it more difficult to relate because I think I should relate to women but really their lives have been so different to my life experiences." Participant H (7 Dec)
>
> "With the women that I worked with in the previous unit there tended to be a lot more behavioural issues tied up in their illness and they were often harder to work with because of that." Participant M (8 Dec)

It is evident that there is a range of opinions in relation to being a woman working with other women. For some, it is seen as advantageous while for others it raises aspects that perhaps highlight differing life experiences. Participants, generally, recognised they had shared similar life experiences with women clients, but saw their clients' experience of mental illness as different. To some extent, the responses reinforce the view that all women are different and should not be seen as the same or as having similar, shared backgrounds.

Challenges were identified in working with women. The main issue raised as a challenge was the behaviour displayed by women patients. Specifically mentioned was deliberate self-harm (DSH), including cutting behaviours and eating disorders. Some group participants stated that women's mental states and their behaviour were considered to be less predictable or less stable than that of men. In relation to this question, the participants discussed three other factors. These included:

- women found it more difficult to prioritise their needs.
- women had reduced self-esteem.
- women generally had access to women workers in the community.

An important aspect was raised by one of the participants, who identified the danger of over-identification by therapists with their women clients. This over-identification could result in a therapist making a wrong assumption about her patient; the need for clarification when working with people was stressed.

Two participants responded that they had not noticed any differences when working with women or men. Other factors mentioned were safety, protecting women, age and motherhood.

Initially, the respondents identified factors relating to them in working with women as listed in Table 7. However, the focus moved to general issues around women in the mental health services, as highlighted above. In addition, they identified that fewer men worked in community mental health teams and that more men were evident in high security environments, both as staff and as patients.

b) In your opinion is your gender and the client's gender a central concern in understanding women's mental illness?

Firstly, as a general comment, there seemed to be a range of different perspectives concerning gender and its impact. The most common response to this question was that participants had not specifically considered gender issues. This is evident in the following response:

> "I wouldn't say it was the forefront but it is probably there. But I wouldn't consciously think about gender issues when I was working with people". Participant P (Dec 8)

Here the participant identifies that gender is not an issue that she consciously considers when working with people. In common with the other participants, she focuses on gender in working with women and does not consider her own gender as impacting or influencing her practice, either in her interactions with women clients or in relation to her place within the organisation. Participants did, however, acknowledge that social and cultural expectations impacted on women:

> "There are a lot of social and cultural expectations and maybe it related to L's point about what women should have done, which is maybe a reflection on what society's expectation of what people should be doing. These may in fact influence women's mental illness and how that takes shape." Participant I (Dec 8)

However, there was no discussion of the impact of society and cultural expectations on the participants themselves. Interestingly, two therapists expressed opposing views; one stating that gender was a major concern and the other that gender was not a concern at all.

The responses to this question suggest that the notion of gender amongst the group members required further exploration and discussion. The next question aimed to ascertain in what ways therapists experienced gender issues in their working lives.

c) To what extent does gender impact on your own practice?

The responses within the groups explored a range of issues in relation to gender and practice. It became evident that there was no structural or organisational policy either addressing or considering gender. As there were no organisational gender sensitive policies in place, participants identified that gender awareness was a component of an individual's practice:

> "I think it is more at an individual level. It is to do with that particular patient and where they are and what's important to them at a particular time."
> Participant H (Dec 7)

This participant stressed that the focus was on the individual and their circumstances. The other participants generally supported this view. Alternatively, some practitioners identified a different response to gender, as illustrated by the following quote:

> "Sometimes, I think of myself as asexual at work. I don't think of myself as being male or female. I think, I'm an occupational therapist in that setting."
> Participant P (Dec 8)

Here, this respondent may consider that she is asexual or genderless in the workplace but others will see her as a woman and interact and react accordingly. This quote perhaps exemplifies what was not overt within the groups: the impact of the therapists' gender not only on their practice directly with clients but also on their place, status and roles within their organisation. These aspects were not raised for discussion. Perhaps further questions should have been explicitly asked.

In relation to practice, limited resources and lack of time were also identified as impacting on the service available, for example, the availability of separate treatment sessions for women and men. Participants identified that where single sex groups existed some differences in the use of these were apparent, with women confiding in, and being supportive of, each other. It was felt that men were also supportive of each other, but that they shared less personal information within their groups.

Another example related to addressing specific individual patient requests. It was acknowledged that although women clients had access to women staff, access to a woman psychiatrist was not always possible, as they were a limited resource within the service.

Significantly, personal safety and risk was raised as an issue in relation to gender. One participant expressed concern about working with men, with previous aggressive histories, within isolated environments. The issue of personal safety was also raised from the perspective of staff within secure wards. Here, aggressive behaviour from either men or women was anticipated and there were staff and procedures to deal with incidents. Gender was identified as a possible trigger for aggression. If such a pattern were established, strategies for dealing with that aggressive behaviour would be constructed within this specific area.

Maintaining the right balance, not over-reacting to the perceived threat of aggression and being realistic were seen as being important in relation to the maintenance of personal safety. So, too, was the need for clarity on what services were provided and how staff were kept informed of potential risks, either to themselves or to clients.

d) Reflecting on your practice, describe any issues/dilemmas or conflicts that have been raised in your work with women with enduring mental illness.

In addressing this question, therapists recounted several issues that had been raised for them when working with women. One example related to negative staff attitudes towards women who were unable to care for their children due to their mental illness:

> "One of the female staff actually brought that up as an issue in a ward round, that as a mother, she couldn't comprehend how this female patient could neglect that side of her life at certain times ...It was very much put across that the patient was just manipulative." Participant H (Dec 7)

In this example, we have a staff member bringing her assumptions to a situation in a way, that could have negatively affected the future outcomes for the woman at the centre of this discussion. The therapist clearly recognised this as inappropriate behaviour. However, it is unclear whether the team in any way challenged this opinion.

Another example related to one respondent's dilemma in working with a woman who was pregnant. The therapist's dilemma was about not knowing how to approach the woman, as a decision was being made as to whether she would be able to keep the child or whether the child would be adopted. A group member recounted another example in relation to one of her patients:

> "She was being assessed to see whether she could have plastic surgery on her arms so that they would look a bit nicer. She was turned down for it because the scarring was too deep or something. Thinking about what kind of effect that would have on you, because you live with that a lifetime, for somebody just in their early thirties." Participant L (Dec 8)

This quote raises two issues; namely, access to resources and the importance placed on women's appearance. Although the therapist identified that the "scarring was too deep or something," one cannot help but wonder if the plastic surgery was perhaps refused because of this woman's past history of cutting. It may have been seen as an inappropriate use of scarce NHS resources. Scarring, particularly on the arms, is very difficult to conceal and results in both unwanted attention and questions from others, thus potentially increasing the psychological distress for this woman.

Other issues were identified:

- the time and space to work with women
- the vulnerability of women when in an acute phase of their illness
- the need for protection of women when placed in environments where they may be at risk
- the recognition of hormonal influences on mental state and behaviour
- the issue of civil liberty

Generally, this question elicited limited responses, with Group One and Two members unable/unwilling to contribute; a reason given for this was that it was something that had not been thought about. However, it may be that the question may have felt too risky for the participants. The examples that were shared were traumatic or extreme and often involved other staff: for example, doctors and nurses. Across the groups, it was noticeable that occupational therapy specific or everyday practice issues were not raised. In light of this, I would suggest that these professional examples may be so personally felt that to raise these in this setting could have been difficult, perhaps even distressing, for the participants. They may have felt unable to admit to problems for fear of losing face in front of their peers.

The final transitional question asked:

e) *To what extent do these issues differ for men clients that you work with, or do they?*

Participants generally felt that the issues were the same for men. However, some identified that they tended to check out things more with men. Others identified that the therapeutic relationship they had with men felt different, but the processes of working with men would be the same. One group member raised the issue of male therapists working with women:

> "All the male colleagues I've come across have all been very sensitive to women's issues probably more than females are to male clients." Participant C (Dec 7)

This quote may indicate that male therapists have had to engage in thinking with regards to gender and gender issues, because of the gender difference or are perceived as having done so, given the small number of men in occupational therapy in the UK. However, it could also highlight that women therapists may not have had to specifically consider gender issues, because they perceive no differences with the women with whom they work or that gender is not seen as being important. A further option already noted is that therapists might not consider their gender to be an issue in the workplace.

The issue of parenting was regarded as being similar for women and men, especially if they had lost contact with their children. In relation to service provision, one participant identified men as being at a disadvantage:

> "I know when women or men are in secure facilities you have to give consideration to child visiting and things. I think the argument around women getting access to their children is always far more important and it is maybe something that is forgotten when men are brought in." Participant M (Dec 8)

This recognition of the inequality of service provision for men in this very specialist aspect of secure provision is interesting. The number of women in these secure facilities at any one time is often small. Although useful to raise, however, it deflects from the common experience of women in secure units and general mental health services.

Findings from the key questions

In the next section, the responses to the stimulus material and the key questions are presented. The stimulus material was derived from the Phase One findings.

1. Occupation as central

Sarah spent 7 years in a wheelchair	**Helen**
"For some of the years I worked in the garden it was the only place I could go out to and probably that's what kept me alive, kept me focused."	"I'm always working through problems, don't get me wrong when I'm doing it [writing] it's like I'm doing something…it stimulates your mind.

The first stimulus, "Occupation as central," presented quotes from two of the women from the first phase of the study. Participants were asked to consider these quotes and give their reactions. The therapists cited several factors with a range of common aspects being generated across all groups. Not surprisingly, occupational therapists identified engagement in occupation as having positive effects for the women. These common, positive aspects were expressed in different ways across the groups. Occupation was seen in two distinct ways: as a subjective experience or as a process that could facilitate emotional needs. These are identified in Table 8; the numbers 1-4 represent the groups in which these factors were raised.

Table 8. Outcomes of Engaging in Occupation

Subjective experience for the individual	**Processing of issues**
Increased self esteem **2 3**	Increase understanding **3**
Sense of achievement **1 3**	Working things through **3**
Sense of purpose **1 2 3**	Seeing things differently **3**
Doing something **1 2 3 4**	Emotional needs met **1 2**
Reaching their potential **1 2**	Distraction **1 3**
Making things happen **3**	Reduce negative thoughts **2**
Being productive **1 2**	
Participation **1**	

The environment was identified as both facilitating engagement in occupation as well as limiting engagement. The environmental factors identified were: poor environment **(4)** restricted environment **(1)** disabling environment **(1)** environment reducing choice **(1)** physical space **(1)** psychological space **(3)** impact on environment **(2).**

The following excerpt of dialogue from Group Two illustrates some of the above.

> G "It's active, it's about doing something outwith, having an impact on the environment rather than being a recipient all the time."
>
> F "I suppose it is productive as well. If you garden you produce flowers. If you write you produce a piece of writing or a book. Both things that they do, they've got something to see for it at the end of the day."
>
> H " I find certainly in an acute setting that people use occupation differently...They are using occupation at the moment as a way of focusing on something other than their suicidal feelings or food".

Here, the participants identified that the environment and occupation could offer opportunities for people to take some control, to enable them to be agents of their own lives as opposed to be being passive recipients of care at the control of others. The group participants discussed two other aspects: the need for occupation to be specific to the individual reflecting what is important to them, and the fact that engagement in occupation facilitated the individual and others to see that individual as someone other than a patient; the occupation provided a different, more positive identity. The second quote was then introduced to the group.

Pat
"I used to walk into the occupational therapy [department] and out the other door. See, if I was asked, I wasn't lying when I said yes. I hadn't lied I'd been in it and straight out."

While discussing the second quote, the participants raised a range of factors. Aspects such as power and control issues, choice and others' perceptions of occupational therapy were prevalent across the groups.

Power issues were identified in diverse ways, for example, clients being put under pressure to comply/conform with staff suggestions or having things done to them. Others reported that because of the power relationships at play, the woman in this quote felt unable to refuse the staff or lacked confidence to make her feelings known. Respondents felt that the woman's decision to leave the occupational therapy department was a way for her to exert her control over the situation in which she found herself. Nonetheless, the issues of power and control are related. Staff in hospital settings will always have power because of their position and degree of control:

> " I thought this person has taken some kind of control. Being in hospital, obviously the locus of control is external and somebody has said right I think you should go to occupational therapy...I suppose it was about them making a choice, taking responsibility back that was what I got from it." Participant I (Dec 8)

In this quote, we have a view of this woman taking control of a part of her life, in a limited way, that facilitates her move from being passive to becoming an agent, actively in her own way resisting or challenging authority. This was an area where she was able to make a choice.

Giving choice to clients was highlighted as very important. Strategies discussed for giving clients choice involved listening to clients, talking though what they would like to do and identifying what was relevant or important to individuals. It was, however, recognised that there were more treatment choices available to those therapists working in community settings than for those working on wards. This greater range of options for clients in community settings resulted in more choices for clients. Therapists highlighted that for some clients the process of making appropriate choices can therefore become increasingly difficult and as such therapists had to support the choices their clients made. This issue is reflected in the following excerpt:

> H "Certainly in a hospital setting it [occupational therapy] is kind of imposed on you. You have to do it, as it is part of the treatment plan and sometimes it takes me a while to break that down and persuade people that it might be something that they might actually enjoy."
>
> F " I think that is why it is so refreshing to work in the community because people choose to come to you or you negotiate. Will I visit you or will you meet me at this place?" (Dec 7)

This excerpt illustrates the differing roles of the therapists within the two distinct environments of hospital and community. The hospital therapist describes persuading clients to become involved in occupational therapy, whereas the community therapist highlights that the choice is with the individual. It has to be remembered that the individual in the hospital setting will be more unwell, requiring greater support than the individual in the community.

Other staff's perceptions of occupational therapy arose in relationship to this stimulus quote. Members recalled that in the past, people were directed to occupational therapy, with some respondents describing similar experiences with clients from their own practice. The participants suggested that the situation described could arise because of a lack of understanding of the function of occupational therapy by other staff, and that this may lead to occupational therapy being imposed on patients. In a different group, one participant discussed the idea that staff in some settings saw occupational therapy as an 'added extra'. Others in this group agreed that it was something that could be removed or withdrawn from clients, if the need arose. Another participant, argued that occupational therapy was not for everyone all of the time, and that clients needed a range of services.

The participants' agreed that clients should have choice in their treatment. The next question asked the group members: *What opportunities are offered for women clients to make choices about their intervention in your clinical area?*

In response to this question, therapists identified a number of processes or strategies that could afford opportunities for choice within an individual's intervention. These included offering choice through the treatment review process, with the client being consulted on their proposed treatment plan. User-led evaluations for services were acknowledged as a potential method for increasing choice. Offering simple choices, having choice in their selection of activities from a unit's programme and identifying small steps to meet client's goals were suggested as ways of increasing choice.

Collaboration and partnership with clients were also identified as processes that facilitated opportunities for choice. However, it was acknowledged that this way of working could be challenging for the therapists:

> "I always try and reinforce it as a collaborative thing, that there is always choice and that we will be working in partnership with one another. I always try to enable the woman to come up with aims or goals of what she wants to get out of the time we have together. Participant D (Dec7)

This participant described how she had to "reinforce" the collaborative nature of the treatment relationship. Therefore, it could be suggested that for clients the idea of collaboration, as both parties equally working together, is a notion with which clients are unfamiliar or it may indeed, conflict with their previous experience or expectations of being a patient. Alternatively, clients might not wish partnerships, just treatment.

As the participants discussed this question, a range of common responses emerged. They identified the many ways that making choices can become compromised for clients. They stated that opportunities for choice were removed or limited in some instances; that clients did not realise that they had a choice; and that making choices could be frightening. Furthermore, clients might be scared of making choices because they were wary of staff reactions. The following quote highlights that participants recognise the difficulties that clients have in making choices:

> "I think it is quite hard...initially they are not really sure what they want. So I suppose you need to be directive to an extent and when they are able to make a decision you try and be non-directive." Participant I (Dec 8)

This recognition places the onus on the therapist to support the client as they become less ill, and increasingly aware and more able to identify possible choices and future directions.

The environment again emerged here as a significant factor in offering opportunities for choice, with therapists identifying that choice was limited or increased for clients, depending on where they were placed in the service. At one extreme, within some ward environments opportunities for making choices were few. However, as people moved from wards to day units or to community services opportunities for choice were seen to increase. The following quotes illustrate the spectrum of possibilities.

> "...In acute admissions choice is taken away from people as a soon as they walk through the door really. Maybe they are not sleeping in their own beds, they are not eating their own food, they are having to comply to a routine...Where I work most people would say it is a lousy, lousy environment, not literally." Participant A (Dec 7)

> "It's all based on choice in the community" Participant E (Dec 7)

These quotes illustrate the extreme of the treatment continuum. In hospital, people have little or no choice, whereas in the community choice is presumed to be the foundation stone of treatment. Participants believed that working in the community offered the greatest choices to their clients. However, there was little recognition of the difficulties within this area of work. In relation to an early point, it could be argued that staff, whether based in hospital or community contexts, have power over their clients because of their very position. However, the amount of power they have will decrease in the community as clients are able to exert more control over their lives.

What also emerged from the therapists' responses was a focus on decision-making generally. They indicated that for some clients few opportunities existed for them to make any kind of decisions. Furthermore, therapists identified that when the client's locus of control was external to them, making their own decisions became difficult. Some participants expressed frustration that their clients found making simple decisions difficult. This is not surprising as mental illness does impinge on people's thought processes and their decision-making capacities are at times severely reduced.

The discussion around choice related to other factors, such as resource implications, availability of transport and the needs of ethnic minority populations. All these were factors that impacted on occupational therapy provision.

Having explored opportunities for choice at the individual level, discussion addressed choice at a programme level. The next question asked: *What opportunities are offered for women clients to be involved in programme development within your clinical area?*

Therapists indicated that they did work from the needs of the group with whom they were working, as the following quote illustrates:

> "I tend to work from what the patient group is saying...I work that way and follow it through." Participant K (Dec 8)

This therapist acknowledged that working at the level of her patients was one way to encourage involvement in the development of their treatment and service development, even if this was in an informal setting.

In responding to the final question in this section, *Do women clients use these opportunities?* it became clear that opportunities were limited in some areas. The answers reflected this, with few women or indeed men being actively involved in programme development. However, in some instances changes were taking place.

> "We are just in the process of carrying out our user-led evaluation so it will actually involve the women in asking each other what they think about the service that is currently being offered." Participant E (Dec. 7)

This example of user-led evaluation is a method to encourage user involvement and therefore greater user feedback on mental health services. The involvement of service users is recognised as one approach to elicit valid and open responses to mental health services. This is seen as a positive method to promote engagement and change.

2. Women's Roles.

Stimulus Three presented the roles that the women in phase one of the study had identified.

Roles

Workers, mothers and grandmothers, carers, lovers, patients/clients, colleagues, sisters, daughters, counsellors, activists, volunteers, mental health service user, choir members, gardeners and writers...

The following question was asked: What are the implications of a lack of recognition for women clients in contact with mental health services? In responding to this question, the participants identified three areas:

- implications for women
- implications for therapy outcomes
- implications for practice.

In considering the implications for women, the participants highlighted that lack of recognition of women's roles led to the complexity of the lives of women being negated. As a result, their life roles and the losses they experienced might not be considered fully. The loss of their parenting role as mothers was specifically mentioned, with participants highlighting that women's status as mothers or grandmothers might not be given enough consideration in the therapeutic relationship. Other losses raised by the therapists included loss of relationships, loss of function and loss of face for women clients. The point was made that some women may not have achieved diverse roles and may have little opportunity to develop or fulfil these roles in the future:

> "I suppose the roles that you have had and the roles you have missed out on as well. We get women with a really long schizophrenic history and they maybe haven't brought up their own children. Actually there is a young girl, she was only nineteen she had two babies but they have both been adopted. She was so horrendously ill, she couldn't even look after herself."
> Participant A (Dec 7)

The enormity of this woman's loss is evident. She has had both her children adopted and her own care lies in the hands of others. The psychological impact on her current and future life roles is unknown, but may not be particularly positive. Her life may have many unfulfilled roles as well as unmet hopes and aspirations. In relation to such loss, the participants thought that lack of recognition within the mental health system may mean that women are not given the opportunity to discuss their situation fully. The focus is on their illness, not on their life roles. Therefore, the opportunity or time to grieve may not be available or may even be discouraged.

With regard to the second implication, participants believed that the outcome for therapy would be failure if women's lives were not understood or were diminished by staff. One participant summed it up:

> "I think if you don't acknowledge that they have all these things going on…you are not going to be able to engage successfully and be successful with any treatment intervention." Participant I (Dec 8)

This participant stressed that failure to recognise the complexity of women's lives could lead to unsuccessful engagement in the therapy process or that the treatment offered was inappropriate or not relevant. Therefore, the treatment would be unsuccessful.

The final area of implications for practice highlighted the therapists' belief that they should appreciate individuals' current and past lives: indeed, this was a central goal for them as professionals. They believed they must be proactive in seeking out their clients' histories. Informal and formal methods were used to collect clients' information to gain an understanding of their client's life:

> "... When they are in a group and you ask them, you catch something about them and you can pick it up and ask them about it. You can see them becoming more animated." Participant N (Dec 8)

This therapist reported that in her interactions with clients she was aware and followed up information that clients might disclose. This is one way to build their understanding of the client's life and thus create appropriate treatment solutions. It was felt that a lack of recognition of clients' lives could lead to a focus on the problem or illness, not the person.

> "You're defining them as the totality of their illness." Participant C (Dec 7)

Such a limited perspective of the person as the sum of their illness, as described, could result in the medical model and medication becoming the main driver for treatment.

One respondent raised a different but related issue, that therapists may be focused on their own thoughts and plans and not attuned to the person with whom they are working. This, too, the therapist thought could lead to a lack of recognition of what was important to that person. Two other factors were also raised in the discussion. The first was that occupational therapists had a different approach to their clients than that of other staff members. The second was concerned with therapists becoming involved in working with clients' significant others or families, as opposed to meeting the needs of the client.

In light of the above, the next question asked: *What do you think occupational therapists can do to prevent/reduce this lack of recognition of the complexity of women's lives?*

In response, the participants identified a range of strategies that would reduce or prevent the lack of recognition of the complexity of women's lives. They identified that a client-centred focus would help to develop an understanding of the person's life. Assessment processes should centre on what is important to the client, by asking women about their roles and responsibilities. The importance of looking holistically at the very onset of intervention was emphasised by one respondent:

> "It is often at the very beginning of your intervention when you are getting to know the person, you are looking holistically and you are trying to find out where they have come from, what are their previous roles have been and really exploring that with them." Participant M (Dec 8)

This work at the beginning of treatment is essential if the therapist is to fully comprehend her client's life situation. However, this is an on going process with new insights developing as treatment continues over time. It has been suggested elsewhere that if therapists' narrow their treatment focus too quickly, perhaps basing it on too little information, they may miss the window of opportunity at the outset to identify the client's situation and the most relevant intervention.

In addition, clients should be enabled to develop their own goals for treatment with therapists providing choices and working in partnership with the women. The need for feedback on progress and for written work to document the intervention was also highlighted to prevent lack of recognition amongst other staff. As Participant P stated:

> "…Writing a summary of what has been done with that person and your plan for intervention with them and the results, so that other professionals can look at it"(Dec. 8)

Participants also identified that intervention must be realistic and future orientated. They acknowledged that they could not change a person's past. However, there was a belief that looking back on their past lives can help people move forward with their treatment. Some respondents thought that there was a danger in assuming too much about the client and that if on occasion information received from clients was not considered thoroughly this could lead to ineffective therapy. As Participant D explained,

> " I think at times we don't tease things apart enough...its not just what is in your face but there are other layers to it. Sometimes I think we don't maybe spend enough time looking at that." (Dec 7)

This quote relates to the above section on therapists' narrowing the perspective too soon, or in this case not giving the information thorough consideration, both may result in a restricted occupational therapy programme being designed and implemented. The need for time to understand and consider the client's life is essential.

Several other factors were raised in response to this question. These included the view that occupational therapists have a different focus from other mental health professionals. In addition, women clients might have difficulty finding time for themselves, as they were often the main carers for others.

3. *Meeting Needs*

The final stimulus material addressed meeting needs.

Pam

"I mean I went there, the day hospital, about three times a week...I mean you were well cared for. You really did have your own occupational therapist and carer. You know anything you needed it was like that (snapped her fingers) they made a time for you."

This quote was shared with the participants. Several group members in one group felt particularly negative towards Pam's quote, stating that it displayed her over-dependence on the service and that being looked after somehow implied lack of responsibility or empowerment to do things for herself. However, other groups disagreed with this view.

The question asked the participants: *In what ways do you hear women in your practice?*

They identified a range of methods they used to hear women in their practice. Significantly, they identified both verbal and non-verbal communication as being important. These methods included being explicit and planning together, actively seeking people's consent to treatment, providing space that is safe and non-threatening, as well as providing the opportunity for discussion. Writing information down for people was also mentioned. The need to make the discussion meaningful to the client was highlighted. The following dialogue illustrates some of the above:

> J "Quite often you hear from what they don't say, what is left out or just their body language, what they don't talk about initially. That maybe goes back to people putting on a front, you know, trying to appear more well than they are."
>
> I "I suppose its about giving them space and the opportunity make them feel safe in that kind of environment they can say what they want to say or you can give a space that is safe, even without saying anything you can pick things up that are going on."
>
> K "Yes I would agree with [J and I], it really is about giving someone the space. Pretty often I don't have a lot to say, just chat as we are maybe doing something even if it's cooking or art...as they relax all sort of things can come up as long as the environment is non threatening." (Dec 8).

Creating space, non-threatening environments and maximising opportunities that arise were all identified as important in enabling women to feel able to vocalise what is important to them and for therapists to hear what is being said.

Some of the participants identified lack of time, owing to other commitments, impeded their ability to listen to women. Others felt that the environment had an impact on how well patients needs could be heard and met. For instance, it was perhaps simpler to hear and respond to needs in day unit settings, than in in-patient settings. Interestingly, one participant brought to the fore the idea that a woman's experience of not being heard may indeed be the same for staff within the organisation:

> "I think, the way organisations work, if you ask me how I feel about my role, I'd probably say I don't feel listened to within the organisation, that's within the organisation we are talking about being a patient." Participant N (Dec 8)

This experience of not being heard as a staff member of the organisation may go some way to explain, perhaps, the lack of discussion within the focus groups regarding therapists' positions within the organisation. If they feel unheard, they may not be vocalising their situation.

An important factor highlighted was that therapists may build distance between themselves and clients. This strategy may enable them to cope with the distress of the client's situation. Overall, therapists identified a range of strategies that would help them to better listen to clients in their practice. However, they also realistically identified factors that interrupted or impaired their ability to hear and meet their clients' needs.

4. Safe & secure

In relation to safety and security the question asked: *Within your clinical areas are there women-only environments/groups*?

Taking the environment first, in general there were no women-only environments across the service. Toilet and washing facilities were supposed to be women-only, but in some areas, such as acute admissions, men could gain access to the facilities, as is highlighted in the following quote.

> "In the acute environment you could have men getting into bed beside you. It has happened." Participant P (Dec 8).

This quote identifies that women on wards can be vulnerable, or at risk within these areas, even though there are supposed to be restricted areas. The acute wards, in particular, are where people are admitted to hospital, when they may be at their lowest point, mentally and physically. They are therefore highly vulnerable.

Within the forensic unit, a new facility, an all-women environment for sleeping could be created, if the need arose. One participant raised the issue that within this area, some women would be coming from external high-security women-only environments to this mixed gender unit:

> "It is a real issue …these are women who have been abused by men in the past. It is really real for them." Participant M (Dec. 7)

This situation may cause women who find themselves in this position much concern. Within this unit, women staff always supervised access to toilet facilities so women could be reassured that no men could gain access. However, it is recognised as an issue, the solution is potentially available; but this would carry with it a cost implication. To create this women-only environment would reduce the total number of beds and therefore restrict admissions and result in reduced income. However, this is not just an issue for forensic and acute facilities. Within the rehabilitation wards similar anxieties were found. As one participant noted,

> "Quite a number of the women that I work with have ideas about some of the other male patients on the wards and they get quite worked up about that, but they are in there in the same space, day in, day out. They obviously do feel quite unsafe." Participant G (Dec. 7)

The need for women-only environments was felt to be an issue from the perspectives of personal safety and dignity but not from the stance of being a preferred choice for women. In respect of this issue, within this particular NHS Trust women-only environments were seen as a priority area in the reprovisioning of mental health services due in 2003. It is hoped that in the new acute in-patient service, all patients would have single rooms with en-suite facilities.

This lack of women-only facilities was also considered by some of the therapists, to be a factor that, perhaps, influenced women from ethnic minority populations accessing in-patient mental health services:

> "It is a big issue for women from ethnic minority backgrounds...some will actually refuse to be admitted because it is a mixed ward or their communities would not let them be admitted because they cannot guarantee single sex facilities." Participant P (Dec 8)

An interesting observation was made by one of the therapists, that on her ward the sitting areas tended to evolve into same-sex areas, perhaps reinforcing the need for same-sex spaces to be created.

Personal safety and the risk of danger were raised as issues both for women clients and for staff living and working in isolation within local communities. One group member summed it up thus:

> "We go into these environments on your own with no mobile phones, we're not provided with anything like that and there is the potential for risk." Participant J (Dec. 8)

This issue of personal safety had arisen previously. It is worthwhile to note here that the majority of staff in community mental health teams were women, while there were a greater number of men working in secure wards or within the hospital environment. The potential for risk is greater in the community, with backup support being some distance from community workers. The reported lack of strategies to facilitate staff safety is of paramount concern. It may reflect a lack of recognition of the importance and implications of gender at an organisational level.

In relation to women-only treatment, it emerged that there were a number of women-only groups, both within the day services and the community. Some were set up especially as women-only groups, for example a self-care group and support group. Others had evolved into women-only groups. The lack of treatment groups for men specifically in the community was also identified as a need.

Overall, the need for a balance to be drawn between safety and putting people in unrealistic situations was acknowledged. Similarly, if a need arose for women-only environment or treatment then therapists would try to accommodate this within their service area.

5. *Education*

The final key question on education, asked: *In your opinion is there a need for staff development or education in relation to working with women with enduring mental illness?*

Overall, there was agreement among the group members, that there was a need for further staff development, with members identifying that more discussion around women's issues, including the changing roles of women, would be useful. However, the form of this staff development activity was not fixed. Participants suggested that it could be considered at an individual level within staff supervision sessions or a component of the continuing professional development programme.

Others thought that education should take a multi-disciplinary approach and be available across the organisation. It became apparent that no gender sensitive policy was available within the trust, although an equal opportunities policy did exist. Anti-discriminatory practice and education on this, was not raised in the discussion. Some participants queried what the content of any educational event would be; others offered biological issues, diagnosis, women's issues and gender as possible aspects to be included. Few members had seen any educational opportunities addressing the needs of women. As one stated:

> "It's my impression there doesn't seem to be many things or training courses available which specifically look at women's issues or maybe, it has not arrived on my desk. Recently there have been things going on like the high prevalence of suicide in young men with schizophrenia. It seems to be the thing at the moment." Participant I (Dec. 8)

This quote indicates that women's issues may not be high on the educational or policy agenda or that other areas are being prioritised. Although targeted mental health courses concentrating on women's issues may not be available, courses related to womens' health and gender are well-established and widely available within educational environments and are open to the general public. That said, several members voiced concern that education on women's issues should not be dealt with as a separate topic. This is illustrated by the following excerpt from Group Four:

> P "...there's obviously a need for continuing education in all spheres and that would obviously be one of the areas but I wonder if it needs to be separate."
>
> O "I think you could argue that there should be the same for the men or [people] from ethnic minorities." (Dec. 8)

Participants felt that everyone was different and that this should be to the fore when working with people. Other aspects raised included discrimination, working with transsexual individuals, and the need for gender issues to be considered within teams.

The closing question asked the members: *What for you has been the most important aspect raised in their discussion?*

A range of responses was offered by the group members. Four main aspects emerged as being important. The first aspect related to the focus on women as clients. One therapist stated:

> "...Now that I work with fewer women maybe just thinking am I aware enough of what their issues are and what is it like to be coming into a very practical workplace?" Participant L (Dec. 8)

The experience of being in the group had provided the therapists with an opportunity to reflect on how they work with women.

Secondly, participants underlined the importance of listening to and understanding clients and working with them to meet their needs:

> “It is very important for us to keep getting feedback from our clients. Are we providing what they want and what they need at that time? Participant C (Dec. 7)

This wish for feedback from an individual on their treatment is welcome. However, the recognition of the need for evaluation of the service from the service user's perspective to bring about service change is also important.

The third aspect group members identified as important was the opportunity to discuss women’s issues. They reported that time for discussion of such issues was not available in their workplace:

> “I think what has been highlighted for me is just not anything that has been said specifically, but the whole opportunity to sit down and think about it. Maybe it is something that we don’t do enough or it’s not an area that we explore enough or talk about enough not just with our clients, but talk to other staff about.” Participant D (Dec. 7)

This recognition that within practice the need to discuss and explore practice issues does not get addressed at the personal, professional and multi professional levels raises concern and perhaps indicates pressures on practice.

The main aspect was the focus on working with the individual and reinforcing the belief that everyone is not the same. There was apprehension that services could constrain the therapist’s ability to work with the person as an individual, as the following extract from Group Two makes clear:

> F “But, surely people should be treated as individuals.”
>
> G “I think sometimes we ignore the differences and that is still like an unresolved thing underneath and we try and treat people the same when they are not and it gets lost.” (Dec.7)

This excerpt highlights the gap that exists between what therapists believe and the way they practice in given environments. The profession advocates a client-centred way of working. Three other factors were also raised:

- The need to review services to meet needs.

- The occupational therapy profession's focus on clients' needs.
- The large number of male psychiatrists. It was felt, however, that in the future this would change with increasing numbers of women psychiatrists.

This section has presented the findings from the focus groups. Table 9 summarises the collated findings from the focus group and aims to address the question: *What are the perspectives of occupational therapists who work with women with enduring mental illness?*

Table 9. Summary of Focus Group Findings

Being a woman therapist can be beneficial when working with women.
Challenges and frustrations exist.
Women are perceived as having difficulty in prioritising their own needs over others.
Gender is not specifically considered in understanding women's mental illness.
There is uncertainty in regard to the notion of gender.
Occupational therapy can be therapeutic if focused on the individual and their needs.
Enabling choice is important.
Amongst other health professionals there is a lack of understanding of occupational therapy.
Occupational therapy is different from other mental health professions.
The environment including the organisation is important to the practice of occupational therapy.

These findings were used as an initial start to the discovery phase of the constant comparative analysis. (This analysis process was described in Chapter Two).

Section Two: The Focus Group Themes

This section will discuss the main themes that arose from the constant comparative analysis. Five main themes emerged from the constant comparative process through an active search for either confirming or negative evidence embedded in the data.

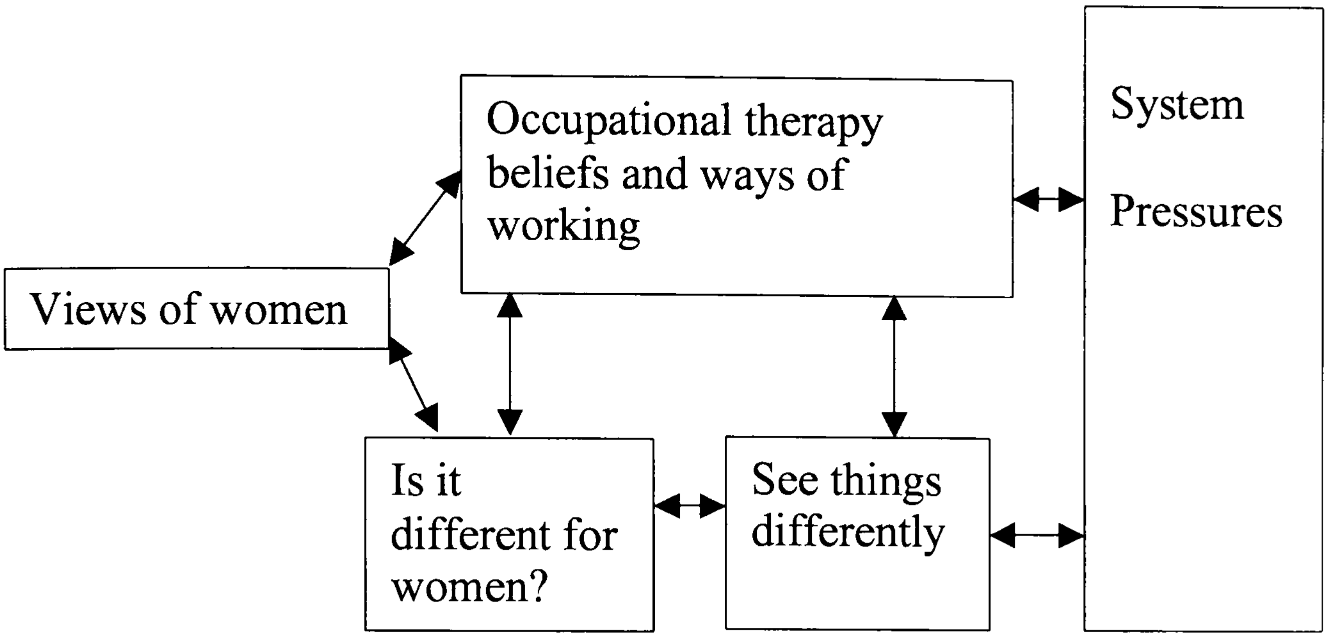
These themes present only one interpretation of the data. Miles and Huberman (1994) remind us that "qualitative analyses can be evocative, illuminating, masterful – wrong" (p. 262). However, to counteract this, strategies outlined in Chapter Two were employed to increase validity issues. The findings presented here have been shared with group members and scrutinised by an external auditor. Each of the five themes will be presented in turn, using quotes or extracts from the data to illuminate the findings. The five themes and sub-themes are presented in Table 10. These themes do not represent a hierarchical construct.

Table 10. The Focus Group Themes

Themes	**Sub-Themes**
Views of women	Identification with women and their issues The whole juggling process It's the loss of roles women find difficult Sometimes you can't help They do feel unsafe
Is it different for women?	People treated without reference to gender I think of myself as asexual at work
Occupational therapy beliefs and ways of working	Occupational therapists have a really different approach We treat people as individuals What is their life like? Collaboration with clients Offering choice
Opportunities to see things differently	Need for education
System pressures	There are lots of barriers 'Lousy environments' The service would never be perfect.

Rather, in constructing the data in this way there is an increasing level of complexity as one moves from considering how therapists work with women with enduring mental illness to the processes that underpin therapists' interventions and the inter-dependency of these actions within the specific contexts that therapists are employed. Figure 5 represents these themes and the relationships between each.

Figure 5 The Relationships between the Focus Group Themes



VIEWS OF WOMEN

The first theme concentrates on the ways therapists view women clients. Identification with women and their issues will be considered first.

Identification with women and their issues

First, participants clearly identified that they, as women working with women, were able to identify with women's life experiences. On the whole, they believed this was an advantage in developing treatment relationships. There was, nonetheless, recognition that in some cases there was a gulf between the therapists' and the women's lived experiences which could impact negatively on therapeutic relationships. As one of the participants put it,

> "... As a professional woman, fairly successful and having all these things, I come in and things are not going so well for them that sometimes can affect the relationship" Participant I (Dec. 8)

This quote points out that the therapist and her client may have had different life experiences. As a result they each bring different perspectives to the treatment relationship, and this can to some degree impact negatively on the treatment process. To some extent, what was being emphasised by the participants was that women clients were different from them. As if to highlight the difference, the participants commonly used the term 'female' in their discussion, although all questions put them used the term women. For example:

> "The female patients that we have, not all but a lot of them, do have behavioural type stuff going...That can get quite annoying I think as a woman working with that." Participant R (Dec. 8)

It perhaps could be argued that the use of this language within this context has the effect of distancing the therapists from the women by emphasising an impersonal view.

It's the loss of roles that women find difficult

This sub-theme considers that therapists indicated that women have many occupational roles that may be affected by mental illness and in a number of ways. Women may face a reduction or a complete removal of their roles or, alternatively, they may have had limited opportunity to develop a range of life roles. The parental role was highlighted as being especially relevant for women clients, as many were mothers and grandmothers. Other female roles were not mentioned. Therapists believed that women might experience grief at the loss or reduction in these roles and relationships. However, services may not recognise this aspect and may fail to provide opportunities for these issues to be discussed.

> "We have a lady at the moment, her two daughters were adopted ...She was actually saying that people would say to her don't talk about, just get on with your life." Participant C (Dec. 7)

On this occasion, the woman in question was effectively silenced by those around her. The failure to acknowledge her situation negated the importance of what was occurring to her and the consequences of that in terms of loss not only at time it occurred, but also in the future.

The whole juggling process

When considering women in treatment, the therapists perceived that, in the main, women clients were involved in a juggling process, balancing their own needs with their family's needs. The result was difficulty in prioritising their needs over those of others and a tendency to place themselves under pressure because of the demands they were experiencing. In some ways, participants felt that their involvement added to these pressures for their women clients, as one respondent commented:

> "...Working in the community, it is difficult for women to have the time to allocate to actually speak to you because they have children to collect from school; they have got things to do. They find it difficult to actually give themselves that space to come and talk about what is wrong." Participant J (Dec. 8)

The difficulty has to some degree been compounded by the move to community provision, the crux of which is a service tailored to the individual in their context. For women, their treatment becomes something else to be included in their schedule of daily activities. As such it may not be given a priority and if it takes place in their home, the importance of 'time out' or indeed time away from family pressures is lost.

The situation described above also raises issues for therapists attempting to provide interventions in less than ideal situations. They must, to some degree, find these situations frustrating, although in the focus groups this was not discussed in any depth. The participants were, however, able to express some negative feelings, as highlighted in the following sub-theme.

Sometimes you can't help

Here, some participants highlighted negative feelings towards certain types of behaviour exhibited by woman, for example deliberate self-harm. These behaviours are commonly found in women but are also found in men. Therapists voiced a lack of understanding of the behaviour:

> "I find for example deliberate self-harm, whether that is through cutting or even I suppose eating disorders, as a way of self-harm I find that really I can't relate to that." Participant H (Dec. 7)

This quote suggests that some of the participants, may have difficulty in relating to this type of behaviour. Here the issue is deliberate self-harm but it could be other mental illness symptoms. This raises the issue that therapists may also find other behaviours difficult to relate to. If the therapist is unable to relate to the behaviour or fails to understand what brings it about, then the issue of how they can work therapeutically with a self-harming client may be questioned. It may be that further education is necessary to increase understanding beyond the basic information that may or may not be present in undergraduate curricula. Also some opportunity for individual therapists to raise such issues in non-critical situations, such as supervision should be created.

They do feel unsafe

Within this sub-theme, most participants identified personal safety issues as a valid concern in relation to themselves as practitioners and for women within mental health services. Personal safety issues were related to the vulnerability of women in acute phases of illness and in certain contexts, for example, wards and community settings. The need for environments to offer protection and the need for provision of accurate information regarding possible risk situations was highlighted:

> "It is just something I am conscious of...I could sit in a group, there could be eight guys and one female patient...As a staff member I can do lots of things, I can leave the room, I can phone for assistance, I can pull my alarm. Whereas, a female patient has to find her own way in that interaction in the sitting room. Participant N (Dec. 8)

This quote emphasises staff personal safety. It draws a contrast between the vulnerability and the levels of protection offered to a woman staff member and to a woman client. The potential for risk is recognised as an issue for women, whether patients or staff, within this specific, secure, mental health context. Indeed it was considered in the planning stages as the following quote makes clear:

> "In the new unit...we have single bedrooms and they are en-suite we couldn't just say that this was strictly for females because we would restrict the number [of men] we would potentially take in" Participant N (Dec. 8)

There is the ability to provide women-only environments and therefore increase safety levels, but this can be overridden by resource implications. The need to address personal safety across the mental health service is essential, especially to increase safety for those working in the community and make environments and working routines congruent with safe practice, for both clients and staff.

IS IT DIFFERENT FOR WOMEN?

This theme deals with the gender agenda and its perceived lack of significance for the participants.

People treated without reference to gender

A major finding was that the majority of participants agreed that gender and related issues were not something they considered overtly in their practice. They acknowledged, however, that it was an area that perhaps required more attention:

> "An increased consciousness again that women are maybe sidelined a bit and the concentration is on the male side of it" Participant K (Dec. 8)

This participant acknowledged that perhaps women's needs are not considered fully and that there is a need to raise awareness; at a personal, professional and organisational level.

I think of myself as asexual at work

This sub-theme explored the fact that no consensus emerged from the participants regarding gender. However, within the findings examples of gender issues were identified as being multi-factorial including cultural, social and biological issues. Sexuality was specifically raised in relation to transsexuals. Across the groups, there was discomfort amongst some members about the study's focus on women. They actively placed men into the discussion, and on occasion, made the point that people from ethnic minority groups faced similar issues. They considered that the focus should be on similarities and not on seeking differences, indicating, a belief in gender neutral practice and contradicting their stated stance on client-centred practice.

The following excerpt from Group Two has been included to illustrate some of the above issues. This incident took place within the closing section of Group Two, when the participants were asked individually what was the most important thing raised for them from the group’s discussion. One group member (F) had been becoming visibly uncomfortable, changing her position in her seat: she finally took the opportunity to express her concern:

F “I’ve got a slight feeling of unease here. So OK its been 2000 years and we are fighting for equality and suddenly we are talking about gender issues, women in mental health, Dalmatian dogs in races. Are women a separate species that is what is coming across? Why should there be a difference?”

Res “I think if you look at the literature and how women have been in mental health services there is a difference.”

F “I mean obviously there is a difference between men and women and there are gender issues and hormones and things but it seems as if people are homing in on the differences rather than the similarities.”

Res. “The problem is that psychiatry has been seen as gender neutral.”

F “But surely people should be treated as individuals?”

G “I think sometimes we can ignore the differences and that is still like an unresolved thing underneath and we try and treat people the same when they are not and it sorts of gets lost.”

F “But you can’t be treating them all the same if you are treating them as individuals.”

G “But if there is a whole service, a whole structure that is set up, can be set up in a certain way that constrains your ability to work with a person as an individual sometimes.”

D “I guess what we’re saying or what I’m saying personally is that I do think about my individual clients whether they are a man, woman or something in between. I don't really know, I don't formally think about well what are the gender issues around, but I do think globally about what is around for this person, or I like to hope I do. What’s affecting where they are right now? But I don’t formally sit down and think OK what’s around that really relates to their gender”.

E “This study is specifically for needs of women, hopefully, not every study or research will be focused on women as long as every one thinks about them as individuals and then to think gender issues as well. As long as we don't think females are more important or have got higher needs or whatever."

H I think you mentioned earlier about cultural differences and well as gender I think we are getting better in sort of health care professionals looking at the needs of different people because of their culture. I suppose it is similar.

Within this exchange several key issues are raised; the first participant's discomfort with the focus on women and the gender question; working with the individual; treating everyone the same; and the idea that women should not be regarded as more important than men. Clearly, for this participant addressing difference was something that caused her concern.

What is interesting is how the other group members reacted to this statement. Firstly, several are involved in supporting my position and seek to explain why there is an issue. However, some are still unsure about the focus on studying women only and balance this with other future research focusing on men. The participants are trying to highlight that differences are present, that practice can be constrained even with a focus at an individual therapist's level on the client's needs and that the organisation's structures can limit practice. However, finally they follow the line of least resistance and return to an equality for all position.

To explain the situation the participants find themselves in, we need to consider their belief that they treat each patient as an individual, equally. This is supported by their belief in client-centred practice. These beliefs are firmly held and highlighted in the data, and they may shape how the individuals work. However, it could be argued they cannot be treating people as individuals if they do not consider the client's gender as fundamental to the client and their practice. There seems to be a paradox for the therapists around treating equally and treating individually.

For the most part, the participants' examples with regard to gender focused on clients and not on themselves. The exception to this was in relation to personal safety.

OCCUPATIONAL THERAPY BELIEFS AND WAYS OF WORKING

This third theme portrays the process and beliefs underpinning the practice of occupational therapy in working with individuals within mental health services.

Occupational therapists have a really different approach

It was evident that all the therapists believed they offered an approach that differed from that of other mental health professions. They believed that engagement in meaningful occupation was positive in facilitating personal change in their clients and that the experience of doing has many benefits for the individual.

> "I think we are one of the few people who pick up on roles." Participant O (Dec 8)

As the above quote highlights, the participants perceived that their focus on an individual's roles and needs contrasted with the focus of other professions on such aspects as diagnosis and medication or other agendas:

> "They [clients] get caught in the debate about occupational therapy, not being a punishment or an award...with say an assault on the ward being punished by not getting down to occupational therapy for the next six months." Participant M (Dec. 8)

This statement demonstrates the position that occupational therapists and clients can find themselves in when other staff groups hold a particular view of occupational therapy. Often these groups have more power within the organisation and are able to effect changes that impact directly on therapy provision. Insofar as this is the case, other professions' working practices and understanding of occupational therapy can impact on and limit occupational therapy provision.

We treat people as individuals

Within this sub theme it was clear that therapists valued working at the level of the individual, identifying personal goals that were relevant and important to that person. However, there is also acknowledgement that they and the organisation can constrain the ability to meet individual needs:

> "It sounds really clichéd but remembering that they are individuals, their lives are unique, yes they have common factors in terms of illness, but they are people. Sometimes I forget, you know if I'm thinking about other things I'm just not giving them that space. Participant C (Dec. 7)

The respondent here recognises that treating people as individuals requires commitment, time and attention from staff. To treat people as individuals requires an understanding of their life world.

What is their life like?

This aspect identifies that through assessment processes, both formal and informal, therapists require at the outset to seek out their clients' past histories. The therapists require to listen to and understand the complexity of an individual's life, checking out their understanding throughout the duration of the intervention. This process enables a greater understanding of the individual's life and situation:

> "Often, at the very beginning of your intervention, when you are getting to know the person, you are trying to find out where they come from. What their previous roles have been, really exploring that with them...You can be talking to another member of the team who is viewing the person very much as a patient. That can get missed if people aren't looking at the history." Participant M (Dec. 8)

The importance of understanding the person's life is clearly evidenced in this quote. Participants identified that other team members can fail to understand or engage with the person other than as a patient.

Collaborate with clients

Therapists highlighted that clients need to be included in their own treatment and they advocated working in partnerships: in a client-centred manner. However, they acknowledged that partnerships can be difficult to develop and sustain, and may be unrealistic in certain environments. This is particularly the case when the balance of power within any treatment relationship always lies with the professional.

> "We have all the professional power in our roles and how much you are willing to give up to hear what people have got to say, you might not actually like to hear. There is a risk there." Participant P (Dec. 8)

The power balance between patient and staff may be more visible in certain settings, for example within forensic settings. However, Participant P raises an important issue: that power is inherent in the professional role and that it gives some status and perhaps some degree of protection. One important way that therapists collaborate with clients is discussed in the next sub theme.

Offering Choice

The respondents perceived that offering choice through treatment is essential to a successful outcome. Clients should be offered choices to attend occupational therapy, with choice being built into the individual treatment plan. The participants recognise that choices may be limited and that making choices can be difficult for clients for a variety of reasons:

> "I think the thing I try to do differently is giving people choices and encouraging them to make decisions for themselves and taking responsibility. I think a lot of the time that's taken away from people." Participant C (Dec. 7)

The therapist here is emphasising that she works differently from other team members and that this difference is demonstrated by offering people choice and decision-making opportunities. Occupational therapy is portrayed as working with the client to meet their needs.

OPPORTUNITY TO SEE THINGS DIFFERENTLY!

The fourth theme that was evident was the need for education. Overall, a need for increased education regarding women and gender was felt to be relevant, although some of the participants were tentative about this topic.

> "I felt there definitely is a need for more discussion and realisation of women's issues." Participant A (Dec. 7)

> I'm not sure it is unique to women, I think all of us could do with education about our general practice, about fundamental stuff. I think I have faults in my practice and they are there whether it's a man or a woman". Participant B (Dec. 7)

These excerpts may reflect uncertainty or lack of awareness or knowledge about gender issues. The second quote indicates the need for practice to be explored and for this to include further education on issues relating to both men and women. Clearly, education needs to encompass gender issues across both sexes. A further aspect identified was the time needed for professional discussion and education to take place.

The group members highlighted the need for such educational activities to be delivered in a range of formats: uni-disciplinary formats, such as professional supervision or peer support and multi-disciplinary formats across the organisation such as workshops or taught courses. Anti-discriminatory practice was not raised in any groups, although equal opportunities were and this could be included within any educational activity.

SYSTEM PRESSURES

The fifth theme presents the background against which occupational therapists provide their services.

There are lots of barriers

This sub-theme highlights that therapists identify that lack of resources, including staff, finance and time, can prove detrimental in the delivery of their interventions. As one participant put it,

> "I think, one thing I am very conscious of is allowing time because I don't always do that I know, when you are visiting people in their own homes you make all kinds of excuses there's more travelling da di da. Participant A (Dec. 7)

Time pressures clearly impact on the service, as highlighted above. External barriers such as cost and transport availability can also impact on a client's abilities to make the most of treatment opportunities.

It is interesting to note that the barriers identified are all physical and tangible. There is limited recognition of psychological barriers, either on the part of their clients or on the part of themselves, for example frustration, stress or burnout. People who suffer from mental illness can and do suffer from fluctuating motivation and energy levels and at times their ability to function is severely compromised. Similarly, working in mental health services can be extremely stressful, distressing and frustrating for staff, who work closely with clients and their families over long periods of time. It could be that the social context of the focus group did not allow for these issues to be raised in a safe and secure environment.

'Lousy' Environments

The environment, including the organisation, was seen as being an important element that could enhance or restrict occupational therapy. Hospital wards were generally portrayed as offering poor surroundings with limited choices available to clients. The community was considered to be a more favourable environment, from the perspective of increasing clients' treatment choices.

Not surprisingly, those individuals placed within secure environments had the least choice available. Therapists too, were the most constrained by this setting:

> "You are talking to people who work in the institution whereas if I was in the community I hope I would work that way." Participant N (Dec. 8)

The implication is that as clients moved towards the community, treatment choices would increase for both clients and therapists.

The service would never be perfect

This sub-theme considers that services need to be reviewed to maximise meeting people's needs. However, the process of what information to collect, when to collect it and who to collect it from was identified as problematic with no overall review process being identified.

> "We don't have any formal mechanism for any kind of feedback for all the clients, we don't have any community user groups or anything like that." Participant C (Dec. 7)

Several services, particularly those in the community, were in a process of change. The point was made that for the individuals who use the services, such change can impact on an individual's health status. As one participant reported,

> "We are going through this process of change, we have just taken away the day unit. There has been a lot of resentment and anger from a lot of the clients who attended. Actually, one woman, in her forties, actually I can't say it was a direct result of that, she ended up in hospital. But certainly it was an important part because she couldn't deal with all the change and felt we were abandoning her." Participant D (Dec. 7)

This service change has already occurred. However, it begs the question in what ways were clients consulted about the change and how and were their wishes heard. It also highlights the clients' levels of vulnerability, and their need (and the service's responsibility) to support them through such changes. Care in the implementation of change needs to be uppermost in service providers' minds.

This concluding theme has highlighted some of the tensions and barriers inherent in working with clients within the context of a large organisation. Ultimately, therapists are trying to balance what they can achieve with clients against a background that on occasions seems to less than supportive to their ways of working. In some cases it seems to stand in opposition to their professional practice.

Conclusion

This chapter has presented the findings from the focus groups. The evidence from this small number of therapists suggests that gender issues are not central to occupational therapists' understanding of mental illness or to their practice. There may be several reasons for this. It could be that occupational therapists believe that they are working in a gender neutral setting or that they are uncomfortable with the concept of gender differences. Alternatively, through their practice they may be implicitly addressing gender differences. In addition, the participants' own gender seemed of no particular relevance to their practice. This may highlight the need for gender awareness training to be an integral part of under-graduate and postgraduate education.

In exploring the study themes, the therapists highlighted the importance of hearing their clients' life histories and needs as a way to understanding their lives. It became clear that the therapists' belief in working with the individual and the ideal of partnership was significant in meeting clients' needs. However, some dissonance was evident in their discussion of practice. Also identified as important was the environment. The view emerged that community working offered clients greater choice than was the case in the various hospital contexts. It was seen by some as the way ahead. Furthermore, the environment as an organisation was considered to impact on the practice of occupational therapy. The discussion of these findings will be presented in Chapter Six.

Reflections on the focus groups

On the first day of recording, I was apprehensive about many issues. Although I had been in contact with all the participants prior to the recording of the event I still had some concerns. How would I perform as a group facilitator? Would the questions facilitate discussion? How would the participants react to the studio situation?

The first group started late, as the participants had some difficulty locating the studio. Once we began, the three group members were immediately engaged in the task. As the group proceeded, they built on each other's perspective. They made links to their practice and illustrated aspects with examples from their own experiences. This *group seemed supportive of my position and to some extent eager to please. In regard to this aspect, the observer at the first debriefing session stated that in this group she observed "performance or pleasing going on" amongst the participants.*

The second group had five members and a different feel from the first session. There was participation across the members, although at times some members appeared ambivalent towards the subjects. In addition, there was an indication of discomfort, particularly from one of the older members. Throughout, the members contributed their perspectives, listening to others and offering examples from their practice. The group member, who had appeared uncomfortable, was towards the end of the session able to express her unease and to some degree she challenged me directly. What was interesting was the groups' reaction to this challenge. (This incident was discussed in the chapter.)

At the end of day one, I was glad to have had an observer present to assist me in the review of the focus groups. During debriefing, the observer made some insightful comments about the group dynamics and my role as facilitator. She commented, initially, on my anxiety at the beginning of group one. However, this receded as I became more involved in the group process. The observer highlighted two things of interest: the dynamics between myself and the person seated directly across from me in the 'hot' seat, and the narrow nature of some of the participants' responses. In considering the 'hot seat' dynamic, within Group One the woman in the 'hot seat' appeared to take on an intellectualising role, on several occasions bringing some theoretical perspectives into the group discussion. Within Group Two, the person seated across from me was the participant who had became ill at ease as the group progressed.

The other aspect the observer commented on was the narrow, parochial nature of some of the responses from the participants. We considered that this perhaps reflected the particular cultural context and might not have been the case if the focus groups had taken place in other parts of the UK. As the observer was not in attendance on day two these issues were recorded for future consideration.

The first group of day two had a very different feel than the previous groups. This group consisted of five members, but was to some degree monopolised by a few members at certain times. Within this group, discussion was less fluid than it was in the previous two. The group and I seemed unable to get into a rhythm. I was very conscious of having to work hard to engage the participants. One group member was very supportive of my role as facilitator. She worked hard to encourage the others to engage. Members did contribute but there seemed to be little interaction between the members.

With regard to the 'hot seat' issue, in this group the person sitting opposite me appeared no different from other members. Once the members had left, the studio technicians commented insightfully that this group had been like "pulling teeth". This may have been due to several reasons; my own performance, perhaps, I was less sharp than the day before, or it may have been due to the mix of members. However, of all the groups, it felt the most staccato.

The final group had an interesting potential dynamic on paper, due to external factors; two managers from the service found themselves in this group, with only one other senior therapist. An additional factor that has to be considered was that both managers and I were well known to each other. At the beginning of the groups and this one specifically, I was very careful to omit my previous relationship with the service. However, in the introduction one of the managers made the link to our long acquaintance. This seemed to set the tone for the group. Here were three people with common experiences, with another who was not party to this shared history and therefore to some degree, she was excluded. Both managers participated freely. The other group member seemed constrained to contribute her views in the presence of the managers. She was encouraged to contribute. However, her limited participation is evident in the transcript. At the time, I recorded in my diary "Participant O seemed flanked by the other participants: it seemed difficult for her to come through". Indeed, she ended up in the hot seat directly across from me. This positioning was intended to make her feel central and included. However, it may have had the opposite effect of closing her down, perhaps in some way threatening her and thereby further limiting her participation.

Overall, the four groups were very different in their dynamics although similar issues were raised across all. On reviewing the focus group organisation and management, several practical aspects were highlighted. For example, information for participants about finding the venue and sign-posting at the venue could have been clearer. The composition of the focus groups was carefully thought through with regard to participants' designations. However, at the time several changes occurred and one group, Group Four, was particularly affected.

With regards to the management of the groups, the questioning route and the use of stimulus material were both useful. That said, I was aware that during the groups I adhered to the questioning route. This may have limited spontaneity, although it ensured similarity across the groups. With regards to follow-up questions based on the participants' responses, these were asked in all the groups. Sometimes these were productive routes whilst others were limited. Nonetheless, due to the nature of the responses these questions were not always the same across groups. The most arduous group overall was Group Three. The participants within this session did not interact with each other as other group members had and my attempt to encourage dialogue between members was not very effective. This may have been due to the composition of the group, anxiety or my performance. Whatever the reason, it was the least fluent group. Furthermore, due to the explorative nature of this work it may be that for more personal information to be revealed by therapists, individual interviews should be considered for future research.

CHAPTER SIX

Women's words and therapists' thoughts: Voices from the verges.

Introduction

At the outset of this work, the lack of literature specifically considering women with enduring mental illness was highlighted, so too, was the dearth of occupational therapy literature regarding working with women. This study explored these two area: using qualitative strategies, namely, life-history and focus group methods, to fulfil the following aims:

1. To explore the experiences of women with enduring mental illness, across the life-span.
2. To examine and identify the factors that influence women occupational therapists working with women with enduring mental illness.

The findings presented in Chapter Three and Chapter Four addressed the first aim of the work: to explore the lived experience of women with enduring mental illness. Their five unique narratives portrayed the lives of these specific women. Their stories explored their roles, their relationships, their personal struggles and victories. At times, their narratives revealed that they had experienced living on the verge of their own community. Their personal narratives were set against the broader socio-cultural context that influenced their lives including the Depression and World War 11 and changes in legislation (for example, the Abortion and Mental Health Acts). Other social trends they experienced included the increase in divorce and lone-parent families, the right to buy council property and increased awareness of sexual abuse. If we are to understand their lives these trends must be taken into account.

Chapter Five considered the second aim, examining the factors influencing occupational therapists working with women with enduring mental illness. Their practice was unpacked and analysed. What emerged was therapy that focused on the individual and that was delivered in a context on the periphery of mental health services. This chapter will develop these issues in more detail, anchoring the outcomes in existing literature. The resultant findings complement the existing body of knowledge by offering a better understanding of the women's lives and therapists' practice. In some cases the findings contribute to the development of new knowledge in these areas, providing alternative insights and understanding. As a result, different literature will be introduced to support the evidence that emerged from the process.

Section One of this chapter will consider how the women perceived that a range of negative experiences throughout childhood and adulthood had a detrimental effect on their mental health. Significantly, the women identified several roles as meaningful to them: specifically, those of mother, employee, carer and volunteer. The findings around mothering give new insights to the impact of mental illness on this role. Furthermore, the role of grandmother was highlighted as a particularly satisfying one. This role which has received little attention in the literature, was extremely significant and meaningful for the participants.

In mapping their life journeys, the study participants highlighted the impact of various factors. Several of these factors have been identified in previous literature. However, what is different here is the humanisation of these factors and the lifelong consequences on the women's lives. The participants believed that mental illness had adversely influenced their lives and their relationships, limiting their choices and opportunities. The presence of suicide ideation throughout their narratives was a finding that raised concern, particularly as this group may be increasingly vulnerable as they grow older.

In reviewing the women's narratives, both agentic and victimic plots were evident. These participants were at times active in speaking out to improve local mental health services. What emerged as new were the informal, support frameworks that women created and maintained to enable their mental health to be sustained and their possible futures to be considered and attained.

Section Two highlights the shared experiences that were evident in the women's and the therapists' narratives. Three aspects were common to both groups: the need for personal safety and safe environments; feelings of powerlessness; and the importance of being heard. A new insight was that the women had similar feelings about their interactions with the mental health system, to a greater or lesser degree. In relation to the occupational therapists' perspectives of their work, these findings offered new insights.

Finally, Section Three will discuss the focus group findings. This presents the perspectives and beliefs of the therapists working with women with enduring mental illness under three headings: ways of knowing and doing; treatment issues and women; and pressures on practice. 'Ways of knowing and doing' presents the core beliefs of the occupational therapists. These included occupation and client-centred working. These beliefs and the therapists' view of occupational therapy as different from other professions are also discussed. Some of these aspects have been further developed in light of this research.

The section titled, 'Treatment issues and women' will present a range of factors that impacted on the therapists' work, including age, race, gender and class. Discussion around gender issues seemed to raise issues for the therapists and it was evident that few had considered gender in relation to their role as therapist. In considering women's roles, therapy was geared to facilitate the women's return to their main roles as carers. There was little discussion about work or vocational rehabilitation. It was perceived that the therapists offered a traditional treatment approach. Much of what was evidenced has had little attention in past research, although parallels can be drawn from existing literature beyond occupational therapy.

The final section, 'pressures on practice' highlights the problems and dilemmas that some of the therapists experienced in their practice. It became evident that some therapists found themselves holding contradictory positions and beliefs. To some extent a number of these issues have been highlighted elsewhere. Here the prominent finding was the influence of the environment. This impacted significantly on occupational therapy practice. Another pressure on practice highlighted by the participants was their need for continued professional development at a range of levels, including practical support and supervision. A second level of development was also called for in the shape of in-service courses and education. These participants also highlighted postgraduate education opportunities.

Section One: Women's words illustrating their worlds

FORMATIVE EXPEREINCES

From the findings, there are many factors that have shaped and constructed the women's experiences and their perspectives of their life worlds. The participants recalled factors such as abuse, relationships, poverty and other traumatic events from their childhood and through adulthood.

Experiences of Abuse

Physical abuse was an aspect of Pat's childhood. Pam identified her relationship with her father as affecting her development, and Sarah was sexually abused as a child. Ritsher et al. (1997) and Repper et al. (1998) have also identified physical and sexual abuse and they endorse the view that women with enduring mental illness have had adverse emotional and sexual experiences that predated their mental health problems.

In relation to sexual abuse, Ritsher et al. (1997) highlighted that the most common abusers were often parents. For Sarah, her sexual abuse by her father and her later abuse by a teacher marked her life profoundly. The impact of child sexual abuse can not be underestimated. Rather, Sarah believed that as a result she suffered from Multi Personality Disorder (MPD) and this specific diagnosis has been linked to child sexual abuse (Russell, 1995). Sexual or physical abuse in childhood may well be a factor in a range of psychiatric diagnoses: Williams et al. (1993) estimated that as many as 50 per cent of women using psychiatric services have experienced sexual or physical abuse as children or adults. More recently, Goodman, Rosenberg & Mueser (1999) identified that for women with serious mental illness the prevalence of sexual or physical abuse ranged between 51% and 97%. They proposed that as a result these women experienced a range of negative implications, including long periods of hospitalisation and histories of suicide attempts or suicidal ideation.

Relationships

These women identified that their relationships with parents impacted significantly on their lives, with some of the women experiencing physical abuse from their parents. However, others identified that they experienced relationships with their parents that could be described as emotionally abusive with parents exerting excessive control over their lives. Two women said that their siblings seemed to be favoured, receiving both material and psychological advantages.

Poverty and Divorce

As is evidenced in the data, the poverty Helen experienced in her childhood laid the foundation for her whole life. She perceived that poverty contributed to her poor childhood health as well as reinforcing her position as "poor" within her wider community. Repper et al. (1998) gave prominence to the social disadvantages faced by women. Although it has to be borne in mind that these factors may also affect men, some may impact on women more. For Pat, the financial strain involved in bringing up her children single-handed with only state support, contributed to the onset of her mental illness. Related to this, Weich & Lewis (1998) explored "poverty and unemployment" (p. 115), concluding that both of these factors increased the duration of episodes of common mental disorders but also that they were not responsible for their onset. They suggested that continued financial strain was a better predictor of future psychiatric morbidity. The issues of poverty and divorce apparent in Repper et al.'s (1998) work found parallels in this study.

However, low incomes and the threat of limited finance continued to cause concern for these women. Holmshaw and Hillier (2000) stressed that "the proportion of women living in poverty has steadily risen over the past 30 years despite the overall reduction in poverty" (p. 52). Furthermore, this group face the prospect of smaller occupational pensions or, for the majority here, state pensions only. This may lead to further financial strain and may increase their vulnerability to future mental distress.

Divorce was experienced by three of the participants. Two of the women were divorced following mental illness episodes. Hart (1995) explores this dimension. Pat, however, sought a divorce from her abusive husband before she had any contact with psychiatric services. It could be that the stress of living with a partner who has a mental illness led to the divorce, or that the marital relationship contributed to the mental illness. These participants bore out Owen et al.'s (1998) findings that women with enduring mental illness were more likely to be divorced or widowed.

To summarise, the women identified that negative experiences throughout childhood and adulthood had a detrimental effect on their mental health. They offered firsthand knowledge of the multifaceted ways in which these negative experiences can cause or compound mental distress. For some, these factors may have led to the onset of mental illness; for others they may have influenced the course and the duration of mental illness.

WOMEN'S ROLES AND MEANINGFUL LIVES

The women's narratives provided evidence of the roles that made their lives meaningful. Mothering significantly emerged as a valued role for the participants, as did 'working' and 'caring' roles. Mothering and the issues inherent with this role will be considered first.

Mothering Experiences

Mothering here emerged as a multi-dimensional occupation. Mothering was considered as a co-occupation, with both mother and child being active participants in the shared occupation (Primeau, 1996). The women considered that it was an occupation that was longitudinal, with their mothering roles and issues changing over time (Larson, 2000). Three of the four women were grandmothers: the meaning of this specific role to the participants will be explored, as this is an aspect not generally found in the literature relating to mental illness. The continuum of motherhood, from being pregnant to being a grandmother, was represented in this group of women's narratives (Figure 6). Although at first glance this continuum may seem self-evident, it raises key areas that may have implications for service providers.

Figure 6. The Mothering Continuum: Issues for mothers with a mental illness

- Pregnancy
    - Fear
    - Adjusting
    - Coping
- Childbirth and infancy
    - Attachment
    - Separation
    - Developing caring
- Early childhood
    - Children's needs first
    - Sustaining contact
    - Providing for their needs
- Adolescence
    - Resentment
    - Changing dynamics
- Adulthood
    - Support: practical and financial
    - Guidance
- Grandmother
    - Revisiting motherhood
    - Experience and practice
    - Positive identity

Ruddick (1989) identified that mothering involved sustaining the child's health and promoting the child's development to facilitate their progress to adulthood and enable them to contribute to society. The above continuum highlights issues that occur at different life stages. A large body of work records the rate of mental illness in mothers (Cleaver, Unell & Algate, 1999). In general, however, research on parenthood is often focused on early parenting and on caring for elderly parents (Rossi and Rossi, 1990). Francis-Connolly (2000) has called for research on parenting over the life-course.

Although motherhood was included in the three studies on women and severe mental illness (Ritsher et al., 1997; Owen et al., 1998; Repper et al., 1998), there was little exploration of this specific role or the impact and consequences of the mental illness from the mother's perspective. This study provides evidence of the ways in which the participants' capacity as mothers was affected by mental illness and other long-term consequences. It is significant that the participants in the study emphasised their early mothering experiences, perhaps because these are recalled as very stressful times. However, it is clear that their experiences as mothers affected them and their families across time, as each of their personal narratives reveal.

The need to maintain a mother's ability to respond to the needs and well-being of her children is paramount, as there can be potential adverse effects for children of parents with a mental illness (Oates, 1997). The possible effects of parental mental illness may include the lack of stimulation, neglect and isolation resulting in developmental delay, the risk of emotional and physical harm to the children, and, at the extreme end, risk of fatal abuse (Göpfert, Harrison & Mahoney, 1999; Thomas & Kalucy, 2002). That said, Oates (1997) argued that "serious mental illness would appear to exert its maximum effect on children through marital discord, social adversity and multiple changes in caretakers"(p. 25). These effects can to some degree be compensated by other family members' involvement with the children. This study took place at a time in the women's lives when there was some distance from their early mothering experiences: their children were all adults, with the youngest being twenty-seven at the outset of the study. This distance offered the women an opportunity to view their experiences of mothering retrospectively from their current life stage. Francis-Connolly (2000) highlighted that the occupations of mothering were different across the life span. She emphasised that with pre-school children the focus for the mother is on "care-taking activities and meeting the basic needs of the child whereas with young adults the focus of motherhood is emotional and supportive activities" (p. 281).

For these four mothers, the idea of falling short of being "a perfect mother" recurred throughout their narratives. This conforms with the findings of Ritsher et al. (1997): 29% of the mothers in their study felt that their mental illness had made it harder for them to be good mothers. This finding has also recently been supported by a study of mothers with arthritis (Grant, 2001). Francis-Connolly, cited by Farber (2000), reports:

> Women …held an "illusive ideal" of the perfect mother that was socially constructed. Her participants were constantly comparing themselves to this ideal and at the same time, feeling guilty for not being perfect" (p. 267).

It seems that the women in this study were similar to other groups of mothers and that seeking maternal perfection may be the unattainable goal for all mothers. Perhaps for mothers with disabilities, both visible and (in the case of mental illness) invisible, this is an added factor that they have to come to terms with and be supported through. However, being seen as a 'good mother', and later as a good grandmother, was a powerful motivator for the participants in this study.

Several key issues were evident for these women, including those of bonding and separation. Bonding with their children was a major issue for Helen and Marguerite. Helen did not know that she was pregnant and she recalled that she did not want the child. These factors may have made her ability to establish a sound bond with her daughter difficult.

Marguerite's difficulties came to a head when she experienced postpartum psychotic illness following the birth of her daughter, in 1968. At this time there were few specialist community services available. Mother and Baby Units were not generally found in psychiatric hospitals in the UK, although they had been suggested much earlier to avoid the twin dangers of separating the mother and child (Main, 1948). As postpartum psychosis carried the risk of child neglect and infanticide (Kohen, 2000), Marguerite spent almost two years in hospital. Due to this hospitalisation, her opportunities to develop a positive relationship with her baby were severely constrained over this crucial period. She believed that as a result she did not have the opportunity to form a positive attachment with her daughter.

Marguerite found herself in a situation where she was unable to be involved in caring for her young daughter in anything but a peripheral role. This separation continued to affect her subsequent relationship with her daughter. Her situation was recognised by Stein et al. (1991) who identified that separation can affect the mother's relationship with the infant and may set up long-term worrying influences.

At different stages in their childhood, Helen and Pam felt unable to cope with their roles as mothers: both felt unable to look after their children. However, they each took a different approach to compensate for their perceived inability to cope. As Helen's depression continued she felt increasingly unable to care for her six-year old daughter. She felt that her family would be able to help her, so the family returned to Glasgow. Once there, Helen seemed to hand over the parenting of her daughter to her husband. This action by Helen may have reinforced her belief of her less than positive relationship with her daughter. As Kohen (2000) stated "insecure attachments are more frequent in children who have mothers with a history of depression" (p. 169).

Pam took a different tack. She commenced her first teaching post and this part-time job proved to be a turning point. Her return to work enabled her to cope better with her role as mother as it provided a counter balance to the demands of mothering she found so difficult. Her resolution to return to work may in the long-term have also benefited her son, Craig, as research shows that depressed mothers may have a range of negative influences on their child. Stein et al. (1991) studied 19-month-old babies of depressed mothers. They found that these children were less responsive, less interactive and showed less positive affect than the control group. Craig may have doubly benefited, first by having time away from his mum with the childminder and second, through experiencing better quality time with mum when she returned from work. These compensatory strategies adopted by Helen and Pam seemed to assist both of them to cope emotionally and practically with their roles as mothers.

Pat's experiences offer a different perspective of motherhood. In 1971, Pat was a 33-year-old single parent with responsibility for three children. Life for Pat was arduous: she had financial problems and her main concern was the children's welfare. She became increasingly depressed. Popay and Jones (1990) found that mothers who bring up children alone have consistently worse health than those in two-parent homes. Pat felt unable to care for her children and was concerned for their safety both from the perspective of not being able to meet their needs and also from that of worrying who would care for them if anything happened to herself. As her health deteriorated, she was admitted to a local psychiatric hospital, and the children were placed in local authority care. Pat had continued anxiety about her children being in care and the care they were receiving. Göpfert et al. (1999) found that parental anxiety concerning their children's care can impact negatively on the parent's mental health, hindering their recovery.

Pat and Marguerite had to deal with the loss of their children and the loss of their mothering relationships. Such losses were highlighted in the UK studies conducted by Owen et al., (1998) and Repper et al., (1998). Both these women worked hard to maintain a relationship with their children following their separation. They demonstrated courage, strength and resolve to continue their relationships with their children, sometimes against the backdrop of physical and institutional barriers.

Following the continuum of motherhood, three of the women in the study were also grandmothers. Doyal (1995) reminds us that the role of grandmother is a much valued role "offering women greater autonomy than at any other point in their lives" (p. 40). Involvement as a grandmother was highly valued by the women, although their experiences as grandmothers were very different.

Helen, as grandmother, became the legal guardian for her two grandsons. Pat's role as grandmother was marred by her poor relationship with her eldest son. However, she was an active participant with her daughter and her grandson. For Marguerite, maintaining a connection with her daughter finally came to fruition with the birth of her granddaughter. Her involvement with her granddaughter was an opportunity for her and her daughter to develop their relationship further. It was clear that being grandmothers offered a way for the women to play an active role in their children's lives in both a supportive and financial way. This was endorsed by Francis-Connolly (2000) who saw mothers as "invested participants … they provided emotional support to [their children] and gave them advice on everything from car loans to parenting" (p. 287).

In light of the above, this final section will discuss the implications for practice. For the women in this study, whose experiences spanned several decades of mental health care, the message is clear: mothers with mental illness need support. Each experienced little support or indeed little recognition of their unique and complex roles as mothers. Not all mothers with mental illness will require support with the occupation of mothering, but some will, and all should be asked if they have unmet needs in respect of their capacity to mother. Assessment procedures concerned with maternal capacity should be supportive rather than punitive. In addition, such assessments should acknowledge mothers' strengths and not undermine the mother's identity or confidence.

Mothers must be partners in the process as they may have a range of strategies or developed solutions that will work for them, if they are provided with the necessary information or support. There is a need for the development and provision of services across in-patient, and community services. Importantly, such services should support not only new mothers, but also those mothers who have recurrent episodes of mental illness. Such mothers face a range of different issues as their children grow up and their caring demands change. There is also a need to work with mothers and families to include their insider perspective to change or design better services.

It is important, too, that children and young people have access to explanations and support when their mother becomes ill or is hospitalised. The difference such an approach may have made for Helen and Pat's children we will never know. Explanations and age appropriate education on what was happening to their mums may have helped the children to understand they were not to blame or how they could best help. In Pat's case this might have kept her family together. That said, children's contact with services should be welcoming and informative. Appropriate resources should be available for children when they accompany mothers or visit hospital or mental health facilities. The provision of suitable environments, and for staff able to interact appropriately with children is essential.

Furthermore, the family should be placed at the centre of the decision making process. Health professionals, including occupational therapists, have a part to play in working with women to support their roles as mothers. This may include co-ordinating practical support or developing effective coping strategies to deal with the pressures of mothering. The use of occupation to develop positive infant-mother relationships is well documented. Occupational therapists can be involved with mothers in structuring their day, maximising their abilities to encourage appropriate play and create environments that facilitate their child's development. We have a responsibility to provide information and advice on local community supports and possible networks. These may not be necessarily linked to mental illness organisations. For example, local mothers and children's group can be found in churches and community centres. Awareness of local groups that can offer support and reduce the isolation often experienced by mothers is essential. Therapists may need to help mothers engage with such groups. In working with mothers we must remain sensitive to their needs and therefore our interventions need to compliment their needs and not burden them further. We should work in partnership with mothers, identifying suitable times and places for interventions to occur, ensuring that childcare facilities are available where necessary.

Children should also be included in the occupational therapist's reasoning, as there is increasing recognition of the needs of children with mentally ill parents

(Hetherington, 2000). Such children require a range of support mechanisms, including education on mental illness and opportunities to discuss their own experiences and develop coping skills. Professionals must understand the mental health issues, and be aware of the effects of mental illness. They must also be aware of child protection issues.

This section has presented an overview of mothering. It has highlighted that until recently the women who are the focus of this study had received little attention and that little was known of their lives and their experiences of mothering. What emerges clearly from this study is that mothering was a significant and meaningful occupation for these women and that they had received little or no support in this role either from mental health or social services. If we are to create better services for future mothers and their children, we need to be proactive to ensure that in whatever area of practice we find ourselves, we do not ignore the reality that mothering is the core role and the most meaningful occupation for many of our clients. By giving opportunities to women to highlight their needs and issues we may be in a position to offer practical, educational and emotional support. Such support may make a real difference to the lives of women with mental illness. It may enable them to experience mothering as a positive occupation they can share with their children and families.

The importance of doing

'Doing', whether paid work or otherwise, was important to all the participants and they all shared the experience of paid work. As Holmshaw & Hillier (2000) stated "it is well accepted that employment generally has a beneficial effect on psychological health." (p. 52). Two of the women had attended further education and had careers for many years. The other three women's employment reflected the usual opportunities open to women including clerical, nursing and the service sector. Work provided the women with income, relationships, status fulfilment, structure and self-esteem (Yuill and McMillan, 1998). Work was especially vital to Helen as it allowed her financial independence without having to be supported by her husband.

Having established the benefits of work for the participants, Test and Berlin (1981) found that women with enduring mental illness may experience limitations with regards to their working lives. Ritsher et al., (1997) supported this position, finding that mental illness had forced women to change jobs or even stop working. Similarly, Owen et al., (1998) found that their participants experienced loss of work and as a result loss of independence.

For the women in this study, the ability to engage in work was central to their lives. Marguerite experienced the loss of jobs early on as a direct result of her illness. Her re-entry into the workforce was particularly important to her following the separation from her daughter. Her work became highly significant, enabling her to support herself initially and later, her parents, as well as giving her life some focus and purpose. For Pam, too, as highlighted previously, beginning her career as a teacher enabled her to cope with her new role as mum.

Marguerite and Pam's narratives illustrated how their lives, including their working lives, were disrupted over time because of episodes of illness. Whiteford (2000) described occupational disruption as "a state that is usually temporary or transient rather than prolonged…it occurs when a person's normal pattern of occupational engagement is disrupted due to significant life events such as becoming ill" (p. 201). Although the concept of occupational disruption is concerned with occupational engagement in its totality, it is particularly useful in relation to employment. Both Marguerite and Pam experienced significant periods of time away from their workplace due to their mental illness. In Marguerite's case she had blocks of six to eight weeks off work at any one time, whereas Pat experienced longer time periods of up to a year away from her job. On their return to work, they experienced difficulties such as lack of support or understanding from co-workers. Indeed, Marguerite on one occasion was relocated to another department on her return to the workplace. Nevertheless, both women showed determination to return to their workplace and had social networks and families that supported their decisions.

That said, both women acknowledged their workplace environments did tolerate their absences. Jamison (1996) stated that when she was depressed, she was able to delegate her work and rely on others to cover her duties and importantly, offer her support. The situation she described is far removed from the common experience and her high level status within the organisation facilitated this favourable arrangement. Work was very important to Marguerite and Pam and the need to engage in their jobs was vital for many reasons, including financial independence, relationships, social contacts and status.

Sarah, on the other hand, experienced what Whiteford (2000) has described as occupational dysfunction. This can arise as "a by-product of non resolved occupational disruption as a result of specific occupational performance deficits" (p. 201). Sarah's life and her work as a missionary were severely curtailed as a result of her diagnosis of epilepsy and her resultant confinement to a wheelchair. During this time, she was unable to work or engage in her past range of occupations. Her environment for the majority of this time was limited to her home and garden. She experienced a much more severe dislocation from her work and her life than the other women.

Although work was important and teaching especially so for Pam, ultimately, (following several psychiatric admissions) teaching proved to be too stressful and she left the profession. With regards to the place of paid work in these women's lives, it appears there was a fine balance to be struck. Walters (1993) found that even the least satisfying job offered some protection from depression. However, the most satisfying and rewarding job can increase stress levels and lead to anxiety. When work meets the person's capacities, it is valued, but as mental illness can reduce abilities and confidence in skills, continuing in work without necessary support systems can become a great source of stress for individuals.

Within this study, as paid work opportunities lessened, with increasing age or deteriorating health, several of the participants became involved in a range of other occupations such as church activities or voluntary work. These provided similar benefits to those of paid employment. On the other hand, following her retirement, Marguerite re-entered the world of work on a part-time basis in a clerical post. Her reasons for taking up such a post echo the benefits of work highlighted previously.

Taking care of others

Another life role that proved meaningful for the women was that of caring for others. Doyal (1995) found that "many women actively choose to look after dependent relatives and experience great satisfaction in doing so" (p. 41). In this study, this was best illustrated by Marguerite's narrative, as she was the main carer for her parents. She had lived with her parents since her early twenties and as a result she may have felt that this was a natural role for her to undertake. Her father died from cancer and she cared for her mother at home following her mother's stroke. Indeed her willingness to care for her mother enabled her to stay at home for a longer period of time. For Marguerite, this was something that she chose to do and it was a role that she personally found fulfilling. This taking care of others took other forms, too, such as the running of support groups by Sarah and Pat.

In summary, this section has shown that being occupied and productive, whether as a mother, employee, carer or volunteer, was extremely significant and meaningful for the participants. They gained in a variety of ways; all identified the positives of their involvement, although at times they had to struggle to overcome barriers or difficulties.

MAPPING THE ILLNESS JOURNEYS

This section explores the participants' mental illness experiences, affirming and expanding the existing literature. A significant finding that emerged from the study was that these women experienced difficulty with regards to the naming and framing of their diagnosis. All the participants highlighted that not knowing or understanding their diagnosis had consequences on their ability to make sense of what was happening to them or what could have happened to them. Howe (1998) emphasised that:

> It would seem reasonable to suppose that most of us want to be told what is the matter with us if we are not well, particularly if knowing the truth gives us a better chance of protecting ourselves from any further damage from our illness (p. 15).

Only, Ritsher et al. (1997) of the three studies that focused on women with enduring mental illness considered their participants' views of their diagnosis. Of the 107 women studied, 67% were aware of their diagnosis but one third did not believe that they had a mental illness. However, this study did not explore how the participants came to know or understand their diagnosis.

There may be several reasons for this apparent lack of clarity regarding the giving of diagnosis. It may be that each participant's recall was problematic. However, the occurrence of the phenomenon across all of the women's narratives suggests that other factors were at play. The process of assessment and diagnosis is important as it is concerned with gaining access to services and treatment within services. Orme (2001) proposed that assessment tools, contexts and practices may adversely influence the assessment process. These factors, when coupled with the notion of gender bias and the reliability issues associated with diagnostic criteria, may shed light on why the participants here found receiving a diagnosis and getting it confirmed so problematic (Busfield, 1996). The length of time it can take to be sure that a diagnosis is correct, may also increase the reluctance of professionals to 'label' their patients.

Howe (1998) suggests that the non-giving or withholding of a diagnosis is inappropriate and instead of lessening fear, it increases anxiety and stigma. Her work with consumers of UK mental health services offers confirmation that there are "benefits in knowing and understanding your diagnosis" (p. 22). These consumers proposed that patients should have a legal right to their diagnosis: that this was in fact a civil rights issue. Furthermore, they suggested that the diagnosis and the implications of a diagnosis should be an issue for the multi-disciplinary team, not only the doctor.

Treatment

Following on from the issues of diagnosis, these women raised concerns about the treatments that they had received. These treatments included ECT and a range of medications. Women are more likely to receive ECT (Frank, 1990). Amongst my cohort, Marguerite and Pam were treated by ECT and both found it beneficial. However, both identified loss of memory following their courses of treatment. Nonetheless, ECT continues to be used widely within psychiatry, although the way in which it works is still uncertain (Foster, 1995). Recently, Palazidou (2000) stressed that concerns about memory loss or cognitive impairment were unsubstantiated.

With regards to medication, Helen believed that the medication she was given by her GP was a panacea, as the GP could not resolve her social problems. Sarah, too, believed she had been prescribed medication as a way of silencing her. Similar results have been found previously (Foster, 1995). Orme (2001) cites the work of Miles (1988) who described that "women felt that GPs lacked sympathy and that prescriptions were given to get rid of them" (p. 136). The participants also raised the issue of the overuse and continued use of medication. Harlene & Bernhard (1994) support this aspect; they found that the overprescribing of drugs was an aspect of the literature concerning women with severe mental illness.

Another issue raised by all the participants was the side effects of their treatments. These women described a range of side effects, including thirst, tiredness, and weight gain. Such side effects, they reported, adversely affected their ability to function. For example, Pam was unable to drive for several months as a result of her medication. Owen et al. (1998) found similar results.

The issue of medication and related side-effects has recently been reported in "A Question of Choice" (2000). This was the largest ever study conducted in the UK of people's views on medicine and other interventions for mental illness. Surprisingly, little work has been conducted with mental health consumers of medication to ascertain their views. The "Question of Choice" study used both questionnaires and focus groups with users and carers to discover what people thought were the most relevant interventions. The work confirmed that the "side effects of medicines used in the treatment of mental illness are widely experienced and mostly not tolerable"(p. 6). The study's main recommendation was that people should be offered choices. These choices should include being informed about what medications are available, and what the likely effects are, both wanted and unwanted. (Hogman and Sandamas, 2000). Such choices, they proposed, will lead to increase positive outcomes for users.

These findings, in conjunction with the women's experiences of diagnosis and medication, indicate the importance of being informed and of being offered choices at all stages of the treatment process from assessment and diagnosis to treatment and evaluation.

Suicide

Another important facet to emerge was the prevalence and prominence of suicidal ideation amongst this group of women. Suicide can be considered as a subcategory of deliberate self-harm. Isacsson & Rich (2001) defined deliberate self-harm "as any act by an individual with the intent of harming himself or herself physically which may result in some harm" (p. 213). The study participants expressed suicidal thinking with some reporting suicide attempts. Of the three participants who had attempted suicide, drug overdose was the preferred method. It is known that rates for attempted suicide and deliberate self harm are greater amongst women, although men have higher completed rates of suicide (Moscicki, 1994). Holmshaw and Hillier (2000) identified that suicide in women was related to " poverty, deprivation, psychological distress and a history of physical and sexual abuse" (p. 55). Importantly, these factors correspond to the formative experiences that the women in this study identified previously.

A Finnish study by Heikkinen et al. (1995) explored the social factors related to suicide. They found that in women, suicide increased with age, particularly if they were living alone or were widowed. Widowhood was especially common among female suicides aged between 60-69, and it is possible that suicide is associated with the bereavement experienced by these women. Helen could be included within this category even though she became a widow in her seventies. She clearly expressed suicidal thoughts, following her husband's death. As the women age, suicide may become a real risk for this group.

That said, a recent editorial in the British Medical Journal by Davies, Naik & Lee (2001) highlighted that although depressive disorders are common, suicide is rare. They highlighted that "every week 10% of the UK population aged 16-65 report significant depressive symptoms and one in 10 of these admits to suicidal thinking. But fewer than two people in a million will kill themselves" (p. 1500). Two other factors emerged as important to the women: stigma and discrimination

Stigma and discrimination

Stigma refers "to a sign or mark that discredits a person in the eyes of others" (Jones, 1998, p. 100). Stigma can be seen or unseen, and it considers difference that is "evidence exists of an attribute that makes an individual both different from and less desirable than others in his/her category"(Saylor, 1990, p. 66). This difference can lead to an individual being perceived as less valid in their society. Importantly, this devaluing can be so powerful that it negates an individual's other positive attributes.

The women in my study experienced stigma and discrimination in a variety of ways. They identified a lack of understanding both of what had happened to them specifically and mental illness generally from their families, friends and the public. This led to them feeling misunderstood and marginalised within their homes and communities. Deponte (2000) reported that lack of awareness and understanding about mental health issues extends beyond families and friends, to include GPs, health professionals, employers and colleagues. The label of mental illness has always been associated, and continues to be associated, with stigma.

Goffman's (1963) seminal work explored stigma and the impact of labelling on the interactions of those who were stigmatised. A study by Piner and Kahle (1984) built on this work. They concurred that it was that label of mental illness that was powerful. The label negatively affected participants in their study, even if no unusual behaviours were evident. Furthermore, Link, Mirotznik, Cullen (1991) explored three strategies aimed at reducing the labelling effects of stigma: keeping mental illness a secret, avoiding situations and educating others. They established that none of these strategies were effective in reducing negative labelling. They concluded that the problem lay "at the sociocultural level – and is not effectively addressed by individual coping" (p. 316).

An editorial in the British Medical Journal highlighted the Royal College of Psychiatrists' five-year campaign to reduce the stigmatisation experienced by people with mental health problems (Britten, 1998). Britten argued that for public perceptions of mental illness to be addressed, psychiatrists should begin by looking at their own practice. She stressed, "the need for psychiatrists to do more than make a diagnosis and provide an appropriate label. People with mental illness need help in making sense of the experiences" (p. 964). It could be argued that reluctance to give a diagnosis is related to the negative connotations and stigma related to mental illness. If practitioners are unwilling to name and frame illness appropriately, this can only add to the stigmatisation and therefore increase fear of mental illness. The need for better education for all has been recognised. The National Service Framework for Mental Health (1999) Standard One recommends that:

> Health and social services should promote mental health for all working with individuals and communities; combat discrimination against individuals and groups with mental health problems and promote social inclusion (p. 14).

In order to implement this standard, the Department of Health established a Mental Health Promotion Project. Part of this project was "Mindout for mental health", a national campaign to address stigma and discrimination. This aimed to reduce the stigma and discrimination attached to mental illness by educating young people, employers and the media about the realities of living with mental health problems. This campaign is not widely known about. Winchester (2001) suggested that when mental illness "becomes something you can chat about over dinner with friends the investment will have paid off"(p. 9). The lack of awareness of the campaign may raise questions regarding the level of commitment to education on mental health issues. It may also reflect the fact that the stigma associated with mental illness is still powerful.

In addition to stigma, the women also experienced discrimination. Their narratives provided examples of a range of discriminatory practices, particularly in the work place, and in their dealings with other health services or institutions. Both Helen and Pat removed their psychiatric notes from their general medical files to avoid any possible future discrimination in physical hospitals. Stigma and discrimination led to dilemmas for the women: for example, to tell or not to tell about their mental illness particularly in relation to work.

Overall, the study participants believed that the mental illness label had in many different ways adversely influenced their lives and their relationships, limiting their choices and opportunities. Their experiences left them feeling marginalised and at times on the verge of their worlds.

VICTIMS AND AGENTS

The women's narratives demonstrated that they had been both passive and proactive travellers during their life journey. Bateson (1990) stressed that the "forging of an identity is never finished (p. 219). The continued forging of the women's identities were evidenced throughout their unique narratives. Bruner (1994) defined identity as "a complex mental edifice that one constructs by the use of mental processes" (p. 41). Each woman's identity, her sense of self, was evident as she gained meaning and understanding of her experiences. Polkinghorne (1991) stressed that "a person's life unfolds over time and is expressed through a series of changing thoughts, feelings and actions and [therefore] the self is best conceptualised as a process" (p. 299). As a result, the individual has many stories that contribute to the construction of the overall self. McAdams (1993) argues that as a result of people's attempts to do things in their world they develop a life tone that prevails throughout their life stories. This life tone becomes central to their live stories, the life tone either exudes optimism and hope (agentic) or mistrust and resignation (victimisation).

Polkinghorne (1996) further discussed the notion of victimic plot and agentic plot. He defined victimic plots as those where "the protagonist is seen as passive and receptive …their lives are out of control", whereas in agentic plots "the protagonist is persistent and shows purpose and commitment" (p. 301). He stressed that physical and mental illness can lead to deterioration of the person's previous agentic life and this can result in its replacement by a "victimic [plot] of submissive acceptance" (Polkinghorne, 1996, p. 302).

At various stages in their life-stories, the women's identities could be perceived as being either victimic or agentic. Examples of their transition from one to the other, was indicated by a change in their purpose, actions and behaviour. There are several episodes within each of the women's lives that seem to be adhere to a 'victimic plot'. There are individual experiences as well as collective experiences. Sarah's victimic plot is perhaps best illustrated by the 7 years she spent being cared for by others and the her life immediately following her withdrawal from her epilepsy medication. Prior to her withdrawal from the medication, her life was very much controlled by others, who were responsible for her every need. Following withdrawal, she was placed in a position of being unsupported. She had no access to either practical or financial assistance and was in no position to take control of her life. She was vulnerable, unprotected and abandoned by services to her own devices. It is a time that Sarah recalled as terrifying. However, Sarah eventually was able to take back the reins of her life and disengage from the victimic story, with support from friends, she moved on to a more agentic life.

Collective experiences of victimic plots are evidenced in the care these women received within the mental health services. The women mostly expressed feelings of powerlessness; they felt they had few or no choices to influence their care. They felt disenfranchised and that they had little involvement in their treatment process. The women perceived that staff attitudes towards them impacted on them negatively. At such times, they clearly perceived themselves to be victims within the system of care. These results find parallels elsewhere (Repper et al., 1998). Their study highlighted that staff attitudes adversely influenced the women's care. Such staff attitudes, instead of helping people to become agentic, reinforced the victimic role. For the most part, the picture these women painted was of being on the edge of the treatment process, rather than being at its centre.

However, within each of the individual's narratives there are examples of each trying to re-establish their own agency in small and varied ways. Agentic plots, or personal agency, are considered to have eight elements: "self determination, self legislation, meaningfulness, purposefulness, responsibility, confidence, active striving and planfulness (Polkinghorne, 1996, p. 301). Sarah's decision to address and to resolve her experiences of sexual abuse demonstrated a move from a victimic plot to an agentic plot. She actively decided to address her past experiences; she was purposeful, determined and took on responsibility for her actions. This was not an easy journey but it facilitated her move to being more confident and it enabled her to develop and plan ways to help others with similar experiences. Other examples of movement to more agentic plots were Pat and Helen's actions to remove their psychiatric histories from their general medical records, and Pat and Pam's stances with regard to the care they received.

Taking action or speaking out for others and themselves to improve mental health services reflected the transition to more agentic plots. These actions were steps in each of their individual lives to deconstruct their past victim stories and construct their future agentic life stories. Most of the women utilised this concept of agency in describing where they were in their lives at the time of the second interview. This was captured to some extent in the theme "Present Life". The women highlighted concepts that correspond to agency, including acceptance, self-responsibility, self-management, personal planning, purpose and direction. Only Helen's narrative seemed to be dominated by the victimic plot. She appeared to have become passive in her later life and accepting of her life circumstances. Her continued, physical ill health had perhaps contributed to her perceived status as a victim. Significantly, she saw no future for herself other than death. Having an envisioned future was an important component of the women's narratives.

POSSIBLE FUTURES

Agentic plots relate to possible envisioned futures. Bruner (1990) stated that "agentivity - is action directed towards goals controlled by agents" (p. 77). Having goals alludes to future-orientated life. The participants here identified such goals in their narratives; some of these were small, for example having interests or significant goals, employment opportunities, or hopes for a future positive relationship. Again parallels can be drawn with the findings of Repper et al. (1998), who found similar aspirations amongst their participants. However, there is a cautionary note: they also found that staff attitudes discouraged their aspirations where staff perceived the women as unable to cope or achieve. They concluded, "It seems likely that it may be difficult to hang on to your dreams in the face of negativity and pessimism on the part of those purporting to be experts"(p. 511). The need for all staff to acknowledge clients' personal goals and their future hopes is part of their role. They need to reinforce small improvements and link these to a possible different future, thereby facilitating the clients' continued agency.

Having hope is therefore paramount. White and Epstein (1990) stated that "the existence of these intentions and hopes can...inform persons that things might be different in the future" (p. 61). Wilcock (1998b) proposed that the concepts of doing, being and becoming are central to humans. The women identified that doing was important to them and that working towards possible futures highlighted the significance of being and becoming. They were for the most part happier with their lives now than in the past, but they were also working to very different futures. Several factors impacted on their ability to meet their future goals. These positive frameworks will now be explored.

SUPPORTIVE FRAMEWORKS

This study highlighted the importance to the participants of a range of supportive frameworks. These included faith, friendships and social networks. Three women were actively engaged in church activities and organisations, and their spirituality was meaningful to them, offering them fellowship and faith.

The significance of friends and the maintenance of friendships were also highlighted. For some of the women, they had maintained friendships with people from their childhood. Friends were predominantly other women although some men were counted as friends. This finding relates directly to Ritsher et al. (1997) who found that women maintained mutual long-standing relationships. Additionally, in the present study, all the women had developed friendships with people that they had met as a result of their mental health experiences.

Wright (2001) surveyed friendship and mental health, with results that correspond to the findings here. Wright's survey highlighted that "80% of the respondents reported that their friends provided them emotional support, while 46% identified that friends provided practical support" (p. 40). However, some identified that they had lost friends as a result of their mental health problems: 1in 10 of the respondents lost all or most of their friends due to their mental illness (Wright, 2001).

In addition to the benefits of identified friendships, the women also recognised that they contributed to informal networks through which they received support and also gave reassurance to others. The significance of informal networks or social networks in protecting individuals with mental health problems has been acknowledged (Turner and Marino, 1994, Langford et al., 1997). However, there is also some work that suggests that social networks can become the location for stressful experiences and that these may increase the risk of psychiatric disorder. Avison (1996) reminds us that social networks can be considered therefore as "two-edged swords" (p. 151).

However, for the women here, for the most part the informal networks had positive outcomes for them and others. To sum up, relationships of different types emerged as being important to the women in maintaining their mental health by providing support and, importantly inclusion in their communities.

Summary

This section has discussed the life worlds of the women, drawing on literature to support and complement their experiences. It has been demonstrated that aspects of the women's narratives have been found to some degree in earlier literature. Their gender, their socialisation as girls and women and their status within society have no doubt affected their experiences across a period of many years. Their lives span the period from 1926 to the present day.

The women's journeys with mental illness have many similarities although they had contact with health services at different times and in a range of different locations. The shared aspect of their narrative is that of being excluded from their own health care, of having little control or influence both as patients and as women in wider society. They have survived in spite of systems that should have theoretically assisted and supported them by drawing on their personal resources, relationships and social networks.

Section Two: Common ground – A meeting of minds

This section considers the aspects of commonality that were evident in the womens' and the therapists' narratives. Three areas were common to both groups. These were the need for safe environments; feelings of powerlessness; and the importance of being heard.

THE NEED FOR SAFE ENVIRONMENTS

All the participants identified that a place of safety where they felt secure was a necessity for the women to recover and for the therapists to work. Therapists identified that women were vulnerable and at times at risk, especially in the acute phases of their illness. Both groups of women felt that specific environments, such as acute admission units and community settings, did not always provide contexts in which either the women or therapists felt safe or secure. This finding concurs with the earlier work of Repper et al. (1998) which found that women patients felt vulnerable and isolated when in contact with psychiatric services. However, women staff were also at risk in the workplace. One of the most serious incidents to date was the murder of occupational therapist Georgina Robinson in an acute admission unit.

The Inquiry into her death recommended that risk assessment and risk management were the responsibilities of all involved in the patient's care and concluded that "assessment of risk needs to be a continuing process"(Bloom Cooper et al., 1995, p. 177). As a consequence, risk and the assessment of risk have become increasingly important in mental health environments and in the delivery of mental health services in the community. The identification of risk and its communication to all those involved, whether in hospital or community settings, is paramount for everyone's safety.

The need for the creation of safe environments has already been highlighted by Mind (1992). They advocated that service providers should create contexts where women will be as safe as possible from "abuse, sexual and racial harassment" (p. 26). In addition, they proposed that policies on harassment and abuse require to be displayed so that all users and staff were aware of them. These policies also need to make the complaint procedures explicit. Furthermore, this report highlighted the need for women to be given a choice of accessing women-only wards and the right to have a woman key worker in charge of their care. The need for women-only units was an issue of contention amongst the therapists in this study. Some were in favour of such units whilst others disagreed. This is in contrast to the Framework for Mental Health Services in Scotland (1997), which advocated the development of services that addressed the special needs of women.

Read and Wallcraft (1995) expanded on Mind's (1992) recommendations. They produced guidelines on equal opportunities and mental health for both service users and staff. Furthermore, they also advocated women's involvement in the planning and monitoring of mental health services.

The monitoring and the standard of service delivery of non-statutory services emerged as an important aspect from the women's narratives. Two of the participants, Sarah and Helen, discussed their vulnerability when using such services, for example, some counselling services. Their involvement with these agencies had left them feeling exposed, unsafe and exploited.

Personal safety, risk assessment practices and complaints procedures require to be co-ordinated and communicated effectively to all (Blank, 2001a). An approach that is explicit and embedded in practice can work to ensure a greater level of safety for all clients and staff. The need for non-statutory services to be regulated was also stressed as being important. Being safe and being in control were aspects that all the women identified as essential. Despite this, both groups experienced a lack of power.

POWERLESSNESS

The second aspect that was common across both groups was the issue of power or lack of power, although it was encountered differently by each group. The women experienced powerlessness as having little control over their lives in their relations with mental health services. This finding of reduced power concurs with the work of Owen et al. (1998), which stressed that women felt powerless in their psychiatry care.

On the other hand, for the therapists powerlessness involved having little influence to change the system in which they worked. Griffin (2001) highlighted that traditionally occupational therapists have been accepting and non-assertive and that this has detracted from their ability to change their environments. She found occupational therapists' lack of power to be multi-factorial and related to their occupational status, the medical profession's dominance and the organisational perspective of power. Occupational therapy as a profession continues to be predominantly female and its status as a profession within psychiatry is viewed less positively than medicine, which continues to be male-dominated. The women whether staff or clients, did appear to be diminished by the relationships and the systems in which they either received care or worked. They had little or no power in the wider organisation and were often on the periphery of decision-making, both in their treatment and in the wider organisation.

BEING HEARD

The final aspect of shared experience was the importance of being heard. The women had previously identified that they often felt that they were unheard in their care process. They identified that being heard encompassed many aspects, including being accepted and recognised as the experts in their own lives. A recent study by the Mental Health Foundation (Faulkner & Layzell, 2000) which drew on the experiences of 71 mental health users, found that most users valued the opportunity to discuss and make sense of their symptoms and illness.

The therapists, for their part, concurred that hearing their clients was important. However, on occasions they acknowledged that their ability to hear their clients was negatively influenced by a range of factors, including time and context. Kmietowicz (2000) urged mental health professionals to listen to patients to help them design services to meet their clients' needs. However, the women's experience of not being heard was to a certain degree reflected in the therapists' experience of not being heard within the larger organisation. These shared aspects come together to highlight the subordinate place of women, whether therapist or client, within the mental health organisation. There is little difference in their experiences although the consequences may be very different. For both sets of women, being safe, being heard and having some sense of either personal or professional power was limited and constrained by others. For both groups their ability to be their own agents was hindered by people, procedures and systems.

Section Three: Practising in psychiatry - Therapists' thoughts

This section discusses the findings that arose from the focus groups with occupational therapists. The perspectives and beliefs of the therapists working with women with enduring mental illness are considered under three headings: ways of knowing and doing; treatment issues and women; and finally, pressures on practice.

WAYS OF KNOWING AND DOING

This section explored the beliefs that underpin the therapists' practice. It considers that what they know influenced how the occupational therapists' practised in mental health contexts. This "knowing" is considered first, as it provided the paradigm that influenced the therapists' practice on a daily basis, whether working with women or men.

Occupation as Treatment

This group of therapists believed they offered a unique approach to treatment. They identified that occupation was beneficial to clients in two main ways. The first related to the subjective experience of occupation for the individual for example, increased self-esteem, sense of achievement and sense of purpose. The second aspect related to clients' ability to process issues through engagement in occupation. The therapists cited facilitating clients' understanding, working things through and reducing negative thoughts. Moll and Cook (1997) reported similar positive aspects of occupation in their work. They also found that therapists had diverse beliefs with respect to occupation that included the benefits of occupation for the client and the benefits in facilitating the process of therapy. The use of occupation as positive treatment was a clear message given by the therapists in the present study.

Occupational therapists as different

Another clear message from the therapists was their belief that occupational therapy differed from the other mental health professions. This finding is in agreement with the research of Fowler-Davis and Bannigan (2000). Their study associated the therapists' notion of being different to a lack of recognition by other mental health staff. Similar findings were reported by Craik, Austin & Schell (1999), in their survey of occupational therapy managers working in mental health. They, too, found that the unique and different contribution of occupational therapy was not recognised by other professionals. Hagedorn (1995) gives a more positive perspective: "We have gained ground there is more understanding of our role, but that understanding is restricted to limited circles of influence" (p. 324). The place of occupational therapy and its recognition could be considered as being on the verge of mainstream, which may or may not be an ideal place to be.

The need to increase understanding of occupational therapy and therefore recognition and perhaps influence could to some extent be addressed by research. Fowler-Davis and Bannigan (2000) suggest that research can develop the profession's knowledge base but that such research must be grounded in clients' needs. They warn, "research is not a conduit for raising the status of individual professionals within multidisciplinary teams" (p. 103). Therapists need to demonstrate their efficacy and their uniqueness by addressing clients' needs through effective interventions and client-focused research. If occupational therapy has something unique to offer clients, then the profession has to come to terms with being different and celebrating the differences. This difference may place them in a better position to work at a community level with diverse groups of people in settings outside the medical model or beyond the institution.

Client-centred practice

Another finding that was strongly emphasised by my participants was their acknowledgement of the individualisation of occupational therapy; their focus was on intervention that met the individual's unique needs. This belief was not surprising as the concept of individualised care or client-centred practice is embedded in College of Occupational Therapists (The College), Code of Ethics and Professional Conduct for Occupational Therapists (2000). This states, "The College is strongly committed to client-centred practice and the involvement of the client as a partner in all stages of the therapeutic process (p. 612). However, client-centred practice is not defined in the document. Sumsion (2000) defined the concept of client-centred practice within the UK context as:

> A partnership between the client and the therapist that empowers the client to engage in functional performance and fulfil his or her occupational roles in a variety of environments. The client participates actively in negotiating goals which are given priority and are at the centre of assessment, intervention and evaluation. Throughout the process the therapist listens to and respects the client's values, adapts the interventions to meet the client's needs and enables the client to make informed decisions (p. 308).

However, Corring and Cook (1999) highlighted that although occupational therapy has valued client-centred practice, little work has addressed the client's perspective of client-centred practice. Recent work by Blank (2001a) a UK therapist, has attempted to address the user's view of client-centred practice. She interviewed seven clients involved with a community mental health team. The participants identified several inequalities that were barriers to being partners in treatment. These included the degree of sharing within the relationship, with clients sharing personal and sensitive information while this level of disclosure was not reciprocated by their therapists. In addition, clients identified that their economic status was lower than that of therapists. Importantly, they further recognised that the overuse of professional language led to them feeling inferior. These aspects highlight the power of the professional and indicate that a practice and power shift is necessary if clients are truly to become active partners in their healthcare.

Nonetheless, the College of Occupational Therapy has been at the forefront, amongst health professionals, to make client-centred practice the core of the profession's Code of Conduct for several years. The client-centred stance has been taken up by the Government and is reflected in a range of policy documents (The NHS Plan, 1999)

What is important is that therapists understand the significance of the Code of Ethics and Professional Conduct and work to meet the standards in the code. As client-centred practice is explicit in occupational therapy's guiding principles, it is necessary for occupational therapists to fully understand the concept and consider the issues of implementation that may arise in practice. Client-centred practice offers opportunities and the possibility of conflict for therapists. For example, within this study some therapists identified strongly their belief in client-centred practice, whilst others argued that with their clients therapists should be looking for similarities not differences. Therefore, there existed a contradiction, a practice dilemma. Finlay (2001) too, identified dilemmas with therapists who were struggling to be both holistic and client-centred.

An aspect of client-centred practice for the therapists is the requirement to understand the client's life and their needs. This is essential for the client to be the primary decision-maker in directing his or her own treatment and to maintain personal agency. The therapists in this study valued seeking out and hearing their clients' past histories and their life situations, to discover what was important to them. Corring and Cook (1999) used focus groups with clients to discuss the meaning of a client-centred approach to practice. The crucial message from the participants was that if health providers wished to practise in a client-centred way they needed to "value and appreciate the life experience of their clients and recognise their expert knowledge of themselves" (p. 76). Their overall experience of health professionals was that they had a superficial understanding of their life history and their current situation. The focus on the individual aimed to facilitate the client to take a lead role in their therapy, working collaboratively with the therapists.

These aspects knowing the client, partnership and choice were explicitly acknowledged by the therapists as key elements of client-centre practice. Law, Baptiste and Mills (1995) identified the concepts underpinning client-centred practice as: autonomy/choice, partnership, contextual congruence, responsibility, enablement, accessibility and the respect of diversity. What is interesting is that the other elements identified above did not feature in the therapists' discussion of their practice. Perhaps these aspects are less understood or more difficult to implement in practice.

At times, the therapists contradicted their own valued beliefs. This dissonance between what some of the therapists believed and did could be potentially problematic for them in their practice. This was highlighted in relation to the therapists' beliefs with regard to working with clients who self-harm. Several therapists had difficulty understanding this type of behaviour. Client-centred practice, however, requires an acceptance of others.

To some degree, the client-centred perspective as identified by the participants may be constraining occupational therapy's ability to influence and contribute more dynamically to shaping service developments. Their focus on the client's life situation, autonomy/choice and partnership is to be applauded. However, they have not highlighted the other aspects of client-centred practice such as contextual congruence, accessibility and respect of diversity. Perhaps further consideration of these aspects may increase occupational therapy's influence. Cowan (1996) goes further advocating for a move from client-centred practice to women-centred services that place women's needs at the centre of treatment. However, it is acknowledged that such a move and its benefits would not occur unless it was specifically fostered and nurtured (Subotsky, 1991). Furthermore, the adoption of a women-centred philosophy without full understanding of the implications of such an approach would not necessarily improve care for women.

It is clear that a focus on meeting the individual's needs is enshrined in occupational therapy. Nonetheless, there could be an inherent problem with this way of working. The practice described by the therapists focused on promoting change for a specific client, but this individual orientation has two drawbacks. First, it locates problems with the individual and places the onus on the individual to change; as a consequence, if there is no change the failure is said to lie with the individual rather than with the therapist or the intervention (Abberley, 1995). This may lead to further individual distress (Perkins, 1992). The second drawback is that it may limit the definition of service needs and therefore service planning for populations of clients. Therapists may become expert in working with a range of individuals but fail to address problems or offer solutions that would impact on wider society. Clients' needs could be addressed through development of both service provision and individual care. By investigating a broader knowledge base, changed ways of thinking could develop alternative working practices that should lead to system changes (Roberts, 2002).

Feminism in a post modernist world may offer the profession a way forward, as it acknowledges diversity, context and temporality (Lyon, 1994). This view is essential for understanding health and sickness as it recognises the individual's interpretation of these concepts. Mitchell (1996) advocated that healthcare professions should revise their knowledge and oppose dominant practices that limit individual's choices. For occupational therapy, that requires the profession to reconsider its beliefs and stop trying to compete with the dominant medical model of psychiatry (Creek, 1997). The profession is in a good position to forge new relationships and to play a distinctive part in health and social care. Furthermore, as the composition of the occupational therapy profession continues to change to include women from different backgrounds, including more working class and black therapists, there will be an increasing need to review our understandings. Shifting practice away from our institutional-based settings has to some extent occurred. However, our thinking still lags behind. To move our thinking forward, consideration of social and cultural theories is necessary if we are to question our theoretical underpinnings and our understanding of women's lives. We need to create local solutions and develop different partnerships that meet women's needs within their own contexts (Weinblat & Avrech-Bar, 2001).

This section has provided an overview of the core beliefs of the occupational therapists namely, occupation and client-centred working and it has considered the influence of these on practice within mental health contexts. These beliefs and the therapists' perspective of occupational therapy as different have been discussed and it is proposed that there are some key issues that require to be addressed further if practice is to move forward.

TREATMENT ISSUES AND WOMEN

The therapists reported that as women they were able to identify with the women with whom they worked with on the whole. It is fundamental that those who are working with women must understand women's experience as women and how these experiences may have affected their development of their illness. It is suggested that only then can effective services be created for women (Newbigging, 1996).

Factors influencing relationships

From the therapists, there was recognition that on occasions their life experiences were very different and that these differences could obstruct working with clients. The therapists explicitly acknowledged age, class, race and, to a lesser extent, gender and sexuality. The discussion will focus on these aspects.

Age was identified as an issue from the perspective of a "young" therapist working with older clients. Some of the therapists identified that their age, (they were for the most part significantly younger than their clients) could be a barrier to their establishing a positive working relationship. They identified that their perceived "limited" life experience could result in their credibility as a professional being called into question. Others, however, recognised that on occasion being younger was of benefit.

Social class and resulting issues were raised by some of the therapists in this study. Class has always been an issue for occupational therapists, although not explicitly addressed. Traditionally, the early pioneers of the profession were women originating from the upper and middle-class who provided assistance to others, often women, less fortunate than themselves. Another class-related factor was acknowledged by the therapists, with some identifying they had very different life experiences from their clients. As a result, difficulties could arise if therapists had little experience of the social conditions in which the majority of their clients lived (Pollard and Walsh, 2000). This can act to distance the therapist from the client and for the client to disregard the treatment offered as being irrelevant.

Race and ethnicity were for the most part superficially discussed during the focus groups, with therapists identifying that women from ethnic minority backgrounds might have different treatment needs. The location of the study may have influenced the nature of this discussion and the therapists' experience of working with clients from different cultures. However, they identified that as a result of a lack of appropriate facilities women from ethnic minority backgrounds were not using the current services.

The therapists identified that gender was not overtly considered in their practice, whether in terms of themselves as women working with women or in relation to their women clients. Some stated that gender was not an issue considered explicitly by them whilst others strongly believed that it was. A further group said they were unaware of gender issues. Clearly, within this small number of therapists contradictions existed. Nahmias and Froelich (1993) report that gender related issues are virtually absent in occupational therapy literature. Indeed, many standard UK textbooks make only a fleeting reference to gender issues (Pollard and Walsh, 2000).

This absence of gender awareness may have occurred for several reasons; gender was implicit in practice, discussion of gender issues may have caused discomfort or alternatively gender was not considered as an important factor. For whatever reasons, with gender issues little included in the profession's literature the lack of debate in the workplace may reflect this situation. The therapists' expressed opinions may relate to underlying beliefs that practice is gender neutral. An alternative explanation could be that the therapists believe the focus for their intervention is tailored to the individual and that gender is implicitly taken into account. Townsend and Brintnell (1997) support this perspective, stating "client-centred practice respects the worth of all persons regardless of gender or other characteristics" (p. 23). They proposed that gender equity that is "fairness in opportunities for men and women" should be of great relevance to occupational therapy.

The therapists did agree that there was a need to raise awareness of gender issues at the personal, professional and organisational levels. The therapists considered however, that the focus should be on similarities and not on seeking difference. This contrasts with their stated belief regarding client-centred practice. However, Faugier (1992) contradicted this stance. She argued that health professionals needed to understand and analyse the nature of gender differences, thereby working to improve the services for all. Her message was supported by a recent document from the Commonwealth Secretariat on Gender and Health (Harding & Sills, 1999). This advocated that:

> All categories of health workers to undergo training in how to analyse issues from a gender perspective and how to consult, plan and implement activities that take account of the different health needs and health experiences of women and men" (p. 2).

This aim to permeate health education with a gender perspective should facilitate the translation of the principles into practice and actions. For occupational therapy, part of this education involves considering gender and its relationship to occupational therapy as a predominantly female profession and the resultant implications and consequences of that when working mostly in the patriarchal world of psychiatry. It is acknowledged that while more women than men work in the national health service, men continue to occupy positions of power (Newbigging, 1996). Sexuality was little considered in relation to women. There was no discussion of lesbianism, although there was some mention of transsexuals and their specific issues. Sexuality, too, may be an invisible issue in working with women (Kingsley & Molineux, 2000).

Women's Roles

The therapists in this study identified that loss of roles was difficult for their women patients. Furthermore, they also identified that the maternal role was the major concern for women. This perspective, it could be argued, placed women in the traditional stereotypical position: women in the home, caring for others as the primary caretakers (Test and Berlin, 1981; McGrath et al., 1990). The therapists here suggested that women clients had difficulties in prioritising their own needs over those of others. Again, it could be argued that if women placed their own needs over their care-taking duties they would be criticised for failing to meet the demands of their primary role. Therefore, women are faced with a dilemma: either choice makes them vulnerable to criticism from health care providers and wider society.

Of interest was the therapists' belief that they further contributed to the women's difficulties by providing intervention in their clients' homes. The home environment, although in the community, may not be the ideal place for receiving treatment when the women is burdened with the normal responsibilities of daily living, children and partners. There is a need to develop contexts that facilitate their treatment, and if necessary they should include flexible patterns of treatment delivery and childcare facilities.

With regard to women, previous work has highlighted that mental health services perhaps have had lower expectations of women and therefore provided fewer opportunities for their needs to be met (Bachrach and Nadelson, 1988; Perkins, 1992). There is work to suggest that clients have been critical of occupational therapy's tendency to offer activities that are stereotypical or reduced to the lowest common denominator (Pollard and Walsh, 2000). Lindsey (1996) highlights her own experience: on attending occupational therapy she was offered cookery or sewing classes. However, she wished to participate in the woodwork group, something few women had done before. She recalled, "To get my one morning a week in woodwork I had to compromise, I agreed to go to sewing classes" (p. 85). She was fortunate to be able to negotiate an occupation that met her interests, although her experience reinforces the previous findings that women may have fewer treatment opportunities and that those offered may be gender specific in a stereotypical way.

Experiencing negativity

An important aspect that arose from the findings was the negative feelings of some of the therapists with regard to certain types of behaviour exhibited by women, such as deliberate self-harm or eating disorders. Arnold and Babiker (1998) highlighted that most professional training provided little or no preparation for working with individuals who self-injure. Therefore, deliberate self-harm poses a problem for health professionals who are generally motivated by a desire to improve health and prevent injury.

LeFevre (1996) offers a vivid account of her experiences of being a recipient of care:

> ...when I came to see you in the surgery with two open wounds that I had inflicted upon myself, you said to me that you had better things to do than sew me up. I could not believe that you could be so hostile, so cruel when you must have known how wretched I was feeling (p. 33).

Such feelings can only compound the helplessness of the individual. Certainly, acts of deliberate self-harm elicit strong reactions from health staff, including discomfort, despair, helplessness, frustration and rage (Johnstone, 1997). These feelings can create a dilemma for the practitioner who is struggling to accommodate the realities of practice with conflicting valued professional beliefs. For some occupational therapists their feelings regarding self-harm runs counter to their professed beliefs in client-centred practice. For individuals who self-harm, this is their choice for whatever reason. Therapists need to work to support individuals who self-harm. If they are unable to do this they should be supported to declare their position, inform the client and organise for treatment to be delivered by another occupational therapist. This situation is not covered explicitly within the Code of Ethics but could be considered under Section Four 4.2:

> The College considers it unethical for occupational therapists to indulge in relationships which may impair their professional judgement and objectivity and/or may give rise to advantageous/disadvantageous treatment of the client. (p. 615)

If there are no mechanisms for the practitioner's emotions to be addressed safely, such as monitoring, support or supervision, the practitioner may develop strategies that may ultimately affect their relationship with the client and impede their treatment. The practitioner's strategies may include avoidance, denial, condemning the client, simplistic explanations of self-harm, and taking an authoritative stance. As a result, staff may distance themselves from such patients rationalising that the patient is manipulative, attention-seeking or cannot be helped.

This section has addressed the issues that the therapists highlighted in working with women. What emerged was practice that was infused with contradictions for the practitioners. The therapists identified a range of issues that impacted on their work, including age, race, gender and class. Age, race and class seemed to be discussed easily. However, discussion around gender seemed to create more discomfort and raise more issues for the therapists. Prior to these focus groups, it seemed some of the therapists had given little thought to gender. Therapists were willing to say that further discussion, debate and education regarding women and gender was warranted.

They discussed women's roles. For the most part these were seen to involve caring for others, and therefore treatment decisions were taken to help assist this role function. Most treatment options were focused on community living skills or activities of daily living. There was little discussion about work or vocational rehabilitation. The therapists offered a traditional treatment approach. This of course may have been what their clients identified as being most useful. However, awareness of alternative ways of working was not raised.

The final section highlighted dilemmas that therapists experienced in relation to clients who self-harm. This aspect of work requires much further study. What is clear is that therapists have found themselves holding contradictory positions: being client-centred but having difficulty in accepting aspects of their client's life-style. Self-harm was the issue identified here but it could be other aspects that need greater professional attention.

PRESSURES ON PRACTICE

This final section considers the pressures and the barriers that exist for occupational therapists in the provision of their services. The environment, including the organisation, was identified as a major influence. It is interesting to note that amongst the participants there was little recognition of psychological pressures such as stress and burnout. These were not raised during the focus groups. They, did, however identify frustration with their contribution not being recognised by other mental health staff. Similarly, some raised aspects of their individual practice that caused concern and could lead to increased stress in their work. Finally, the participants highlighted the need for continuing professional development.

Environmental concerns

The therapists stated that the environment was important for enhancing or restricting occupational therapy practice. Within occupational therapy literature, the environment has been considered as encompassing cultural, economic, legal, physical, political and social environments (Sumsion, 1999). Furthermore, the environment has been considered at length in occupational therapy literature particularly, the physical environment (Law, 1991; McKay, 1996; Townsend 1996; Sumsion, 1999). The importance of the environment to clients is well considered, indeed, Kielhofner (1997) discussed "the environment as a critical factor in human performance (p. 60). Recently, what has begun to be considered are the ways in which the environment may limit the occupational therapist's capacity to meet clients' needs. As French (2001) stated, the "organisational environment is a legitimate, but neglected target for occupational therapy" (p. 176).

Townsend (1996) further emphasised the importance of the environment on occupational therapy. She proposed a theoretical representation of how the mental health context shaped everyday occupational therapy practice. She identified that for the therapists their primary concern of enabling empowerment through occupation became subordinated in the context of the organisation, which incorporated the medical and psychological professions, management and funding. She argued that the organisation silenced occupational therapy at many levels, advocating for changes that "not only empowered our clients but ourselves" (p. 193).

The significance of the environment and its relationship to client-centred practice has been considered previously. Occupational therapy as a profession must somehow address the dilemma of working on the edge by addressing the wider environment and its potential to limit or offer opportunities to occupational therapy and therefore to clients. Alternatively, the profession could utilise its position on the edge to develop relationships and partnerships beyond the traditional boundaries of psychiatry.

For the participants in this study, physical environments, the wards, the corridors and day hospitals were identified as being "lousy". They were of poor design and the decorative order was largely shoddy. These environs did not stop therapy progressing. However, they did contribute to the perceived value or otherwise of the client, the staff and the work they undertook.

The therapists also identified that the economic environment created barriers to practice and these incorporated aspects such as a lack of resources, including staff and finance. These culminated in a loss of clinical time and all impacted on care negatively. Away from the institutional settings, the wider community or the social environment included factors such as transport availability and transport costs, which also curtailed clients' capacities to make the most of treatment opportunities.

Evaluation and review

Important aspects raised were evaluation of an individual's care and review of the service. These can be considered as an aspect of the environment. These were internal processes aimed to monitor and evaluate changes. However, the therapists perceived that at the organisational level there was no coherent monitoring and review structure. They acknowledged that service users and staff should be actively involved in any such evaluations and in the implementation of service changes.

Nurturing development

The participants highlighted their need for continued professional development at a range of levels, but they emphasised that time for such activities was restricted. At an individual level, practical support and supervision are already present. However, these could be used more to engage therapists in thinking about such aspects as women and mental health. A second level of development was also called for in the shape of in-service courses and education. The participants also highlighted post-graduate education opportunities.

The need for changes to the undergraduate curriculum content was highlighted. The aim was to enable students to be more aware of mental health issues and the wider socio-cultural factors that influence their work.

The pressures on practice described here have been highlighted elsewhere. The prominent finding here was the influence of the environment, including the organisation's impact on the therapists' practice and the ability of the therapist to contribute and to make changes to the environment that would benefit both the clients and the profession.

Overall, this section has highlighted the pressures that impact on therapists within their work environment. Within the study, the environment has emerged as crucial to both fostering and limiting the therapists and their practice. The need for continued review and strategies that facilitate services users' views were identified. The need for continuing professional development across a range of subjects was also considered.

Conclusion

To conclude, this chapter has presented new insights into and understandings of, women's lives and therapists' practice. What has emerged are findings that portray life and practice as complex, messy and contradictory. The five women and the sixteen therapists shared their stories and their perspectives; their experiences were unique to them and describe their specific contexts. Nonetheless, the findings did meet the aims of the study by describing the women's experience of living with enduring mental illness and examining the factors that influence therapists' practice. To strengthen the findings, these have been supported by additional literature. However, the literature rarely captures the diversity and manifold human aspects of life and practice.

Reflections - mapping my research journey

When I started out on this journey I had little idea of my final destination. At the start, I had an idea of the route and the possible stages but the pathways to and through these stages were not visible. My journey has enabled me to meet amazing, complex and warm travellers who have been eager to share their past journeys with me. This is true for both the women and the therapists. Both groups placed their trust in me that I would hear about their lives and their practice and that I would do them no harm. The women's lives particularly have touched me in many ways and at many levels, I have gained much from hearing of their lives and recreating their stories. I may have on occasions wandered off the most direct route. Sometimes these wanderings have proved significant, at other times they have been cul de sacs sending me back to my original idea or to my supervisors for guidance.

This has been a journey not only with the participants but also with ideas. It is no surprise that ten years previously this type of work within

UK occupational therapy would not have been considered important or indeed valid. Times have changed and thinking has shifted. There is now a recognition that occupational therapy research is interested in the individual's or the group's experience of living. I, too, have changed, as have my views and understandings of people, practice, research and education. Moving these insights into the professional domain is the next step forward.

CHAPTER SEVEN

Learning the Lessons:

Critique, Implications and Conclusions

Introduction

This chapter critiques the study, highlighting the strengths and weaknesses of the research design and methods. Consideration will be given to the implications of this work for practice, education and research.

Critique of the study

The study design addressed the following questions:

1. What is the lived experience of women with enduring mental illness?
2. How do occupational therapists work with women users of mental health services?

A qualitative methodology offered the most appropriate route to gain the depth of information required. With regards to the methodology chosen, consideration was given to which particular epistemological stance I would adopt. In exploring others' lives and therapists' practice, it was acknowledged that it is not possible to separate the individual's experiences and perceptions from the outside world: therefore, a social constructionist stance was a significant influence.

In addition, in considering each woman within her wider community and the therapists in their practice contexts, I wished to develop collaborative, non-exploitative relationships to empower them to share their experiences. It was hoped this approach would lend authority to the participants' perspectives and reduce the element of power inherent in such research relationships. Therefore, this aim was central to the research methods chosen and the procedures followed. This hope that the researcher and the researched would be equal and active participants, jointly constructing knowledge, was admiral. However, in reality, creating contexts for empowering individuals cannot alone guarantee empowered individuals.

With both sets of women, I wished to acknowledge the collaborative nature of the work by having them contribute at every stage of analysis and interpretation. Importantly, with the life historians, I wished them to share authority for the final product. The life history participants all took the opportunity to contribute to this process; however, these were unequal contributions in the end. This also occurred with the therapists' contributions. Several therapists did not respond to opportunities to shape the work, and only six therapists replied to the final presentation of the focus group findings. This may be accounted for in a number of ways. My own wish to be collaborative may not have been reciprocated by the research participants; they may have perceived the relationship as a time-limited, working partnership. Furthermore, their motivations to be involved in the study may not have included continued input. They may have indeed been exercising their power by choosing to limit their participation in the study at a given point. On reflection, a tension existed between the researcher and the participants' perspectives of empowerment and it may be that in the end the power inherent in the researcher's position may always influence the relationship.

From the outset, I adopted a reflexive approach seeking to be aware of how I was impacting on the whole of the research process. My past role as an occupational therapist who worked in mental health could have impacted on both phases of the study. As was described in Chapter Two, my past roles were made explicit to the participants.

At this stage, it is useful to state what this research was not. Although this work was conducted by a woman, exploring women's living, working experiences and social roles within the wider socio-cultural context, it was not defined as a feminist study. This was for several reasons. My knowledge and understanding of feminist theories has grown throughout this study, but it was not central to the development of the research. This design drew on the principles of sound qualitative research which have been acknowledged as useful for conducting research with women and have been much promoted as feminist methods. I came to this field of research to be open to the women's and the therapists' meanings and understandings. If I had come to the work from a feminist perspective, my lens for categorising and interpreting the data would have been influenced or limited by that particular stance. This would have produced very different work. That said, feminist theory has much to offer future occupational therapy research and practice.

METHODS

The next aspect to be considered was which qualitative methods should be employed in this research. There were certain aspects that also had to be carefully thought about. First, the vulnerability of women with enduring mental illness was acknowledged. Second, the issues that may arise from practitioners who may feel their professional practice is under scrutiny required sensitivity and, perhaps, safety in numbers. Methods were required that would facilitate the women to share their life experiences, and the therapists their practice stories. Therefore, life-history narratives and the focus group method were chosen to facilitate hearing the voices of the two groups of participants. These methods will be critiqued below and other relevant aspects addressed, including analysis, credibility and representation.

Life-history

Life history is a qualitative research method for gathering information on the "subjective essence of a person's entire life" (Atkinson, 1998, p. 3). Having acknowledged the vulnerability of the women an approach that placed them in control was required. Therefore, the use of a "grand tour", open question in the first interview, with little questioning from myself, was selected as a deliberate approach (Anderson & Jack, 1991). This had the advantage that the participants were in charge of the information that they shared and the direction of their story. On reflection, overall, the participants seemed to have little difficulty with starting their stories. They began from their childhood and moved forward to the present. Only one participant started from the onset of her depression and worked forwards and then backward.

Each of their narratives was different. This was expected: as Reissman (1993) stated, "telling about complex and troubling events should vary because the past is a selective reconstruction" (p. 64). The women's narratives revealed their story, emphasising some parts, playing down others and undoubtedly omitting others. Their story, initially, was deliberately not structured or influenced by an external tool, for example an interview guide. This unstructured interview format achieved its goal: the participants drove their story forward in their own way and in their own words. As identified previously, this unstructured technique could have a major drawback, namely, that participants retell dominant narratives from their lives. In this case the women may have only told of their psychiatric histories. However, this did not transpire, with women sharing narratives across the spectrum of their lives.

However, this strategy meant that with the first interview, in particular, I had to listen carefully. During these interviews there were many occasions where I wished to ask for more information but held back, not wishing to disrupt their flow or importantly remove their sense of personal control over the process. Therefore, opportunities for what I thought may have been fruitful questioning to give more depth or gather specific incidences were lost.

The second interview did allow for further information to be gained and for examples or clarification of issues to be addressed. In addition, at this time follow-up questions were also asked of participants. However, it became clear from the participants that some questions would not receive further responses. Striking examples come from Sarah, who was not willing to discuss her childhood, and from Marguerite, who did not wish to revisit her hospital experiences. Although this limits the information gathered, it was necessary for me as the interviewer to judge how far an individual would go. I chose to respect both the verbal and non-verbal feedback from the women that indicated that they wished to conclude a particular questioning route, preferring to balance some information with no information. The discussion of the chronological profile and the concept map, developed from the first interview data and shared at the beginning of the second interview, further facilitated the participants' recall and re-orientated them to the work.

The concept map was particularly useful way to visually represent the patterns and the inter-relationships that were evident in the first narrative (Atkinson, 1998). The participants seemed to find these methods useful and an engaging start to the second interview. However, the use of these tools, although useful for re-orientation, could have influenced the participants' input into the second interview, by limiting perhaps the scope of the session.

During the second interviews all the women revealed more about their lives and their situation, perhaps as a result of our prolonged contact and the trust that we jointly had built up. Perhaps they were reassured that I was handling their lives with the respect and care they demanded. Alternatively, the process of engagement with this research may have allowed the women time to reflect and review their own position.

On returning their completed narrative to them, the participants' responses to their own story indicated their engagement with them. For example, Pat stated her story had not captured her sense of anger with her psychiatrist and it was revised to reflect this aspect. The women expressed that my representations of their life stories were on the whole a credible representation of their life and they were able to recognise this particular portrayal of the "self". Several acknowledged their feelings on seeing their life represented in this manner. It is acknowledged that my interpretation and representation would be different from those of another researcher at another time. Reissman (1993) reminds us that such member checks, although useful for building trustworthiness, can be questionable as the participants' perspectives may change over time: they have their own issues and may try to present themselves in a particular light.

An additional aspect that must be considered with regards to the use of this method with this particular group was the inherent therapeutic potential of the method (Atkinson, 1998; Jones, 1998). This research was not meant to be therapeutic but the telling of one's story, having someone listen to and value your perspective, can combine to create a process that can mirror therapy. Moreover, the production of a final representation may enable the participant to review, or to reposition themselves with regard to their past actions and understandings. This overview of their life can help them make sense of certain aspects of their lives (Rickard, 1998).

The life history method was successful in that it met its purpose of accessing first-person, detailed accounts of these women's experiences. The narratives are unique portraits of the women's lives. Nonetheless, it was a time-consuming methodology, rich in data, which required commitment from the participants as well as the researcher. It was a process that enriched my understanding of their lives: their stories were created from a collaborative effort that helped their voices to be heard.

Focus Group Method

The four focus groups by necessity, took place over a two-day period. Ideally, I would have preferred at least a day between the groups to allow myself time for reflection on the process and the content of the groups. However, finance and studio availability determined the focus group timetable. The structured interview format, "questioning route" employed for the groups seemed to be useful. It appeared to be logical and coherent, enabling the members to contribute to the group early on and to become more involved as the group progressed. The interview questions and the stimulus quotes used seemed for the most part to generate interesting responses and debate. Questions following up on participants' responses were asked on occasions. However, it is acknowledged that on some of these occasions such questions could have been more strongly followed through. Within Focus Group Three attempts to widen the discussion by using follow-up questions proved unfruitful. It is essential to remember that the nature of focus groups demands a similarity of questions across all groups. Therefore, too many follow-up questions could have disrupted the construction of the groups and detracted from the use of a semi-structured questioning format.

With regard to specific questions, a general question about gender and the participants' understanding of the term should have been included; this would have given a base-line of the range of understandings around this term. There was an assumption that my understanding would also be the same as that of the group participants. A more experienced researcher may have utilised a less structured interview style and this may have led to different responses.

The focus groups did work as a method to explore practice issues in a dynamic and supported context. On some occasions, I was aware that participants were addressing their responses to me directly. However, for the most part there was a flow of discussion, with spontaneous involvement with all the group members (Kvale, 1996). Needless to say, some were more involved whilst others required an invitation to contribute. As with the individual interviews, some opportunities were lost to seek further detail or explanation within the group for fear of interrupting the flow or imposing my perspective.

The use of the observer on Day One of the focus groups was extremely useful for a variety of reasons. She was able to contribute to the debrief following each of the first two groups, to make relevant comments on my performance as an interviewer and on the questioning route which was most helpful. These comments certainly contributed to the focus groups being useful. Furthermore, she acted as the external auditor, examining both the process and the product of the focus groups (Cresswell, 1998).

In the light of some surprising omissions from the participants' responses with regard to personal practice issues (for example stress, and frustration) further consideration was given to the social context in which the groups took place. It was felt that this "created" context presented a non-secure environment for the disclosure of such information. It may indicate that for personal aspects of practice to be explored, individual interviews may be a more appropriate method.

Overall, the focus group was a very useful method for facilitating discussion of a range of issues. On reflection, the methods facilitated further understanding of the women's experiences and the ways in which they made sense of their lives and their practice contributing to the evidence base of the profession.

ANALYSIS ISSUES

Management to allow for successful analysis of the data resulted in the adoption of a practical approach, the creation of a range of word processing files that facilitated accessing and moving the data between codes, categories and across files. From the outset, I preferred the physical handling of the data as this process facilitated my immersion with the material and developed the analysis. The decision not to utilise computer software such as NUD*IST or any qualitative data-handling programme was influenced by my past experience. I considered that the data obtained would be manageable and that the coding, storing and rearranging of sets of data could be done effectively without the use of such a programme that requires the researcher's engagement with the data in reading and coding (Depoy & Gitlin, 1998). Further, Cresswell (1998) says that such programmes provide "little assistance in procedures used in writing narratives" (p. 156).

Narrative analysis and constant comparative analysis were utilised within this study. Narrative analysis, as a method of dealing with biographical data has few structured procedures, whereas by comparison, the constant comparative method has reasonably detailed protocols for conducting analysis (Cresswell, 1998). The narrative analysis criteria identified in Chapter Two proved useful tools to process and consider each woman's data. The majority of data was examined under the relevant headings, thereby highlighting different facets, relationships and patterns between these elements.

Particularly illuminating was the domain of the "embodied nature of the protagonist" as this crystallised the importance of the body for experiencing emotion and life. This domain focussed attention on the body, and the internal and external ways the body bears witness to the women's lives. Best examples that demonstrate different aspects of embodiment come from Sarah and Marguerite. Sarah commented on how her body shape has changed. She discussed how previously she was very thin and childlike and described herself as "empty." She now recognised that physical changes to her body had occurred. She has filled out, becoming an adult woman as she has worked to resolve her abuse. Marguerite's body bears witness in a different but equally powerful manner. She was able to identify physical scars and damage, such as her limp, that attest to her life with mental illness. This is an important area which may have otherwise been overlooked.

The constant comparative method achieved its purpose capturing the themes of the women's lifetime experiences and the influences on therapists' practice. Both methods created a significant amount of data. The analysis procedures were time consuming and required my engagement with the data. I also needed to remain open and be reflexive with the emerging findings.

Issues were evident in maintaining the trustworthiness of the data from transcription to text. Throughout analysis, interpretation and construction of the findings, both sets of participants were involved as partners. Therefore, individual and focus group transcripts were forwarded to the participants for member checking. Some participants made comments, some clarified points, whilst others returned their transcripts unmarked. Likewise, findings were forwarded to all participants for further comments.

CREDIBILITY

Several methods to ensure the accurate representation of the participant's perspectives were identified in Chapter Two: these included triangulation, member checking, reflexivity, peer debriefing and a coherent audit trail. The women were involved throughout and their amendments were incorporated in the final versions of their narratives, thereby strengthening the trustworthiness. Similarly, the participants of the focus groups had an opportunity to respond to the transcripts and to input to the final findings. It is acknowledged that ultimately, as the storyteller, although I wished to respect my participants' ideas, I had the final say over the production of the narratives and for the findings (Reissman, 1993).

These measures woven into the method enhanced the trustworthiness of the work produced. Furthermore, credibility was increased by the use of quotations, both thick description and dialogue from the informants to support issues raised. To reduce the imposition of my interpretations, the continued use of *in vivo* language acted to maintain the insider's perspective throughout. Where appropriate in reporting the focus groups' findings, excerpts of dialogue were also included to illustrate the dynamics of the conversation and the ambiguous nature of the findings.

REPRESENTATION

The purpose of qualitative research is to discover patterns and themes through the exploration of particular phenomena through thick description and thoughtful analysis of the research topic. Here, across both phases of this work a small number of women were interviewed individually or as part of a group: five women were interviewed in phase one, with sixteen therapists being interviewed through the focus groups in phase two. This study set out to explore and describe their lives or their practice. It did not seek to generalise but to describe rich contextually bound findings.

In relation to phase one, there were no women with a diagnosis of schizophrenia in the study cohort. This could be seen as a limitation, as women with schizophrenia are considered within the spectrum of enduring mental illness. However, it is acknowledged that this group of women can be problematic to engage in research (Mayers, 2000). The recruitment strategy used a mental health resource centre as a point of access. At an initial meeting at the centre with possible participants, two women identified that they had schizophrenia but neither opted to take part in the study. The most common diagnosis, depression, was represented in this group of women. There were no women from an ethnic minority background in the final cohort. One woman from an Asian background consented to take part but withdrew at a later stage. The final group may reflect the make-up of the women users of this particular mental health facility, with few users being from the ethnic minority population.

The small number of women, five in total, cannot claim to be representative of any, let alone all, women with mental illness. However, the methods used, the depth of information gained from the women's lives, the similarities and the differences they experienced, and their unique perspectives strengthen the value of the work. Moreover, to some extent these findings are reinforced by other literature. The women's narratives highlight their experiences, beliefs, personal meanings and feelings. Although they constitute a small sample, there are similarities and variations among the women's experiences, and so inferences can be drawn from the work. The unique narratives of the women and the comparison across their narratives may help others to consider and understand their lived experiences.

Another factor to be considered in relation to being representative was the Scottish context of the work. Scottish mental health services have been slower to close large psychiatric hospitals than their English and Welsh counterparts. This has led to a slower, more planned development of community care. Therefore, although community services exist, the psychiatric hospital as an institution still has a significant role in both power and place. This context may have had implications for the focus groups as the therapists involved were drawn from the foremost psychiatric service in Scotland, which in comparison to other services still has a significant way to move forward. This situation may result in a particular perspective being put forward that may or may not be borne out with a group of therapists located elsewhere.

The focus group members reflected a range of ages and grades, but there were no therapists from an ethnic minority background. Again, this situation realistically reflects the small number of occupational therapists from an ethnic minority background who are currently on the UK occupational therapy register. Furthermore, the Scottish context has to be considered in relation to ethnicity, as there are few therapists from an ethnic minority background practising in Scotland. An additional concern was the membership composition of the fourth focus group, which was not ideal. Unfortunately, because of member changes two service managers participated in the same group. This group was also the most difficult one for me as the researcher, as both managers were well known to me as past colleagues. This group could easily have lost its focus, as I found that a blurring of my roles as researcher, therapist and past colleague occurred. I had to draw back from the discussion and re-assert my researcher's role.

In summary, several key strengths of the study have been indicated as well as aspects that could be improved. The prolonged engagement with the participants has led to a depth of work that would not have been possible with alternative methods. The collaborative nature of the work, particularly with the women, has been beneficial to the final product. To an extent this is less true of the occupational therapists who ultimately had less invested in this research process. Another strength was the observer who also acted as an external auditor: her contribution ensured that the final findings reflected the data. My own understanding and familiarity with the world of occupational therapy and mental health practice provided me with an insider's perspective. This to some degree was a two-edged sword: I was aware of my own assumptions and had to work to identify my subjectivity and how this could have influenced the findings and the study's implications. As a footnote, for both groups permission for the tape and video recordings to be placed in appropriate archives was not requested; therefore a valuable opportunity was lost. With future, similar work, permission would be sought as part of the consent process for such tapes to be incorporated into an archive.

Implications and conclusions

This study has juxtaposed the stories of two groups of women: women who have lived with mental illness for the majority of their lives and women occupational therapists who work in mental health services. The women's narratives have unveiled the complex interweaving of their pasts with their present and their possible, future lives. The therapists' stories revealed the intricacy of their practice, their professional beliefs and dilemmas within the mental health context.

Previous research has indicated that women are disadvantaged socially, particularly so when they have contact with mental health services (Showalter, 1987; Ussher, 1991; Repper et al., 1998). This study has further demonstrated that this is indeed the case, with the majority of the participants expressing widespread dissatisfaction with services they received. Furthermore, disadvantages and dilemmas were also found amongst a group of mental health professionals, namely occupational therapists, who worked with similar women clients. Both groups of women were restricted and controlled by the organisations in which they were treated or worked. Organisational forces impacted on the provision and delivery of occupational therapy within mental health services.

The key outcomes from this study clearly indicate the potential for lessons to be learnt, specifically by occupational therapy. Implications arise in the areas of occupational therapy practice, education and research. Each of these three areas will be considered in turn. However, there are also messages for other professionals working with women.

Key findings from the study

Overall, this work has emphasised the women's lived experiences and the myriad ways in which the women perceived they had been failed, by mental health services in particular and society in general, when they had mental health problems. The women's lives spanned the greater part of the twentieth century. For one of the participants contact with psychiatric services began in the 1950s. What emerged in varying degrees for all of the women, were portraits of their lives that were changed as a result of their mental illness. Key findings included the women's experiences as both victims and importantly, as agents for themselves and others. Related to this personal agency was the need for future goals and hopes to be recognised and nurtured by health care professionals. Furthermore, the significance of the women's experiences along the continuum of motherhood adds to our understanding of the long-term impact of continuing mental illness on women, their children and families. Overall, what emerged were women who identified that they were experts in their own life. The women's accounts highlight that against the background of the rhetoric of Government initiatives and National Health Services directives little has changed from their perspective. In the past 10 years, however, there has been a growing awareness of the need for gender sensitive services. The overall findings to emerge from these women's narratives and the focus groups are summarised below.

Women's words illustrating their worlds

- The significance of formative experiences
- The importance of women's roles
- The need for occupational engagement
- The shared experiences of mental illness
- The presence of suicidal thinking
- The impact of stigma and discrimination
- The emergence of victimic and agentic roles
- The place of supportive frameworks

Common ground – A meeting of minds

- The need for safe environments
- The experience of powerlessness
- The wish to be heard

Practising in psychiatry

- The uniqueness of occupational therapy: something unique to offer
- The client-centred dilemma
- Treatment issues and women
- The invisibility of gender on practice
- The pressures on practice

In hearing the women's stories and recognising the similarities that emerged, it is hard to dispute the power of their experiences. Furthermore, it is difficult to ignore their call for changes. These changes appear reasonable and, on the surface, some have few financial implications. Their recommendations included the right to be heard, to be valued and respected, to be safe, to be cared for, to have access to women carers or women-only environments, if requested, and finally, most importantly, to be the seen as the experts on their own lives. The question arises how can mental health practitioners meet these requests? The answer to this question is not simple and involves changes across a range of spheres including practice and education.

However, there is an overarching aspect that should be considered first. As health and social care continues to change and demand different responses from its employees, occupational therapists must have a dynamic professional thinking capability in order to demonstrate to stakeholders that occupational therapy offers a valid and necessary service to health and social care arenas. Occupational therapists need to think out their roles within the wider sociocultural contexts in which they practice and be proactive in developing and changing not only their practice, but also the wider services in which they are employed (Roberts, 2002). Therapists need to be encouraged to engage and debate issues beyond the professional literature. This need to build professional capability has implications for practice, research and education.

Implications for Practice

The findings of this work reflect the College of Occupational Therapists research priorities, namely the incorporation of users' perspectives, the relationship between occupation, health and well-being and research concerning service configuration. (Illot & White, 2001). The contributions of these findings to the above priorities are modest. However, possible implications for practice have emerged. These are presented under four headings. The first considers the need for therapists to acknowledge aspects of working as women with women. The second deals with principles for how occupational therapists work with women. The third aspect considers the need for safe practice, thereby ensuring better services for women. The final section addresses wider issues in relation to mental health services.

Women working with women

- There is a need for occupational therapists to raise awareness of the factors that impact on women clients and themselves, as women. These include issues of stereotyping, oppression and the multiple aspects of discrimination: gender, age, race and class. Anti-discriminatory education needs to be available to all staff and be integrated within their practice. This aspect of practice is well established in social work education and this could offer a useful model.

- Therapists need to recognise their status and related issues of power and powerlessness in their work and to advocate for change and empowerment within their practice by developing communication and political skills to work effectively in the ever-changing climate of health and social care. Higgs and Edwards (1999) identify the above as 'entrepreneurship'. However, it is recognised that such transformation will only occur if wider organisational changes also take place.

Practice intervention principles

In this study, life history and narrative offered a way to gain insight into the lives of the women. It proved an extremely useful method, eliciting rich accounts of the women's experiences that went beyond the superficial (Corring & Cook, 1999). Recognising and incorporating narrative within occupational therapy practice would help women to tell their own stories, importantly, in their own way. Therapists through collaborative working can help share and shape their client's future life-story, helping them to become different, to be transformed. Mattingly (1998) stated, that "recovery…rarely means a return to a life one once had. It means, rather, the remaking of a life" (p. 64). Burke and Kern (1996) advocated the use of narrative in occupational therapy stressing it "is not a matter of it taking more or less time, it is a matter of being the essence of practice" (p. 391). Therefore, the use of narrative within occupational therapy practice should be further explored and developed.

- Narrative strategies should be incorporated into assessment procedures. For example, the assessment tool, the Occupational Performance History Interview (a historical interview) seeks to gather information about a client's past and present occupational behaviour (Kielhofner, 1997, p. 203). The challenge is to develop better means of eliciting clients' narratives that acknowledge the client as the expert.

In relation to assessment, given the prevalence of sexual and physical abuse in women's histories there is a need for these issues to be explicitly considered in the assessment process. Therapists should be open to these issues when working with women.

From the evidence, the women had significant roles and they valued engagement in occupation throughout their lives. The women identified the importance of occupation to their well-being and health; being able to do what they wanted and needed to do was highly regarded by them. This included recognising the importance of women's roles, especially as mothers and primary carers.

- A specific recommendation is for therapists to acknowledge the significance of mothering, and work collaboratively with women who are mothers to assist the development of effective coping strategies. This is particularly important in the early stages of infant-mother relationships when the primary role is that of caregiver. This may include the provision of advice or demonstration: physical and emotional contact with children, types of play and equipment usage, practical assistance in the home and information on support networks available. However, as the mothering role develops over time, therapists need to be attuned to meeting the client's changing needs.

Therapists should aim to optimise the quality of life for women by providing support to facilitate improvement in their functioning.

- Women and therapists should work collaboratively to provide intrinsically meaningful occupations, with consideration given to the provision of appropriate treatments that do not stereotype or limit opportunities. An important aspect relates to that of supporting clients to re-engage with their employment, if they wish to return to their workplace. If paid work is not appropriate then women should be supported to preserve and develop social networks that maintain their inclusion within their wider communities.
- Intervention should focus on strengthening the client's agentic self, and supporting the client's sense of self. Therapy should offer hope to women by acknowledging their goals and future aspirations and by supporting these to be met.
- The concept of client-centred practice within occupational therapy requires further development and understanding by therapists. The least known aspects of the concept namely, contextual congruence, accessibility and respect for

diversity, should be given further consideration as to how they can be implemented in practice and the consequences that may arise.

Occupational therapists have much to learn from those who use our services. We should be proactive in consulting women users, engaging them and supporting their involvement in service reviews and evaluations. Similarly, they have a pivotal role to play in the wider planning and monitoring of service development. We must, however, be careful not to exploit or abuse these users' perspectives or use this information once given ineffectively. Moreover, some service users may be prepared to share their knowledge through staff development by acting as consultants.

Support for safe practice

The issues of practising safely and risk-taking were evident in the findings in a variety of ways. Practising safely will be considered first. It is apparent that there should be appropriate support for all women in mental health settings including:

- confidential opportunities to confront fears or their own feelings of distress raised in their practice, for example, feelings raised by a client's self-harming.
- access to regular supervision providing an opportunity to reflect on their practice experiences and to debrief from critical incidents or situations.

Supervision is already acknowledged as a core element of occupational therapy practice, especially in mental health settings. The benefits and the perceived need for professional supervision within occupational therapy have been dealt with elsewhere (Scholtenberg & Delworth, 1987; Hawkins & Shohet, 1989; Allen & Ledwith, 1998; Sweeney et al., 2001a; Sweeney et al., 2001b). Stories from practice can be shared and different perspectives can be considered. This mechanism could be used to address some of the above issues.

Additional support may be necessary for staff who work with women who have been sexually abused. This should include opportunities for women workers to explore their own history of sexual abuse, if necessary.

- Staff should be encouraged to access other supportive frameworks that may already exist within their own organisations, such as staff counselling services. It is recognised that individuals may be wary of such workplace resources in light of confidentiality issues.

Existing policies for risk reduction, safe working, sexual harassment and violence at work should be displayed and be accessible to all clients and staff members.

- Individual therapists and organisations must maintain safe working practices and environments and continue to be aware of the potential risk for violence in the course of their work (Blank, 2001a). Risk assessments of work practices should be undertaken in a regular and systematic manner.

Wider issues related to mental health intervention

Mental health services need to encourage the maintenance of parenting roles by providing appropriate areas for children's visiting or crèche facilities in hospitals and mental health day centres where women are receiving care. As was evidenced, the home environment in some instances may not be the ideal place for women to receive their intervention if their home responsibilities impinge on the effectiveness of that treatment. Therefore, there is a need for suitable community resources to be available, with appropriate childcare facilities such as community drop-ins or other facilities.

An area for further consideration for mental health staff is the team's responsibility for initially giving information about diagnosis and support agencies. Occupational therapists, like others, have the responsibility to assist their client to make sense of what is happening to them. The need for informed choices is paramount throughout the treatment process. The continual existence of stigma and discrimination as experienced by the participants places a duty on all mental health professionals to actively promote understanding of mental health and mental illness in the wider community. This also reflects current Government policy.

Implications for Education

The College of Occupational Therapists' Statement on Lifelong Learning emphasised the importance of continuing personal and professional development for all members to meet the goal of delivering safe, efficient and effective person-centred interventions (COT, 2002). Therefore, professional education activities require the incorporation of aspects of concern to women within relevant course content.

Undergraduate courses

There are several areas to be considered within the undergraduate curriculum: gender and anti-discriminatory practice; communicating effectively; developing critical thinking; client-centred practice and mental health education.

The undergraduate curriculum for occupational therapy within the UK is based on national guidelines from the College of Occupational Therapy. The existing guidelines do not stress gender issues or anti-discriminatory practice. Several measures are proposed:

- Review COT guidelines to emphasise and incorporate gender issues and anti-discriminatory practice, thereby placing these as integral components of the undergraduate curriculum. The new benchmark statement for Occupational Therapy from the Quality Assurance Agency for Higher Education (QAAHE, 2001) states that healthcare professionals "... should be able to practise in an anti-discriminatory, anti-oppressive manner" (p. 2.). These benchmark statements are to be used as a source of reference when new occupational therapy programmes are being designed and developed. Therefore, anti-discriminatory practice should be a key component of learning, both in university and fieldwork settings. Social Work courses may provide a model of best practice of teaching and learning anti-discrimination within their curricula.
- Inclusion of women's specific issues in the curriculum.

Communicating effectively

Students need to develop the skills to interview and listen to clients through both verbal and non-verbal communication. The use of structured assessments may limit or narrow the focus, since these are driven by the profession's view in contrast to the client's perspective. Meyer, a prominent figure in the development of occupational therapy, stressed as early as 1912 the importance of taking and recording the person's life history to understand the client's situation (as cited in Serret, et al., 1985).

- Ensure that students can facilitate clients' telling their own story of their lives in their own way through multiple methods including narrative. This requires opportunities to practice these skills in the university and the fieldwork setting.

Developing Critical Thinking

Students need to be able to engage in debating the issues that impact on occupational therapy in particular and on the wider sociocultural aspects in general. This requires structured engagement with topics that encourage the expression of their personal and professional views. This in turn can lead to a shift in thinking and therefore a change in behaviour. They must continue to develop their practice and knowledge in an uncertain, ever-changing world (Higgs & Titchen, 2001). Many undergraduate courses already utilise myriad teaching and learning methodologies, including problem based learning which aims to develop the learners' thinking and their problem solving skills. Undergraduate courses should present students with:

- More use of literature to explore individuals' perspectives of health, illness and care. Medical humanities offers a possible way forward by using literature to encourage and facilitate the discussion of a range of issues, allowing the personal story of each participant to infuse the discussion and thereby leading to a rich and meaningful learning experience (Murray, 1997).
- Increased use of debate to encourage the verbalisation of ideas, including opportunities for argument of professional and social issues. This would enable the development of evaluative practitioners who are able to scrutinise their own and others' knowledge base.

Client-centred practice

The concept of client-centred practice needs to be fully explored and understood by learners and academic staff. The implications of client-centred practice, barriers to its use and the responsibilities it places on these future therapists must be considered and debated.

Continued professional development

Maintaining and developing a skilled practitioner is at the forefront of the Government's changes within the National Health Service. The following measures would develop the necessary knowledge and skills:

- Education that deals with specific issues including sexual abuse, physical abuse, deliberate self-harm, consequences and treatment implications.
- In-service education to develop gender awareness within their own practice. (This already exists in some areas for example high security hospitals. This could provide a framework for inclusion in general psychiatry areas).
- Access to assertion training for professionals.
- Women's studies and feminist perspectives

Implications for Future Research

Women & mental health

The commissioning of collaborative research with women service users to:

- Investigate their occupational needs including possible occupational therapy solutions.
- Explore mothering further as an occupation and the implications for occupational therapy.
- Develop and evaluate women-centred mental health projects.
- Ascertain the user's perspective of client-centred care.
- Explore the effectiveness of narrative as assessment and treatment.

Educational research

There is a need for research within occupational therapy to:

- Determine the benefits of narrative on graduate's understanding of mental health issues.
- Establish students' and occupational therapists' personal and professional understanding of discrimination issues.
- Ascertain the impact of anti-discriminatory education within educational programmes at the under-graduate and postgraduate levels.
- Identify the implications of anti-discriminatory education on practice.

This work, although small in scale, has highlighted many areas that may require further attention or research. Realistically, the implications focused on education may have the greatest impact in the shortest time.

Conclusions

The findings of this study have contributed to the body of knowledge of women and mental illness, whether of women who live with mental illness or of women who work as occupational therapists in this speciality. It has given insight into the realities of the women living with mental illness and of occupational therapists practising in mental health settings, creating both increased knowledge and understanding of the experiences of the two groups.

The occupational therapists here were committed to their clients. They clearly wished to value each person as unique and aimed to provide a meaningful service to the individual. However, as they were part of a larger system they were also limited by that system. Their work and status within the broader organisation were little understood, and to some degree was perceived by the therapists as unrecognised. The therapists articulated their work roles and they were aware that they offered something different from other team members. This sense of being different could be capitalised on to develop localised, creative solutions beyond the dominant organisation.

The women's individual narratives uniquely told of their lives, past and present. They have many messages for practitioners who wish to understand their clients' lives more fully and adapt and develop their practice accordingly.

In conclusion, occupational therapists can gain much from the women who use their services. It is imperative that occupational therapy listens to, and learns from, women users and that the profession employs this knowledge to shape and develop future occupational therapy theory and practice.

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Appendix A

Wanted

Are you a woman who has a severe mental health problem?
Would you be willing to tell your life history?

I am undertaking a study investigating the life histories of women with severe mental health problems. As part of the study I am seeking to interview women about their life and experiences. The findings will be used to inform the education and practice of occupational therapists.

If you are willing to take part, you will be interviewed at home or at a suitable local venue.

Your story will be tape-recorded. It will then be used anonymously to inform occupational therapists both in health and education. The interview will last from 1 to $1^{1/2}$ hours.

Please contact
Elizabeth McKay on 01524 383 386
or write to
Elizabeth McKay, St Martins University College,
Bowerham Road Lancaster La1 3JD.

Appendix B

Research Information Sheet

EXPLORING LIFE HISTORIES OF WOMEN WITH MENTAL HEALTH PROBLEMS: A QUALITATIVE STUDY.

Researcher:	**Elizabeth Anne McKay**
Contact Details	**St Martins University College, Bowerham Road, Lancaster LA1 3JD**

The Study

This study aims to explore the life histories of women who are identified as suffering from mental health problems. The study will focus on you as a woman who has a mental health problem. I am interested in hearing about your life experiences. I hope that this information will be useful to mental health professionals in their work.

Your involvement

The study will give you an opportunity to tell your life story in your own words. This would be achieved by in-depth interview, the interview will be directed by you. Interviews will be used as the main way of collecting your story, these interviews will be audio taped. Interviews may take up to 1 to 11/2 hours. Later on some follow up time will also be required. You will determine a suitable time and place for the interview to take place. All tapes will be destroyed after the study is complete. All information will be confidential and your name will not appear in any documentation or papers.

You will be given as much time as it takes for you to decide about participating in the study. You are under no obligation to participate and you are able to withdraw from the study at any time without your care being affected.

Once the data analysis is complete I am very willing to share the findings with you. Thank you for taking the time to consider the study. If you have any questions or would like clarification please contact me at the above address.

Appendix C

Participant's Consent From

I have read and understood the information provided.

I am willing to take part in the interviews.

I am aware that I am under no obligation to participate

I am able to withdraw from the study at any time without my care being affected.

Signature...Date.....................

Address ....

....

....

Telephone Number...

Appendix D

Department of Health
Brunel University
Osterley Campus
Borough Road
Isleworth
TW7 5DU

July 2000

Dear Colleague

Focus Group Research
First let me introduce myself. I am Elizabeth McKay a lecturer in occupational therapy at Brunel University, London. I have been given permission to approach the occupational therapy staff by (name removed). I have just completed Phase One of my doctoral study ' the lived experience of women with severe mental illness: an occupational therapy perspective'. This phase involved in-depth interviews with women with enduring mental illness. Following analysis and interpretation of these interviews I would like to discuss the findings with occupational therapists within mental health settings, who regularly work with women with severe mental illness. For the purpose of this study enduring mental illness is defined as

> A mental disorder (i.e. psychotic disorders including schizophrenia, manic depression, severe depression or severe neurotic conditions and personality disorders) of such intensity that it disables people, preventing them from functioning adequately as determined on the basis of their culture and background (The Sainsbury Centre for Mental Health, 1998, p. 12).

To allow this discussion to take place I am aiming in December 2000 to run a series of Focus Groups at (name removed). I would like to invite you to take part in one of these groups to discuss the findings with other occupational therapists. The focus groups will take a maximum of two hours, if you agree to participate you will only attend one group. The groups will be video taped to ensure an accurate record of the sessions. In addition an observer will be present to monitor the session. Confidentiality will be maintained at all times. The videotape will only be viewed by myself and following the research it will be destroyed. Any quotes used in the research will not be identifiable.

As I am aware that you have busy schedules, to maximise possible participation I would like to plan the timing of the sessions to meet your needs. If you are interested in participating can you please complete and sign the attached information sheet. Please indicate what day and session would be best for you. I enclose a stamp-addressed envelope for your convenience. I would welcome a reply by September 4, 2000. Thank you for your time and interest. I will be in contact in the very near future with regards to date and timing of the group.

Yours sincerely
Elizabeth McKay MSc BSc, (Hons) Dip COT, SROT

Appendix D

Focus Group Volunteers:
Consent to Participate

Name ....

Designation...........................

What area do you currently work in (please tick)

Acute admissions Day hospital Community mental health team

Rehabilitation Unit Forensic Unit

How long have you been in your current post? ....

Contact Address ....

....

....

Telephone Number...

I................................ am willing to take part in the focus group. I agree to participate in the session and to maintain confidentiality following the group.

Signature...Date......................

Monday		Tuesday		Wednesday		Thursday		Friday	
AM	PM	AM	PM	AM	PM	AM	PM	AM	PM

Appendix E

Follow Up letter

Department of Health
Brunel University
Osterley Campus
Borough Road
Isleworth
TW7 5DU

October 2000

Dear

Focus Group Research
Thank you for agreeing to take part in this research, by being a participant in a focus group. The location and the time of your allocated group are listed below. The group you will be attending will be formed from occupational therapists that work with women with severe mental illness. The focus group will begin with a number of general questions before moving on to discuss with you questions derived from the first phase of the study. Throughout the session your perceptions and views on these will be sought. <u>Please note there are no right or wrong answers.</u>

As the groups will be small the success and quality of the discussion is based on the people who attend. Your participation in the discussion will aid making this research project a success. In making the allocation I attempted to meet all requests. However, due to the hiring of the studio, this was not achievable for all. You have been allocated to the group below.

<u>Date and Time of Focus Group</u>
Friday 8 December 10.00 – 12noon
Location:
A map is enclosed

If for some reason you are unable to attend, please call me as soon as possible We may be able to allocate you do another group. My telephone number is 020 8891 01212 Ext. 2483. Thank you for your support with this research

I look forward to meeting with you on December 8.

Yours sincerely

Elizabeth McKay
MSc BSc, (Hons) Dip COT, SROT

Appendix F

Questions for Second Interview

Standard Probes: What was that experience like for you, what happened next. Tell me more about that?

Review of life summary to aid telling the story, bring back to the focus. Atkinson(1998).

Internal Questions (concern the story as told previously)
1st phase:

B. Review chronicle with the person. Add or alter the information there, (get DOB if not already got)

2nd phase:
Present main plots (NB. different for each)

External questions (New questions)

3rd phase: Reflective overview

1. How do you see yourself today?
2. What or whom motivates you?
3. What has been the most important learning experience in your life?
4. What relationships in your life have been most significant?
5. What have been your greatest accomplishments?
6. What matters, the most to you now?
7. How have your life experiences shaped the person you are today?
8. When you think about your future how do you feel and why?
9. Do you have any advice for people who work in mental health?

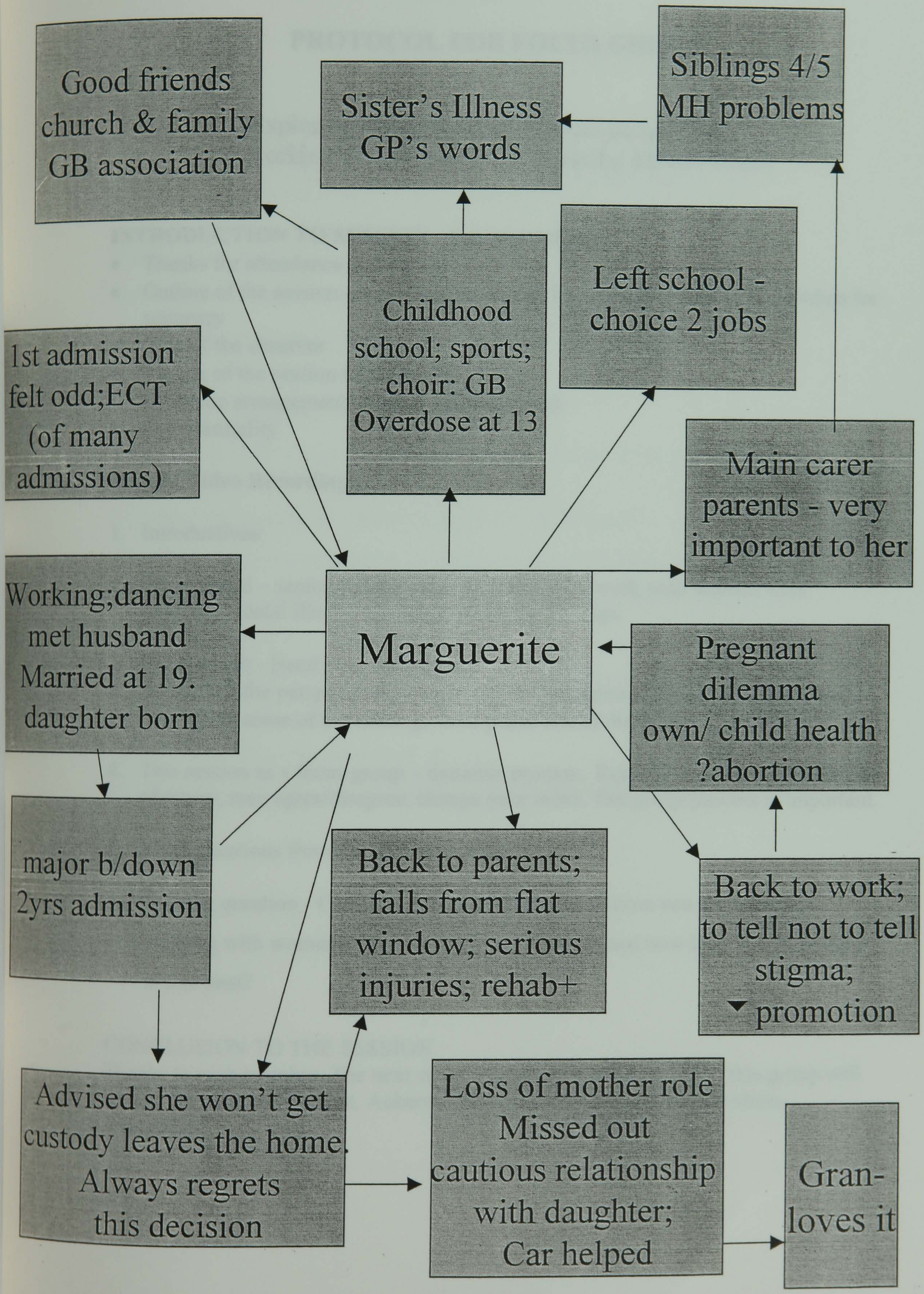
Closure

1. What, if in any way(s) has telling your story had on you?
2. What are you feelings about this research and all that we have covered?
3. Is there anything we've left out of your story that should be there?
4. Do you feel you have given a fair picture of yourself?

Is there anything else you would like to add?

Thanks

Appendix G


Good friends church & family GB association
Sister's Illness GP's words
Siblings 4/5 MH problems
Childhood school; sports; choir: GB Overdose at 13
Left school - choice 2 jobs
1st admission felt odd;ECT (of many admissions)
Main carer parents - very important to her
Working;dancing met husband Married at 19. daughter born
Marguerite
Pregnant dilemma own/ child health ?abortion
major b/down 2yrs admission
Back to parents; falls from flat window; serious injuries; rehab+
Back to work; to tell not to tell stigma; ▾ promotion
Advised she won't get custody leaves the home. Always regrets this decision
Loss of mother role Missed out cautious relationship with daughter; Car helped
Gran- loves it

Appendix H

PROTOCOL FOR FOCUS GROUP

Exploring occupational therapists perspectives of working with women with enduring mental illness

INTRODUCTION TO SESSION (pre-recording)

- Thanks for attendance and welcome
- Outline of the session – how the session will be organised, notes will be taken for summary
- Role of the observer
- Timing of the session (1hr 45mins)
- Domestic arrangements (toilets, refreshments)
- Confidentiality

Start of Video Recording

1. Introductions

2. Why invited – senior occupational therapists who work with women with enduring mental illness in a range of clinical settings.

3. My research - Need their assistance.

- To explore the perspectives of occupational therapists working with this group.
- To explore some of the findings from phase one of the study.

4. This session as a focus group – dynamic process. Respect the views and opinions of others, may agree/disagree, change your mind. The group process is important.

5. Invite questions from the group members

6. Opening question - Can each of you tell the group where you are currently working with women with enduring mental illness and how long you have been in that post?

CONCLUSION TO THE SESSION

Thanks to each member. The next stage: Feedback: transcriptions of this group will be sent for your verification. Acknowledge for their contribution. Re-stress anonymity

APPENDIX I

'The Questioning route'

Exploring occupational therapists' perspectives
of working with women with enduring mental illness
FOCUS GROUP RESEARCH: 7/8 DECEMBER 2000

Opening question

Can each of you tell the group where you are currently working with women with enduring mental illness and how long have you been in that post?

Introductory question

What interventions do you utilise with women with enduring mental illness?

Transitional questions: ***exploring: forum to think about***

What does it mean to you being a woman working with other women?

In your opinion is your gender and the client's gender a central concern in understanding women's mental illness.

To what extent does gender impact on your own practice?

Reflecting on your practice describe any issues that have been raised in your work with women with enduring mental illness?

To what extent do these issues differ for men clients that you work with, or do they?

Transition their reactions to my research/my interpretations

Key questions

Occupation as central

1 Occupation was crucial and was identified as essential by all the women.

STIMULUS Pat's quote (what does this say - not meaningful not meeting her needs).

- What opportunities are offered for women clients to make choices about their intervention in your clinical area?
- What opportunities are offered for women clients to be involved in programme development within your clinical area?
- Do women clients use these opportunities?

2 **Women's Roles.**

STIMULUS: The complexity of their lives and their occupational roles were not always recognised by mental health professionals.

- What are the implications of this lack of recognition for women clients in contact with mental health services?
- What do you think occupational therapists can do to prevent/reduce this lack of recognition of the complexity of womens' clients' lives?

3. **Meeting needs**

STIMULUS – Not all this positive. Women in this study felt that they were unheard – they wanted mental health professionals to listen to them.

In what ways do you 'hear' women in your practice?

4. **Safe & secure.**

Within your clinical areas are there women only groups/environments?

Describe these groups/environments?

5 **Education**

In your opinion is there a need for staff development or education in relation to working with women with enduring mental illness?

‘The Questioning route’ (continued)

Ending questions

The summary - Was this an adequate review of the session?

Final question – Have we missed anything?

The ‘all things considered’ question - What for you was the most important aspect raised in this group’s discussion?

CONCLUSION TO THE SESSION

Thanks to each member
The next stage: Feedback: transcriptions of this group will be sent for your verification.
Acknowledge for their contribution.
Re-stress anonymity

Appendix J

Focus Group – Stimulus Material

Stimulus One: Occupation is essential

Sarah spent 7 years in a wheelchair:
"For some of the years I worked in the garden it was the only place I could go out to and probably that's what kept me alive, kept me focused."

Hilda:
"I'm always working through problems don't get me wrong when I'm doing it (writing) its like I'm doing something…it stimulates your mind.

Stimulus Two: When one door opens:

"I used to walk into the occupational therapy department and out the other door. See, if I was asked - I wasn't lying when I said yes. I hadn't lied, I'd been in it and straight out."

Stimulus Three: Lives are multi-dimensional

Roles: workers, mothers and grand mother, carers, lovers, patients/clients, colleagues, sisters, daughters, counsellors, activists, volunteers, mental health service user, choir members, gardeners, writers…

Stimulus Four: Meeting needs

Pam
"I mean I went there, the day hospital, about three times a week….I mean you were well cared for, you really did have your own occupational therapy and carer you know anything you needed it was like that (snapped her fingers). They made time for you."

Appendix K

Example of Units of Meaning from Transcript

Transcript	Essence
I took the first sort of serious breakdown I suppose you would say and I had already my friend, my friend I was telling you about that's had an Accident to her eye she went to night school and there was a special thing they were doing at night school an exchange to Germany we had arranged to go on that it was the year that	My friend's trip
I had I wasn't really well and ehm my minds gone blank(laughs) eh right I had been ill I had ended up in the hospital but also I remember she reminds me of it I had got out of the hospital and I was swithering whether it would be all right to go the holiday and	I wasn't really well
Then it ended up I had this hairspray in my hand and I sprayed it all over her eyes and face it was really totally out of character I don't know why I did it or anything it was really weird but anyway was that before or after I'd been in the hospital I think that might have been before I went into the hospital.	Totally out of character
I was in the hospital I was only as I say seventeen I had whatever they gave me medication then they decided to give me ECT which if ever I was asked to take it again I wouldn't take it I just wouldn't take it any more I've had more after that but I really don't think they know they don't knew how it works basically so I had ECT I was a bit better I said to the doctor we had this holiday arranged and they said yes it was all right	ECT they don't know how it works!
I had been out for a couple of weeks but I had to keep taking my medication which was liquid cosh and of course that meant I was on a	Falling asleep

lower dosage but poor M had to put up with me falling asleep nearly all the time and when we were away it was very warm as well it was July when we went and she I mean she nobody else knew they knew I hadn't been well but nobody knew what but she knew what I had sort of been through I really felt it spoiled her holiday (laughs).	nearly all the time
We do have a lot of happy memories of this holiday. There was one of them we went into this café it was called the 'copedolemento' that was there top thing was this ice-cream called the copedolemento so we kept getting this for the fortnight then we discovered the base was rum (laughs heartily) so that was why we liked the copedolemento. That was a little aside	Holiday memories
Beth How long were you in hospital the first time?	
I was in I think about six weeks as far as I can remember so it must have been earlier in the summer right and actually at that point I was still on a sort of trial with the civil service and they extended it because I had been ill	I was still sort of on trial
I did eventually what is you become permanent they don't call it permanent there's a name for it but I thought I was going to end up never ever getting made permanent. Cos everyone that came after me seemed to be getting made permanent but eh I was in about six weeks now I don't remember an awful lot about it but I know….	Never getting made permanent.
(telephone rings)	
Interview stopped for 6 minutes	

Appendix L

Unitising the data

(Example)

Marguerite

Page	**Word or phrase the essence of the unit of meaning**
1	Earliest childhood memory
	Coming to O.
	Brothers and sisters
	One died of diphtheria
	I was at the opening of school
	Catching lice – worse thing about primary
2	My friend's holiday
	I wasn't really well
	Totally out of character
	ECT they don't know how it work
	Falling asleep nearly all the time
	I was still on sort of trial
	Never getting made permanent
3	I liked sports
	Don't want to be in a class of boys.
	I stayed off, and stayed off
	Two jobs at the same time
	Working when I was sixteen
	Rosebud and speedwells
	30 year medal
	Sunday school
	I liked sports and team games
	I didn't get anything – o levels
	Delayed reaction to leaving school
	First sort of serious breakdown
2	My friend – exchange to Germany
	I wasn't really well
	Totally out of character
	Given ECT – they don't know how it works
	Medication – falling asleep all the time
	I was still on a sort of trial
3	I was probably high
	Sister's breakdown a cause?

Mother – she has a heart like a Mountie
Parents - mum; highly strung dad: depressed
It's difficult to remember

4 It just wasn't like me
It had taken me two years were normally it would take a year
I liked working with people and I like working with figures
5 I've not got him anymore
Friend christened together
Met husband – that went on and the next year we got engaged and then the next we got married

7 Everybody was getting married
I wasn't very well
I was whipped into hospital

6 Didn't get to bond with my daughter
Mother-in-law – she nearly moved in, she more or less took over
Very little chance of getting custody – that was his advice and I took it.
I wondered if I had done the right thing
I just often regret never having tried
I choose to leave and I left my daughter
Do I want to do this do I want to do anything

7 A few folk know but not everyone knows
I've nothing what is there?
It was in the paper they got it wrong thank goodness.
They weren't sure whether I was going to survive
My angel of mercy
I thought it was self inflicted
? Medication

8 I had a couple of wee goes – suicide attempts
Still here with my funny walk
Recovery and reconstructionboring job good crowd.
I don't know whether to tell

9 Abortion
GP was a catholic doctor she wasn't entertaining anything
It ended up I went in ad got a termination
It was a very difficult decision to make
I've got mixed up with who knows and who doesn't
I didn't know what to do
My mother wasn't daft
Others - it was going to be an inconvenience
I don't think I could cope with another child

You have regrets

10 Hardest decision I've ever had to make
Every so often you think
You can't undo that one
Doctors were very particular
I wouldn't have been able to deliver
I didn't want to stay – so I left
I had never put it on the form – mental illness

11 Job wasn't going any place
Mum and dad were finding the stairs difficult
Work - they upgraded me
I'm more manic than depressed
Spend lots of money
14 She didn't want me in her section
I was sure that was then put on my record
They could have fired me
As soon as you put it (mental illness)

15 I tried for a few promotions –
But if you were male you didn't get anywhere.
I never got any higher
Do I need to stay here and get all this hassle – early retirement?
I've not hung about

16 I was eating them (painkillers) like sweeties
Too young for artificial hip
You're going to have a limp
Friend at work

17 You've had a real shake
You're a risk to their figures
Triggers – dead died breakdown in September
Sister is very aware

18 Dad's cancer
Too far gone to do anything

19 If I'd known
I had been in and out that often

20 Various doctors – somewhere along the way you should see the
Consultant
Come off medication
Lots of side effects with lithium
Being monitored

21 ECT and medication
If I had had a supportive husband

22 I took the whole bottle
I feel in a way this is as cured and I'm going to get
Brother's illness

Appendix M

Discovery Themes

1. What are the recurring words/ phrases and topics in the data.

Initial Codings

Surviving, People not recognising, Experiences of care - Insensitive handling, Safety Issues, Not being protected, Stigma, Discrimination, Parental relationship, Diagnosis, Medication and side effects, Being busy: doing, Being a mother, Relationships with men, Having survived, Lack of power, Guilt

2. Other codes arising from the data

Using my voice, Supporting others, Understanding mental illness
Help available or not! , No cure, Relative problems* moved to mother section
Growing up, Friends, Catalysts & tell tale signs,
Suicide, Taking control, Faith
Siblings, Becoming

2. What are the concepts the interviewees use to capture their experiences

Treated badly: Surviving; Living with mental illness; destroying your life

Others not understanding; Helping others; Doing it for themselves

Mental health services being inadequate; writing as helpful

3. Other concepts that capture re-occurring phenomenon in the data that helps sensitise you

Caring for others; being valued - being validated; making the best.

4. Patterns

Poor relationships; childhood experiences and environments
Mental health experiences not always good

Surviving

Marguerite
They weren't sure whether I was going to survive
Still here with my funny walk
I feel in a way this is as cured as I'm going to get
It's how you manage the illness
Not overcoming but living with manic depression
I'm taking care of myself
Helen
I'm helping myself the best way I can
Pam
I've got to work my day out right
Pat

I needed to know my rights
I was hanging on
You just kind of plodded on from bit to bit
You've got to survive
I don't know how I survived
One of them is surviving the mental health system really
Sarah To have survived my life experiences to see a future

- **People not recognising**

Helen
They didn't see it
I told you for weeks I knew I was ill
How did people not notice?
How did nobody else know?
My husband never noticed
Pam
You could cry your heart out over there
Listen more to what is being said to you
Definitely listen
Pat
listen to the patient and accept what they are telling you
Sarah
But they wouldn't let me talk about it

- **Insensitive/neglectful handling**

Marg
I didn't know you had a daughter
It's like you were a second class citizen
Helen I was condemned for being ill; You were condemned
They would stand and have a blether
It's very sensitive because you would love a bit of bacon
They didn't come up to her standards.
Pam I didn't feel I belonged anywhere
Pat They would shut the door in your face
You can't do that you're working here

Sarah
Putting me out of my house
I haven't said a word about the hospital the treatment I had in hospital
She was shouting at me for wasting her time

Safety issues

Helen
I felt safe for the first time in my life
I went there for safety I was afraid

Pam
Insisted I go to hospital that was the best thing ever

Pat
I had to for the safety of myself for the safety of my children

Sarah
It is a very scary thing to expose
It wasn't a secret it was to keep me safe

- **Not being protected**

Pat
Both boys were sexually abused when they were in care

Sarah
I needed to be protected during that time
They weren't making sure I was alright

Stigma/discrimination

Marg
I was still on a sort of trial
It had taken me two years were normally it would take a year
Very little chance of getting custody – that was his advice and I took it.
A few folk know but not everyone knows.
It was in the paper they got it wrong thank goodness.
I don't know whether to tell
GP was a catholic doctor she wasn't entertaining anything
I had never put it on the form – mental illness
She didn't want me in her section
I was sure that was then put on my record
They could have fired me
As soon as you put it (mental illness)
I tried for a few promotions
Too young for artificial hip
You're a risk to their figures
Why should we be ashamed?
Talk about it openly

Helen
TB a big lot of trouble
At least this is a real illness (GP's attitude)
They were all running for X-rays

Stigma/discrimination (cont.)

They were all ashamed TB
It's a shame
If you're in their books you'll always be reminded
Rip that whole book up, I've changed I'm not that person.
They were putting it down to nerves again
We were treated for being poor
wearing designer labels since I was five
I thought it was normal to be poor

Pam

Mental health gets the least amount of money
I haven't told my parents I wouldn't like them to know

Pat

The minute the social worker said L attends Leverndale not a thing was done
You're an unfit mother
Nobody here knows by the way
she would tell everybody
In that house they are all out of Leverndale
she not to come near me
You are not coming near me
It's none of your dam business
Take all references to that out of my file
All references of the mental hospital are taken out of my notes

Sarah

That's me finished I'll never be able to do anything

- **Parental Relationships**

Marg

Mother – she has a heart like a Mountie
Parents - mum; highly strung dad: depressed
Mother-in-law – she nearly moved in, she more or less took over
My mother wasn't daft
Mum and dad were finding the stairs difficult
Dad's cancer: too far gone to do anything
If I'd known
I had been in and out that often
Caring for mum
Everyone's mother is part of their lives
Caring for mum it was difficult time
My mother was very important to me

Helen

Parents they were there all the time
They were a mixed couple
They were good parents
Mum's support to get the right job

Pam
broken promise – my father didn't get the farm
No matter what I did it was never quite good enough
I never reached a standard that was acceptable to my father
I thought the world of him(father)
My dad has power of attorney for me

Pat
My grandmother on my father's side was a bit loopy
My father was bothered with his nerves
My mother – she was a very positive women
You two will never get anywhere you are hopeless
My mother never ever
My mother never forgave me for that
Surely a mother was never like that
You've got to ask your parents first
Parents never get it right
She nearly broke the whole family up (mother)

Sarah

The only thing I was remembering was the abuse in my home
Parents – I'm not in communication with them
I know my dad has abused me
The terror of being angry at my mum or angry at
my dad.
He was coming across like my dad and in my way I was dealing with
my dad and I couldn't take it
Feeling the pain of being abused by my father
Because eof my parents

Discovery themes - Reflective Diary (example)

Essence
Amazed at the openness
Impressed by the richness yet ordinariness of this life
A sense of loss intermingled against a background of tragedy
She and her family have coped; I knew nothing of her
Listen to her story; Feeling inferior less valid than others
A battler who had met her fights face on
Daughter and husband didn't feature much in her story
Hearing about things I hadn't expected
How comfortable I felt with her hatred towards her psychiatrist
Insensitive belligerent approach to his parents
I felt unhappy with my way of responding
A woman who has survived in spite of what the world threw at her
Sadness disappointment and dismay
Her own family made fleeting appearances; Not being listen to
Doing being and becoming
She is using her skills and abilities to focus on mental health issues
New roles with the local community; This can be different
She has become an agent for change; Not believing or feeling her life her existence

Complex and convoluted;
I left feeling confused and horrified at the life this woman led.
Let down by others who should have known better
Put the pros and the cons of the data and argument
I do feel responsible for ensuring theses women are "treated well"
I feel somewhat guilty….
She'd never get her o'level and she did
It was important to hear Pat's story (time pressure)
Missing hospital stories
Helen opened the door I was taken aback by how different she looked from the last time
Been trying to sort out things in her own mind
Trying to make sense of her life perhaps a kind of closure
Interview would not follow my plan
I just let her talk
On reflection her account felt like a winding up a sorting out a final act
So painful with H taking a lot of responsibility for how things turned out
It felt very business like almost like applying for a loan
I began to get the feeling that she was allowing me access to a fuller 'her' than before
The finding of herself through the illness experience
She had been OK as a mother (psychologist told her)

Appendix N

Categories and rules for inclusion

1. Category: **Still here with my funny walk**

Inclusion rule: The women highlight that at times in their lives surviving is of paramount importance. Surviving can be a life and death experience or it can be just getting through a period of their life. Included within this concept are the ideas of acceptance e.g. as good as it gets. But importantly both self- responsibility and self-management are also evident in enabling people to cope. For the women there is a feel of coming through the war but not unscathed.

2. Category **I discovered that I was bipolar, it meant nothing to me.**

Inclusion rule: All of the women experienced difficulty in getting to know and understand their diagnosis and the consequences of their diagnosis not only to themselves but to their family. Not knowing left them unable to make sense of what was happening to them or what could happen to them. In addition not being told left them unable to seek out further information that would have been beneficial to them. It made them the passive recipients of a care regime.

3. Category **I went there for safety**

Inclusion rule: The women recognise that there is a need for a "place of safety". This for the majority initially was the hospital. However some felt unsafe in the hospital. Others felt that they were not being kept safe or indeed protected whilst at home.

4. Category **It's an unsaid you're the patient and you have no rights**

Inclusion rule In their interactions with those in authority the women fell they had no sense of power. They felt they had few or no choices, no rights and were considered of low status.

5. Category	**You have regrets** *
Inclusion rule	The women experience a sense of blame for things that happen to them or to family members. This results in them feeling unworthy, undeserving and perceiving themselves as invalid. *(**This category became part of the category “I hadn’t discovered quantum physics or anything!)**
6. Category	**You’ve had a real shake**
Inclusion rule	The physical painful effects of mental illness are not generally recognised by others. Most of the women believe that current physical ailments are either directly or indirectly related to their mental illness history. The women believe that physical illness is often negated in the presence of mental illness. More emphasis should be placed on monitoring the physical health of people.
7. Category	**You were my voice** *
Inclusion rule	Evidence of women taking up the challenge of speaking out for themselves and advocating for others.*(**This category became part of the category “I ‘m doing something about this!)**
8. Category	**I phone her on a Tuesday**
Inclusion rule	The women are offering in a variety of ways informal support systems. These include regular meetings and telephone calls. to advocating for others and providing emergency telephone support.
9. Category	**Everybody can understand pain, mental pain they can’t!**
Inclusion rule	The women have identified a lack of understanding of mental illness amongst others. They perceive that they can understand physical illness more easily. Some acknowledge that as a result of their experiences their own understanding has increased.
10. Category	**A place to walk into….**
Inclusion rule	The women felt that help was generally not available. The help that was available was limited by its location or opening hours. In addition, help that women found for themselves had been

	experienced as not good or indeed unhealthy. Help takes a range of forms from day centres, support groups to practical help such as home-helps.
11. Category	**It's the loss of your life**
Inclusion rule	Mental illness for some was viewed as something that negatively influenced your life to something that ruined your life resulting in significant loss of life.
12. Category	**But mostly just to be.**
Inclusion rule	The women believe that they have in a sense 'found' themselves, the majority feel happy with themselves now than in their past.
13. Category	**I still drink a lot of irn bru**
Inclusion rule	The women believe that physical treatments and drug regimes have impacted and continue to significantly affect their lives.
14. Category	**It came from childhood***
Inclusion rule	Each of the women identify aspects of their development that are ordinary shared human experiences i.e. starting school. In addition some felt that their childhood experiences had significantly influenced their adult hood. ***(This category became part of the category Because of my parents)**
15. Category	**My friends were the ones who stuck by me**
Inclusion rule	All of the women valued the important roles their friendships had played on their lives. Significant friends identified were also women.
16. Category	**I even scrubbed the coalbunker**
Inclusion rule	The women identify behaviours that were unusual or out of character for themselves either before or during illness episode.
17. Category	**I haven't discovered quantum physics or anything**
Inclusion rule	The women recognised that at some point in their lives, for some prior to contact with MH services, that they had contemplated or actively engaged in suicidal behaviours.

18. Category	**I'm doing something about this!**
Inclusion rule	The women demonstrated times in their lives when they actively altered the direction of their life to bring about change.
19. Category	**My sanity was my faith**
Inclusion rule	For the majority spirituality holds an important place in the women's lives offering support, help and friendships.
20. Category	**Because of my parents**
Inclusion rule	Parental relationships were recognised by the women as impacting on their lives in either a constructive or destructive manner.
21. Category	**I always wanted to be a teacher.**
Inclusion rule	For the women involvement in meaningful occupations across the stages of their lives was of paramount importance. Occupation is considered as paid and voluntary work, leisure, and self-care. Occupations mentioned are many. Occupation is considered as being multifaceted and experienced as unique to the individual.
22. Category	**I was going to be a perfect mother**
Inclusion rule	Represents the continuum of motherhood and the affect of mental illness on this valued role.
23. Category	**Rip that whole book up, I've changed I'm not that person**
Inclusion rule	The women have experienced both stigma and discrimination as a result of their mental health.
24. Category	**Brothers and sisters**
Inclusion rule	Relationships with siblings raised both negative and positive feelings and attitudes. In general where siblings had similar issues relationships were more positive in contrast to siblings who had no mental health issues.

25. Category	**For better or worse**
Inclusion rule	Represents the impact of marriage and its possible consequences for the women in the study
26. Category	**You could cry your heart out over there!**
Inclusion rule	This represents the participant's experiences of care which has been both negative and positive.
27. Category	**Listen to the patient**
Inclusion rule	This women belief that health professional require to listen and believe individuals.

Categories Subsumed: 5, 7, & 14.

Appendix O

Focus Group - Initial Themes

- Being a woman therapist can be beneficial when working with women
- Challenges do exist
- Women are perceived as having difficulty in prioritising their needs over others.
- Gender is not specifically considered in understanding women's mental illness
- There is uncertainty in regard to the notion of gender.
- Occupational therapy can be therapeutic if focussed on the individual and their needs
- Enabling choice is important
- Amongst other staff members there is a lack of understanding of occupational therapy
- Occupational therapy is different from other mental health professions
- The environment is important to the practice of occupational therapy

Appendix P

Focus Group
Category and Rules for Inclusion (RI)

Category: Sometimes you can't help

RI: Therapists highlighted negative feelings to certain types of behaviour or when people were unable to make the simplest decisions.

Category: Opportunity to see things in a different way

RI Education in a range of formats at uni-disciplinary and multidisciplinary levels was felt to be used for all staff.

Category There are lots of barriers around

RI therapists identified that lack of resources staff; finance and time can be detrimental to their work.

Category They do feel unsafe

RI Participants highlighted that personal safety, as an issue was a valid concern for both clients and themselves.

Category Lousy Environments

RI Environment was seen as being an important factor that could enhance or restrict treatment. Hospital ward environments were portrayed as poor only offering limited choices. While the community was considered more favourable with increased treatment choices. Although a need for women only environments was acknowledged few existed.

Category People treated as people without reference to gender
RI Participants identified that gender issues were not something they considered. They acknowledged that it was an area that perhaps required more attention at a personal, professional and organisational level.

Category The service would never be perfect
RI The members highlighted that services need to be reviewed to maximise meeting people's needs. However the process of what information to collect and when to collect it was identified as problematic. As service changes may

impact on an individual's health status care must be taken in the implementation of service change.

Category: The whole juggling process

RI Therapists perceived women clients to have difficulty in prioritising their needs over others they care for and that women place themselves under pressure because of their expectations of themselves.

Category: It's the loss of roles women find difficult

RI Therapists indicate that women have many occupational roles, which may be affected by mental illness in a number of ways. A reduction in roles, complete removal of these roles for a time period, or alternatively limited opportunity to develop a range of roles. The parental role is highlighted specifically. Woman may experience grief at the loss or reduction in these roles and relationships. However services may fail to recognise the severity of this and may not provide opportunities for these issues to be discussed.

Category Occupational therapists have a really different approach

RI OT's believe that they provide a unique approach that differs from other MH professionals. This approach focuses on the individuals roles and needs. This differs from other professionals who focus on diagnosis and medication. Other professionals understanding of occupational therapy can impact negatively on occupational therapy provision.

Category Collaborate with clients

RI therapists identify the need for clients to be included in their treatment and suggest working in partnership in a client centred manner. However, they acknowledge that partnerships can be difficult.

Category Feedback from clients

RI Processes both informal and formal exist to facilitate feedback from individuals.

Category What is their life like?

Through assessment processes both formal and informal therapists require at the outset to seek out their clients pats histories, to listen an understand the complexity of that individuals life checking out their understanding throughout the process.

Category Offering Choice

RI therapists identify that offering choice though out the treatment process is essential to successful outcomes. Clients should be offered choices to attend occupational therapy or not with opportunities for choice being built into the individual treatment plan. They recognise that choices may be limited and that making choices can be difficult for clients

Category We treat people as individuals

RI Therapists stated that the focus of treatment was on meeting individual needs that are important and relevant to them. They acknowledge that the organisation can constrain their ability to work at the individual level.

Category Occupations gives people a different role

RI Therapists identified that engagement in meaningful occupation was positive in facilitating the person ability to do, be and become.

Category Identify more with women and their issues

RI Therapists identified that as women working with other women this was advantageous to the treatment relationship.

Category Gulf between them and us

RI Recognition that for some therapists their lives and lived experiences were very different from the majority of the women with whom they work and that this can impact on therapeutic relationships.

Category I think of myself as asexual at work

RI Gender issues were considered as multi-factorial including cultural and societal, biological and sexuality. Therapists were uncomfortable with the focus on women. They actively placed men in the discussion, similarly so to were ethnic minorities they considered similarities should be the focus not seeking differences. Reflecting perhaps the idea of the gender-neutral practice.

Appendix Q

Comments on Focus Group Findings

Your personal thoughts on the overall findings

How do you as an occupational therapist react to them?

What do you think are the messages of this research for individual practitioners?

What do you think are the messages of this research for the profession?

In light of the findings please comment on gender and its significance to practice.

In light of the findings, please comment on the issue of deliberate self harm and its impact on the therapists and their practice

Please feel free to comment on these or any other aspects.

Appendix R

Instructions for external auditor

Check videos and the transcripts.
Overall are the transcripts accurate and a reflection of what occurred in the groups.
Comments please.

The groups were identified by photocopying each group in a different colour.
Green Group I; Blue Group 2; Pink Group 3; White Group Four. Each group's transcript was deconstructed with responses relating to a question being placed under the appropriate question number; for example, all the questions one, twos etc.
For each question area, my initial impressions of the responses are included. (hand-written)

In the text, there is coding across all the questions. I am looking for the essence of a response. You are free to disagree and note anything you think I should have noted or included. I used underlining and the shorthand of those words in the texts. I then created a file for each question and placed all the codes into the appropriate file.
I address the responses across the questions.

Please read draft 1 pages 1-20. Comments please. Is it a fair reflection of the groups' responses? Are there other interpretations that I have dismissed too soon or missed completely?

On page 20 I have a table which I use the perceptions (as headings) for the discovery phase. That is to say using these headings the data across the questions is reconstructed under different headings. I also use a few more headings that I feel have been evidenced in the data. Do these seem accurate? Are similar things under the headings? Some data left over at this stage.

Following this process, these headings are searched for look alike feel/alike categories and these are grouped together. These categories are searched for the meaning, put forward as propositional statements with accompanying rules for inclusion.

You need to be thinking are these groupings realistic, do they fit or are they forced. Do the groups hang together?

P21-28 will give you the final version. Comments please.