

**A biographical narrative study exploring mental ill
health through the life course**

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Mr. Robert Collier aka
Grandad Bob circa 25th
March 1897-18th January
1982.

Photo; Age 16.
circa 1914.

He never spoke of the
effect of his experiences as
a teenager in the trenches
of WWI.

This thesis is dedicated to
people who live with
emotional struggles.

List of Abbreviations

APA	American Psychiatric Association
BME	Black and minority ethnic
BMH	British military hospital
CPA	Centre for policy on ageing
CV	Curriculum Vitae
DH	Department of Health
DHSS	Department of Health and Social Security
DLA	Disability Living Allowance
DSS	Department of Social Security
DWP	Department of Work and Pensions
ECT	Electro convulsive therapy
GCE	General Certificate of Education
GP	General Practitioner
JRF	Joseph Rowntree Foundation
LTR	Long term relationship
MJ	Management job
MO	Medical Officer
NSFMH	National Service Framework for Mental Health
NSFOP	National Service Framework for Older People
PDSS	Prolonged duress stress syndrome
PTSD	Post-traumatic stress disorder
RAF	Royal Air Force
RCP	Royal College of Psychiatrists
SCIE	Social Care Institute of Excellence
TC	Training certificate
VW	Voluntary Work

Abstract

This thesis is about people with mental health problems who happen to be older, rather than older people with mental health problems. Health policy that has focused on older people as a category has maintained a narrow focus on recognising depression and dementia, with older people being excluded from mental health policy aimed at adults of working age. This has resulted in age discriminatory practices, but in addition, the unique needs of people who have lived long term with mental ill health into later life have been ignored. Older people have been often conceptualised as consumers of care rather than citizens with aspirations and research about long term experience of mental ill health and recovery commonly excludes older people. This study aimed to redress this marginalisation and lack of knowledge by exploring the experience of long term mental ill health to older age from a strengths perspective congruent with recovery principles.

The study is based on a social constructionist epistemology and narrative inquiry methodology. The research questions were: 1) How does living with long term mental ill health affect achievement and 2) How does long term mental ill health affect life in the present? People who were aged over 50 and who had at least 20 years duration of mental ill health that started before the age of 45 were included. Seven people were recruited through posters placed in GP surgeries, leisure centres and libraries and contacts through mental health services. Four women and three men between the ages of 52 and 76 participated. The study develops the curriculum vitae as a research tool, a method unique in mental health research, in order to root the enquiry within participant relevancies and perspectives to ensure that this previously unheard voice is captured. This tool is congruent with a biographical method that informs the development of two personalised interviews and enables the implementation of this method within a recovery (strengths) frame of

reference. The resulting individual narratives were interpreted with reference to the principles of over reading and life course theory. A collective text was also developed which discusses the key findings.

The novel approach taken in this research study resulted in an original contribution to current knowledge which provides evidence that can be used to challenge beliefs about people who have lived a lifetime with mental ill health. The study revealed a lifelong process where participants returned to their early life in making sense of their experiences. Long term mental ill health appeared to create an environment whereby participants maximised their chances of success by avoiding stress which has a myriad of personally relevant causes. This appeared to be achieved by keeping silent, which, whilst self-protective, nevertheless potentially exacerbated their stress further and resulted in further stressful consequences. In later life the changed sociocultural and personal environment became part of an autobiographical reasoning that sustained self-theory. This created a situation whereby the participants felt better but also worse at the same time, where personal growth co-existed alongside stress burnout but was coupled with a renewed sense of hope in later life.

The implications for health and social care are discussed in relation to policy, practice, research and education in the context of age equality, recovery and long term conditions. Recommendations include: to focus on extensive durations of mental ill health as a special characteristic, to review the use of stress assessments and trauma histories in practice and research, for practitioners to establish the hopes and aspirations of older people who come into contact with services and for researchers to examine the presence of hope in older people with long term mental health problems.

Chapter One

The origins and foundations of the thesis

Introduction

This thesis is about people with mental health problems who happen to be older, rather than older people with mental health problems. These two groups are distinctly different given that the former have lived long periods of time with mental health problems that have continued into older age whilst the latter develop such problems for the first time in later life. However, in policy and research such subtle distinctions are lost and the commonalities of being older have taken precedence with all the assumptions that this can entail. Figure 1 shows a poem written by me aged 14 which seems to capture many of these assumptions, assumptions that do not seem to have altered much in the 32 years since it was written; loneliness, memory loss, poverty, madness, confusion, exclusion and marginalisation. Although there may have been some artistic licence surrounding the exercise when I wrote the poem, it does illustrate many conflicting feelings I have today regarding how the knowledge we have about people who are older is constructed and the implications inherent in how this is put into practice in health and social care. The assumptions that inform such constructions can lead to a compassionate ageism (Friedan, 1993); often unintentional but nevertheless one that marginalises older people and invalidates their autonomy as adults. Conceptual and theoretical errors have led to faulty conclusions that can result in ageing fallacies where any differences between individuals of different ages are wrongly attributed to the effects of ageing (Riley, 1973, Riley et al., 1988). When mental ill health is added to the picture it contributes a further potentially alienating complication, a double jeopardy (Jenkins & Laditka, 1998). These complications are made more difficult by persistent long term mental health problems from early in life

into 'old' age with the needs of such people being largely ignored in research and policy. It is people such as this that this thesis will focus on.

Figure 1. Poem from 1979: The Old man

24th October 1979. The Old man. (Poem)

Old age is drawing near, a time for rest,
The time for putting the wrong things right.
In mind, for the earthly soul.
An old man sits on the cold park bench.
Oblivious of the noise, he thinks,
Tries to fathom out this much-changed world.
He sees the first group of children on their way
home from school,
They have learnt something new,
But he has forgotten something old.
Soon the children are gone,
All is quiet, nothing stirs,
He feels the cold and the dampness enclose
him as the night draws near,
Winter had come.
He breathed gently, occasionally mutter-
ing words meaningless to the ignorant passerby.
His threadbare scarf falls from his face
and the frosty air grabs for his warm
neck,
Quickly he wraps himself up again.
He gets up and begins to make his way home,
He is a lonely man of the world,
Becoming less important to himself and
others everyday.

Correct - (A)

I write this thesis from the point of view of someone who has had many formative relationships with people who are much older, and who has also always worked with older people as matter of choice in a mental health nursing context since qualification as a Registered Mental Nurse in 1989. I learned then in a mental hospital (former asylum) that we were the experts and the patients were disabled, hopeless and there to be cared for. They were schizophrenics, manic depressives, cutters and psychopaths, and the long term dementia patients were the worst of all, a place where staff were sent to be punished for their misdemeanours (Butterworth, 1988). It was paternalistic and we looked after people who were ill and thought of as not likely to ever get better. After 22 years of experience in practice and education my views are very different. However, one of the consistent challenges during my career as a staff nurse, ward manager and academic, has been tackling negative thinking and ageism about people with mental health problems and people who are older.

The influence of medicine: the ‘graduates’

Until the 1980s, knowledge regarding later life mental illness remained based on the belief that dementia (an organic, progressively deteriorating illness) was a normal part of the ageing process and older people therefore untreatable (Hilton, 2005). It is unclear whether such classifications influenced ageist beliefs, or the ageist beliefs of society influenced psychiatric classifications (Collier, 2008a). However, ageism appears to have contributed to the persistent care narratives evident in discourse about older people (Department of Health, DH, 2003a) creating the context by which older people are viewed in health care settings which is a potential barrier to meaningful relationships (Collier & Yates-Bolton, 2011).

Challenges to knowledge about mental illness in old age began to emerge in the mid-20th century (Post, 1944; Roth & Morrisey, 1952; Roth, 1955; Kay et al., 1955), but it was not until 1987 that for the first time psychiatric classification manuals included the possibility that schizophrenia for example, could be developed after the age of 45 (American Psychiatric Association, APA, 1987). Schizophrenia was believed to be a hopeless and deteriorating condition, with a dementing process (Bridge et al., 1978). The people diagnosed with schizophrenia were expected to grow old in the mental institutions in which they lived and they became the ‘graduates’ (Dale & Burns, 1997; Campbell & Ananth, 2002; Kalim et al., 2005), ‘graduating’ into their old age with continued mental illness. It is from these people that we seem to have acquired much of our knowledge of growing older with mental illness as samples in medical research (referred to below), were drawn from such populations. However, the well documented disabling consequences of institutionalisation (Goffman, 1961; Harding, 1991; Mental Health Media, 2000; Carney, 2005), was apparently not considered in such studies and was even viewed as more of an advantage for research due to the believed lack of environmental influence such as life events and expressed emotion, common in the community (Soni & Mallik, 1993). Uncritical assumptions such as these resulted in nihilistic expectations regarding ageing with mental illness, for example that old age began earlier and was characterised by feeling useless, lonely and despairing (Quam, 1986).

Although the previously institutionalised sample was acknowledged as a flaw in the ‘Vermont studies’ (Harding et al., 1987a, 1987b), their 25 year follow up study found that over half of the people had improved so much in their functioning it was considered remarkable. Such improvement was also found in other studies (Bridge et al., 1978; Ciompi, 1980; Harding, et al., 1991; DeSisto et al., 1995; Harrison et al., 2001), but

inconsistencies were emerging with others finding that as many improved as deteriorated (Carpenter & Strauss, 1991), most remained stable (Jeste et al., 2003), or people remained unwell, got worse, or one set of symptoms was replaced by another (Soni & Mallik, 1993; Hegarty et al., 1994; Roberts et al., 2000; McNulty et al., 2003; Schimming & Harvey, 2004). In a meta-analysis of 320 studies, the worst outcome was found in those followed up for the longest (Hegarty et al., 1994), suggesting that people who have lived the longest with mental health problems were more likely to be less well. The perceived lack of positive symptoms (hallucinations and delusions) and continued apathy and lack of social skills at follow up was considered evidence that schizophrenia ‘burned out’. This belief continues today although there are variations regarding beliefs about the meaning of the term and its origins are elusive (Collier, 2007a).

The prognosis studies (referred to above) focused on schizophrenia with people who have been institutionalised but most mental health care now takes place in primary care rather than specialist environments (Lloyd et al., 1996; DH, 1999; Rethink, 2005; Cummings & Kropf, 2011). Studies of other types of mental illness such as anxiety or clinical depression are noticeable by their absence and surveys of mental illness have been deficient in their representation of older people (Henderson et al., 1998; Cohen et al., 2000; Brewin, 2007). However, the few studies that investigate long term outcomes relating to other types of mental health issues have found, using measures of depressive symptomology that mental health improves as people get older (Nilsson & Persson, 1984; Henderson et al., 1998; Jorm, 2000; McMunn et al., 2004; Rice et al., 2011). The participants of these studies however, are not people who have previous diagnosis of mental illness. Indeed Lloyd et al. (1996) found very high levels of attendance to General Practitioners (GPs) in an eleven year follow up for people with long term anxiety. Negative life events have also been

shown to be associated with later life depression (Kraaij et al., 2002) though only one study investigated events from early in life (Kraaij et al., 1997).

Community samples in research became more popular with the closure of the mental asylums in the 1990s (Cummings & Kropf, 2011). A speciality of old age psychiatry was established in 1988 (Jolley et al., 2004), and a new definition of 'graduates' emerged when people now living in the community were transferred from 'adult' to 'old age' services at the age of 65. Many of these people however appeared to become lost to services at this transition point as a result of death by natural causes, suicide, or homelessness (Campbell & Ananth, 2002), which had been identified as some of the key issues for this population (Abdul-Hamid et al., 1998; Abdul-Hamid et al., 1999). The needs of 'graduates' therefore have been identified as being significantly different from people who develop mental health problems for the first time in older age (Harding et al. 1987a, 1987b; Meeks & Murrell, 1997; Wynn Owen & Castle, 1999; Rodriguez-Ferrera et al., 2004; Jolley et al., 2004; Cummings & Kropf, 2011) as they have had to contend with social and economic disadvantage and disruptions in relationships in earlier adulthood (Cummings & Kropf, 2011).

The needs of people growing older with mental illness are invisible to policy makers (Abdul-Hamid et al., 1998; Cohen, 2001a; Wrigley et al., 2006a). The reason for this is two-fold; firstly because the number of people affected is unknown (Royal College of Psychiatrists, RCP, 2002; Bawn et al., 2007), and secondly there is also a risk that they are ignored by both general psychiatry (adult services) and old age psychiatry (Campbell & Ananth, 2002).

Problematic Policy Practices

Although there is little published evidence about the needs of ‘graduates’, it has been recognised that being transferred between services was problematic. It has been found to result in reconfigured relationships, resigned acceptance, and a catalyst for re-examining what it means to get old with access to certain types of care becoming limited or impossible (Dadswell, 2005; RCP, 2009a). The practice of transfer between different services was challenged by a National Service Framework for Older People (NSFOP) which introduced a standard on rooting out age discrimination (DH, 2001a). However, this policy itself has been accused of ageism (Baldwin, 2003; Benbow, 2005; Collier, 2005a) as it prioritised being ‘old’ over issues of mental ill health. This effectively excluded older people with mental health problems from the benefits of the comprehensive mental health policy aimed at 18-64 year olds (DH, 1999; DH, 2001b) and older people policy maintained only a narrow focus on recognising depression and dementia (DH, 2001a; DH, 2002a; DH, 2005a).

Developments for older people with psychosis related illness, considered severe and enduring mental illness, were said to be addressed within the National Service Framework for Mental Health (NSFMH) (DH, 1999; Dewing & Ford, 2001). However, the NSFMH directs attention to the (then anticipated) NSFOP (Collier, 2005a) which failed to offer guidance in this respect. Nevertheless, the recognition of the problematic nature of moving from one service to another on the basis of age led to the implementation of transition policies in community services where people were no longer automatically moved from ‘adult’ to ‘old age’ services at age 65, but remained with the team they may have been with for some time, only moving to an old age team if they developed significant changes related to dementia or physical ill health (RCP, 2009a).

Services should be accessible on the basis of clinical need rather than age (DH, 2004; MIND, 2005; DH, 2005a; DH, 2005b; DH, 2005c; DH, 2006a; DH, 2008) but age discrimination remains commonplace in health and mental health services (Bytheway et al., 2007; Age Concern, 2008; Beecham et al., 2008; DH, 2008; DH, 2009a; Mental Health Foundation, 2009; RCP, 2009b; DH, 2009b; Centre for Policy on Ageing, CPA, 2009). Government statistical records do not appear to record the incidence of the numbers of people over the age of 75 diagnosed with psychotic related disorders, despite evidence of a substantial numbers of older people being affected (Rodriguez-Ferrera et al., 1998; Cohen et al., 2000; Kai et al., 2000; Burns et al., 2002; Evans, 2003).

For people of working age with long term mental health problems, high proportions seen in a typical GP practice are considered a neglected majority living without effective support (Rethink, 2004; Sainsbury Centre for Mental Health, 2005), and the figures for people over the age of 65 are unknown. Consequently, as access to severely mentally ill people as participants in research relies on them being in some kind of contact with a support organisation, large numbers of people are missed who by their nature are hidden (Rethink, 2004). This is of particular significance for people who have lived into their old age with mental health problems as recommendations for primary care practices to survey how many ‘graduates’ they have registered has been ignored (Bawn et al., 2007). Even with a new mental health policy that has adopted a lifespan approach (DH, 2011) the risk of indirect discrimination continues to be of concern (CPA, 2009).

The invisibility of people who have lived with long term mental health problems into old age creates a situation where knowledge is undeveloped and ageing theory offers little in terms of understanding. Ageing theory appears to be focused on ‘normal’ or ‘ordinary’

ageing with mental illness being considered to be ‘abnormal’ or ‘pathological’ ageing with deference to psychiatry for explanations. This is unsatisfactory as psychiatry itself is controversial and is not the only model for understanding mental distress. Distrust has developed in the science of psychiatry, with its common misdiagnosis and/or multiple diagnoses, and its trial and error approach (Unzicker, 1989; Chafetz, 1996; Sholtis, 2002; Morisey, 2003; Schiff, 2004; Russell, 2007; Moeke-Maxwell et al., 2008). It has been suggested that mental health services themselves have been implicated in adding to mental distress. People often cope reasonably well with the symptoms of their illness, but it is other people’s attitudes that disables them, for example in gaining or sustaining employment and/or low expectations; negative attitudes that have to be incorporated into a person’s recovery (Deegan, 1988; Deegan, 1993; Sayce, 1998; Sayce, 2000; Deegan, 2001; Ridgway, 2001; Lilja & Hellzén, 2008; Happell, 2008a, Happell, 2008b).

Psychiatric patients are citizens capable of contributing and being included in society (Sayce, 2000; Repper & Perkins, 2003), a principle with which I wholeheartedly agree. In the process of developing this thesis however, I found that I came up against some uncomfortable challenges as my thinking developed, and a dawning realisation of the continued influence of the medical model on my understanding of mental ill health and how difficult it could be to shift ones assumptions and world views once they have been established. Part of the challenge to this thinking came about as I broadened my reading to non-academic sources.

Personal influences: The Railway Man and other tales

The Railway Man by Eric Lomax (Lomax, 1995) is a book about the personal experiences of being a Japanese prisoner of war, an experience that resulted in on-going mental distress

throughout Eric Lomax's life, distress he did not tell anyone about until he was in his 70s when he wrote the book. He had chosen to keep his experiences private, but they did not stop him from marrying, having children and living a successful life. His many achievements happened despite his mental health difficulties and I wondered how he had managed to do this without his family ever knowing about his struggles. I was also aware that to some, in certain circumstances or places, he might have been described as having had chronic mental health issues. The two images clashed in my mind: the successful man who kept his mental distress private and the people who had shared their distress and become chronic mental patients with the more restricted opportunities this potentially created. The latter image was informed by having been exposed to attitudes in mental health care that did not value 'chronic' patients, people who would not get better. This lack of value was illustrated to me more recently, when I told a mental health nurse delegate at a conference what my thesis was about. It was dismissed with a wave, 'oh, the chronic stuff', followed quickly with an apologetic smile and the recognition that we should not think like that, 'oh, that's the point isn't it?' she said. It seemed to me that there was a great deal to learn from people like Eric Lomax who managed himself and apparently avoided mental health services and the risks of institutionalisation, despite on-going mental distress.

I sought out more personal tales of people living with long term mental health problems, particularly those written by people who were older. Personal biographies demonstrated private suffering and public achievement, for example, Constance Briscoe (2006), Liz Smith (2006), Julie Goodyear (2006), Jane Fonda (2006) and Kim Woodburn (2007). These biographies were written by successful people who present their successes and the challenges they faced, rather than conceptualising their personal narrative around being a 'mentally ill' person. In contrast, people such as Sylvia Fraser (1987), Kay Jamison (1997),

Ken Steele (Steele & Berman, 2001), Ruby Wax (2004) and Rosie Childs (2007) communicate a more specific focus on experiences of mental ill health and the kind of things that helped and challenged them. However, my email communication with Sylvia Fraser demonstrated that she did not see her life framed in terms of mental ill health, which is how I had understood her book 'My Father's House' (Fraser, 1987). She wrote;

'I don't consider that I suffered mental ill health; rather I had highly negative experiences with which I coped, short term, in a lifesaving and reasonable way' (Personal communication, 12/8/2007).

Such differences in interpretation are problematic in a culture that values medical models of mental illness and where psychiatry and its services are the dominant voice (Crossley & Crossley, 2001). It demonstrated a world view outside of psychiatry and illness constructs, a position congruent with more recent discussion regarding a concept of 'recovery'.

Recovery: a frame of reference.

In the past, it was believed that schizophrenia was incurable, and people who were found to improve in research were often considered to have been misdiagnosed and therefore excluded from analysis (Kruger, 2000). Research that found large numbers of people improving however was further validated by an American woman diagnosed with schizophrenia who was residing in a rehabilitation service, when she published a personal account of her experience that questioned the negative perceptions and low expectations that professionals had of people like her (Deegan, 1988). She argued that people with schizophrenia can get better but challenged the use of the medical concept of recovery which did not reflect her experience. Pat Deegan argued that she was not recovering from schizophrenia, but was recovering a new sense of self and purpose despite the challenges of helping services that created barriers to this. Shortly after being told she had schizophrenia she made the decision that she would become a doctor so that she could change prevailing

beliefs and assumptions (which she has achieved), and notes that had she voiced this at the time she would have been thought to have delusions of grandeur (Deegan, 2001).

The subsequent emergence of recovery approaches in mental health services aimed to challenge the previously discouraging evidence about the hopelessness of mental illness and empower service users by focusing on individual strengths, abilities, aspirations and the transformative processes involved in life's challenges (Anthony 1993; Deegan, 1993; Spaniol et al., 1997; Reeves, 1998; Brown, 2001; Deegan, 2001; Jacobson & Greenley, 2001; Turner, 2002; Roe et al., 2004; Rethink, 2005; Campbell, 2007). This new philosophy that validates service users' accounts of their own definitions and understanding of mental ill health has been described as a new paradigm (Barker, 2003; Double, 2005; Onken et al., 2007; Watkins, 2007) and I realised it was the lens through which I had been considering growing older with mental ill health. This was because of an apparent lack of knowledge regarding this area of practice and the attempt to find a framework that could inform the development of such knowledge other than a medical one.

However, there is much confusion regarding the concept of recovery as the same term has been used for different meanings (Jacobson & Greenley, 2001; Wallcroft, 2005; Rethink, 2005; Till, 2007; Collier, 2010a). It has been suggested that the concept remains abstract due to the ambiguity of definitions of mental illness (Onken et al., 2007). The medical research about long term mental illness is clear in its aims to discover the outcomes of the process of recovery from diagnosed mental illness, that is, the recovery of health being the central purpose for psychiatrists (Whitwell, 1999). This traditional perspective is clearly dominant in pre 1990s literature and different from what I will refer to as contemporary recovery although this literature dates from the late 1980s. Davidson & Roe (2007) suggest

that two notions of recovery can be distinguished: 'recovery in' and 'recovery from' mental illness. This acknowledges that people can remain 'ill' as measured by medical symptoms, but be 'well' in that they can live with or manage their experiences whilst achieving in other aspects of life (Jacobson & Greenley, 2001; Davidson et al., 2005a; Buchanan-Barker, 2009). Service users question the validity of clinical professional measures of recovery where they do not match those of their own (Patching & Lawler, 2009) particularly when misguided interpretations of their experience distresses them (Lovejoy, 1984; Unzicker, 1989). There is an accumulating body of narrative evidence that offers examples of surviving mental health services, demonstrating that despite oppression, people found ways to survive (Read & Reynolds, 1996; Barker et al., 1999).

Individual definitions of contemporary recovery commonly refer to a journey, a transformative process without an end point, the overcoming of challenges and taking control of life, growing beyond any limitations and realising hopes, dreams and aspirations through personal growth, vision and healing (Deegan, 1988; Deegan, 1993; Anthony, 1993; Spaniol et al., 1997; Reeves, 1998; May, 2000; Jacobson & Greenley, 2001; Brown, 2001; Deegan, 2001; Bledsoe, 2001; Turner, 2002; Repper & Perkins, 2003; Rethink, 2005; Campbell, 2007). It is generally accepted that the concept of recovery has evolved to accept and depend on individual definitions (Social Care Institute for Excellence, SCIE, 2007). Individually constructed meanings of experience results in multiple realities where individuals can offer their own explanations in keeping with their own way of making sense of the world, and/or of any experience of an unusual or distressing nature (Collier, 2010a). It does not mean that all symptoms or suffering has disappeared or that biological treatments are rejected, but that people can choose what models and interventions suit them in reclaiming their lost roles, responsibilities and self-knowledge (Deegan, 1993; Repper,

2000; Perkins & Repper, 2004; Till, 2007). Suggestions have been made to delineate between clinical and social recovery (SCIE, 2007) but in contrast with traditional notions of recovery, contemporary recovery ideas include the possibility that individuals can reject psychiatric diagnosis when they do not have a place in personal understanding of mental ill health (Onken et al., 2007). This places medical models of understanding mental ill health and associated notions of medical recovery as one choice amongst many and it has therefore been suggested that medical recovery becomes subordinate to what has been termed life recovery (Collier, 2010a).

It would seem that in searching for a process of recovery from mental illness, what has been discovered is a process of life, that people who are classed as mentally ill live their lives as others do but within a particular life context (Davidson & Strauss, 1995). Life is a process and is not changed by one thing (Unzicker, 1989; Buchanan-Barker, 2009) and recovery of one's life or life recovery (Collier, 2010a) encapsulates the personal nature of living with mental ill health that accepts the reality that individual narratives create. Although mental health services have embraced the challenge to negative attitudes that recovery principles offer, current systems do not have the capacity to honour the principles or incorporate paradigm shifts in practice (Lester & Gask, 2006) for example, when psychiatric diagnosis is required for national statistics or access to benefits such as disability living allowance.

The debate regarding classifications of mental illness, and the more personal descriptions of experience promoted within recovery principles show how slippery words can be, creating various meanings depending on how they are interpreted (Maykut & Morehouse, 1994; Church, 1995). As this thesis draws on the many different perspectives of what others say about their experience and all terms are equally meaningful or meaningless (Casey & Long,

2003), the terms mental distress, mental illness, mental health problems, mental disorder, mental health difficulties, mental health issues and mental ill health will be used interchangeably, often dictated by the context in which they are used or as a term a particular narrator uses.

Overview of the Thesis

The literature review, presented in the next chapter (two) will focus on locating the evidence regarding personal experiences of ageing (long term) with mental health problems. It will review the research literature and peer reviewed autobiographical accounts on the experience of long term mental ill health and experience of recovery. The chapter provides an explanation as to the rigorous process of searching for and locating such literature which raises questions about the nature of age inclusions in research and the adherence to medical frameworks in understanding individual experience. The exclusion of older people from the literature about experiences of mental ill health and recovery is highlighted as is the largely unexplored extensive histories of mental ill health for some individuals.

Chapter three explains the methodology and methods used in this study and the related philosophical underpinnings, that is, social constructionist epistemology, narrative inquiry methodology and biographical research method. It will describe the use of the curriculum vitae, a tool as yet unexplored in a research context, but which enables a structure to be established for life history by which interviews can be individually tailored. It also describes and discusses the practical implementation of the research methods as well as outlining the methods of interpretation using over-reading (Poirier & Ayres, 1997) and life course theory (Elder & Giele, 2009).

Chapters' four to ten present the individually interpreted narratives, one in each chapter for seven participants. Chapter eleven then presents the discussion of the findings within a collective text that draws the individual narratives together and provides discussion with reference to relevant literature. Chapter twelve then provides a discussion of the implications of the findings for health and social care and the final chapter, chapter thirteen makes recommendations and the thesis concludes with some personal reflections.

Conclusions

This chapter has introduced the study topic and provided some reflexive context that has influenced the development of the thesis. It has examined how relevant policy and theory informs our knowledge of ageing and mental ill health, noting that there is very little understanding of this. It has highlighted an absence of any understanding regarding individual's personal experience of living with long term mental ill health to older age due to the nature of methods that focus on measurable concepts in the prognosis of illness. There is no qualitative information in these outcome studies about participant's views or their satisfaction with their choices. In trying to understand this area of knowledge, the literature review presented in the next chapter will focus on locating evidence regarding the experience of living with long term mental illness.

Chapter Two

Literature Review

Introduction

Theoretical issues such as psychiatric classification, old age, life span and recovery are implicated in a study of long term mental illness into older age, and these issues shape decisions about searching for relevant literature. Databases are organised by way of categorisation and this can create some practical difficulties. If terms representing ‘old age’ were included, this would locate literature focused on experiences relevant only to ‘old age’ as a category of interest unlike research on mental ill health in younger adults which rarely if at all considers age of any notable importance. The arbitrary divide that defines old age in choosing age specific research samples so often utilised, creates a barrier to identifying relevant literature that examines the long term experience of mental ill health into older age.

This chapter will discuss the development of a search strategy that aims to overcome such problems and will provide a critique of published literature that focuses on personal experience of long term mental ill health. The rigorous exclusion criteria for the literature review has enabled a prioritisation of those papers that represent listening to and hearing people’s experiences of mental ill health, an issue that is surprisingly limited in the academic literature (Casey & Long, 2003; Jensen & Wadkins, 2007).

Search issues and strategy

There are a number of databases available that have the potential for locating relevant literature related to mental health issues. These are CINAHL, Medline, psycINFO, PsycEXTRA, BNI, ASSIA, AMED and additionally, one focused specifically on old age,

AgeInfo. Between them these databases contain professional and academic literature that covers a wide range of professional disciplines including psychiatry, nursing, psychology, sociology, complementary therapy, social sciences, and allied health such as occupational therapy and social work. Each database has a different focus and style and therefore needs individual consideration as to the most effective search method. AgeInfo is a bibliographic database on social gerontology that provides access to references held at the Centre for the Policy on Aging from 1975 to the present. A simple search using the term ‘mental’ is an efficient way of determining what themes there are in this database on old age and mental health/illness issues. On 13th January 2010 there were 4744 hits using the term ‘mental’. 106 of these were published in 2009 and an examination of the themes that occur in these articles reveal the following;

➤ dementia related articles	15% (16)
➤ mental capacity related articles	16% (17)
➤ policy/consultation in health and social care	12.2% (13)
➤ mental and physical health	12.2% (13)
➤ functional mental illness	14% (15)
➤ others including safeguarding adults, end of life care, BME	6.6% (7)
➤ other including driving, carers, attitudes, long term conditions (physical), education	23% (25)

This selective example reveals that 31% (33) of the articles are about dementia or mental capacity and only 14% (15) focused on functional mental illness (such as schizophrenia, depression, anxiety). This demonstrates a relative neglect of functional mental health issues in the available literature, and a continuing disproportionate focus on organic issues in later life (Cohen, 2001a; Collier, 2005a; Collier, 2006a) despite the far greater prevalence of the former in the population (Burns et al., 2002). This highlighted two problems for locating literature about long term mental ill health, first, that old age

literature itself neglects functional mental ill health issues and second, that finding literature relevant to lifespan experience of mental ill health into old age could be extremely limited.

Prior to the identification of the research questions shown in chapter three, ad hoc searches were conducted at regular intervals throughout the duration of the study and revisited more systematically at the later stages. This enabled a broad consideration as to what the key issues might be that informed the search plan and selection of key terms. The key concepts for an initial scoping search became ‘experience’, ‘mental illness’, ‘achievement’ and ‘life course’ (appendix 1). These were used in searching the databases psycINFO, psycEXTRA, BNI, AMED, Medline, CINAHL, ASSIA and AgeInfo.

Searches were limited to English language only, and those databases that contained records prior to 1950 were limited to 1950. This time limit was chosen as it represents a time when standardised diagnosis was formalised in statistical manuals (World Health Organisation, 1948; APA, 1952) and prior to this date research focused almost exclusively on illnesses rather than people.

Inclusion and exclusion

There were many terms excluded from the searches that had no relationship to experience of mental illness, for example, biological ageing or carer perspectives (appendix 2). In addition, inaccessible international dissertations, and book chapters that had not been peer reviewed were excluded. The initial scoping search found 7210 hits and abstract screening resulted in the identification of 151 potentially relevant articles (appendix 3). Many of these were about the experience of hospital or treatment as psychiatric patients and these were therefore excluded as they were focused mainly on the experience of services rather

than of mental ill health, 'patient' rather than 'person' narratives (Frank, 1995). Similarly, papers on quality of life were excluded as they tended to focus on personal experience as a resource in developing standardised tools to measure quality of life. Their inherent purpose was to generalise about populations or groups, and this inevitably lost sensitivity to individual experience or meaning making. Knowing that a person's symptoms are improved six years after contact with a service or that they now have a job, tells us nothing of their struggle to achieve this, nor does it capture individual differences that vary over time depending on the person's expectations, aspirations, self-appraisal, coping strategies and current life experience (Holloway & Carson, 2002). On excluding quality of life and patient experience papers, 114 papers remained.

A focused search was then conducted which replicated the searches but with terms associated with excluded papers omitted. Subject headings for each of the identified search terms were utilised and the full range of terms used in the search can be seen in appendix 4. Searches were conducted using permutations of these terms (appendix 5). This focused search located 128 papers. Most of the new papers found in the focused search were first person accounts. Citation referencing located a further ten papers. There appeared to be four broad categories of papers;

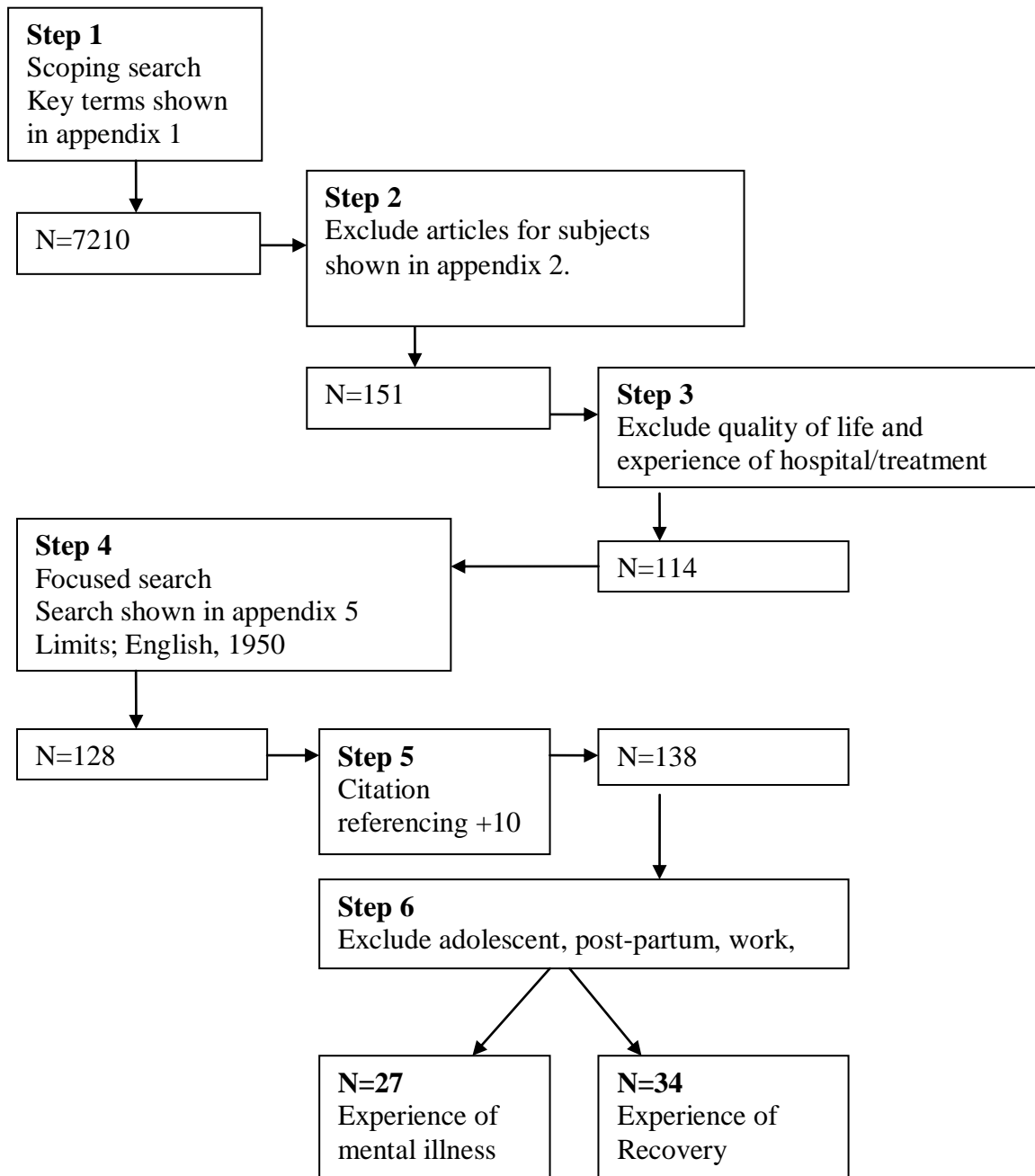
- research investigating selective aspects of life e.g. work, religion
- first hand personal accounts
- papers focused on recovery (including some personal accounts)
- research investigating personal experience of mental illness

Most of the papers that investigated *mentally ill person's* experience of some aspect of life were about paid work, that is, the effect of mental illness on the experience of this. This is inherently excluding of people outside of workforce age groups and therefore not representative of the life course experience that would include older people. It was also

selective about an aspect of life that provided only a narrow focus on a particular area of experience. For this reason these papers were excluded. Those focusing on *person's* experience of mental ill health were retained. This included autobiographical accounts as they provide 'storied knowing' that add to the depth of knowledge provided by 'distanced' researchers (Smith, 1999). Papers focussing on adolescent experience and post-partum experience were also excluded at this stage due to their specialist focus. The autobiographical accounts were further reduced by excluding papers that had a dual purpose, making reference to personal experience within an integrated theoretical discussion, as they did not contain sufficient detail of the individual story to enable conclusions to be drawn for the purpose of the literature review. In addition, it is acknowledged that there is considerable confusion regarding the theoretical perspectives in recovery literature (Jacobson & Greenley, 2001; Wallcroft, 2005; Rethink, 2005; Till; 2007; Collier, 2010a), and clinicians and service users have different measures of recovery (Patching & Lawler, 2009). Therefore, the recovery research and autobiographical accounts about recovery located during the search were examined separately. Once the final exclusion criteria had been applied and duplicates had been removed 27 papers focused on the experience of mental ill health remained and 34 papers focusing on recovery. Summary of the searching process can be seen in Figure 2. The 34 papers on recovery are outlined separately at the end of the main review of literature focusing on the long term experience of mental illness.

Figure 2.

Search Strategy Summary



Review of the literature

Overview

The main review of literature focuses on personal experience of mental ill health which includes 19 research papers and eight autobiographical accounts.

With regard to the quality of the papers, the inclusion criteria established that only papers published in academic journals and subject to peer review were included, ensuring that the papers had already been subject to assessment. Data extraction tables were created for the research papers and these informed their evaluation. The autobiographical accounts are not neat, linear accounts and they articulate personally significant memories, events and relevancies at the core of their stories. Reference is therefore made to TAPUAS (transparency, accuracy, purposivity, utility, accessibility and specificity) to guide the process of appraisal for these papers (SCIE, 2003). What is most striking about the autobiographical papers when compared to research is the breadth and depth of experience recounted. The authors are not restricted nor their accounts shaped by researchers questions and they tell the story they choose to tell.

Of the 27 papers reviewed, 19 were research papers published between 1994 and 2009 the majority of which (14) are post 2000. Studies published before 1995 appear to rely on aims related to aetiology and medical constructs, leaving gaps in knowledge of the subjective experience (Karp, 1994; Lewis, 1995). Indeed Lewis (1995) notes that prior studies had in fact considered subjective experience to be a bias. The growing number of research studies focused on subjective experience may reflect the change influencing international policy that has redefined the role of the service user and sought out this voice. However, not all

people may be considered service users, and personal experience of mental ill health continues to be captured in a variety of ways.

The research studies were conducted in America (6), Canada (3), Sweden (6), Australia (1) and the UK (3). There are six personal accounts from the US, one from the UK, and one from Australia published between 1984 and 2004.

Congruent with the expectation for qualitative studies that seek to provide in-depth understanding rather than generalizability from large sample sizes (Silverman, 2000), numbers of participants are relatively low with between four and 48 participants included in all but one study which surveyed 166 people (Ritsher et al., 1997). Three studies were reported as ethnographic (Erdner et al., 2002; Erdner et al., 2005; Erdner et al., 2009) and three used grounded theory approaches (Karp, 1994, Lewis 1995, Repper et al., 1998). Two studies simply describe a qualitative research method approach (Roe et al., 2004; Thompson et al., 2008). The philosophical underpinning of methods is not discussed in four studies; Chafetz (1996) using a life chart history approach, Chernomas et al. (2000) using focus groups, Ritsher et al. (1997) who undertook a quantitative survey and Lester & Tritter (2005) who refer to a focus group study utilising disability theory as a specific frame of reference through which to explore the experience of serious mental illness. The approaches taken are congruent with studies that have a range of purposes the majority of which are exploratory studies.

Table 1. illustrates the specified concepts of interest in all the papers reviewed (Research papers are indicated as R; autobiographical accounts as A).

Table 1. Key concepts within articles reviewed

<u>Mental illness</u>	Mixed gender samples/gender unknown	Women/ female	Male	Elderly
Depression	RR	R*R* A		R*R*
Eating disorders		R		
Bipolar disorder			A	
Schizophrenia/ schizo affective	R A	R AAA	AA	
Psychosis	RR			
Mental health problems		R		
Serious/severe mental illness	RRRR	RR		
Long term mental illness	RRR			

* *same two studies*

Many of the papers focused on single specific diagnosis, with a number also investigating this within a gender perspective and the aims of the studies varied.

Aims

Table 1. illustrates that the aims of seven of these studies pertain specifically to women's experience and in addition that most relate to specific classified mental illnesses. Within this context, the aims relate to; achieving deeper understanding (Hedelin & Strandmark, 2001; Hedelin & Jonsson, 2003), contrasting women's issues to men (Ritsher et al., 1997), explore women's lives (Repper et al., 1998), their perceptions (Chernomas et al., 2000), the nature of the problems and their needs (Nehls & Sallmann, 2005), and their understanding and interpretations (Broussard, 2005). Two papers have a particular focus on elderly women and these papers are both part of the same study (Hedelin & Strandmark, 2001; Hedelin & Jonsson, 2003). Those with mixed gender samples similarly aim to seek understanding (Roe et al., 2004), meaning (Karp, 1994; Lewis, 1995; Nyström et al., 2002), experience of life (Erdner et al., 2002; Erdner et al., 2005; Erdner et al., 2009), experience of illness (McCann & Clarke, 2004; Thompson et al., 2008) or experience with ageing

(Tryssenaar et al., 2003). Seven studies are distinguished by their focus specifically on long term or severe mental illness (Chafetz, 1996; Repper et al., 1998; Erdner et al., 2002; Tryssenaar et al., 2003; Erdner et al., 2005; Thompson et al., 2008; Erdner et al., 2009). One study does not state its aims (Lester & Tritter, 2005).

The reference to specific named mental illnesses is consistent apart from three studies (Roe et al., 2004; Nehls & Sallman, 2005; Erdner et al., 2009) two of which instead focus on psychosis as a symptom, as recommended by the British Psychological Society (2000), and one on mental health problems. As the studies aim to understand subjective experience, this appears to be based on the assumption that illnesses are definable and experience reflects them. The aim of the autobiographies is not stated, but presumably there is a desire to educate others, in particular an academic audience, and to achieve personal satisfaction. It appears that some authors received a request to submit their story, and the Schizophrenia Bulletin requires that they describe a novel or unique aspect of schizophrenia (McGrath, 1984; Leete, 1989; Chapman, 2002).

Recruitment

Many of the studies (15) recruit participants through mental health service locations or practitioners in touch with participants. Consequently, most samples were convenience samples with some people taken as sub-groups from previous studies (Karp, 1994; Hedelin & Strandmark, 2001; McCann & Clarke, 2004; Roe et al., 2004), one additionally employing snowball sampling (Karp, 1994). One study recruited through Primary Care Trusts (Lester & Tritter, 2005), and one through statutory and non-statutory health services and a university (Lewis, 1995). Only two studies do not locate any participants within health services (Karp, 1994; Broussard, 2005) instead meeting them through personal

acquaintance, newspaper advertisements, snowball sampling, and through posters and newsletter advertisements within a university.

The choice of agencies for recruitment relies on people accessing such agencies and may reflect a particular type of participant (Tryssenaar et al., 2003). However, in recruiting only from a university, Broussard (2005) discovered that eight of the 13 women who participated had never confided in anyone before and had never sought treatment thus highlighting the existence of an invisible population of people with mental health problems.

Classification of mental illness

The reality of a disorder model is largely accepted, that is, participants are often required to have a psychiatric diagnosis as an inclusion criteria (Karp, 1994; Hedelin & Strandmark 2001; Nyström et al., 2002; Hedelin & Jonsson, 2003; Roe et al., 2004; Lester & Tritter, 2005; Thompson et al., 2008; Erdner et al., 2009), are described in terms of classified mental illnesses (McCann & Clarke, 2004; Lester & Tritter, 2005), or self-identified with a mental illness (Lewis, 1995; Chernomas et al., 2000; Broussard, 2005). Those requiring that they had a severe or long term mental illness for inclusion were also described in terms of their diagnosis (Chafetz, 1996; Ritsher et al., 1997; Repper et al., 1998; Erdner et al., 2002; Tryssenaar et al., 2003; Lester & Tritter, 2005), though Nehls & Sallmann (2005) require only that they have ‘mental health problems’, substance abuse and a history of abuse.

Ten studies had a significant focus on schizophrenia or psychosis reflected in their inclusion criteria or in participant characteristics (Chafetz, 1996; Repper et al., 1998; Chernomas et al., 2000; Nyström et al., 2002; Erdner et al., 2002; McCann & Clark, 2004;

Roe et al., 2004; Erdner et al., 2005; Lester & Tritter, 2005; Erdner et al., 2009) though a wider range of diagnosis were represented in some studies (Ritsher et al., 1997; Tryssenaar et al., 2003; Nehls & Sallman, 2005; Thompson et al., 2008). Depression was the specific diagnosis of interest for four studies (Karp, 1994; Lewis, 1995; Hedelin & Strandmark, 2001, Hedelin & Jonsson, 2003) and eating disorder for one study (Broussard, 2005).

Psychiatric classification is organised around sets of characteristic symptoms. To have a particular diagnosis as an inclusion criterion positions the research somewhat around illness as the primary focus. Although this enables further understanding as to how individual experience can differ in relation to such diagnosis, one difficulty is that it is not necessarily the case that the diagnosis is representative of the person's experience. Some people reporting multiple different diagnoses having been given to them either over time or at the same time further implicate the process of diagnosis in additional mental health challenges (Chafetz, 1996; Sholtis, 2002).

Disagreement or questioning of diagnosis as an explanation or description of experience is common (McGrath, 1994; Karp, 1994; Lewis, 1995; Ritsher et al., 1997; Lundin, 1998; Hutchinson, 2004) with high proportions of people citing stress, bad nerves, spiritual fight, life's woes or problematic early experiences as alternative explanations (Ritsher et al., 1997). For those researching 'severe' or 'long term' mental illness (the former apparently implicated in the latter), detail is unavailable as to how people identified themselves as having severe mental illness apart from diagnosis, perhaps reflecting the locations used for recruitment, that is, specialist mental health services (Repper et al., 1998; Ritsher et al., 2007; Nyström et al., 2002; Erdner et al., 2002; Tryssenaar et al., 2003; Erdner et al., 2005; Lester & Tritter 2005).

Classification is also a feature of the autobiographical accounts and appears to be an integral part of individual sense making. Five of the authors describe themselves as having schizophrenia, (one including substance abuse), one schizoaffective disorder, one clinical depression and one bipolar disorder. However, there is evidence of these diagnosis being incorporated into complex personal formulations of mental illness that include genetic predisposition and environmental stress (Walker, 1999), irritable brain supersensitive to stimulus (Leete, 1989) and emotional disjunction and chemical imbalance (Sholtis, 2002).

Duration of illness

Long term duration of mental illness is specifically required for inclusion for six papers (Chafetz, 1996; Erdner et al., 2002; Tryssenaar et al., 2003; Erdner et al., 2005; Thompson et al., 2008; Erdner et al., 2009), but only three provide definitions. These are; in treatment for more than two years (Thompson et al., 2008), illness for more than five years (Erdner et al., 2009), and illness for a minimum of 15 years (Tryssenaar et al., 2003). It is unclear why being in treatment is a parameter other than reinforcing a central importance of health services. Those studies that imply long term through their use of the terms 'severe' or 'serious', (but not defining long term as an inclusion), often report characteristics representing significantly longer duration than defining features specified elsewhere. These are; long term contact with mental health services for more than ten years (Repper et al., 1998), more than 30 years (Chernomas et al., 2000), 10-22 years (Erdner et al., 2002), 15-40 years (Nyström et al., 2002), 1-32 years (mean of 8.8) (Lester & Tritter, 2005), or 1-23 years (mean of 6.3) (Broussard, 2005). The relatively low mean durations cited in the latter references demonstrate that there may be a minority of single individuals in research samples having a particularly lengthy experience, some from childhood and adolescence (Broussard, 2005).

The autobiographical accounts consistently illustrate a particularly long term experience of mental ill health though one account has no temporal parameters defined (Walen, 2002). For those which do, at the time of writing the duration of their ill health was in excess of 15 years (Sholtis, 2002; Hutchinson, 2004), with three authors recounting more than 20 years (Leete, 1989; Lundin, 1998; Champ, 1998).

Age of participants

Age as an inclusion criterion varies, in some cases restricted by the specific focus, for example elderly people (Hedelin & Strandmark, 2001; Hedelin & Jonsson, 2003). Studies that state age as an inclusion criterion and/or describe age characteristics can be seen in appendix 6. Two studies do not report age (Chafetz, 1996; McCann & Clark, 2004). Chernomas et al. (2000) indicate age groups from age 21 years in decades up to 60 years, then an over 60 category is described (two people). Although providing any detail of adult age groups is unusual, it betrays a dismissal of any significance about adult age groups beyond 60 years, of older people classed in a homogenous group, a distinction that is not explained.

It is possible that the upper age inclusions and descriptors (shown in appendix 6) demonstrate decisions about recruitment that depend on the geography of mental health services and where participants are to be found. For example, in England, adult services have been commonly designated for people aged 18-64 and later life services for those over the age of 65. Given that the aims of the studies do not relate to service provision there does not appear to be any theoretical justification offered for age limits. Only Chernomas et al. (2000) attempts to address the temporal nature of the experience within life stages. Repper et al. (1998) note that there were considerable differences in the findings between

the 'younger' and 'older' women (undefined) in their study that had an age range of 25 to 65 years. It is surprising that the one study that specifically aims to understand the experience of ageing with mental illness (Tryssenaar et al., 2003), achieves a sample aged up to only 64. Within this study, community agencies serving adults with serious mental illness developed a list of possible participants. This suggests that either there was a potential selectiveness by those personnel acting as gatekeepers; that the services were for a specified age range only or, older people did not put themselves forward for unknown reasons.

The age of the authors of the personal accounts is not always clear and for some there is no indication other than long length of experience (Walker, 1999). Where age is indicated or implied they appear to be over 30 years (Hensley, 2002; Hutchinson, 2004), over 40 years (Leete, 1989; Lundin, 1998; Champ, 1998; Chapman, 2002; Sholtis, 2002), and over 50 (Walen, 2002).

Demographic information

Different demographic characteristics (Table 2) were collated within many studies but do not appear to have any relationship to their discussions, apart from Ritsher et al. (2007) who in a sub-analysis found no significant differences between men and women in their survey for age, race, education, employment and diagnosis.

Table 2. Demographic characteristics reported

Characteristic	Paper
Marital status	Karp, 1994; Repper et al., 1998 ; Chernomas et al., 2000; Erdner et al., 2002 ; Tryssenaar et al., 2003; Broussard, 2005; Ritsher et al., 2007
Parental status	Repper et al., 1998 ; Chernomas et al., 2000; Erdner et al., 2002; Tryssenaar et al., 2003; Nehls & Sallmann, 2005
Living situations	Chafetz, 1996; Repper et al., 1998; Tryssenaar et al., 2003; Nehls & Sallmann, 2005; Ritsher et al., 2007
Employment or benefit status	Karp, 1994; Chernomas et al., 2000; Tryssenaar et al., 2003; Erdner et al., 2005; Nehls & Sallmann, 2005; Ritsher et al., 2007;
Race/ethnicity	Karp, 1994; Chafetz, 1996; Repper et al., 1998; Roe et al., 2004; Broussard, 2005; Erdner et al., 2005; Nehls & Sallmann, 2005; Lester & Tritter, 2005; Ritsher et al., 2007
Education level	Karp, 1994; Ritsher et al., 1997 ; Chernomas et al., 2000; Broussard, 2005; Nehls & Sallmann, 2005
Religion	Karp, 1994
Age of onset	Erdner et al., 2002
Hospitalisations or service use	Roe et al., 2004; Erdner et al., 2005; Lester & Tritter, 2005

There is a lack of consistency in the demographic information inferred in the personal accounts with no indication of ethnicity or living situations. There are indications of roles as parents and spouses and occasional references to religion. In addition, not all refer to their schooling or education (McGrath, 1984; Leete, 1989; Champ, 1998), possibly highlighting its relative unimportance to the individuals or the desire to forget. Many people attended university (Lundin, 1998; Walen, 2002; Sholtis, 2002; Hensley, 2002), some indicating education to masters level (Sholtis, 2002; Hensley, 2002), whereas Hutchinson (2004) did not complete college. There are indications about education in relation to employment, Walen (2002) being employed in a professional role as was Sholtis (2002) who now claims disability benefits and undertakes ‘undemanding’ jobs. Four of the authors were employed in a service user role or employed to work with service users (Leete, 1989; Lundin, 1998; Hensley, 2002; Hutchinson, 2004), and one an artist and government worker (McGrath, 1984).

Data collection and analysis methods

A variety of methods were used to collect data. All but one study employs interviews, several with additional strategies; one followed a period of participant observation (Erdner et al., 2005), two utilised photographs taken by participants for points of discussion (Thompson et al., 2008; Erdner et al., 2009), and four conducted multiple interviews (Erdner et al., 2002; Nyström et al., 2002; Roe et al., 2004; Broussard, 2005) with the aim of enabling reflection and opportunity to add or change narratives. Roe et al. (2004) conducted interviews with each participant every six months for up to three years. Three studies used focus group interviews (Repper et al., 1998; Chernomas et al., 2000; Lester & Tritter, 2005), one participant observation in a self-help group (Karp, 1994), and one a survey developed by service users (Ritsher et al., 1997). Chafetz (1996) utilised a life history interview adapted from the Vermont longitudinal questionnaire.

Four studies were selective about areas of inquiry (Karp, 1994; Chafetz, 1996; Chernomas et al., 2000; Erdner et al., 2002), which included living arrangements/housing, support/family/personal/social relationships, use of services, daily activities, work, finance, treatment, substance use, coping strategies, reproductive health, sexuality, parenting, menopause and getting older. Roe et al. (2004) specifically aims not to predetermine areas of questioning, but goes on to utilise a semi-structured interview that assesses course of disorder focusing on symptoms, treatment, social relationships, employment and perceived role. Predetermined areas of inquiry can hinder emerging new insights, and methodology that does not use a pre-existing template, such as a life history approach is thought to be beneficial (Patching & Lawler, 2009). Life history method has other benefits illustrated by Repper et al. (1998) who reconstructed eight biographies from focus group interviews after

they found that the thematic analysis of group transcripts reduced the impact of individual stories and did not reflect the women's actual experience.

What Chafetz (1996) describes as a life history method appears in fact to be a socio-medical history method. The pre-defined template results in themes that are all related to the mental health system and treatment, with additional reference to residence and relationships, work and income. This perhaps comes about due to the sampling frame which encompasses people who had lived long term in hospital environments, a population also apparently targeted though its relevance not properly discussed by others (Nyström et al., 2002; Erdner et al., 2002; Tryssenaar et al., 2003; Erdner et al., 2005; Erdner et al., 2009).

Most of the studies utilised thematic analysis. However, in the study of 'ageing with mental illness' (Tryssenaar et al., 2003) this thematic approach is particularly limited as it results in the compartmentalisation of the stories which appears to lose sensitivity to the long term aspect of the experience that the study aimed to capture.

Authenticity of data

Those studies that justify their methods tend to focus on recognition that people with severe or long term experience of mental ill health may find their concentration or ability to express themselves reduced (Repper et al., 1998; Erdner et al., 2002; Erdner et al., 2009), resolved in two cases by more than one interview that enabled collection of meaningful data (Erdner et al 2002; Nyström et al., 2007). This may have also been enabled by providing interview questions prior to the interviews (Tryssenaar et al., 2003). The use of visual and interactive tools contribute to a solution to concentration problems (Chafetz,

1996; Thompson et al., 2008; Erdner et al., 2009), however Chafetz (1996) also demonstrates a rather more paternalistic solution by seeking to verify individual narratives with reference to clinicians ratings and notes. In contrast self-selection was thought to facilitate participation of people ready and willing to talk about their lives (Chernomas et al., 2000).

Despite recognition of the impact of long term problems, further requests were made of the participants for methodological purposes. This included the return of transcripts for verification (Erdner et al., 2002) and returning interpretations for comment (Hedelin & Strandmark, 2001; Broussard, 2005).

Findings

The findings reported in the papers reviewed were organised into themes. This was done by noting all key words and concepts evident for each individual paper throughout the reported findings and from the whole article for personal accounts. These key words and concepts were clustered together as they emerged from the reading of the papers, and this resulted in eight broad categories; fear, explanation seeking, stigma, disability, coping, support, change and learning and life history, the detail of which is discussed here.

Fear

Fear was a recurring theme in the papers, but experienced in different ways and across different types of illness experience. For some it was experienced as a motivator to stay well and stay out of hospital (Chafetz, 1996), for others, a fear of stress which acted a barrier for seeking work (Chernomas et al., 2000) and most commonly, fear of illness and revisiting distressing experience (McGrath, 1984; Champ, 1998; McCann & Clarke, 2004;

Hutchinson, 2004; Lester & Tritter, 2005). This resulted in living fearfully in a restricted world (Nehls & Sallmann, 2005), because of abuse experiences (Thompson et al., 2008), alienation (Hedelin & Strandmark, 2001), fear of losing children (Walker, 1999), or rejection resulting from stigmatising public perceptions and discriminatory judgements (Chernomas et al., 2000; McCann & Clarke, 2004; Broussard, 2005). Fear of death was also evident (Erdner et al., 2009), as was terror of gaining weight (Broussard, 2005).

These fears appear to have a relationship with loss or anticipation of loss associated with a sense of hopelessness and loneliness. However, there is a wide variation as to the perspective of these losses that overlaps with other issues noted in this literature review, for example the loneliness that comes with stigma and alienation (Hedelin & Strandmark, 2001; Tryssenaar et al., 2003). In addition, grief is experienced as a result of wasted years (Hensley, 2002). Isolation and loneliness features as a main theme in two studies, reflecting an inability to establish friendships and dissatisfaction with interpersonal relationships when wanting to appear normal (Erdner et al., 2002; Broussard, 2005). There is also emptiness and lost feeling associated with depression (Karp, 1994) as well as a lack of love and care in early life (Nyström et al., 2002).

Explanation seeking

This theme reflects a number of perspectives. Generally, a process of developing a personal philosophy and explanatory framework is evident (Karp, 1994; Lewis, 1995; Chafetz, 1996; Ritsher et al., 1997; Chernomas et al., 2000). Participants however lacked the language to explain their experience (Karp, 1994) but many theorised about the causes. One aspect of explanation seeking is the concept of personal responsibility where looking internally to oneself for explanation is found (McGrath, 1984; Lewis, 1995; Hedelin &

Strandmark, 2001) though age differences are reported. Repper et al. (1998) found that younger people are more likely to look for external explanations, that is, not take personal responsibility but find blame elsewhere, though this is not consistent (Chernomas et al., 2000). Leete (1989) describes taking twenty years before the realisation that she would survive schizophrenia and this was achieved by taking responsibility for her life and developing coping mechanisms.

The confusion associated with diagnosis and the questioning of this (McGrath, 1994; Karp, 1994; Lewis, 1995; Ritsher et al., 1997; Lundin, 1998; Hutchinson, 2004) may be explained by a realisation of the arbitrary nature of measurements of sanity (Champ, 1998) and/or the multiple diagnoses experienced over the years (Chafetz, 1996; Sholtis, 2002). Diagnosis is actively sought and experienced for some as a relief (Erdner et al., 2005) but for Champ (1998) it is rejected as cultural conditioning. Beliefs vary regarding conclusions in sense making, but there appears to be a complex personal logic relevant to each person's life context that largely encompasses mixed concepts. A biological perspective is not the most common explanation however as Ritsher et al. (1997) found only one third of their sample attributed their problems to chemical imbalance. Hutchinson (2004) perceived his mental health problems as a physical illness requiring medication enabling him to remove himself from the stigma associated with mental illness.

Stigma

Stigma is a key theme for Chernomas et al. (2000) but is also significantly reflected in other studies referred to within the theme fear and also reflects shame (Lundin, 1998). Its effect could impede participation in social life (Hedelin & Standmark, 2001; Tryssenaar et al., 2003; Hutchinson, 2004) resulting in attempts to pass as normal or less bizarre (Leete,

1989; Karp, 1994; Chafetz, 1996; Repper et al., 1998; Walker, 1999; Tryssenaar et al., 2003; Lester & Tritter, 2005; Broussard, 2005). This is also perhaps reflected in why people made decisions about their privacy, making a distinction between their private and public selves and not disclosing their experiences, largely because of their expectations of how others would react, including close family (Karp, 1994; Lundin, 1998; Chernomas et al., 2000; Hedelin & Strandmark, 2001; Broussard, 2005). Feelings of failure were reinforced by stigma imposed by others (Champ, 1998), however involvement in the workforce, a 'normal' activity, decreased stigma and made life easier by being accepted as part of a community (Leete, 1989).

Disability

Disability is a common framework for interpreting the effect of mental ill health (Sayce, 1998) and is reflected in a variety of ways in the findings of the studies that includes isolation and loneliness outlined earlier. In addition, there is a suggestion that both individual impairment due to experiences, and social disadvantage due to outside influences impacts on all aspects of life (Leete, 1989; Champ, 1998; Erdner et al., 2002; Tryssenaar et al., 2003; Nehls & Sallman, 2005; Lester & Tritter, 2005; Erdner et al., 2005). This includes invalidation of opinions resulting in being disbelieved, not taken seriously and without a voice (McGrath, 1984; Leete, 1989; Chernomas et al., 2000; Sholtis, 2002; Tryssenaar et al., 2003; Lester & Tritter, 2005) as well as leaving people open to the pressure from authoritative professionals (McGrath, 1984; Tryssenaar et al., 2003). This was contrary to what was needed which was to have their story heard (Tryssenaar et al., 2003; Nehls & Sallman, 2005).

Chafetz (1996) found lower function and increased disability scores for people where more care was available, though this could be because they were seeking care because they were less able to be independent, or they have been deskilled by institutionalisation. However, she concludes that their illness management is partly because of individual learning and choice making. People tend to make adaptations to any limitations in functioning (Thompson et al., 2008), and respond to the restrictions that symptoms can impose (Erdner et al., 2002).

Coping strategies

This theme is more explicitly notable within the autobiographical accounts which share many idiosyncratic and personally constructed complex ways of coping that result in strategies for control and organisation as a method of self-care (Leete, 1989; Hensley, 2002; Walen, 2002; Sholtis, 2002; Roe et al., 2004; Hutchinson, 2004). Control is achieved through creating an environment of structure and routine (Leete, 1989; Erdner et al., 2002; Hensley, 2002; Tryssenaar et al., 2003; Roe et al., 2004) and with determination and desire to win (Chernomas et al., 2000; Roe et al., 2004; Hutchinson, 2004). Similarly, setting goals for self-improvement gives something to look forward to and is motivation for getting up each day (Leete, 1989).

Coming to terms with experiences or illness can result in changed self-image or challenged identity (McGrath, 1984; Karp, 1994; Chernomas et al., 2000; Erdner et al., 2005; Lester & Tritter, 2005) and for some pride was reclaimed in survival (Leete, 1989; Champ, 1998), though over time this all results in emotional exhaustion (Sholtis, 2002).

Although 30% of the 166 participants in Ritsher et al. (1997) survey acknowledged that severe mental ill health had significantly shaped them, illness occupied the mind frequently in only 17% of the sample. Their preoccupations were usual life activities and pleasures rather than mental ill health.

Support

Coping is also achieved through on-going support which is acquired through personal relationships with family, friends, professionals and animals. Relationships were found to be one of the five key areas of life that participants identified as shaping them (Ritsher et al., 1997). However, these are sometimes unsupportive with relationships implicated in the violation of mental health. Avoidance, difficulty and/or loss of relationships due to illness and/or hospitalisation resulting in loneliness and isolation can be problematic (Chernomas et al., 2000; Nyström et al., 2002; Erdner et al., 2002; Hedelin & Jonsson, 2003; McCann & Clarke, 2004; Erdner et al., 2005; Thompson et al., 2008; Erdner et al., 2009). Relationships with animals are found to be important as they provide joy and give meaning to life without making demands (Walen, 2002; Erdner et al., 2009).

Change and learning

As people get older they are found to get better (Chafetz, 1996), though this is clarified as 'better but not well' indicating a relative element to their experiences. There is also evidence of reduced aspirations or pessimism, an inability to look forward, anticipate the future or to learn (Repper et al., 1998; Hedelin & Strandmark, 2001; Tryssenaar et al., 2003; Erdner et al., 2005; Thompson et al., 2008). This evidence is contradictory however as determination, individual learning and management of illness, increased ability to cope with symptoms and hopes for the future is also demonstrated (Chafetz, 1996; Ritsher et al.,

1997; Tryssenaar et al., 2003; Roe et al. 2004). Also, the Tryssenaar et al. (2003) study shows both a transition to becoming more hopeless with ageing whilst at the same time suggesting that people cope better as they age and learn through practice. This process is perhaps reflected more clearly in the individual accounts that are commonly more positive and demonstrate learning about what works, that is; medication and behaviours to manage situations; skills and improving self, how to manage thoughts, learning from feedback, and learning to concentrate, to be careful and be persistent (McGrath, 1984; Leete, 1989; Lundin, 1998; Champ, 1998; Walen, 2002; Hensley, 2002; Sholtis, 2002; Hutchinson, 2004).

The process of learning, whether embracing a strange world (Champ, 1998), changing personal attitudes and responses to own experiences (Leete, 1989; Champ, 1998), going easy on oneself and accept oneself (Hensley, 2002), or going through the trial and error of treatments (Leete, 1989; Hutchinson, 2004), is lengthy and can be a journey of fear (McGrath, 1984).

Life history

A number of papers (11) report reference back to childhood, adolescence or early adulthood and find significant experiences of abuse or trauma (Karp, 1994; Chafetz, 1996; Ritsher et al., 1997; Repper et al., 1998; Hedelin & Strandmark, 2001; Nyström et al., 2002; Tryssenaar et al., 2003; Hedelin & Jonsson, 2003; Nehls & Sallmann, 2005; Thompson et al., 2008; Erdner et al., 2009) which is also reflected in personal accounts (Champ, 1998; Walker, 1999; Hensley, 2002; Walen, 2002). Experiences preceding diagnosis such as emotional pain early in life or significant losses are found in two studies (Repper et al., 1998; Chernomas et al., 2000). Similarly, no starting point could be identified for women

experiencing depression (Karp, 1994) and attempts to become reconciled with early life experiences and find meaning in present lives are found (Erdner et al., 2009). Trauma is included in experience such as the impact of hospitalisation and experiences of treatment which had a lasting and disabling impact (Champ, 1998; Nehls & Sallmann, 2005). Significant events or experiences from the past were relived in the present for both older people (Hedelin & Strandmark, 2001; Hedelin & Jonsson, 2003) and young people (McCann & Clarke, 2004).

As outlined earlier, the papers on experience of recovery are reviewed separately in order to explore the nature of the varying concepts of recovery that different researchers and individuals draw on.

Recovery papers

Thirty four papers about the experience of recovery were located that included 25 research studies and nine personal accounts. The research studies included two studies that appeared to be essentially the same paper published in different places (Schrieber, 1996a & b) and a study written in three parts (Davidson et al., 2005b; Marin et al., 2005; Sells et al., 2005). When these five studies are counted two studies, that is, Schrieber (1996a & b) and what I will refer to as the Davidson studies (as Davidson is first author on the first of these and is listed as an author in all these papers), 22 research studies remain. The research papers reflected investigations in relation to three general themes; the meaning of recovery, the process of recovery and the experience of recovery.

However, as discussed in chapter one, there is much confusion regarding defining recovery and this is exacerbated by the diversity and inconsistency in methodological processes

(Schrieber, 1996a & b) and authors lack of explanation regarding the perspective from which they are writing (Davidson et al., 2005a). Each recovery paper was therefore also categorised according to whether it appeared to be philosophically situated within a medical recovery or life recovery perspective (Table 3.).

Table 3. Medical or life recovery perspectives in recovery literature

	Medical recovery	Life recovery
Process	Davidson & Strauss, 1992 Sullivan, 1994 Schrieber, 1996a & b Roe, 2005 Davidson studies, 2005	Spaniol et al., 2002 D'Abundo & Chally, 2004 Weaver et al., 2005 Lamoureux & Bottorff, 2005 Ridge & Ziebland, 2006 Jensen & Wadkins, 2007 Bradshaw et al., 2007 Borg & Davidson, 2008
Meaning		Young & Ensing, 1999 Smith, 2000 Matussek & Knudson, 2009 Piat et al., 2009
Experience	Hsu et al., 1992	Thornhill et al., 2004 LaFrance & Stoppard, 2006 Patching & Lawler, 2009 Armour et al., 2009

Table 3 illustrates that most of the papers have a life recovery perspective most of which are about the process of recovery. Most of the earliest studies from the 1990s show a medical recovery perspective, apart from Young & Ensing (1999) who are clearly early pioneers of research from this perspective with participants with 'psychiatric disabilities'. Unlike the two related studies focused on the experience of older people (Hedelin & Strandmark, 2001; Hedelin & Jonsson, 2003), the recovery studies had no papers at all focused exclusively on older people's experiences and only three studies that included anyone over the age of 64 (Schrieber, 1996a & b; Thornhill et al, 2004; La France & Stoppard, 2006) (appendix 7), again possibly because the majority recruit in mental health services catering for certain age groups. Thirteen of the recovery studies recruited

participants from mental health services only, and nine from mixed locations including public and primary care environments (Lewis, 1995; Schrieber, 1996a & b; Thornhill et al., 2004; D'Abundo & Chally, 2004; Weaver et al., 2005; LaFrance & Stoppard, 2006; Piat et al., 2009; Matusek & Knudson, 2009). Five of the latter studies are about eating disorder, not traditionally treated in hospital; three are about depression and one psychosis. Studies that include participants over the age of 64 (up to age 70) in their samples are those recruiting from a variety of public and primary care locations (Schrieber, 1996a & b; Thornhill et al., 2004; LaFrance & Stoppard, 2006).

Methods

The Davidson studies, Davidson & Strauss (1992) and also Roe (2005) all utilise subsets of data from the Yale longitudinal study with 48.5% of people reported as improved (Davidson & Strauss, 1992). Hsu et al. (1992) had a 20 year follow up, and Spaniol et al. (2002) a four year follow up. Six studies employed grounded theory (Shrieber, 1996a & b; D'Abundo & Chally, 2004; Lamoureux & Bottorff, 2005; Weaver et al., 2005; Ridge & Ziebland, 2006), one ethnography (Sullivan, 1994) and three did not have specified methodology (Young & Ensing, 1999; Smith, 2000; Armour et al., 2009). Four used narrative approaches including a narrative analysis of psychosis (Thornhill et al., 2004), discourse analysis (LaFrance & Stoppard, 2006), a biographical interpretive study (Matusek & Knudson, 2009) and one life history (Patching & Lawler, 2009).

Recovery findings

It is difficult to collate themes in the recovery papers, due to the largely incomparable data and complex varieties of philosophy and method. What they appear to have in common however, is that they uncover processes of development and personal achievement. Those

focusing on the process of recovery are fairly consistent in their findings in tending not to include improvement of medical symptoms but instead relate to personal efforts that lead to adaptation, learning, acceptance and functioning (Young & Ensing, 1999; D'Abundo & Chally, 2004; Lamoureux & Bottorff, 2005; Weaver et al., 2005; Ridge & Ziebland, 2006). In addition the unique nature of personal goal setting is observed (Smith, 2000; Matusek & Knudson, 2009; La France & Stoppard, 2006; Patching & Lawler 2009; Armour et al., 2009).

Piat et al. (2009) however, finds a distinction between recovery in relation to wellness and recovery in relation to illness, the former focusing on self-determination, control and transformation and the latter medical treatments. The findings of some studies surprised researchers, contrary to the attitudes they appeared to be challenging. This is true of Hsu et al. (1992) and Schrieber (1996a & b) who clearly refer to medical constructs such as prognosis of illness, and biologically defined perspectives on recovery congruent with medical criteria. They question their assumptions when life history, transcendental aspects of lives and depression as a growth experience emerge in their findings. Surprise has also been expressed at the high percentage (63%) of respondents who had the ability to control or monitor their illness or played an active role in their own recovery (Sullivan, 1994; Marin et al., 2005; Davidson et al., 2005b) despite Davidson & Strauss (1992) having found people reflect on their capabilities, take stock of their personal strengths and develop explanations as to what happening to them.

In contrast, phases of recovery were found to have no precise boundaries. Explanations were developed, disability was lived with and lives continued beyond disability. People used self-help literature and relationships maintained a sense of purpose and meaning

(Spaniol et al., 2002; Borg & Davidson, 2008). Both Spaniol et al. (2002) and Bradshaw et al. (2007) found four phases of recovery that included acceptance, preventing relapse, decreasing stigma and helping others, whereas Armour et al. (2009) with an African American subset of participants found more focus on being active and persistent. Narrative approaches found personal transformation included being 'as good as', 'gaining control', being a 'victim', 'saying no' and 'self-care' (La France & Stoppard, 2006), and also enlightenment, endurance and escape (Thornhill et al., 2004).

Experience of recovery: autobiographical accounts

The personal accounts of recovery are all from North America and Canada. Similar to the literature on experience of mental illness, first person accounts in choosing the story they want to tell, are particularly detailed. They appear to demonstrate a process of developing understanding of personal experiences over exceptionally long durations of mental health problems ranging from approximately 10-15 years (Lovejoy, 1984; Fekete, 2004; Chovil, 2005), 20 years (Deegan, 2003; Weingarten, 2005), 30 years (Morisey, 2003) and 38 years (Henderson, 2004). Medical diagnosis is commonly used to describe experience, however, Fekete (2004) constructs his mental ill health as a physical illness associated with biochemical changes in his brain, and discusses his fear and hopelessness concluding that people are misinformed about what they have to accept. Many more thoughts are offered regarding personal understanding of mental ill health such as anger, distrust, rejection and trauma of hospital experiences (Lovejoy, 1984; Unzicker, 1989). Common also is what hard work recovery is (Deegan, 2003; Morisey, 2003; Weingarten, 2005), as it requires determination and personal strength (Deegan, 2003; Morisey, 2003; Schiff, 2004; Henderson, 2004; Weingarten, 2005), as well as hope and seeing others do well (Lovejoy, 1984). Personal strengths had to be discovered within a process of recovery over time,

sometimes 20 years before seeking support (Deegan, 2003) and getting by by passing as someone without a mental illness (Schiff, 2004). The time of recovery included overcoming personal trauma and time finding explanations before accepting that there was a problem, at which point it was felt recovery could start (Chapman, 2002; Weingarten, 2005), though it remained an on-going process, not an end point (Henderson, 2004).

Updated literature search.

An updated literature was undertaken in December 2011 which re-ran the original searches limited to May 2010–Dec. 2011. Only one paper was located (McKay, 2010). This paper explored the experience of women living with enduring mental illness using life history methods, narrative analysis and constant comparative method. Five women aged between 42 and 74 who defined themselves as having had bipolar disorder, schizophrenia or depression for longer than 5 years participated in two interviews.

The longest duration of illness is noted to be 50 years though the shortest duration is not recorded in the paper. Six themes emerged; present life, relationships, help, life roles, illness transitions and cultural context. These highlighted the participant's affirmation of their own lives, the importance of occupational engagement, constructive and destructive relationships, inability to make sense of what was happening when diagnosed, the frequency of suicidal feelings, the inability of services to meet their needs, personal strategies for coping, and lack of understanding of their mental health problems or abusive experiences. All the women were volunteers recruited through voluntary mental health providers, advertisement and personal contact, and their life experiences were noted by the authors to be largely invisible. McKay (2010) suggests that their role as agents for

themselves in the face of challenging attitudes that reinforced a victim role were in contrast to their perception of themselves as experts in their own life.

This study, unlike other studies has managed to include adults to an older age, including people up to age 74, and the duration of their use of mental health services is considerable. The specific areas of interest in this paper are female gender and occupational functioning, having noted that there is no new literature regarding long term experience and an area of study omitted from the occupational therapy literature in particular.

The findings are presented differently than previous studies, but mirror issues of control over life and support. In this study however, this support was mainly a network between people in similar circumstances that they had formed by themselves, remaining ignorant of any professional support services and the limitations of these where available. Relationships were similarly found to be destructive as well as constructive, with experience of unsupportive husbands. Indeed, there was also confusion surrounding diagnosis and the need to make sense of both diagnosis and experience of mental ill health. This also included narratives on the adverse impact of hospital experiences and fear and distress at systems that worked against them. Stigma was also experienced during this time. Occupation was severely disrupted for women in this study but remained important to them for all the positive things this could bring.

The participants' achievements and aspirations are discussed within a theme of 'life roles'. They show the effect of both sociocultural and parental influences on their choices and the achievement of their goals, despite periods of sickness. In contrast to previous studies, a sense of feeling happier in the present after surviving adverse circumstances was found, a

position which was not what they expected earlier in life and the women became experts in their own life (McKay 2010).

Conclusions

The themes of fear, explanation seeking, stigma, disability, coping, support, change and development and life history have been identified as key themes across the literature on personal experience of mental illness. These themes include concepts of loss, trauma, privacy, identity, having a voice and a difference between younger and older people which are similarly reflected in the recovery literature though this showed longer durations of mental ill health.

The review highlighted that most of the research is compartmentalised within age groups, most often utilising a cut off of 18 and around 65 years old. Similarly in the autobiographical accounts there is a marked absence of people representing traditionally defined older people, that is the over 65s, and in addition, there are only two studies that are identified as investigating the personal experience of mental ill health with older people. This is despite recognition 30 years ago of the predominant concern of studies of chronic illness being the middle years of life and the need to look to wider aspects of the life course (Brown & Harris, 1978). Age categories can be a flaw in research where generational or ageing differences are not taken into account (Riley, 1973). Those studies that employ longitudinal or lifespan perspectives are less common but arguably provide us with a more comprehensive understanding of people who are older and the relevant issues in ageing for different generations.

Participants in the studies identified here are most often consumers of mental health services and as such are exposed to the language of mental illness and recovery. This means that most papers report the findings of people who; attend services, identify as mentally ill and are assumed to have a concept of recovery. It is perhaps less likely that people not involved in such services, for example those engaged as participants from primary care or general public settings, have been introduced to contemporary recovery language.

There is a risk when relying on medically defined models of mental illness, that ambitious goals are dismissed as delusions of grandeur (Deegan, 2001). Examination of individual differences and constructions are lacking in the current literature despite recognition of some disagreement with medical constructs of mental illness. Locating participants within mental health services, which the majority do, may result in guardedness and incomplete information, as the research findings do not demonstrate the same level of criticism of hospital and treatments as the autobiographical accounts often do.

Investigation of personal experience of long term mental ill health within mental illness literature appears to maintain a central place for diagnosis/illness, rather than the life being lived. What continues to be lacking is any investigation of the personal experience of mental ill health for people who are older, and similarly experience through life to much later adulthood.

The main gaps and unanswered questions identified from the literature concern the lack of detailed investigation into individual life course issues. Both the systematic research, and even more so the autobiographical accounts, demonstrate that there are individuals whose

whole adult lives have been lived within a context of mental health difficulties. In addition, it has been demonstrated that there are some people who are never identified as people with mental ill health due to never having sought professional help or told of their problems (Broussard, 2005). This was only found through recruitment procedures that did not rely on health services.

In the literature review, evidence of personal achievement is common, whether this is surviving against the odds or achieving education or work, but this is not always discussed. For people with severe mental illness, work and accomplishments were reported as the most significant aspects of what had shaped them, far more than mental illness itself (Ritsher et al., 1997). These achievements include marriage, family, educational attainment and work.

Considerable duration of mental ill health is implicated in this review but those with the longest experience, often in excess of 30 years, are not singled out for discussion despite the unique nature of this noted in the medical literature discussed in chapter one. Inclusion of people of older ages in relation to longer term experience would address the near absence of papers that include any focus or inclusion of older adults. This therefore forms the rationale for this study. The next chapter will discuss the development of a methodology that enables this knowledge to be developed.

Chapter Three

Methodology and method

Introduction

Betty Friedan (1993) states;

'It takes a heroic scholar to break through the model of decline and study age professionally as another period of human development to see its unique emergent aspects' (p.116).

These words are important, written from the point of view of an 80-year-old woman frustrated at the compassionate ageism surrounding benevolent but unintentionally patronising and invalidating attitudes and beliefs held about older people. These words challenge our knowledge of growing older and reflect something about what I am trying to achieve in a particularly challenging context of those older people considered not only as having mental health problems but of the prolonged and persistent presence in their lives.

A number of gaps were exposed in the existing literature about the personal experience of mental ill health, in particular highlighting a neglect of the study of older people's perspectives of long term mental ill health. What the literature shows however is that alongside any loss individuals may experience, many participants are describing significant achievements in work, family and personal accomplishments. This is the particular focus of the contemporary recovery literature that challenges professionals to work on the premise that people with severe mental illness can achieve their aspirations.

The medical literature (chapter one) is inconsistent and inconclusive with regard to why people do better or worse as they age and so leaves a knowledge gap regarding how people

live their lives with long term mental illness. The experience literature (chapter two) provided such qualitative information, creating a shift of focus from patients to citizens, though many studies do not go far enough in casting off the identity framed by diagnostic categories. In addition, there also appears to be inconsistency regarding changes that may occur in relation to ageing with a mental illness. The many achievements evident from the experience literature are little examined in relation to how these were accomplished in the context of difficult experiences. It is such gaps in the literature that have led me to the identification of the following aims and research questions.

Aims of the study

The aim of this study is to explore the unique and emergent aspects of human experience from the perspective of people in later life who have lived long term with mental ill health. In exploring people's perspectives regarding their life achievements whilst living with mental health problems, it is anticipated that a re-examination of the assumptions that inform the current knowledge concerning people who grow older with mental health problems will be possible. It offers a different way of thinking about older people with mental health problems by starting from a strengths perspective congruent with recovery principles.

Research questions

- 1 How does living with long term mental ill health affect achievement?
- 2 How does long term mental ill health affect life in the present?

The term achievement has been used as a proxy term for positive aspects of life, with a view to starting from a strengths perspective (Saleeby, 1992; Perkins & Tice, 1995)

congruent with the principles of recovery as a frame of reference, and an opportunity to focus on abilities rather than disabilities (Leavey, 2005). To address these questions it is important to explore what achievement means to the people concerned and also what mental illness means. Both are descriptive terms that may mean different things to different people. In academic searches of the literature achievement relates to school and educational contexts and is usually measured through quantitative methods. Lay definitions of achievement, for example, '*something that has been accomplished especially by hard work, ability or heroism*' (Collins dictionary, 2000, p.11) focuses on the means rather than the outcome, that is, what has been accomplished remains ambiguous but the effort of getting there defines achievement. Achievement is therefore interpreted as a relative term which requires exploration in order to understand its meaning and value (Cumming, 2000).

The aims of the study and the associated research questions have informed the choices regarding methodology and method (Crotty, 2003). This chapter will discuss the philosophical underpinnings to the study and also explain the methods that were used in its implementation.

Previous research

Research about experience of mental illness and experience of recovery has been grounded in three main philosophical positions: ethnography, grounded theory and phenomenology, the latter representing the most common position. These are common choices for qualitative researchers who attempt to capture aspects of experience (Smith et al., 2011). All the reviewed papers make reference to the complexity of experience in the context of mental illness as a justification for their approaches. The aim of ethnography is to understand behaviour in the context of its meaning and purpose which is achieved through

taking an 'insider' or 'emic' point of view (Crookes & Davies, 1998). Traditionally it aimed to document ways of life of a culture in its familiar environment (Leininger, 1985). As such it is appropriate for the study of groups of people who have shared unique experiences such as those studied in the research which concern the lives of people who have left long term institutionalisation or other mental health service systems. It does not lend itself to any observation of people living independent lives in community settings, nor can such people be assumed to have shared experiences as a starting point.

Grounded theory aims to develop explanatory theories from observable events in the real world which makes sense of a phenomenon (Streubert & Carpenter, 1999; Polit et al., 2001; Starks & Brown Trinidad, 2007). It seeks to provide evidence on which to design interventions (Starks & Brown Trinidad, 2007). Theory emerges from the data gathered rather than from the findings of previous studies and it has been a useful tool for understanding nursing as it recognised the need to move away from positivist methods, though it has been criticised for remaining wedded to positivist concepts (Denzin & Lincoln, 2000; Charmaz, 2008). Constructivist grounded theory attempts to develop the method within a qualitative paradigm that enabled a focus on meaning without the same rigid strategies (Denzin & Lincoln, 2000; Charmaz, 2008). What remains consistent in these approaches however is that the aim is not just to understand but to generate theory from data. Interpretive methods often remain porous or blurred (Lincoln, 2010) with areas of similarity, and grounded theory like phenomenology examines the experience of a specific phenomenon in the place in which the experience occurs.

Phenomenology attempts to see the world from another's point of view, describing in detail the 'lived experience' of particular phenomenon (Smith & Hunt, 1997; Streubert &

Carpenter, 1999). One of its strengths has been noted to be its potential for generalisability in clustering themes (Field & Morse, 1985; Smith & Hunt, 1997). However, phenomenological approaches can limit our knowledge of the experience of individuals with this focus on pre-defined phenomenon (Polkinghorne, 1995; Murray & Chamberlain, 1999). In addition, content and thematic analysis, usual in phenomenological studies and in fact common to almost all the research papers reviewed, leads to 'fractured texts', a process of 'fragmentation' or 'dismemberment' of data that can suppress context and meaning (Mishler, 1986; Polkinghorne, 1995; Murray & Chamberlain 1999; Carson & Fairbairn, 2002). Although this does not have to mean the individual cannot still be central in the analysis (Charmaz, 2000), Repper et al. (1998) illustrated in their re-analysis of the data from thematic to narrative methods, a more sensitive account of the women's actual words and meanings. This attention to the voice of the participant is more clearly evident where narrative methods are used, for example, discovering how people with psychosis might move toward recovery rather than toward being a 'chronic patient' (Thornhill et al., 2004). Similarly, within narrative inquiry Matusek & Knudson (2009) achieve more clearly the detailed attention to the voice of those experiencing eating disorder in utilising an interpretive biographical method. Their resulting biographical narratives 'sparingly' interpreted, lead to the conclusion that '*attention to the whole human being in all its mental emotional, physical social and spiritual richness is needed in order to understand what it is to overcome an eating disorder*' (Matusek & Knudson, 2009, p.703).

Biography or Life history as a method is used in a variety of ways across six methodologically different papers (Chafetz, 1996; Repper et al., 1998; Tryssenaar et al., 2003; Thompson et al., 2008; Patching & Lawler, 2009; Matusek & Knudson, 2009). Patching & Lawler (2009) argue that complete life histories enable a broader understanding

of experience, avoiding the imposition of pre-existing frameworks that shape new knowledge in particular ways and reduce compartmentalisation. Such methodological pragmatism enables flexibility in meeting the needs of the research, drawing on a wide range of theoretical and epistemological perspectives that can best answer the research questions, rather than searching for methodological purity (Roberts, 2002; Merrill & West, 2009; Smith et al., 2011). Narrative approaches, including life history approaches are shown to be more holistic in attending to the uniqueness of each individual (Thornhill et al., 2004; Matusek & Knudson, 2009; Patching & Lawler, 2009).

Qualitative research

The overview of the methods utilised in previous research demonstrate a wide range of approaches aimed at capturing the experience of people in a variety of ways that have in common a qualitative philosophy. The subjective knowledge that is produced in qualitative research offers an equally valid alternative voice (Holstein & Gubrium, 2000). The complexity of human experience requires a gestalt or holistic perspective that can only be understood in real life settings and explanations are derived from the meanings made by the people we are investigating (Williams & May, 1996; Crookes & Davies, 1998). Silent and unheard voices in particular will not be captured using realist methods (Rethink, 2004). For this reason, when human experience is the area of inquiry, a qualitative paradigm offers the most appropriate approach. Therefore the study is located within a qualitative paradigm and is underpinned by relativist ontology, social constructionist epistemology and a narrative inquiry methodology. These decisions are justified through discussion relating to realism, relativism, social constructionism, reflexivity, narrative inquiry and authenticity. This discussion will then lead to an explanation regarding the operationalization of these theoretical positions through biographical method and the associated practical issues.

Realism

Diagnostic frameworks and the use of measurable outcomes have largely informed our knowledge of growing older with mental health problems. From a realist perspective this accepts that mental illness, for example schizophrenia exists as a disease independent of human belief, a position of considerable controversy (Bentall, 2003; Bentall, 2009; Barker & Buchanan-Barker, 2010). Whilst providing only one framework, medical models often silently and uncritically guide research practice (Davidson & Strauss, 1995; Carson & Fairbairn, 2002) stripping away the context that gives meaning and replacing this with researchers' own interpretations (Burr, 2003). Such traditional approaches reflect a positivist paradigm where realist perspectives aim to discover one objective 'truth'. Often such an approach aims to collect quantitative data that can be generalised to populations. However the ethics of this method that results in detachment, hierarchy and lack of interpersonal relationships has been criticised (Mishler, 1986; Miller, 2000).

Mixed methods have developed in popularity as a way of benefiting from the advantages provided by both quantitative and qualitative approaches (Pope & Mays, 1995; Creswell & Plano Clark, 2011). The strengths of each enhance knowledge; however, the former does not lend itself to exploration and emergent aspect of human experience. Indeed the medicalisation of old age has contributed to a construction of older people that focuses on care narratives, and ignores aspirations (Bowers et al., 2005; Collier & Yates-Bolton, 2011). Within the context of mental illness, there are many challenges to the realist position not least from people who reject psychiatric diagnosis or have found themselves receiving multiple diagnoses, none of which offer explanation for their experiences. It does not offer any way of listening to personal experience but imposes one set of privileged knowledge over another which does not always help those who seek assistance.

Relativism

Unlike realism, relativism accepts the existence of multiple realities. It has been criticised as idealistic (Gibbs, 2002) though dismissal of complex and individually meaningful interpretations of experience is considered a misunderstanding of its purpose (Burr, 2003; Holstein & Gubrium, 2008). Relativism is an analytic concept that allows for the critique of all types of knowledge where assumptions' concerning the relative value of forms of knowledge is suspended (Atkinson & Gregory, 2008), and thus enables researchers to develop understanding of the knowledge that arises from human beliefs (Holstein & Gubrium, 2008). As Burr (2003) states;

'If the scientists or researchers account of a phenomenon is seen as 'fact' as a result of the warranting voice of science, we must then acknowledge that other accounts, for example the accounts of respondents in interviews, must be equally valid in principle. There no longer appears to be a good reason to privilege the account or reading of the researcher above that of any one else, and this puts the researcher and the researched in a new relation to each other. The subjects own account of their experiences can no longer be given an alternative interpretation by the researcher who then offers their reading as truth' (p.154/5).

In contrast to realism, or reality, a relativist position about how the world is viewed underpins social constructionism (Denzin & Lincoln, 2000; Gibbs, 2002; Crotty, 2003), a position that enables acceptance of individual narratives as truth.

Social constructionism

Although medical constructs appear to be the fundamental basis for much of the available literature it is perhaps indicative of a culturally available language that does not necessarily communicate intended personal meaning but informs how individual experience is constructed (Church, 1995; Holstein & Gubrium, 2000; Stickley & Timmons, 2007). Individuals who experience ill health interact with medically defined symptoms in a way that constructs illness as a social experience (Hardey, 1998).

Social constructionism aims to explain how experiences are constructed and how the narrative of such creates the on-going reality for individuals (Burr, 2003). All reality as personally meaningful reality is socially constructed (Crotty, 2003) and if a person believes something the belief is real in its consequences (Denzin, 1989; Bond & Coleman, 1990; Williams, 2000). This leads to a number of assumptions;

- 1) the story they have to tell about their experience is their truth
- 2) each person has a different story based on their own unique experience and interpretations of these, therefore there are many different realities, not just one.
- 3) these multiple realities are informed by social norms, language and culture, and therefore relative to each other.

By allowing for the possibility that different people have different philosophical beliefs about the world and ways of making sense of their experiences, the researcher accepts that there is no one definable reality. This also implicates the researchers own perspective and its impact on how the research is co-constructed, recognising that they will have a part to play in the construction of the particular accounts presented in the research.

Reflexivity

Reflexivity is a central feature of social constructionist approaches (Taylor & White, 2000; Burr, 2003). Relationships between the researcher and the participants cannot be reduced to data collection only (Frank, 2002), and the co-constructive nature of research narratives will inevitably shape the story told (Denzin, 1989; Burr, 2003). Where a person brings a particular story to an encounter with the purpose of making sense of it, the final narrative is co-constructed between the people present (Leder, 1990; Frank, 1995; Frank, 2000; Greenhalgh, 2001). This places an ethical responsibility onto the researcher to be honest about their own motives as each person who reads the story will understand it through their own experiences.

The concept of constructionism is not well explored in the research about long term experience of mental ill health due to the philosophical approaches taken that either focus on particular phenomenon, or ethnographical observations that rely on an acceptance of the researcher being on the 'inside'. However, given the ambiguity regarding the nature of mental ill health and the absence of literature regarding growing older in this context, a narrative inquiry can contribute to the understanding of this as it has the potential to show what is important and significant to the narrator (Denzin, 1989; Coffey & Atkinson, 1996).

Narrative inquiry

Narrative inquiry has the potential to produce evidence regarding participant's lives that includes the meaning they give their experiences and capture its unique and complex nature (Elliot, 2005). Narratives are an important source of knowledge (Wiklund et al., 2002; Reissman & Quinney, 2005; Turner, 2006) where stories are used to describe human action (Polkinghorne, 1995; Josselson & Leiblich, 1995). Although it has been argued that not all text and talk is narrative and telling stories can have different functions (Reissman & Quinney, 2005), it is accepted that story-telling is a meaningful activity and important in making sense of our lives (Polkinghorne, 1988; Bruner, 1990; Freeman, 1993; Turner, 2006; Hawkins & Lindsay, 2006). Affirmation of the person is achieved in storytelling and experience is made meaningful and coherent through narratives (Sarbin, 1986; Polkinghorne, 1988; Denzin, 1989; Bruner, 1990; Freeman, 1999; Frank, 2000).

Narrative inquiry offers a way of ensuring that individuals retain the power to define personal experience, be active agents, rather than have others define it for them (Holloway & Freshwater, 2007). This means that ethical engagement with real life problems can be achieved without imposing pre-existing theoretical frameworks in interpretation and the

holistic nature of individual life experience can be emphasised (Frank, 2000; Carson & Fairbairn, 2002; Ayres et al., 2003; Holstein & Gubrium, 2008). The resulting narratives have also been referred to as stories (Sarbin, 1986; Denzin, 1989; Reissman, 2008) therefore the terms narrative and story will be used interchangeably in this thesis.

Authenticity

The concept of validity and reliability in quantitative research are positivistic principles and are not therefore appropriate measures for the personal and subjective nature of narrative (Atkinson, 1998). Qualitative research more often adopts the concept of authenticity. Oral evidence is unique in that it cannot come from another source and there is no reason to accept one account as more reliable than the other (Thompson, 2000). Authenticity and believability and what is reasonable and convincing to others are therefore more appropriate when advocating for people who are not believed or heard (Atkinson, 1998; Roberts, 2002). These characteristics are established through stability, trustworthiness and scope of the research interviews (Elliot, 2005). Autobiographical memory is considered as imaginative reconstruction of elements of a person's life into a coherent whole rather than literal interpretation (Cohen, 2001b).

Narrative truth rests on the motive of the teller and there can therefore be no false oral stories, as personal narratives reveal a psychological reality (Spence 1982; Plummer, 1983; Rosie, 1993; Hollway & Jefferson, 2000). They are not expected to provide a historical truth, but personal interpretations of events that create reality. As Williams & May (1996) indicate, what matters is;

'...the facilitation of as full a subjective view as possible not the naive delusion that one has trapped the bedrock of truth...the life history reveal like nothing else can the subjective realm, as to understand history we must recognise that it represents a meaningful reality for those who 'create' it' (p.62).

A number of strategies have been suggested to achieve authenticity such as returning the transcript to the participants in order that they can confirm and support what was said originally (Atkinson, 1998). Similarly, some researchers return interpretations, a practice that has shown participants dissatisfied with the simplification and removal of key meanings by researchers (Wiklund et al., 2002; Thornhill et al., 2004), suggesting the need to ensure as much detail as possible is retained. One type of method that may achieve this and is suitable for the narrative study of lives is the biographical method (Froggett & Chamberlayne, 2004).

Biographical method

The value of biographical method lies in its ability to capture probe and render understandable problematic experiences (Denzin, 1989) and it offers a commitment to a holistic approach, focusing on both the personal and the public in its breadth of content (Miller, 2000). It has been suggested that it is a useful approach at the exploratory stages of research, as a sensitising tool where information is limited or conceptualisation is poor (Plummer, 1983). In addition, life history work can contribute to the aim of enabling silenced voices to be heard (Hollway & Jefferson, 2000; Miller, 2000; Roberts, 2002). Given that these are issues already raised in relation to people who have long term mental ill health and who are older, these reasons underpin my decision to employ biographical method in this study.

Because of the history of discrimination and stereotypes of decline associated with late life and also the negative assumptions related to long term mental illness, I was conscious that I wanted to focus on something positive and this was my guiding principle. However, the

power of the dominant medical discourses that I had been exposed to in my professional experiences continued to be a challenge, as I noted in my diary in January 2007;

'I still keep getting cold feet. – a worry I'm being unrealistic that I can be accused of this – that these disabled people who are graduates couldn't possibly achieve any of these things; they're too disabled and part of me (the medical model nurse) agrees with this and says what are you doing?, but there is a part of me that doesn't agree, that knows those people can achieve, do have goals but have been disadvantaged at every turn, that they are stronger than me'.

The dissonance evident in this excerpt was driven by my developing interest in the new recovery philosophy, the focus being on what people could do rather than what they could not. A focus on classification as a way to understand long term outcomes seemed to have limited usefulness (Harding et al., 1987b; Nyström et al., 2002) while life history approaches allowed for the exploration of the extensive experiential component to mental illness (Nyström et al., 2002). Although there was no research on recovery that focused on older people its principles are as applicable to older people as to younger people (Woods, 2007) and citizenship a state as important for older people as others (Craig, 2004; Department for Work and Pensions, DWP, 2005). These ideas led me to identify the curriculum vitae (CV) as a possible research tool that would capture personal strengths and achievements as it represents how the life course is structured in contemporary western culture (Miller & Morgan, 1993).

The terms biography and life history are often used interchangeably, and this is the case in this study, as there is no universal definition (Denzin & Lincoln, 2000). Life history has been described one type of biographical research that focuses on a specific topic of interest (Roberts, 2002). Life history is considered more flexible in its form and enables order and meaning to be brought to the life told (Atkinson, 1998). The life told is a life history

narrative influenced by one's culture and told to an audience in a particular social context (Bruner, 1986; Roberts, 2002).

There are many versions of one's biography as people choose the story they want to tell (Denzin, 1989). In addition, stories can be expected to change, be reinterpreted over time (Clandinin & Connolly, 2000) as we do not know how they will end and have to revise the plot as new events are experienced (Polkinghorne, 1988). Researchers cannot claim to capture whole lives, but a version of life history told at the moment of the interview (Plummer, 1983), a *'slice of the overall totality, merely one frame abstracted from a constantly running movie'* (Davidson & Strauss, 1995, p.50). This idea implicates the complexity of the life course and its construction, rather than accept the biographical illusion that life history is being described (Denzin, 1989). In relation to older people who risk ageism, biographical methods can offer a way of avoiding this potential barrier and enabling a focus on aspirations, relationships and experiences (Clarke et al., 2003).

Life course theory

Life course perspectives provide the potential for examining biographical narratives from a constructionist perspective which helps appreciate sources of experiential variation that occurs within a continually changing social system (Featherstone & Hepworth, 1989; Holstein & Gubrium, 2000; Shanahan & Macmillan, 2008; Elder & Giele, 2009). People construct their own life course, their values, aspirations and goals through their actions, reactions and choices (Shanahan & Macmillan, 2008). These choices may be affected by the various constraints and opportunities available in the historical context of when they occur (Riley et al., 1988), for example, the way in which individual life course is structured by life's institutions, such as school, work or marriage (Alheit & Daulsen, 2002). However,

no phase of life can be understood in isolation from other phases (Shanahan & Macmillan, 2008) as age graded sequence of roles, opportunities, constraints and events are the fundamental building blocks that shape biography from birth to death. Life course perspectives provide a way of interpreting biographies by emphasising social circumstances and experience and helps to avoid the categories and contradictions that occur in definitions of ageing and old (Hazan, 1994). The life course as a paradigm enables researchers to choose a specific topic and think creatively about how meaning can be captured using interpretive formats that weave the subject's life through researcher's interpretations into new theoretical connections (Shanahan & Macmillan, 2008; Merrill & West, 2009). In the research process, this can be achieved through particular types of interviews.

Narrative interviews

Qualitative research assumes that interviews are the most appropriate method for learning about people's lives and in constructionist approaches, research interviews are the focus for the creation of meaning (Elliot, 2005). Capturing such meaning becomes possible as people do not just answer questions, instead they tell stories (Reissman, 2002). In addition, in taped interviews, it has been suggested that people do not tell stories to a tape, they tell them to a person (Ferrarotti, 2003) and this recognises the active part that the relationship between the researcher and the researched plays in the interview process.

An interview design that focuses on the elicitation and provocation of storytelling can be called a narrative interview design (Wengraf, 2001). This favours a non-interventionist approach as pre-planned questions have the potential to interfere with the spontaneous telling of participant's story (Wengraf, 2001; Reissman, 2002; Carson & Fairbairn, 2002). However such an approach assumes all respondents can talk fluently about their

experiences. In addition, there is some evidence that incoherent and unconnected details in interviews created problems for researchers (Tryssenaar et al., 2003). Such difficulties could be anticipated when interviewing people with long term mental health problems that may have difficulty with concentration and/or be distressed (Collier et al., 2003). Concrete reference points can help with the use of visual and interactive tools that promote dialogue (Chafetz, 1996; Thompson et al., 2008; Erdner et al., 2009). Additionally, anchors for memories such as life charts have been found to provide a comprehensive picture of life history (Sunnqvist et al., 2007).

Giving some structure to the data collection process will encourage engagement from those participating in the research. The ‘best’ interview questions are organised around specific times of life rather than one long period of time (Hollway & Jefferson, 2000). In light of this, an anchor point for participant’s recollections was developed, a curriculum vitae (CV) which participants were asked to complete prior to the telling of their story. In doing this the research encounter would be shaped by the participants’ own agendas and interests, their sense of agency, and areas of inquiry could be anticipated when seen from the perspective of the participant (Bornat et al., 2000). Using a CV would ensure the maintenance of the participant’s relevancies as the primary focus.

The next section will discuss the operationalization of the research through its methods.

Methods

Recruitment and selection

The recruitment process focused on meeting people who could contribute to the aims of the research and answer the research questions. The seven people who participated were all the

people who came forward and agreed to be involved. I spoke to two other people in this process, both of whom did not want to participate. The inclusion criteria for this study were as follows;

- Adults aged over 50 years of age
- Experience of mental ill health from before the age of 45 and for at least 20 years.
- On-going experience of mental ill health.

People who lack mental capacity or who have moderate or severe dementing illness were excluded. Organic causes of mental illness, namely dementia, have some predictable features once the early stages are passed, such as severe memory problems and chronic confusion, and such people therefore would not be in a position to contribute to the aims of this research.

In the early stages of the development of the research study, the age of 65 was used to define older person. However, this was challenged when Emma, one of the participants contacted me to say that she had seen the poster in her GP Surgery and could I explain it to her. She said that she was 52 but that she had wanted to be dead since she was 6 years old. This event made me feel as though I had fallen into my own trap, challenging age categories on the one hand but perpetuating them on the other. Emma 'fit' my criteria in that she had long term mental health problems that had affected her whole life, but was not old enough. After discussing this with my supervisor, we agreed that the age of 50 as a cut off was appropriate in answering the research questions particularly given the flexible definitions of old age that occur in different contexts (DWP, 2005).

The age of 50 as a minimum age ensures the participants are defined in an older age group (DWP, 2005) and so represent the neglected perspective addressed in this research. The

age of 45 has been chosen as a framework to inform decision making as it is the only one available, where, in diagnostic manuals, before the age of 45 distinguishes early onset schizophrenia. However, the added conditions that experience of mental ill health be for at least 20 years ensures that a) if they are 50 and developed mental health problems at age 44, they are excluded on the grounds that 6 years' experience at this time of life would not be sufficient to reflect common opportunities for life's achievements and b) if they are 80, their first experience of mental ill health occurs before the age of 45.

The term experience rather than diagnosis was used as a person may have experience of mental ill health throughout their life, but never receive a psychiatric diagnosis. This ensures that no one framework for describing experience is imposed.

In building on the advantages of recruitment outside mental health services (Karp, 1994; Schrieber, 1996a & b; Thornhill et al., 2004; Lester & Tritter, 2005; Broussard, 2005; LaFrance & Stoppard, 2006), the recruitment procedure aimed to communicate with as wide a population of people as possible, particularly given that older people with long term mental health problems may be difficult to locate (Bawn et al., 2007; Bytheway et al., 2007). For this reason a variety of strategies was utilised. These involved;

- 1 A poster sent to all local libraries (17)
- 2 A poster displayed in local leisure centres (7)
- 3 A poster displayed in third sector (non-statutory) mental health support organisations (2)
- 4 A poster sent to local GP practices for display in their surgeries (4)
- 5 The research was explained to;
 - a. Adult Community mental health teams (2)
 - b. One local later life Community psychiatric nursing team
 - c. One later life psychiatristStaff asked potential participants if they would be willing to be contacted by a researcher
- 6 A request posted on the Mental Health Foundation and Age Concern websites asked for volunteers

The recruitment poster aimed to be conversational in nature to make it appealing and therefore avoided technical jargon. The word ‘interview’ was not used following feedback by people involved in an older people researcher’s project where it was suggested that it had negative connotations associated with social services assessments when it usually meant something was going to be taken away (Saying Hello Project, 2007). In addition, given the wide variety of descriptions for mental health problems (McGrath, 1994; Karp, 1994; Lewis, 1995; Ritsher et al., 1997; Lundin, 1998; Champ, 1998; Hutchinson, 2004), broad terms were needed. With this in mind, the final wording for the poster seeking participants was; ‘Have you lived with emotional (‘nerves’) or mental health problems (e.g. anxiety, depression, hearing voices) since before you were 45?’ (appendix 8).

I subsequently met the seven participants as follows;

- One by chance at a meeting for a voluntary sector organisation
- Two people through a non-statutory cultural and wellbeing organisation available to the general public
- Two through a consultant psychiatrist in an adult community mental health team
- One who responded to a poster in a GP surgery
- One who I was put in touch with through word of mouth from another participant

Four of the interviews were conducted in the participant’s homes, one at the university premises where I work, and two at the premises of an organisation that the participants attended. Each participant was given a copy of sample interview questions suggested as good practice in biographical research (Atkinson, 1998; Roberts, 2002) when they returned the completed CV, usually several weeks before the first interview.

Ethical issues

Ethical approval

Ethical approval and governance permission to undertake this study was sought and gained from three organisations: the University of Salford, Bolton, Salford and Trafford Mental Health Trust and Salford Primary Care Trust (Appendix 9). Ethical approval was straightforward and no significant changes were required to the proposal. Quality assurance processes were adhered to where by regular academic supervision was undertaken. This included the completion of yearly reports to local ethics committees, self-assessment, annual progress and learning plans completed as a monitoring mechanism by the University of Salford.

Confidentiality and anonymity

Once ethical permission was obtained, procedures were put into practice in accordance with the health commissioner's guidance (DH, 2002b). This eventually resulted in meeting seven people who agreed to participate. These seven people (Table 4.) were assured of confidentiality and anonymity and each person was given a pseudonym, most chosen by the participants themselves. Anonymity was protected in the first instance within recruitment procedures that enabled people to either volunteer themselves by telephoning the researcher or by making it known to clinicians who they were in contact with that they were willing to be contacted by the researcher. Due to the interviews taking place in the participant's home, a lone worker policy was implemented congruent with the social research association code of practice for the safety of social researchers (Social Research Association, 2001).

The interviews were digitally recorded and although no names were referred to by me as the researcher, participants did refer to first names of people they had relationships with, all

of which were anonymised. The interviews were transcribed by a professional transcriber who provided me with the only copies of these transcriptions. The data was stored in a secure place and electronic files backed up on firewall and password protected computers. Confidentiality was discussed regarding the personal details that would inevitably emerge when using biographical methods (Fischer, 1994; Ruth & Kenyon, 1996). As a result, the on-going negotiated aspect of consent in ageing and biographical research (Moody, 1988; Kenyon, 1996) was achieved through provision of copies of conference presentations and publications achieved during the process of writing the thesis, for the participant's information. Participants consented to use of data in future publications and teaching and were reassured at the outset that references to personal details would be removed as far as possible, and they were happy to consent to this.

Table 4. Participant characteristics

	Gender	Nationality	Year of birth	Age*	Marital status
Peter	Male	British	1930	76	Widowed
Louise	Female	British	1935	72	Widowed
Jon	Male	British	1938	70	Divorced
Celia	Female	English	1941	65	Divorced
Vinnie	Male	British	1944	63	Married
Lucy	Female	English	1951	57	Divorced
Emma	Female	British	1956	52	Single

**Age at time of first meeting*

Consent

An information sheet and explanation about the research study was provided at an initial meeting where it was made clear that the participants were being asked to talk about their

past and their mental health problems during more than one interview (appendix 10). A minimum of a week was given to read the information before a further meeting was arranged to answer questions and discuss the research. None of the participants had any questions and were happy to proceed. Once they had agreed to participate they were asked to sign a consent form (appendix 11) which had been approved by the ethics committees.

Safeguards

No persons without the mental capacity to make autonomous decisions were involved within the research. It was considered however, that there was potential for participants to experience distress when talking about events from the past, and this aspect of the research was made very clear. As a Registered Mental Nurse I was confident in my ability to provide appropriate support should this happen and was prepared to provide information about professional and voluntary support networks available to them locally if necessary. Time was taken at the end of each interview to talk socially and to reflect on the experience in order to ensure participants were satisfied with the process and had the opportunity to ask any further questions.

Developing the narratives

A personal profile

Once consent had been obtained the participants were asked to complete a curriculum vitae (appendix 12) as the first stage in the development of the narratives. No reference to the use of a CV can be found in previous research, and in this study it is used to provide a structure that serves as an anchor for memories and as a framework for designing personalised interviews (see appendix 13 for an example). In addition, it offered an organising structure to capture the essence of achievement for each individual, and

therefore included sections about personal definitions and views of the meaning of achievement.

A brief pilot of the CV with two people in their 70s, one man and one woman, revealed that the use of the term ‘curriculum vitae’ was distracting and out of context. One associated it with job applications, no longer relevant for them, and the other as unfamiliar and confusing when she had spent her adult life within the home environment. It was therefore renamed a ‘personal profile’. Several weeks later, in a conversation about the profile, it became clear that the exercise had triggered a process of reflection that led to retrieved memories for one of the participants that had not been captured originally. This influenced the decision to develop a method that ensured multiple points of contact with each person whereby the potential to build on the last encounter was made possible. The personal profiles were given to the participants as a first stage, to complete at their leisure. Assistance was offered, but none requested it. This was then followed by two interviews for each participant.

Constructing the narratives

The narratives were constructed over a long period of time, utilising completed personal profiles, personalised interviews, interview transcriptions and their interpretation. The process consisted of 16 steps and was implemented as follows;

1. The personal profile was given to the participant for completion
2. Personal profile returned to the researcher
3. Sample research questions were given to participants
4. Personal profile used to develop a personalised interview
5. First interview undertaken
6. Interview 1 was sent for transcription
7. Secondary transcription undertaken (listening and verifying accuracy)
8. Interview 1 transcript was returned to the participant for checking

9. Taped interviews were listened to repeatedly alongside reference to the personal profile. Further questions were identified that either sought to clarify any points made, and developed further understanding about any issues
10. Sample interview questions for interview 2 were given to the participants
11. Interview 2 was then undertaken addressing issues identified in the last stage
12. Interview was sent for transcription
13. Secondary transcription undertaken (listening and verifying accuracy)
14. Interview 2 transcript was returned to the participant for checking
15. The checked transcript was returned
16. Complete set of interview transcripts produced for all participants

Secondary transcription refers to a process of listening to the tapes whilst following the original transcription that had been completed by a professional transcription service. This enabled correction of words that had been presumably misheard or sentences that were incomplete as surprisingly many errors were made in the professional transcription. Familiarity with the participants and the local accent enabled me as a researcher to make many corrections and fill in incomplete transcription, at times including completely missed phrases, and this also provided an initial opportunity to become more familiar with the content of the interviews.

Only five of the total 13 transcripts (one person completed only one interview) were returned to the researcher, some with no changes made. There were no obvious reasons as to why this was the case, but it may have demonstrated that the task was more difficult than anticipated. Once final transcripts were completed, participants were offered copies to keep for themselves.

The final transcripts represented nearly 14 hours (828 minutes) of audio recording and 235 pages of transcript (single spaced) as shown in Table 5, that then needed interpretation.

Table 5. Transcription details

	Interview 1 (no. of pages)*	Interview 2 (no. of pages)*	Total time (minutes)	Total pages in transcript*
Peter	29	19	236	48
Louise	11	12	64	23
Jon	22	8	93	30
Celia	20	13	104	33
Vinnie	24	16	120	40
Lucy	21	12	99	33
Emma	28	0	112	28
TOTALS	155	80	828	235

**single spaced*

Interpreting the stories

There is no single method for interpreting narratives (Reissman, 2002) and there are many approaches, the choice of which depends on the purpose of the research. In applying the principles of narrative analysis, developing a framework that is fit for the purposes of this research is a necessary step in meeting the aims of the study (Wengraf, 2001).

Respect for stories has had relatively little discussion in narrative analysis as professionals have been generally unable to respond to the uninterrupted voice of ill people (Frank, 2000; Smith et al., 2011), and there is a methodological quandary regarding the limits of what can be said about anyone else's story (Frank, 2000). In addition, it is important to avoid suppressing the participants' own meanings through analytic processes (Casey & Long, 2003). Therefore, in developing the method for interpretation, there have been two main aims: first to give voice to the participants' story as far as possible in their words and second, to maintain the narrative as a whole. Narrative research offers a way of analysing an extended account rather than fragmenting it into thematic categories (Reissman & Quinney, 2005). However, this was a challenge when faced with 235 pages of transcript.

There are many layers of interpretation and any attempt to tell the participants' story has to acknowledge the potential for changing the original meaning that comes about at each stage of interpretation, that is, hearing the story, transcribing audio tapes, and any final written interpretations (Poirier & Ayres, 1997; Reissman, 2002). The first stage of this interpretation utilised the concept of a text which takes on meaning through interpretation (Leder, 1990), in attempting to address the tension between a life story and the ambiguous topic of mental illness. Leder (1990) conceptualises a clinical encounter or 'medical text' as the narrative of a 'person as ill' and similarly a 'research text' can be created with participants with mental health problems. The research text is created with attention to various narrative distinctions. The experiential text relays the elaborate interpretive processes of experience that has already been formulated by the participants through their lives. The participants translate their experience into language and then the researcher selects and edits the resulting story thus producing a narrative text, where multiple authors make sense of the stories through a co-constructed narrative (Leder, 1990; Frank, 2000; Greenhalgh, 2001). This framework also provides the potential to meet the aim of ensuring that the participants' stories are told in their own words by keeping separate the participant's story, (the experiential text) from the researcher interpretations (the narrative text), a technique utilised effectively in previous studies (Hedelin & Strandmark 2001; Thompson et al. 2008; Patching & Lawler 2009). This is achieved by following the principles described below.

Although a clinical encounter includes a physical and instrumental text where the patient voice drops out and physiological investigations are interpreted (Leder, 1990), this is adapted for research purposes where it is replaced by a context text which outlines the background to the encounter, useful for biographical research (Wengraf, 2001).

The context text

The reflexive nature of the co-constructed narratives needs to consider the various factors that can affect the research and generation of data, for example, relationships, social setting, roles and power (Wengraf, 2001). This is the context of the interviews, within which words are spoken (Roberts, 2002; Josselson et al., 2007). In the individual findings chapters (4-11) the 'context text' will outline this context drawing on field notes and personal observations.

The experiential text

Developing the experiential text was the next stage of the interpretations. The experiential text presents the participants' story as re-configured from the interview transcripts. In developing the experiential text, ten broad areas of relevance were identified; early life, values and beliefs, achievements, work, mental ill health experience, cohort, management of experiences, changes, goals and advice to others. These aspects of life were incorporated into the process of re-configuring the stories to create biographies that illustrated coherent individual trajectories, presented within a temporally organised whole that followed a chronology from birth to the present (Mishler, 1986; Polkinghorne, 1995; Poirier & Ayres, 1997; Wengraf, 2001; Gibbs, 2002). Other than the reconfiguration of the narratives, no other interpretation was made at this stage and the experiential text relates the experience as told by the participants. This proved more difficult than anticipated.

During a reflection after the first drafts were written, it became apparent that the instinct to make judgements was difficult to resist. For example, in Peters story, it was written; '*one of the most astonishing disclosures is about his service with the Merchant Navy*' (experiential text file Peter, 18/11/08, p.2), and for Celia, '*She can only say that her friends*

were her main influence. This seems unsurprising when she told of the relationship she had with her mother' (Experiential text file Celia, 10/2/09, p.1). Astonishing and surprising as these observations might have been, it was a flaw in my attempt to bear witness to their experience in their words and required some re-examination on my part. This resulted in much iteration, searching for any judgements I had made and remove them to the narrative text, the more appropriate place for my researcher interpretation.

In biographical research, how events are perceived, selected and ordered in time within an understanding of individual life are necessary aspects of analysis (Roberts, 2002). Therefore the chronological order of events and experiences into a timeline was the next stage of analysis. This process revealed some difficulties regarding the chronology in locating the timing of events at particular times of life, and it was necessary to attempt to work out or interpret where events and/or experiences were temporally located in relation to each other. As the meaning of events or experiences was linked with the temporal nature of memory (Mishler, 1986; Charon, 2006; Reissman, 2008) associated feelings and other personally significant events were identified alongside this chronology where possible.

The narrative text

The narrative text offers an interpretation of the stories. This was informed by recovery principles, that is, a strengths perspective and a search for the meaning of experience in relation to personal accomplishments. At this point, some preliminary ideas about the presentation of findings in terms of citizenship were formulated for a conference presentation and this perspective was encouraged when, after receiving a copy of the presentation, one of the participants, Vinnie, rang me to say he thought I had '*put it very nicely*'.

The narrative text was developed by firstly listening to the interview tapes alongside the transcripts, noting the tone and other non-verbal communication as the spoken word must be recognised and re-contextualised in reaching an interpretation as well as taking note of inferences, personal discourses and subjective worlds (Josselson & Lieblich, 1995; Van Manen, 1997; Wengraf, 2001). Second, the listening and reading exercise was repeated for all participant interviews in order to become immersed in the data, and initial impressions were documented (Merrill & West, 2009). This was then repeated again with reference to the principles of over-reading, a method that acknowledges the indirect and multi-layered narratives people tell of their lives and '*the human struggle to make sense of an often confusing world*' (Poirier & Ayres, 1997, p.552). In over-reading, the silences (issues noticeably omitted) can be interpreted as attempts to move away from painful memories and can alert the researcher to evasions and omissions that the text alone does not provide (Poirier & Ayres, 1997). In addition, if people have difficulty answering questions then it may show that this is not a theme in their own lives (Chamberlayne et al., 2000). Narrative inconsistencies can signal points of confusion that prompt the listener to pay particular attention to endings and repetitions, as well as picking up overall meanings of the narratives through its repeated comments and images, and noting the well told story or telling phrase (Poirier & Ayres, 1997; Thompson, 2000).

The personal profile informed a framework for organising the interpretations with a view to answering the research questions. In attempting to be sparing in interpretation (Matusek & Knudson, 2009) but also being faithful to the emerging evidence in the narratives the subheadings for presenting the narrative text became; personally valued achievements, meritocratic achievement, not achieved/lost and, the present and future. This resulted in a system whereby relevant dialogue in interview transcripts was placed initially within the

apparently appropriate subsection. When organised in this way, and with the principles of interpretation outlined above in mind, connections between apparently disparate parts of their stories told became evident. For example, in Vinnie's case, the importance of finance became clear when connections were made between what he said at different points in his narrative and its consistent relationship with its effect on his mental health and the repeated phrase '*to prove himself*'.

Using these interpretive methods, the process evolved into a continual reoccurring pattern of listening, noticing, writing, listening, editing until narratives appeared coherent and understandable, which was a lengthy process that ensured intimate knowledge regarding the detail of the participants' narratives. Reflection on the interview process, conversations and reference to field notes helped manage any temptation to privilege the researcher's perspectives over the participants and a view on whether the participant's narratives would be recognisable to them was used as a reference point. Once this was achieved, a collective text could then be developed.

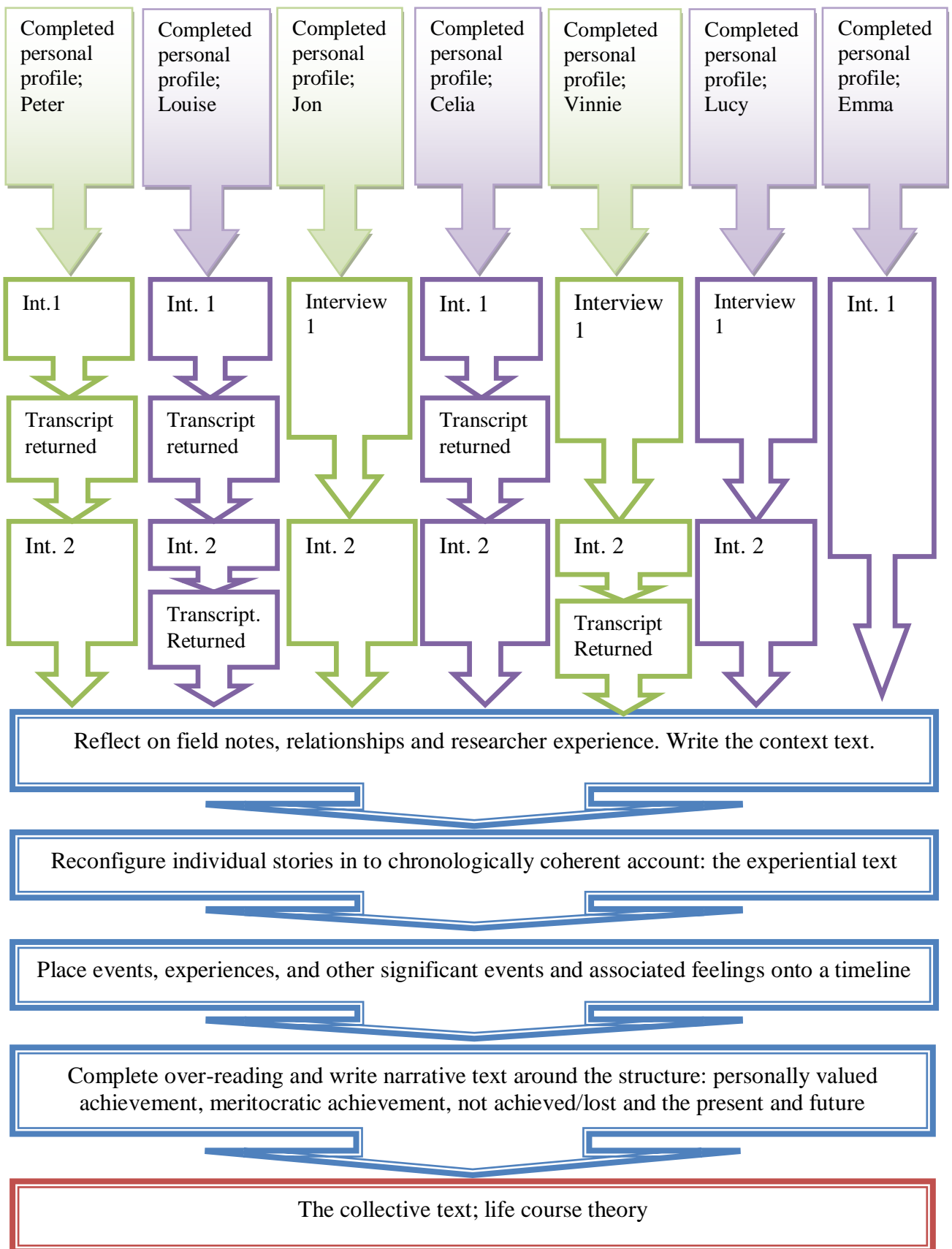
The collective text

The above framework was applied to interpreting individual transcripts. However, there is a need for a collective understanding of the data generated. In narrative analysis individual cases can be compared when presented together with individual narratives that contextualise the findings (Ayres et al., 2003; Reissman & Quinney, 2005). The salient story can be protected in summarising biographies prior to further interpretation (Wengraf, 2001; Thompson et al., 2008; Patching & Lawler, 2009). As this has been achieved in this study it is reasonable to go on to present a collective text. As well as listening to the participants, researchers must learn from their stories by taking leadership in translating

them for research purposes (Poirier & Ayres, 1997). The participants told the stories they wanted to tell to the researcher as the audience. The interpretation as a researcher and the presentation in a collective text is a story for a research audience (Denzin, 1989). Life course theory influenced the development of the collective text (Holstein & Gubrium, 2000; Shanahan & Macmillan, 2008; Elder & Giele, 2009) and it is presented with discussion regarding the key issues from the individual narratives.

The whole process of inquiry is summarised in Figure 3. It can be seen that the plan was not fully realised in practice. The participants took a long time to read and check transcripts and some were not returned at all. Only Peter, Louise and Celia returned transcript one and Louise and Vinnie returned transcript two. Jon, Lucy and Emma did not return any of the transcripts, and Emma only completed one interview as she did not respond to any calls or emails after interview one.

Figure 3. Summary diagram of the research and interpretation process



Presenting their stories

The next seven chapters present the individual interpretations from each of the seven participants. They include a timeline that presents the events in their lives that have been revealed through the telling of their story. Each chapter finishes with their words, rather than any researcher conclusions.

Chapter Four

Peter's story

'So it's been all one big push all the time for me'.

The context text

Peter was aged 76 when I first met him. We met by chance at a meeting in the local community regarding the development of a voluntary agency. At the end of the meeting, I asked all the people present if they would be willing to take one of my recruitment posters to display in their work environments. Peter took one. As everyone was leaving, Peter said quietly to me, *'that's me'* and proceeded to explain that he had post-traumatic stress disorder (PTSD) which had started around 1953, at the age of 23. The meeting was serendipitous because he seemed to have come to a place in his life where he had made a decision to be open about his experiences and talk to people about them. He wanted to educate people, to contribute to a new openness about mental health problems and to remove stigma. It was the reason he had joined the group. However, other motives became apparent for participating in the research. Peter said that he wanted to hold his own story in his hand. His intention, he told me, was to leave it as a legacy for his children whom he had never told of the real extent of his mental health problems. He also expected that talking about his problems would be therapeutic.

When I first met Peter, he wanted to tell me everything there and then and indeed talked for quite some time about his experiences. He brushed aside my attempt to explain ethics procedures insisting I didn't need to worry about it that it was OK, he would sign right

away. This illustrates some inherent power in my knowledge of research processes. I had to keep trying to explain that there were procedures I had to adhere to.

Our relationship was quickly established because he seemed to view me as someone who was *'down to earth'*, a standard he seemed to judge people by. On reflection I think that I responded to him the way I did because I felt aware that to be more interested in my own integrity as a professional would have appeared superior and incongruent with the relationship. I knew he respected what I was trying to do and he was aware of my professional expertise, occasionally referring to what he perceived to be my greater knowledge of mental health issues.

The experiential text

Peter was born in 1930, one of seven children who lived in impoverished circumstances in an inner city environment. His Mum did her best even though she was:

'...four foot nothing...but she bore and she looked after seven of us...she was only about six stone wringing wet through...her determination...her chin used to always stick out...she was a wonderful character' (Int.1, p.3).

Peter did not know who his dad was: he had *'three dads'*. His *'mam'* had the opportunity to go with *'a fellow from Yorkshire'* but she *'wouldn't leave her kids'*. They lived in a *'cockroach ridden'* environment with little to eat, no shoes and *'arses hanging out of our pants'*. His *'mam'* fought to keep her family together and went without herself to provide for them. Despite this, The National Assistance Board would visit;

'...they used to come down every so often with dark raincoats on, you know, and 'we've come to take your kids away' you know, and all that, and my mum said, 'you take 'em away and I'll...you know, no way. So she hung onto us and she worked hard, she worked bloody hard. I always remember that' (Int.1, p.2).

They survived by *'half inching'* apples and bottles of milk, and chopping wood to earn 2p. Although his *'mam'* was unaware, at the age of 10/11 Peter worked in the dairies amongst other endeavours;

'We picked over the tips...picking up coke in whatever weather, to have a fire. We used to have loads of blinking wood from the bomb sites on the fires just to keep warm...we had no electric, we couldn't afford it. We had candles and thing like that. I suppose it made me a better man. I don't know' (Int.1, p.27).

After the war they were given a new flat in a new block that had *'a bath!'*

Peter was the *'runt'* of the family and had *'every disease going'*: diphtheria, pneumonia and scarlet fever, but the most serious was peritonitis at age 10. As there was *'no national health service'*, they searched for help, walking from one hospital to another because they *'couldn't afford buses'*, and each hospital said the same thing *'sorry full beds'*. They walked and walked to different hospitals, Peter in severe pain, until there was only one place left to try; the private Jewish hospital. They took him in and he was *'lucky to survive'*.

Two years later, in 1942, Peter was evacuated to a family in the country. He ran away and, after taking a jacket and boots from his home without anyone's knowledge, he *'lied about his age'* and went off to join the Merchant Navy. He was 12 years old. He sailed with them around the world for three years with no military protection and they often picked up dead bodies from the sea.

After his return at age 15 he worked for a tailor. At age 17 he joined the army and spent much of the time in the Middle East, where he got *'his comeuppance'*. His patrol ended up fighting in Tripoli, *'street fighting'* that they weren't used to. They had to *'watch their*

backs' all the time, they could *'never relax'*, always expecting a *'knife in the back'*. They had to go through mine fields that were supposed to have been cleared by the *'sappers'*, but all too often a mine had been missed. They took sheep off shepherds to throw into the field which meant that they were *'never short of mutton'*. On one occasion one of the *'lads'* walking in front of Peter stepped on a mine and was blown up; *'Well, the radio lad in the front of us stood on a mine ..we're still looking for that lad as far as I know... and then I didn't know what happened'*;

'We thought it was clear and it was supposed to be clear, according to the records and everything...So we went in we was in single file orders...I was in the bleeding back, tail-end Charlie as usual, and I was walking backwards covering...but what happened was the radio man, and I think he was about twelve from the end...It wasn't like they are now with these things, you know, transistors. It was about the size of this, very big things, and he used to have to hook it on his back and it was very heavy with a big aerial and what we can only assume happened was we was walking along the path where the lad was...he must have stepped off the line and I can only think it was the weight, you know of his radio, and he put his foot on this bloody mine and went. So all I remember after that was this flash. The one in front, he copped out - you know, got it all in the back. The one behind him, he copped out, but he saved the others because he took the full doings, but I copped out...Well, I didn't cop out; I got, you know, hit because somehow or other it missed this other guy and hit me, you know, and all I remember after that was being taken to BMH hospital (name)...and that's all I remember' (Int.1, p.26).

Peter ended up in a British military hospital with a fractured skull. On returning to the UK, as an injured soldier, he was not allowed off the boat with the other soldiers to the waving, singing and cheering crowds, but kept on the boat in the bay until nightfall;

'But the public did not see the lads carried off. It was dead of night when the [name] docked at [name] so Hay Ho back to blighty, to what?' (Int.1, p.28).

After his return home, Peter had a period of unemployment and, due to *'boredom'*, decided to join the Territorial Army. By this time he had already met his future wife with whom he shared his *'rough beginnings'*. One *'Christmas time'* after a couple of years together, she came to him *'very upset'* because she was pregnant. He was *'over the moon'* and marriage followed *'hurriedly'*. It was not long after his marriage, when his daughter was a baby and

he was in his early twenties, that Peter started feeling particularly frightened, but he did not know why. He began to experience '*sweats...shaking all over and I just couldn't grip it*', but it was when he left the Territorial Army a few years later that he was '*not the same man in any way shape or form*'. The doctor said it was '*nerves*' and prescribed some tablets. Around this time Peter and his family had the opportunity to take a '*ten pound passage*' to Australia. His wife really wanted to go, but he just '*couldn't do it*'. He was frightened, he could not focus and he wondered '*what the hell's happening to me?*'.

After he left the Territorial Army, he had another period of unemployment. He enjoyed a drink and a bet with his friends and did not always take the work that was offered at the '*labour exchange*'. One day he came home to find his children without food for their tea and this spurred him on to take work that was offered. Several years later he gained employment as a driver of a '*bin wagon*' with the council.

He continued to experience '*dizziness*', '*sweats*', '*fear of going out*' and '*nightmares*'. He could not walk down the street without encouragement from his wife urging him on '*get to the corner this time*';

'I used to brush against the wall all the way down [name] street, brush against the wall...so I'm further away from the traffic, 'cos I kept getting fears...going across the road and getting hit by a bus...this sort of thing, you name it I had it. I was frightened to death' (Int.1, p.7)

Peter feared that he would '*hurt*' someone, '*especially women*'. He thought that he was a '*lunatic*'. He was fearful of his children, about what he might do to them, and said his feelings were '*not the way a man or a woman should think*'. He could not tell anyone, not even his wife about his thoughts and feelings. Peter never told anyone because he knew that if he admitted to being a '*lunatic*' he would '*be in the bloody nuthouse...I'd be gone*'

and my wife and my kids, who'd look after them'. His fears also prevented Peter from having or enjoying family holidays, or to be away from home. If he did make this 'sacrifice' for his family he would sit gripping the side of his deck chair 'frightened of everybody and everything', 'it was hard work'.

He always ensured that his hands were full so that they *'couldn't be used for anything bad'*;

'I used to get two morning papers instead of one and roll them up one in that hand and one in the other so me hand was doing something instead of, you know, hurting anybody or whatever because I was holding something. Now that's silly. You might think that's silly, but it did help me. I didn't want to drop the papers or whatever' (Int.1, p.7).

His fear of going *'mad'* ensured he never had a day off work as he needed to be occupied.

He was seen as *'easy going'*, and he would get up early and arrive there at 5.30am because it was *'very quiet'*. The job, driving a bin wagon meant that his hands were kept on the steering wheel and therefore remained full;

'I used to do a bit of driving...for the council and I remember one day I had to take this load to the tip. That kept me occupied because I had two hands on the wheel' (Int.1, p.8).

Being at work *'rested'* his *'mind'* as he could concentrate on the job and not think about his fears. On one occasion Peter found himself in the *'furnace room'* fighting the compulsion to put his hands on a hot plate because *'if they were burned off'* he couldn't *'hurt anyone with them'*. Around 1959 whilst at work, he found a book;

'It was raining like hell and I had to reverse and then back up right to the edge you know and the wheels were always getting stuck. Anyway I stopped it put the pressure on – up she went...and I went out to make sure that everything went out and this book...I was just stood there tipping and this book was half up and half out in the rubbish and I picked it up and it was something to do with peace from ...nervous suffering by Claire Weekes...and I picked it up and opened it, you know, thought I'd clean it up and have a look put it in the cab...and I took it home and I read it and I think that was the beginning when I realised 'Was I on my own or was someone out there helping me?' So that was on the tip and that was the reason why I started reading up about it, you know...I began to realise ...what it was is, parts in

the book said 'This is what my patients said they do.' So I looked at one that said 'I was afraid of this, afraid of that and I wouldn't do this,' and I thought these are beginning to fit into my fears...and it made me feel a bit better knowing that someone out there in the world had got the same...something similar to mine. So I used to read it and that used to buoy me up' (Int.1, p.9).

During this time, his family was growing and despite his reservations after ten years his wife wanted another child;

'I was looking for something to keep myself going. First of all it was our [name], then it was our [name] when he came along and then after 10 years she wanted another one and I didn't' (Int.1, p.17).

He had been starting to feel relieved that his children were nearly independent and he knew it would not be good for his wife as she was in her 40s, but she *'won in the end'*. After the birth of their third child her health started to deteriorate. He continued in the council job, doing his best for his family, but continued to struggle with his feelings *'for years and years and years'*. He retired around the age of 60 when management changes made his job too stressful.

In the early 1990s a health visitor who came to see his wife organised an assessment for an army pension after noticing Peters *'strange'* behaviour, a *'nervous twitch'*, and his military photos. The health visitor asked him *'how long have you been like that?'* Peter was defensive as he was concerned that she would figure out he was *'daft'* and he needed to keep this secret. She asked him if anything happened to him while he was in the forces and he felt able to tell her about his experiences of injury and deaths of friends. He told her;

'I was just on me back. I finished up in BMA, this is the British military hospital in [name] as a result of that and I had a fractured skull and shrapnel'. She said 'Nothing else?' I said 'Never mind nothing else. It was bleeding bad enough, you know'' (Int.1, p.10).

The process of assessment with military doctors that followed her intervention, eventually led to his diagnosis of PTSD and the award of a pension. He was not able to share this with his wife however, as she died two weeks before he received the letter.

The impact of her death led Peter to request admission to a mental health unit which he did not find helpful and stayed only for a short time. Not long after this he tried to kill himself as there was *'nothing left'* for him but he didn't want to upset his daughter. The organisation Combat Stress became very helpful as he started to mix with others who had similar problems and Peter felt he *'was no longer alone'*, forty years after his first problems.

Peter continued to struggle with his feelings. He went on holiday with friends but;

'...when we got there and we went up to Hitler's lair in the mountains, I couldn't do it. I stayed in the middle of this building up there – and it was a fantastic building right up in the mountain, a sheer mountain. I stayed stock still there. I could not move or do anything because I was frightened to death I might suddenly jump over' (Int.1, p.22).

Peter did not have as much *'depression'* when he was doing things for his wife but he is also relieved that he no longer has to face the fear of hurting her. He feels *'...better in myself than I did before'*, and having a name for what is wrong with him is helpful; *'I knew then what was causing all this. Bloody Fears...It's all an effort but not as much as years ago when I knew nothing'*. He wonders about how different life could have been as he *'would have had a different life if he had stayed as a cook in the army, instead of becoming a trooper'*.

Peter occupies himself in the garden with *'his love'* of birds and breeding finches. He is full of hope that he will meet a friend (female companion), someone who can understand.

His willpower keeps him going, but he is exhausted at the energy it takes to get through each day, putting a smile on people's faces, helping people. He tries to help people he recognises as having '*mental health*' by offering the reassurance that if they can learn to live with it '*that's half the battle*'. This keeps him going and helps manage his own problems even though he still has '*blue days*' and it drains him of energy.

Peter now lives according to a structure that ensures he goes out every morning and has engaged with voluntary work of various sorts. Peter's finches are a significant part of his life and he feels that if you have a living creature that needs feeding then it motivates you to '*get up and do it*'. This gets him through each day, but he is '*lonely now*'. The lady who he employs to help with his domestic work is '*a big influence and help*' and has become his friend, but as Peter reflects;

'...she goes home and the door closes. That's the way it is though. I accept it and it's hard, but what else is there to do...I have that alopecic (can't be bothered) feeling now...if your numbers up your numbers up' (Int.2, p.19).

The narrative text

A timeline (Table 6.), a chronology of events was organised according to a framework that enabled the identification of those issues that had or can be argued would have an impact on emotional and mental health. In addition, it makes clear Peter's achievements in relation to other life events and experiences including those that might be considered common. It was not possible to include personal achievement here as this was often represented conceptually rather than factually and does not necessarily fit into a chronological framework (Table 7.). The column headed Year, also indicates that this is approximate (circa). As a reconfiguration of the narratives, this was estimated with reference to participant references when it had not been explicitly stated.

Table 6. Peter's timeline

Year circa	Age	Common experiences	Achievements	Feelings	Other significant experiences
1930	born				
1936	6	Started school		Happy go lucky	
1940	10		Milk float		Peritonitis
1942	12	left school	joined merchant navy		Carried war dead
1944	14		Various jobs		
1947	17		joins army		
1950	20				Sees colleague blown up and other violent deaths. Receives head injury Time in military hospital
1951	21		Army medals joins territorial army Meeting wife & her getting pregnant	Overjoyed	Left army
1952	22	gets married		starts with headaches	Unemployed
1953	23	daughter born	Several different jobs	dizziness, fears of hurting self & others, sweating.	returns exhausted from manoeuvres Opportunity to go to Australia
1955	25		Several different jobs	Felt he was a lunatic Nightmares, fear of everything, stress.	Left TA
1956	26	son born			
1959	29		council job	'Hard going', afraid might go mad, exhausted, some relief	Found book in the tip
1966	36	son born		compulsion to burn hands off at work	
1992	62	Retired		Shaky, fearful	health visitor notices behaviour Sees MOD doctor
1994	64	Wife died	Awarded army pension	Grief, suicidal.	Diagnosed with PTSD mental health unit admission Carer starts Starts seeing psychologist starts combat stress
1995	65		voluntary work	Nothing matters	Tries to kill self
2000				Compulsion to jump off mountain	holiday
2007	76		Reaching 76 Helping others University of life	Panic, tears, lonely sad, depressed, empty	Physical health problems research interview

Table 7. Peter’s stated achievements and goals

Personally valued achievements	As good as anyone with limited resources, we survive. Reaching 76 Marrying my wife and sticking together in ups and downs Becoming a Dad Bringing the family the best we could Them bettering themselves University of life. Surviving Always trying to help people and put a smile on their face. Doing everyday things that other people take for granted Managing not to get put away (in asylum) Keeping finches
Not achieved/lost	A sex life with wife Going out. Dance halls, walks in the park, fairs, to the pub, going on holidays Emigrating to Australia Not being able to participate properly in activities Not taking an army promotion offered in [name] Taking months to do small jobs
Future	Hopes to meet a woman companion Like to go to India Visit brother abroad Help people

Personally valued/defined achievements

Peter’s personally valued achievements (Table 7.) do not relate to meritocratic achievement but to survival, creating life and his relationships. His interaction with the poverty of his childhood is only understood in retrospect and what he takes with him from this period of his life is pride, and the knowledge that it is possible to withstand hardship, resist authority and survive. He takes vicarious pride in the introduction of the NHS during his era, ending his explanation of this with: *‘that’s why I am what I am and proud of my background and I’m not ashamed of telling anybody’*.

Despite not knowing for sure who his father is and the poverty he lived in as a child, there is no sense of any adverse effect or blame evident in his narrative. Instead Peter’s experience of poverty shaped his motivation to try and ensure his children did not find

themselves in the position that he had experienced where they had to steal for food. Peter considers this as an achievement, that he enabled them to *'better themselves'* as he does not believe that they would have survived the childhood he had;

'You might see it today's poverty, but to me that's living well compared to what we had, do you know what I mean, because in them days you were lucky if you got a pair of socks let alone 'owt else because that was poverty' (Int.1, p.1).

This motive required him to work and support his family, a value shaped by his admiration for his mother. Peter's future orientation is shaped early on with his mother's refusal to give in to the National Assistance Board and keep his family together. The effect of this, rather than a legacy of insecurity as might be expected, is pride in his mother's achievements in the face of adversity, particularly after she herself had been born in the workhouse; *'I'm proud of the fact that she was born in abject poverty, in a workhouse'*. As a child Peter played a role as a resource for that survival, earning money *'...to give it to me mam, you know, to bloody keep us going'*.

The life threatening illnesses at a time when there was no welfare state and they had no money made the threat of death significant. One memory of a frightening event is recalled when he had surgery for peritonitis.

'I remember shouting out and all sorts and I remember pushing...that was the way it was chloroform, and I've always been frightened of that since...the consultant, he used to give me six pence...and I found out afterwards he was so relieved that I was still alive. This went on for weeks upon weeks (Laughs)...because he thought he might get it all back I said to me mam afterwards!...Anyway, I have to say I pulled through and I think that is because I've a stubborn outlook on things that I survived' (Int.1, p.17).

The humour with which this account is told mirrors his sense of humour that he believes has contributed to his long term survival. His attitude demonstrates resilience attributed to his personality as a ten year old, influenced by his *'mam'*;

'Stubborn and to carry on no matter how, what, who or why, not to take no for an answer. I've always been the same. I've followed her as much as anything as regards her determination to keep the kids together and that sort of bounced on me, 'cos I had a rough doing' (Int.1, p.3).

The timeline (Table 6.) illustrates that Peter had a childhood that finished at age 12, when it was interrupted by the Second World War, and he entered the adult world of the merchant navy. He states that this experience as well as other experiences from childhood such as illness, poverty, uncertainty about his father, threats of being taken away by authorities, being an evacuee, have no relevance to his mental ill health at all and have resulted in a pragmatic outlook having known no alternatives. He is *'...proud of the very fact that I and me family and a lot of others in them days went through the mill...but we took it as it is our life'* and despite any assumptions that could be made regarding the impact of such poverty, he had;

'...a happy life as far as jumping in canals...a bleeding song and dance. Before I had a happy go-lucky life' (Int.1, p.22).

This perhaps illustrates the relative nature of such experience for him in comparison to what he subsequently experienced, causing the former to recede in importance in his mind leaving the latter experiences to shape the remainder of his life;

*'If I'd have known then what I was going to go through' (Int.1, p.26).
'I was not prepared that lay before me and still with me to this day' (Int.1, p.28).*

He wrote on his personal profile his best achievement in life:

'Well, for one reaching the age that I am 76, meeting and marry my wife [name] we had ups and downs sort of life but we stuck together and her telling me that she was pregnant I was overjoyed. Just think I was being a Dad and had achieved something that I never thought I would, I was so proud, still am.'

Why Peter never thought he would be able to have children is unclear, but the value he places on life, creating it, *'producing a human being'* was something he valued as a young

boy raising ‘*penny chicks*’ and which has been strengthened by having come so close to death. For Peter his ability to reproduce was a great achievement; *‘I shocked myself, producing a living human being...I started that off’*.

His need to ensure his children were provided for triggers a turning point for Peter. There is incongruence between this motivation and his actual behaviour on returning from the army as all he is *‘interested in then was me mates’*;

‘...we went signing on at the dole...you used to have to sign on twice a day, not like you do now...and after that we split our pennies, we used to go across the road to get five woodbines, have a little bet, and that was me’ (Int.1, p.5).

However, on the day when he saw his children without any food for tea he is driven to change once again by the influence of his *‘mam’*;

‘Once again that clicked in with me mam...I said bugger that for a game of soldiers...So I gave her everything I had, the lot, and she said ‘Where are you going?’ never mind, and I walked out and I went back to the dole...and I said ‘Do you know that job on the railways working for the motoring department, the mechanics?’ He said ‘Yeah.’ I said ‘Give it a try.’ He said ‘I thought you didn’t want it’...I asked the fellow there, he said you start Monday, I said I won’t I’ll start tomorrow’ (Int.1, p.5)

Work itself is a meritocratic achievement rather than a personally valued one, and for Peter it is a means toward an end. His best achievement is bringing his family up, and giving them opportunities he did not have. The need to provide for his family prioritises itself over his emotional struggles, illustrated in this fleeting reference to its context;

‘We did our best for the kids. I always went to work even at times I wanted to...you know kill myself because I was determined to bring them kids up, you know, with a better sort of life than what we had and I think that’s one of the reasons I kept going, I don’t know’ (Int.1, p.4).

This passing inference to suicidal feelings illustrates the on-going presence of his mental health challenges in the context of his ordinary life goals. It also places in context one of

his own identified achievements *'reaching the age I am, 76'*. This is possibly an achievement for a number of reasons: his near death experience as a child, when his army comrade stepped on a landmine, and subsequently, his on-going risk from his own hand, including attempted suicide.

The strategies he developed such as walking down the street with his *'back against the wall'*, keeping his hands full with newspapers, hanging onto wife's hand, were strategies that enabled longer term achievement of his goals. The longer it went on the greater the emotional cost, and it was more important to maintain stability for his family, otherwise it would all have been for nothing. His future was mapped out by the anticipated transition in his children's lives as when they were old enough to support themselves then he could let go;

'Because I was frightened I might suddenly go mad and hit somebody. Honest kid, it was bloody awful, but I was caught between the cross-fire. I kept saying 'I must keep going...for the sake of the kids, otherwise I'll finish up in there' and if I did myself in it'd defeat the object then, wouldn't it, because then the wife and kids would still be branded and they'd be on their own...And what I kept saying to myself was as soon as my kids started work looking after themselves...I couldn't give a toss 'cos the wife wasn't too bad then, I couldn't give a toss what happened to me. I was satisfied to keep going until they started work' (Int.1, p.7).

This becomes a goal that shifts as life changes where, although his children have grown up and become independent, his role as a father and protector remains his motivation for staying alive;

'I used other excuses then. Me daughter had kids, 'I must keep going for their kids' (Int.1, p.17).

'When I'm down suicide grips me but we got to go on it would upset my daughter' (Int.1, p.24).

It is this latter risk however that resonates with his earlier life as he wishes now that he had been *'killed with the lads...I wish I'd have gone with that radio man and 2 others. Gone*

all finished'. However, he survived, and the book he found at the tip helps him through the years;

'Every night I used to read some part of it or what I went through that day...I suppose that kept me going even though I still had it all, but I took it to read. This went on for years and years and years' (Int.1, p.9).

This last sentence illustrates the all-consuming place of his mental ill health in his life which is made clear through its reiteration in other parts of the narrative; *'on and on and on'*, *'day in day out'*.

Meritocratic achievements

None of Peters personally valued achievements are related to meritocratic standards, and his meritocratic achievement of gaining employment is motivated by the lack of an alternative, *'I had to work. I had to work because in them days there was no nanny state like now'*. Because of the need to provide, Peter was able to navigate a way of living with and managing his experiences, therefore making his job sustainable. Work is what kept Peter going and it was essential in managing his mental ill health;

'If anybody says 'oh, I've got depression', Work!. No, work!. Because while you're working your mind is giving itself a rest because you're working. You're not thinking most of the time, you're working, so while you're working your mind and your brain is resting. Your brain is centred on the job and not thinking of fears. That's why it's the best thing to work with depression and that's what I found out. That's why I threw everything in me job, everything' (Int.1, p.17).

Being at work provided Peter with a legitimate and valuable opportunity to keep his hands full so they could not be used for anything bad. Holidays, often an antidote to work stress, were the opposite for him. His boss tried to persuade him to take a holiday, but he begged to stay at work, *'I said 'I don't want to' because I was frightened to death of having a day off work because I might go mad'*. If he did take a holiday, it was not beneficial and his

work colleagues joked that he looked as if he had '*spent a fortnight in cold storage*', remaining ignorant of his emotional struggles.

The place of work in the management of his mental ill health created a situation that enabled him to be a reliable and valued member of the workforce with his early starts, reluctance to take holidays and perceived attitude to hard work. This job also brought him some tangible relief for the first time when he found the book. It also presented occasional challenges such as when he felt compelled to put his hands on the hot plate at work so that he '*couldn't hurt anyone with them*'. Someone entered the room where he was and distracted him from going through with it.

He did not value promotion, illustrated several times where he requests demotion both when in the army where his need to be '*one of the lads*' over-ride any meritocratic achievement and later in his council job. Had he taken the promotion offered in the army he would have been in a different place, out of harm's way which became so significant for his mental ill health;

'These things happen, you know. It's just I regret my life as it is now. I regret...some decisions I made like not staying in the army, you know, because they offered me a post in [name], you know, a promotion which I didn't want, no no no no no' (Int.2, p.11).

His meritocratic achievements such as his service as a soldier, his good conduct medal, campaign medals and medals for bravery, his promotions and offers of promotion do not feature in his own perceptions of his achievements. The losses he experienced take precedence, illustrated by the ironic note '*BIG DEAL*' next to his listed medal on his personal profile. He said;

'That was the reason why I said 'big deal' because it was a big deal to me. I said I didn't want it. I did not want it, but I took it because I thought 'Well, I might help

the lads, ' but I couldn't because I was then a turn-coat. Not for me. Not for me' (Int.1, p.1).

And also;

'Am I hell being bleeding brave! We're just doing the job. Mine and quite a few other lads are just going through the same thing where their lives have been completely ruined and that's why when you hear about these lads in Iraq, you know, having the same problems, I understand. Awful...I think that is a problem and it's a sad thing. I'd got about 4 medals in there somewhere. I flogged them, you know. It's true, kid' (Int.1, p.26).

Not achieved/lost

His conceptions earlier in life, that he was a 'lunatic', informed his thinking and behaviour regarding his life. He interprets his experiences as something that was happening independently and which defines him as 'a lunatic'. When asked '*...so when that was happening then, how did you understand what was happening to you?*' he can only refer to this external interpretation;

'I had no way to make sense of it all I thought of was 'Peter, you're a lunatic', didn't think of the service or anything like that, I was a lunatic. For some reason or another me brain had gone and 'I'm a lunatic and as a lunatic I should be in a bloody padded cell in wherever.' That's the way I looked at it and that's what kept me going. 'I must keep going if only for the kids'. Not for me I couldn't give a toss. In fact, I'd welcome it if something could kill me because at least you'd get some recompense then'. This is the way I looked at it, you know, and that's why, because I was lunatic, because there was there was nothing else for it. It didn't run in the family, do you know what I mean, not as far as I know, but that's the way I looked at it. There was no counsellors in those days and being daft was a terrible stigma' (Int.1, p.8).

This created the environment within which he lived. Doing everyday things other people take for granted is an achievement for Peter, but doing such things is problematic for him as ordinary life is curtailed by his mental ill health;

'It stopped me going out, enjoying life, going into dance halls...enjoyment like going on fairs, going walking in the park with your family. Because every time I went out I did take them, I'd take them every Sunday, but I was always up-tight and I was always fearful. Going out with the wife, you know...go in the corner pub just for a quiet drink of lemon or whatever, you know. Going away, I was frightened to death of going away. I would not go. If I went away it would only be for half a day

to Blackpool...So yeah, it did, it destroyed my life. It destroyed my way of life which I wanted to do and still want to do, but as the MO said at the time I was 'lucky', not so. I wish I had gone with the lads' (Int.1, p.20).

The all present nature of these feelings is difficult to illustrate in the context of a time line, and life events and achievements have to be interpreted within this context. His greatest sacrifices were changes in routine of going on holiday. For the first time he saw women on the beach in bikinis, and as well as this being a culture shock for Peter it was also a further test to his resolve and he hung on to his deckchair, sweating. All his emotional resources are spent on this. He manages his risk by avoiding women, hiding hammers and knives from himself and keeping his hands full;

'I couldn't talk to you like I can talk to you now. I'd have to rush out or I'd have to tell you 'Go on, get out of the way while you're safe,' because these fears were so intense. The sweat used to pour off me...If I was talking to you now then and feeling out of my depth, I'd be sweating and you'd know there was something wrong with me...I'd rush out of the house, 'Get out while you're safe.'...I used to be frightened of handling knives. I used to hide knives away. Anything that could cause...hammers and everything, because I was frightened I might suddenly go mad and hit somebody' (Int.1, p.7).

The strength needed to live like this was gained by conserving every bit he could to get through each day;

'...you burn up a lot of energy or what you call energy because you're not relaxed. You're not completely relaxed. You're always on edge' (Int.2, p.9).

The army had taught him that sex took away your strength and energy, and believing this, he denied his wife sex. Peter did not think it was such a problem as he did not know that women could enjoy sex and so did not, until much later in his life, worry that he had let his wife down; *'After I lost her I regretted what I did because I denied her love thinking that it keeps me with strength you know...No, it was true in them days'.*

Present and future

Since his twenties, Peter has been ambivalent about his future, in part wanting to have been killed with the others and in part enjoying his creation of life and fatherhood. His future was at risk when he realised he was a *'lunatic'*, his brain *'had gone'* and he should be *'locked up in a padded cell'*. He was he says, emphasising each syllable, *'ab-sol-ute-ly daft'*. His experiences have created his keen sense of mortality: *'The clock is ticking away'*, *'if your name is on the bullet...'*. This has changed the parameters regarding what others might consider situations of anxiety, for example, being unconcerned about putting himself in risky situations. It enables him to be unrestricted in terms of going out of his house into the local community, as in his mind there is no future; *'there's no future for me'*.

His motivation and determination to manage his experiences on a daily basis came at great emotional cost. This cost was caused by his military service, a position that set him against other young men just like himself;

'You know, I've never paraded. I remember them and that's, you know, as it is. was...not only for them, but everybody, the Germans and all. So whose side was God on? The lads brainwashed. War is bloody sad. You can say what you like, but I respect them just as I respect ourselves. I mean never fought against Germans as a soldier, but the point was they was only lads like us and they was only fighting what they thought was right... 'Why?' And I still say that to anybody now. 'Why? Why all these lads gone?' For what...I always remember, irrespective of who, what or why, we was all lads doing what we thought we had to. Bollocks...It's so sad, kid' (Int.1, p.26).

Because of this, he now sees that this price was not worth paying. His polemics in the interviews on the state of the country today, indulged children and material possessions serve to illustrate this;

*'These lads, they're turning over in their graves when they see what's happened to this country' (Int.2, p.15).
'...kids of today don't understand unfortunately because now...You're just a silly old git now a pain in the arse' (Int.1, p.27).*

He is blamed by his GP for not disclosing his service experience, but as Peter said *'he wasn't asked'* and he had never made associations between his military experiences and his mental ill health. When Peter tried to tell a visiting psychiatrist his story he is told *'I'm not interested in your past...all I'm interested in is your future'*, an insult that results in his being told to leave Peter's house. His life is about his past and the price he has paid to survive. Peter's chronology (table 6.) demonstrates a time of little change between 1994, when he begins to see a psychologist, and 2007 when he participated in the research, the latter being something he regards as a turning point in his life as it introduces him to a new opportunity to educate others.

Peter's efforts over the years, the book about nervous suffering, the diagnosis, the talking to a psychologist for the last 15 years, have brought about change in the stress he bears, some relief and a lessening in intensity and frequency of particularly bad days, but his mental ill health is *'still there'*. His engagement with the psychologist in his early 60s enables a transition from his lonely struggles in the past to having opportunity to share his struggles;

'But she's there for me. I can tell her what I feel like and whatever...thinking of committing hari kari and all this crap...And it is really, I'm not joking, it is really bad, but so much for tomorrows another day...but I look forward to her coming just so I can tell her...and I'm telling you' (Int.2, p.5).

His future goal is informed by his early life experience, as he wants to *'Help people. maybe that stems from when I was a kid, cos we never had anything...'*, but also by the need to help himself active through engagement in voluntary work;

'What keeps me going is the fact that [name] he's just phoned me up and said 'There's a meeting tomorrow.' I didn't know...It's them sort of things that keeps me going and I'm helping somehow or other in me own little way, whatever it might be, to help other people. I never used to be like this...but it's not now, it's a different story with me. I want to help people, especially in the field which I know more about than people who've not had it' (Int.1, p.22).

This also contributes to a structure for everyday life that gets him out of the house, but which is occasionally supplemented by the use of the Samaritans helpline, *'Now I'm not ashamed to say I've used the Samaritans and I used them about a fortnight ago'*. Although helping others helps him, it continues to be at an emotional cost;

'You know, it's still there and you're still using like the energy up just to keep going and trying to put a smile on my face or other people's face, whatever. And it's hard work and when I come home I'm exhausted and knackered, you know' (Int.2, p.10).

Although Peter sees *'no end...it's still there'* the hope that keeps him going is to meet a person who will understand. And despite everything he would not change anything;

'I wouldn't swap me experience because it's made me what I am now I think daft. It's made me understand a lot...nobody gives a toss about us, nobody. You're invisible' (Int.1, p.27).

'It's my life. It's fate, it's what happened. There's no going back to it' (Int.2, p.13).

Chapter Five

Louise's story

'There was nobody, nobody worse and frightened to death of dying than me'.

The context text

Louise was 72 when I first met her but had reached her 74th birthday by the time we had finished the research process. I was put in touch with her through a psychiatrist via a community mental health team. The psychiatrist acted as a gatekeeper who conveyed his own criteria for his decision making when he told me that she was *'cooperative'*. During the time between our first meeting and beginning the interviews, we had many conversations on the phone which became friendly and supportive in nature.

Louise was someone who I easily fell into personal conversation with. I was invited into her home to undertake the interviews and we were able to chat over a cup of tea each time I visited which led to it becoming a welcoming and comfortable environment. Louise's exact motive for agreeing to be involved in the research is unclear but after having experienced sharing her story she specifically remarked on the therapeutic value it had, and how engaging in the interviews helped her to realise how far she had come.

The experiential text

Louise was born in 1935 two months after her Dad died, the youngest of four siblings. When she was 2 years old her mother *'went in hospital for an operation and she never came out...'* Following her mother's death, she and her sister were *'split up'* from her other siblings, who became *'more like cousins,'* and moved in with her auntie and uncle. Her

auntie, '*...did her best to bring us up, but it wasn't good*' and they were not financially well off. Her auntie was '*...very, very moody...you were frightened of going in because you didn't know what kind of mood she'd be in*'. '*That childhood*' had a '*bearing*' on what she and her sister were like.

Louise experienced a further bereavement at 4 years old when her uncle died. Louise, her sister and auntie then moved in with her Grandma and Grandad until their deaths six years later. She was forced to look at her Grandmother's dead body in the coffin at their house, which she did not want to do. Shortly after this, at the age of ten, Louise started having panic attacks. Because '*such a lot of people had died*' she was a '*very timid and very nervous*' child.

At age 15, Louise left school with no qualifications and she got a job as a machinist, a job she worked at until she had children. She got married at age 21 and found herself pregnant straight away. She had a breach birth, and her daughter was still born, something she found difficult to comprehend;

'I never saw her, I never held her. They just took her away and after that I could feel moving inside. I could still feel her moving inside me, do you know what I mean, and everybody was telling me she wasn't, but I hadn't seen her born, you know' (Int.1, p.4).

She was alone, '*crying under the bed clothes*' because the nurses told her she was '*upsetting all the patients*' and as she had only been married 12 months they said, she had '*plenty of time*' to have more children. When she went home from hospital her panic attacks intensified, '*I can't tell anyone what those panic attacks were like*', to the point that her husband thought she was '*choking*'. She was so '*bad*' after this that she had a '*breakdown*';

'They wanted me to go in hospital but I didn't go in...I was quite bad then. I think I had a breakdown then but I didn't go in hospital' (Int.1, p.3).

One afternoon, when Louise *'was choking'* in panic, she *'ran quite a long way'* to the GPs where she *'fell in the surgery'*. She was *'so hurt'* when the doctor said *'no wonder you lost your baby, running all this way'* and he prescribed her *'phenobarbitone'*.

Louise went back to work as a machinist for a couple of years after her still birth, until she had her second child after which she took work as a part time cleaner. She did this for around 16 years during which time she had two miscarriages then four more children, *'I had [name] 6 years then 3 more children in 2 years 11 months'*. She was never satisfied working as a cleaner as she *'would have liked to train as a nurse, you know, but I didn't, couldn't, so I did the next best thing'* and, in her early forties, she got a job as a nursing auxiliary. She was happy working in this job and she *'loved it, loved it.'* She had occasional periods of sickness but tried to get on with her everyday life;

'I think I managed it quite well really, you know, all in all. I mean I had times when I had to come out, but not for long really. When I was working in the hospital, I never had long periods, the sister would ask...good days and bad days and that's how you get through it, don't you?' (Int.1, p.9).

She tried to hide the on-going effects of her mental ill health from her children as best she could but didn't entirely succeed;

'I was trying to hide things really...and I must have been ill, I was ill, something [name] said to me in his teens, he said 'I'm scared you'll take all your tablets'...he didn't want to go to bed in case I took my pills' (Int.1, p.8).

Her *'bad days'* included a *'bad time'* around the age of 42 when Louise had a hysterectomy, a difficult experience particularly with no support from her husband as he was *'useless'*: He came to see her on the day she was being discharged from hospital;

'...when he come he said 'I've got no money for a taxi,' and I just couldn't have got on a bus or done anything. So I go up to one of me mates and borrow some money and I came back and he'd got money for a taxi and he dropped me off and then went out and he didn't come back till about 3 o'clock in the morning and about 1 o'clock I was on the floor upstairs on me hands and knees, you know, so it was awful' (Int.2, p.2).

At home attempting to recover and look after her children, this lack of support continued *'he was no help at all my husband in any way'*. She struggled to get to the shops during the bread strikes in the 1970s;

'...it was November and it was a time when, I can always remember this very clearly, a time when the bread strikes were on with no bread and I had to...I was really poorly and I had to queue up for the bread. The shop on the corner used to bake bread and I queued up for, you know, about an hour for bread for the kids, you know. That was hard and I never got any help with anything really. I just had to get on with it, you know' (Int.2, p.2).

He would also get drunk and *'he had women aswell'*, having a child with someone else at the same time as Louise was pregnant.

In her early 50s, Louise started seeing a counsellor to whom she was *'sent'* by her doctor. She didn't know where her still born baby was but this process helped her;

'I didn't know where she was, where they'd put her...my counsellor phoned to [name] and he took me up there one day and there was like a plot and it's got like a stone on and it's got on it 'For All The Babies Who Died in [name] hospital'. Oh, it was lovely really' (Int.1, p.6).

A few years later she also separated from her husband after 36 years of marriage. When she left him she had *'a really bad time'* resulting in a hospital admission;

'...after I left him that's when I went in [name of mental health unit], you know, rather than come tumbling down because it was a big thing for me at 57 to do that' (Int.2, p.6).

Following this experience, she retired from work. She remained on good terms with her husband during their 12 year separation until his death.

Her experience of mental ill health now is better than it was, despite some ‘*grey and black*’ days. Church attendance gave Louise something to ‘*hang on to*’ and to confront her personal questions about what happened to her and ‘*what is it all for*’. She makes herself get out of bed and out of the house, even if just for a walk to the shops. Her anxiety continues: if she sees an ambulance in the street she will ring her children to make sure it is not one of them that who has been taken ill. She no longer gets panic attacks in the night, but they threaten in the day sometimes. If she feels a panic attack coming on she can think herself out of it because a book her sister gave her about coping with a still birth, told her that she has already experienced the worst thing that can happen, ‘*nothing worse can happen, I’m not going to die*’.

The narrative text

Louise’s timeline (Table 8.) maps her common experiences, achievements significant events and associated feelings. Her achievements including those that cannot be represented in a timeline and her personal definitions regarding these are captured (Table 9.).

Table 8. Louise's timeline

Year circa	Age	Common experiences	Achievements	Feelings	Other significant experiences
1935					father dies
1935	Born				
1937	2				mother dies moves in with auntie and uncle separated from siblings
1939	4			Nervous	Uncle dies Moved in with Grandma and Grandad
1940	5	Starts school			
1945	10	grandma dies Grandad dies		starts with panic attacks felt she was going to die	pushed to view grandmas dead body
1950	15	left school	gets job as a machinist		
1956	21	gets married		'breakdown' so ill, horrible, panic attacks, choking, heartbroken, crying	gives birth to a still born baby
1958	23	has child	Leaves machinist job part time cleaner	'Cuts deep' Can't cope with life, everything an effort, can't get up in the morning	Husband has affair
1964	29	has child			Miscarriage
1965	30	has child			
1966	31	has child			Miscarriage
1974	39		Left cleaning job nursing auxiliary		
1976	41			'The thought you can't have kids'	Hysterectomy
1989	45			Upset but lovely	Starts counselling finds memorial to babies who had died
1992	57	separates from husband Retired		Not eating, sleeping	six months in mental health unit prescribed lithium
2006	71	finds new partner			husband dies
2007	72	Becomes great grandmother		research interviews	

Table 9. Louise’s stated achievements and goals

Personally valued achievements	By trying to be a decent person and knowing that my family love and respect me My 4 sons, grandchildren and great grandchildren Being able to cope and work as a nursing auxiliary Being my best as a parent and closeness to all my family. Not feeling bitter about things that have happened to me
Not achieved/lost	Having a nice husband Being able to do professional training
Future	To keep well and try to be strong Continue life with current companion and have holidays Take each day as it comes

Personally valued/defined achievements

Louise’s greatest achievement is her family: children, grandchildren and great-grandchildren, and her ‘closeness’ with them. She has measured achievement through standards of behaviour, being a ‘decent person’ and being able to apply these standards successfully to her children who because of this ‘love and respect’ her. Her achievement has been being a good example and doing her ‘best’ as a parent.

Most of her personally valued achievements are framed around family and relationships and being both a mother and wife ensured her future was full, distracting her from emotional pain by creating a situation full of activity and having people dependent on her; ‘I think having the children helped because you’ve got to look after them’. Her children provided her with a structure which mapped out her future that she did not then have to think about. They are her reason for getting up in the morning and what enables her to carry on; ‘I had three children and you couldn’t really... you just had to get on’. Having young children concentrated her mind and ‘pushed her through her grief because they had to be looked after’.

Being the *'best parent she could'* is achieved within the challenging context of the continuing effects of her experiences as *'When you're panicking you're thinking 'Oh, I'm going to die! I'm going to die! I can't breathe!'*. It is also challenged further when her female identity is threatened by a hysterectomy;

'Perhaps that's a woman thing really, you know. I think that was a woman thing because I remember when I went to my GP he was really good at the time and he said 'Well you don't want any more children, do you?' and I said 'No', but the thought that you can't, you know. That was part of it and I didn't have any support, you know' (Int.2, p.2).

This does not prevent her from succeeding however because she is still able to be the best parent she could and her children reflect her success;

'Because I think they've all done well and...I think they've never really been in trouble because they respected my standards' (Int.1, p.3).

One of her life course building blocks has been a belief that *'if your bitter, it'll come back on you'*. She is not bitter and does not want to waste her life, as she has seen others do, on bitterness;

'I always say that if you're bitter...it'll come back on you. I don't want to be bitter. One of my friends is very bitter because her husband left her...40 years ago and she's still bitter and I can't see the point in that really' (Int.1, p.9).

Being able to sustain work was also an achievement;

'That gave me a lot of satisfaction that did...I thought, 'This is not what I want to do. I want to work with people,' and I wanted to help people and I got a lot of satisfaction from it. I really did' (Int.1, p.4).

Meritocratic achievements

There is relatively little included within her meritocratic achievements and her early experience of work is driven by monetary need and family expectations;

'Well I suppose you could go to college or something...you got a job, as I say, we were orphans anyway we lived with our aunty...she didn't get much for us anyway.'

I think she used to get 7 and 6 a week. My sister was working then, it was just expected, you got a paid job' (Int.1, p.1).

Meritocratic achievement has not been the most important area of her life and in the early years of her marriage and motherhood it serves a practical purpose when she '*...struggled with everything, money, no support*'. Her opportunities are limited in part by having to look after four children, responsibilities that are welcomed by her as the children are central to her life. Personal aspirations regarding work or career do not feature as important because she was achieving what she set out to do, look after her family, but also because it did not feature in her expectations influenced by a lack of encouragement at school;

'You wasn't encouraged to, you know, when you was young. As soon as you left school you had to get a job. You know, no matter what job it was you'd go and get off into work, you know. No thinking of what do you want to do' (Int.2, p.9).

Despite this she did have personal aspirations that she realised in part when she got work as a nursing auxiliary;

'That gave me a lot of satisfaction that did. I mean when I started work at 15 it wasn't what I wanted to do, machining, but it was just in order to get a job and then I cleaned office cleaning...and things like that, running for lunches during the day for staff and It's not what I wanted to do...and I thought, you know, 'This is not what I want to do. I want to work with people,' and I wanted to help people and I got a lot of satisfaction from it. I really did' (Int.1, p.4).

Not achieved/lost

Eight significant losses are mentioned in the first two pages of Louise's narrative, six deaths and two miscarriages. The subsequent page adds a further two losses; a mental '*breakdown*' and a hysterectomy. Surviving such loss is not explicitly identified in her achievements, but forms the basis for how she lives her life, it is her building block for life as '*it had to happen that way*', '*that was the way it was going to be*'. It acts as a framework for defining her life as '*life would have been much different with all the family together*'.

She ended up with only one sibling and two cousins and although from age two her auntie and uncle took parental roles, she identifies herself and her siblings as ‘*orphans*’. This is a recurring issue referred to in passing several times, clarifying her relationships;

‘...we lived with our aunty, I call her my mother’ (Int.1, p1).

And,

‘...she had problems, me mother, you know. Well she wasn’t me mother, my auntie’
(Int.2, p.7).

Although she describes herself as a ‘*nervous child*’, a significant memory associated with this is when she was pushed into viewing her Grandmas dead body in the coffin at their house, which she did not want to do;

‘...they said come and look at the coffin...and I didn’t want to do. Do you know what I mean when you really don’t want to do (laughs) but you feel like you’ve got to what they tell you...come and see your gran...I just didn’t want to do it and that made me nervous’ (Int.1, p.4).

This appears to be associated with a time around the age of ten when she remembers having panic attacks ‘*I can remember saying ‘I’m going to die!’ with having panic attacks; and I was only at school. I was very young, about 10’*.

From her narrative there is very little reported in terms of being a child during the war and one explanation of this might be that the all-consuming nature of her childhood bereavements have eclipsed other potentially distressing war time experiences. Likewise her early adolescence and adulthood make no reference to growing up in post-war Britain.

Although mental ill health became significant for her as a child, it is the birth of her still born daughter in her early 20s that had the most adverse effect ‘*...but the main thing was when I lost my baby’*;

'...nothing mattered really. I was unaware of a lot of things around me, and I was very sad, very very sad and probably let a lot of things go. You know, just...I can't really describe it but I just know it was horrible. Everything was grey or black. You know, it was as though you were in another world really, like a big mist had come down on you' (Int.2, p.1).

The sharing of this experience is the longest and most eloquent part of Louise's narrative and is detailed as if it were a recent experience. Louise realised this, even though as she noted herself it was 51 years ago. Its central importance is also illustrated by recurring reference to it and the details clear in her memory;

'...it was a breach birth as well and my legs were up in stirrups and they had to cut me, you know, and it was just all a haze and they took her away, do you know what I mean, and then they were horrible at times, there, then really. Perhaps they didn't mean to be, but they're not like they are now...I was absolutely heart broke! You know, it was terrible' (Int.1, p.4).

Louise's subsequent pregnancies serve to both increase her anxiety and resolve it,

'...and I was terrible. Terrible. I can't tell anyone what them panic attacks were like. Then I started having our [name]...and I worried, you know, the same thing'd happen again. Once he was born things got better...I had the children quite quick anyway' (Int.1, p.5).

She attempts to maintain her pregnant state but has two miscarriages. Six years later Louise had three more children in 2 years 11 months.

All her children are born to her before age 33, but she does not leave her husband until she is in her mid-fifties. Louise's husband's infidelities are significant in her life as they prevented her achieving what she wanted. Louise had achieved gaining a husband and a family, but she did not have a 'nice' husband, which was her goal;

'All I wanted was to have a nice husband and a family and all be close but that didn't happen...there was something missing' (Int.1, p.9).

The closeness to all her family does not include her husband and her relationship with him did not improve, *'The children weren't there, they'd all gone. There was just me and him and it was still the same'*. Leaving him was a self-imposed loss but had catastrophic effects as it precipitated the only admission to mental health services she ever experienced;

'Oh, I just stopped eating and I can honestly say I didn't sleep for three days and three nights. I wasn't eating. You can't cope with life. You can't cope with everyday things. Everything's an effort. You know, just getting up in a morning's an effort. I just wanted to cover myself up and stay there forever really' (Int.1, p.6).

There is very little that Louise considers lost in relation to her achievements perhaps as a result of her conclusion that;

'I think it had to happen that way. I think you've got to...I think yourself has got to come to terms with it, you know' (Int.2, p.4).

This perhaps illustrates the strength of one of her main personal achievements, *'not being bitter about things that have happened to me'*. This includes no bitterness about being unable to achieve her aspiration, to be a trained nurse. She *'wasn't clever enough'* and lacked *'self-confidence'*. Also, the effect of her experiences leads to a need to avoid failure, something she could not face;

'I think when I was younger I would like to have trained to be a nurse...I don't think I would have coped with the training...I didn't want to try and fail' (Int.1, p.10).

The avoidance of failure appears to be an act of self-protection and appears to be more important than achieving the aspiration.

Present and future

At her most unwell Louise *'didn't think I had any future at all. I thought that was how it was going to be'*. This ensured that her future is actually *'a lot better'* than she expected it to be. This is sustained by her decision to leave her husband and although this led to

deterioration in her mental health at the time, it is a step towards a long term goal of a happier life. Her experiences after she left her husband were managed by reference to a future that implies that the emotional turmoil of the past was the cost she had to pay for a better future;

'Well it's been a waste of time all this making myself ill if I'm not going to do anything with my life from now, you know' (Int.2, p.11).

Having been in a psychiatric unit once is a motivator to ensure that she remains well as she feels that there is a 'stigma'. The experience reinforces her need to succeed, to try and manage things at home as '*there is no way am I ever going in there again no way*';

'I think 'Well why have I done it if I'm not going to be any better?' Well that was my thing, you know, when I came out of [name]. I thought 'Well how stupid can you get? You've made yourself worse by leaving him and you've spent six months in [name].' You know, I don't want to go in there again so I thought 'Well I'll have to change,' you know' (Int.2, p.11).

She is still left with questions about 'why' those things happen to her and religion provides a structure within which to explore those answers;

'I go to church and my sister does aswell. At the time you think 'Why? Why? What's happening?' I go back to it you see, because I have nothing else to hang onto I suppose...got to think there's a better place for everybody' (Int.1, p.11).

When referring to her goal of keeping '*...well and be strong...*' she glosses quickly over the physical part of this, eating '*healthily*' to a narrative relating to her on-going anxiety;

'I thought I'd phoned him. My other son [name] rang me back, so I must have dialled...I pressed the wrong one on my mobile and I thought 'Oh, he's not answering,' you know, and he normally answers on his mobile. So I phoned his wife because she's in all day at the moment and she didn't answer. Then I phoned his daughter and she didn't answer and I thought 'God, he's in hospital!' You know, right away I thought 'He's in hospital!' And that's how I am really. I would like not to be like that, but I don't think there's any chance of me not being like this' (Int.2, p.10).

The panic attacks are clearly an integral part of her life something she has taught herself to manage as, '*You have to learn from experience as what you are told is impossible to follow*

if you wake in the middle of the night...I am the biggest worrier in the world, I really am. I wish I wasn't, but I am. There was a time when there was *'nobody worse, and frightened to death of dying than me'* but for Louise getting older has meant becoming less frightened of dying;

'...but now I'm not, you know, not at all. I don't want to yet and I'm quite alright, but I don't have any fear of that. Now when I was younger I did have a fear of that...you know, a real fear, but not now' (Int.2, p.7).

Her main fear has passed, that her children would be left motherless;

'No, I'm not so frightened at all. I think when I was frightened it was because I was frightened of leaving the kids. You know, I thought 'God, I can't leave these on their own,' you know. Perhaps it was that, but I was really. I was scared when I was a kid of dying, do you know what I mean. It was just a fear' (Int.2, p.7).

The motivation for struggling on, having young children, is a repeated story, and although she no longer has this structure or any dependents, she is in close contact with all her children, grandchildren and great grandchildren, with their successes reflecting her own achievement in bringing them up to be *'decent people'*;

'I try to see the best in people, trying to give my children good examples, you know, trying to bring them up to be decent, and they are that. Wonderful' (Int.1, p.3).

Now Louise is *'contented'* and happy with life. She has a new relationship and a social life, as well as good relationships with her children, grandchildren and sister. Having the opportunity to tell her story through the research process enables her to focus on the progress she has made;

'It's been very interesting to talk about things, yes...and you know some people say, you shouldn't look back don't they, but sometimes it does you good to look back and see how far you've come, you know' (Int.2, p.11).

Chapter Six

Jon's story

'I was in a kind of moral battle'.

The context text

I met Jon when he was 70 years old, through a third sector organisation. We met at the premises of the organisation and it was a place that we were both familiar with. His motives for participating in the research appeared to be related to his expectations that talking about his problems would be therapeutic and did say that it had been helpful that someone was so interested and listened to him. In addition, his motivation was guided by his belief that it provided evidence that he was putting in an effort to reduce his own problems, and by doing so he would be rewarded by God; *'if you do the right things you will be happy and God will heal me inside ...that's why I'm here'*.

I found Jon's reference to his Christian values uncomfortable and was aware of an effort on my part to respect and listen to this narrative. Despite my feelings however, I was familiar with the world he was describing as it was very similar to the one I had come from and we consequently had a polite relationship. He appeared to be quite a proud man who valued respectability and he had a demeanour that seemed to me congruent with his military background.

The experiential text

Jon was born in 1938, one of four children. Huddling under the stairs listening to the air raid siren was part of his early childhood during the second world war and he saw aircraft

in the sky, German parachutists falling, and prisoners of war in the village, an adventurous experience, but one that also *'left a legacy'*. His mother managed alone as his Dad was *'an absentee father'*, and on a visit home when Jon was around five years old his dad was taken away by military policemen as he was absent without leave. He was also;

'...a criminal...ultimately he was a criminal...he was a drunkard and a chain smoker and a gambler, a really out and out gambler and he didn't support his wife and his family. He was a nice, affable person and he was everybody's friend, but he was not a responsible person and he eventually went to prison' (Int.1, p.10).

Jon and his brother visited him in prison once when he was around 11 years old. His mother enrolled the boys at Sunday school to counteract the bad influence;

'He had a good side to his nature but a terrible bad side...So that's why I kind of went into the church I think. Mother sent us to Sunday school and I met a lot of good people there, good positive influence and I felt as if I was kind of adopted by the church there' (Int.1, p.10).

He made an association between his emotional feelings and God/religion early on;

'I noticed when I was in my teens I had kind of...I had to justify everything. I had to justify having privileges and pleasures I had to do something to deserve it. That was kind of the reasoning in my mind' (Int.1, p.9).

He *'went to a church school and it was a lovely school, lovely people, but they had no idea about academic matters'* and he failed his *'11 plus'*, *'12 plus'* and *'13 plus'* but instead took a technical school entrance exam as he *'was very ambitious'*. In 1951 age 13 he went to the technical school where he eventually passed four subjects.

He left school when he was 16 and took employment as a laboratory assistant. This job lasted several years but Jon had a sense that he was looking for a *'vocation'*, but as national service was looming he took a job on a steam locomotive for 6 months. In 1956 he began national service, and subsequently signed up to stay in the RAF and worked his way up to an *'elite job'* which;

'...gave me one of the best careers in the airforce, ground wireless fitter, and it was very, very emancipating and encouraging...you know, very elite, you know, so I enjoyed that' (Int.1, p.4).

He left after three years and continued his engineering career with a private company.

Jon got married around the age of 23 to a woman he had met at a church youth club and went on to have two children. He worked hard to support his family, developing himself and his career by attending night school. Long hours and night shifts kept him from seeing his family which was a *'big sacrifice'*;

'...I felt the most important thing was to be with them and to do things with them and for them and so then going to work away from home, I mean this was a big sacrifice, big compromise. It was necessary in order to support the family materially' (Int.1, p.2).

His marriage was difficult as he *'imagined every kind of thing possible'* and his *'jealousy grew to huge proportions'*. Because he was *'unhappy in marriage, grossly unhappy and jealous at the same time'*, this *'wrong behaviour'* caused him to develop thyroid problems. This was when he was around 26 years of age and shortly before this he had had a motor accident. Some people thought he had become ill because of the shock of the accident, but he knew it was caused by his *'gnawing jealousy'* as the thyroid gland has *'a very emotional related purpose'*. It changed him as he;

'...went from being overactive, which was perspiring with a nervous tremor all the time and being saturated with sweat sleeping at night and having a gross appetite and losing weight and then going to the other extreme of being no appetite, my hair falling out, being cold and being lethargic and gaining weight really' (Int.1, p.3).

He felt physically and mentally unwell;

'I became physically affected. Physically and mentally I suppose. Really mentally...Mentally affected physically, you know, because the cause of the thyroid...I mean I should say the control of the thyroid gland is in the pituitary, which is a very small pea-sized gland based in the brain. So it's psychological, isn't it?' (Int.1, p.3).

It had a *'devastating'* impact on his life and he had *'11 month period off with sickness'*.

His work took him to different parts of the country and his general daily commute was long. It went on for 10 years, and he lived away from home during the week. He found it very stressful and on the occasions he got upset his wife was *'unmoved'*. He felt that his marriage was not working as he had not got the *'soul mate'* he wanted. He tried to encourage his wife to share his interests but *'her heart wasn't in anything we could share'*.

He *'got into marriage when I was an idealist Christian, which was wrong right from day one'* and the difficulties caused a mental *'malaise'* but he didn't *'believe'* in divorce so persisted to *'try and make my wife a good wife and love me'*. But it wasn't working;

'...there's something wrong with a religion that says if a marriage is bad it shouldn't be dissolved; and it also came worse than that, I said the church should not have married us because I had a faith and she didn't. In all of marriage we haven't exchanged that many words of true belief and faith and that's a travesty, isn't it? I was blind at the time, blinded by love or lust, whatever you call it' (Int.1, p.9).

At age 49, his wife celebrated their 25th wedding anniversary without him and this motivated Jon to leave her and he *'decided to get divorced'* because this was the *'loving thing to do'*.

The divorce, coupled with the stress of his working life, led him to develop a *'mental blockage'* and being unable to continue with his job Jon finished work;

'I had this mental block and I couldn't consider going to work. I did actually go back for a time to do what was called my job, but I knew I was working in a kind of...a kind of lower level work and I couldn't really...I couldn't really aspire to work the way I used to' (Int.1, p.4).

His family relationships changed as his children took sides against him regarding his wife as the *'innocent party'* which he found *'shockingly rigidly shocking'* and *'treacherous'*.

His wife, previously his *'best friend'*, became his *'worst enemy'* which he found *'completely impossible to accept and rationalise'*.

He defended himself in the divorce courts, something he thought would be *'straightforward and easy, but it wasn't'*. The court decision was *'unfair'* and he appealed against it but ended up with *'a worse second decision – not a better one but a worse one'*. During this process he;

'...felt as if I became worse and I felt as if I wasn't even taking proper part in the proceedings and I felt I wasn't mentally fit...and I told the judge' (Int.1, p.6).

The judge accused him of *'malingering'* so he went to see a psychiatrist as he felt his brain was *'irreparably damaged'*. The psychiatrist said he had *'all the symptoms of a classic case of depressive illness'* and prescribed antidepressants but *'the problem was still there'* and he felt unable to function as before.

After remaining *'mentally clamped'* for some time, Jon did try a variety of new jobs, *'lesser jobs'*, something *'therapeutic'* to help him *'recover'*. It was also motivated by pressure from the employment service to get work and he felt *'bombarded all the time'*.

His search for a *'soul mate'* led him to marry again in 1994, aged 54. He felt he was *'recovering'* his mental health but then his step-grandchild *'got septicaemia and died very quickly'* during a serious illness. This was a *'terrible ordeal'* and led to Jon experiencing the *'same kind of stress'*. He also had a bicycle accident and suffered serious facial injury which was *'traumatic'*. In addition, he was also trying to care for his mother who had Alzheimer's disease and he felt *'tremendously burdened'* as they were *'very close'*. This was *'another kind of state of stress which was stopping me from getting well really'* even

though *'she was probably taking care of me more than I was taking care of her because she was a wonderful cook and baker'*.

He found that his second wife was *'even less amenable'* than his first wife and his marriage failed after three years;

'She didn't accept that I genuinely had difficulties...and that I couldn't support her financially sufficiently and she didn't believe I was suffering mental problems' (Int.1, p.13).

He now tries to *'simplify'* his life; *'retain the things which are conducive to a happy life and jettison the things that make it complicated'*, to reduce stress, for example by avoiding unpredictable things, such as *'accidents'*. He wants to *'retrace those broken relationships and make good'*, and his main future goal is to remarry and live with a *'soul mate in a Christian community...never give up hope'*.

The narrative text

Jon's timeline (Table 10.) maps his common experiences, achievements and feeling associated with other significant events. His stated achievements and goals as identified from the personal profile and stated in his narrative (Table 11.).

Table 10. Jon's timeline

Year circa	Age	Common experiences	Achievements	Feelings	Other significant experiences
1938	born				
1943	5	Brother born			Dad taken away from by military police
1945	7	joining Christian church			hearing bombs dropping
1949	11	Secondary school	Lab. Work	Temperamental and moody, depressed	Dad went to prison
1951	13		Technical college		
1954	16	Left school/ College	Passed 4 GCEs Railways job		
1956	18		Joined RAF		
1959	21		Engineer technical college		Left RAF
1960	22		City and guilds qualification		
1961	23	Married		gnawing jealousy	
1964	26	Has child		Overactive, tremor, sweating, hair loss, lethargic Embarrassed	Motor accident Thyroidectomy
1978	40	Has child	Engineer work		
1987	49	Divorced	School governor Church committee	Treacherous Mentally clamped Mental block Brain irreparably damaged	Children take mothers side Finishes engineering job
1988	50		Various jobs Volunteering work	Gets worse, drastic affect, injustice	Defends self in divorce settlement appeal Sees GP and psychiatrist
1994	56	Married		Burdened, stress	Caring for Mum with Alzheimer's
1995				Stress, ordeal Traumatised	Step grandson diagnosed with leukaemia and died of septicaemia Bicycle accident
1997	59	Divorced			
2006			Choir at major national event		
2008	70			Come out of malaise, Can't think	research interview

Table 11. Jon’s stated achievements and goals

Personally valued achievements	Getting into technical school at 13 Brought up 4 children and supported my wife and home for 30 years Recovered from thyroidectomy and resumed work after long term sickness Successful career as an engineer Good writer Logical thinker Good at playing with children having helped at their clubs
Not achieved/lost	Climbing the ladder of success Mental fitness <i>‘I can’t think and I can’t act’</i> . Unable to respond to letters from grandchildren Can’t travel Driving Being a high flyer Learning how to use the computer properly
Future	To get married again To be happy with my soul mate in a Christian community. To mend broken relationships with family

Personally valued/defined achievements

His best achievement is identified as *‘bringing up 4 children and supporting my wife and home for 30 years’* as well as his education and his successful career as an engineer, but trying to achieve both results in unhappiness as it is impossible to sustain. His belief that God would reward him if he tried hard motivated him to be ambitious from his teenage years. His effort and success in supporting his wife and children was an achievement because it was something his dad did not do for him and his siblings and is evidence of his efforts, but his children’s successes do not appear to contribute to his own happiness.

His personal efforts in overcoming the trauma of his thyroidectomy remain significant in his mind and returning to work was a great *‘achievement’*. However, on being asked why the section on how he measured achievement had been left blank on his personal profile he said;

'I found it hard...to decide in my own mind because I'm more of a spiritual being and tend to think about the kingdom of heaven. You know the spiritual dimension. Success would be having happiness, however you attain that' (Int.1, p.1).

However, happiness was elusive despite his valued achievements in relation to education, work and raising his family.

Meritocratic achievements

Jon has been very successful from a meritocratic viewpoint up to the age of 49 after which he took '*lesser jobs*'. This is particularly pertinent with regard to the pride in what he considers higher achievements, for example his position in the RAF, the '*league of Gentlemen*' which was '*very elite*' and the ultimate evidence of his efforts.

He sacrificed his emotional wellbeing in going away to work. This kind of effort was required in pleasing God and his need to provide for his family. It was also a paradox for him where both were seen as important for achievement but where both together were unattainable and his mental health was '*compromised*'.

Although he was successful in obtaining work when his mental health was particularly disabling, because these were '*lesser jobs*' he views them as a disappointment rather than a success and evidence that he is not the '*high flyer*' he thought he was. Although he identifies being a school governor and a member of the church committee as achievements on his personal profile they do not feature in his narrative. His narrative appears to provide a picture largely of feelings of loss.

Not achieved/lost

The main thing Jon has not achieved is a successful marriage. The importance of marriage as a framework for living is illustrated in the repeated reference to it and it playing a central role in his narrative. His problematic marriage set him up for failure;

'...I think they should make marriage harder in the first place so that people go through some kind of rigorous test or matching in some way before they find themselves with a stranger...I think marriage is a fundamental relationship in life and you really have a tremendous disadvantage if you have problems. Mine was wrong from day one, you see, and I was trying to make it right and in a sense that became impossible' (Int.2, p.8).

His unanswered questions regarding the 'why' of his failed marriage repeatedly emerge. When we were talking about his memories of the war he again switched to the subject of marriage without any apparent relevance to the conversation;

'I had a brother who was born in 1943...He was out in [place]...I don't think my mental problems were quite distinct and extreme till after the divorce or during the divorce I should say' (Int.1, p.13).

Finding that he was not the 'high flyer' he thought he was is difficult because it is indicative of failure which for Jon equates to lack of effort which would lead to rejection by God. Based on these beliefs the 'lesser jobs', a repeated story, are interpreted as therapeutic, an effort to put things right.

Jon's losses are also caused by what he sees as being let down by others in relation to not being offered help for his jealousy. If he hadn't been jealous he would not have had thyroid problems. Even in seeking help he is told by a counsellor 'well you have a perfect understanding of it. There's nothing more I can do or talk about' and he is left helpless;

'I suppose it's a realisation that there's not going to be a magical cure and that there is no help. That there's no understanding and nobody...well they care but they don't care enough to analyse the condition and find the right answer' (Int.2, p.1).

The church also lets him down, ruining his efforts. If his unhappy marriage is the church's fault it mitigates his own responsibilities for any '*wrong behaviour*', given that they '*shouldn't*' have married him. His relationship with the church came about as a direct result of trying to counteract his father's influence, but like his father the church also let him down, deserting him just as his father did. His bad marriage could not have been punishment from God because marriage is '*according to God*'. God would not interfere with this. He cannot work out however what he has done wrong to deserve such punishment, that is, the '*personal disablements*' caused by the adversity around him.

Present and future

Jon has come to the conclusion that he needs to do something more '*radical*' to change his '*condition*'. One of these things is to try to get closer to his family after the rift that has not been '*healed*'. His slow '*adaptation*' includes casting off his '*resentment*' about the side his children took in the divorce and the realisation that maybe they did not know what was really going on.

It is a paradox that religion caused a dissonance in the decisions he had to make but he feels that it is also what has helped him the most. It provides him with the hope that everything will turn out right, that God '*will heal*' him. He still hopes he will find a soul mate and live in a Christian community;

'I've got an unfailing faith that God is good and that things will end up right and that if you do the right things you will be happy and God will heal me inside especially if I do everything I can to reduce it' (Int.1, p.17).

Chapter Seven

Celia's story

'I would like to have worked more, you know. I would have liked to have a break from the children'.

The context text

Celia was nearly 66 years old when I first met her. I was invited into her home to conduct the interviews and her hospitality created a comfortable environment. She was a very quiet person and we got on well partly I think through my acceptance and interest in her noisy and boisterous dog, occasionally heard on the tape, which also provided a source of on-going conversation. Her motives for being involved in the research are unclear and I remain unable to draw any conclusions about this.

The experiential text

Celia was born at the end of 1941. She lived with her mum, dad and a sister. Her relationship with her mum was difficult and her dad liked *'to go out for a drink'* most nights. Celia left school in 1956 age 15 without qualifications and started work as a junior at a department store moving on to more clerical work in different department stores over the following few years.

Celia got married in her early twenties and gave up work when she was *'eight months pregnant'* with her first child in the mid-1960s. She really wanted to continue work but was unable to find any support;

'...my husband worked away most of the time, just came home the odd weekend, about three weekends in 12 months and I had nobody to mind the children...My mother worked and his mother worked, you know, so there was no one, so I had to stay at home with the children, you know' (Int.1, p.5).

Celia's husband was violent towards her and she tried to leave him but her mother said that marriage was *'for better or worse'* and;

'She didn't want me in the house really because of the two children...but I couldn't get anywhere else to live...my mother was all on his side, you know, even though he knocked me about and everything' (Int.1 p.20).

At age 28 Celia had a second child but when he was two she decided that she had to divorce her husband. She had to start work again as she could find no financial support;

'...but when [name] was two...and the other one was four, I did start work because when I was getting a divorce he gave me no money and I went to the social and they wouldn't give me any money' (Int.1, p.6).

During the process of their divorce, her husband struck her violently on the head and she started to get headaches, *'explosions in my head'*, *'having nightmares'*, *'feeling shaky'* and *'hearing things wrong'*. One of her children became ill and had to be admitted to the children's hospital but at the same time she was told that she would also have to go to hospital;

'I was saying 'Can't I stay here please?' you know, and begging him to let me stay and he just said 'You need to go in hospital'...They took me to [name] Hospital, yeah and my son went to the other hospital, you know, for pneumonia...they gave me these injections in my bum they gave me these injections and I was knocked out' (Int.1, p.9).

Subsequently, she received further medications and electro-convulsive therapy (ECT).

When she was discharged she was *'much worse'*, *'unable to peel a potato'*, or *'prepare a meal'*;

'...well I think the electric shock treatment, you know, that they gave me...I mean I was very bad after that; you know, when I came out of hospital, I couldn't remember anything. You know, like before I had a breakdown, I was ill a bit, but I could remember all my shopping and everything like that, but when I came out...whether it was the electric shock treatment they gave me, three doses, I couldn't remember any shopping or anything, you know, so I was worse than when I went in really' (Int.1, p.3).

She felt *'very low'* when she left hospital and started to hear voices *'more so than before'*, voices that gave her instructions and made comments telling her, *'I saw you do this,' and 'I saw you do that'*. They kept *'just going round'* which was *'awful'*. They made her feel *'off colour'* so she took *'paracetamol'*, went to bed and slept it off. She tried to get numerous jobs, but failed because she thought that she *'must have looked odd, shaking and nervous all the time'*. She *'couldn't manage'* and had *'No money for food'*. Her children helped her when she struggled;

'Well when they were younger I used to find it very difficult to do my housework, you know. Cleaning, because my hands would be shaking that much and I'd be like that with a cloth and I remember one time trying for two hours to put a curtain up and I just didn't have the strength to pull it, you know, and me middle son came in and he said 'Oh, what are you doing mam?' He said 'Give it here,' and he just put it up! (Laughs) Yeah. That was...you know things like that. They realised I couldn't do the same as what other people could do, yes' (Int.1, p.19).

She continued to try and find work and in the late 1980s around age 46 she was offered a job in a school. During her occupational health assessment she was told that she *'wasn't fit for the job'* as she was a *'paranoid schizophrenic'*, but nevertheless was offered a trial period which was short lived. This was the first time she had heard about *'paranoid schizophrenia'* and she was very upset as *'she didn't feel like one'*. Once she found this out she thought this was *'probably why'* she had not got the jobs she applied for and she stopped trying.

By this time she also had a grandchild who she often looked after and this was her main occupation from this time. She manages her mental health by getting fresh air, by walking the dog and going to the gym and this is advice she would give to others, *'to get out into the fresh air'*. She is *'a lot better now'* and unlike when she was younger is now able to enjoy a social life;

'I go with a friend and we go in the café afterwards and usually I get home about two o'clock, you know, each day except on Friday we usually go up town, me and my friend, you know' (Int.2, p.9).

The narrative text

Celia's timeline (Table 12.) demonstrates common events, her achievements, and feelings associated with other significant events. Her stated achievements and goals are also shown (Table 13.).

Table 12. Celia's timeline

Year Circa	Age	Common experiences	Achievement	Feelings	Other significant events
1941	Born				
1956	15	left school	Various jobs; office and shop work	nervous	
1960	19		Office work 1		
1961	20		Office work 2		
1962	21	got married	Office work 3		Husband beats her
1963	22		Office work 4		
1964	23	had child	Stopped work		
1966	25	had child			
1968	27		office work	starts with headaches, explosions in head, dizziness, hearing things wrong	starts divorce proceedings husband hits her round the head
1970	29	Divorced		Shaky Wicked bad dreams Tearful, distressed	child ill with pneumonia admitted to hospital admitted to psychiatric hospital, has ECT
1971	30			much worse. hearing voices more	Discharged from hospital
1986	46		dinner lady		Loses job as dinner lady
1988	47	Becomes a Grandma		Crying and distressed	finds out diagnosed with paranoid schizophrenia Unsuccessful getting job at dentist
1992	52	goes on dole	Looking after grandchildren		
2003	62	mother died			
2005	64	joins gym			
2007	66				research interview

Table 13. Celia’s stated achievements and goals

Personally valued achievements	Bringing up a family Managed with little money Family turning out alright Working when younger Tried to be good parent
Not achieved/ lost	Ability to use mind after ECT Too shaky and weak to do housework Withdrawn from the children a lot of the time Affected ability to look after grandchildren sometimes Would like to have worked more Not gone out so much and mixed with others Not got another partner
Future	Keep healthy and strong Continue what I’m doing – going to gym, seeing friends Look forward to more grandchildren

Personally valued/defined achievements

Celia was unable to articulate how she has measured achievement through her life, and the interview transcript shows a drawn out attempt on my part to rephrase the question in order to establish this, but in the end Celia just says, ‘I don’t know’. However, she was able to identify what her achievements had been and these were largely family centred relating to bringing up a family and being a good parent, seeing her family ‘...turn out OK’. This validates her efforts undertaken in adversity and unsupportive circumstances;

‘I did start work because when I was getting a divorce he gave me no money and I went to the social and they wouldn’t give me any money. They said, ‘Get back to your husband.’ That’s what they said to me and they wouldn’t give me any money, yeah...so I had to get a job to put the children...you know, I couldn’t just...My mother didn’t have any money so I had to give her something and I’d gone to my mother’s, you know, and I had nowhere else to go. I didn’t like going to my mother’s, you know, and I had to work’ (Int.1, p.20).

Celia specifically identified managing with little money as a personal achievement on her personal profile and this particular difficulty features a number of times throughout her narrative. For example;

‘...he had to pay me because it went through the courts, so...Well he paid me £9 a week they ordered him first and then when I went to court he said he wanted to see

the children and I said he's not seeing them because he's like...he's knocked them about, you know, and he's not going to lay a finger on them, so I says 'No.' So anyway, they dropped it to £6 a week that he paid me and he didn't offer...he didn't want to see them after that, you know' (Int.1, p.9).

In addition, once she had left her husband her challenges were increased as she is admitted to a psychiatric hospital. This is the one time when telling her story that she becomes particularly animated and speaks for a longer period, describing her experience of admission to hospital at the time when her son became ill with pneumonia;

'I was up in the air, you know, and he said 'And you have to go to hospital as well...So anyway that's when I was taken away to hospital, you know. That's how it happened' (Int.1, p.9).

It is unclear whether the doctors that came to see her detained her using legal processes, but she appears to feel pressurised into admission as she remembers a *'team of them'* and;

'Well me mother was there and a nun came, you know, and I just thought 'Well I'll come, you know, and I'll have to go because...well they said I'd got to go, you know. They said 'You've got to go'. The doctor said I had to go, you know' (Int.2, p.3).

Celia did not understand why she has to go to hospital and could only think they decided this because she was very thin about *'five stone'* as she had been only *'eating bits myself'* in order to feed her children. Celia did not feel it necessary;

'Well I was upset about my son being ill and I didn't think I needed to be in that hospital. I felt that I could have just done with somebody there' (Int.1, p.9).

Her reasons for *'begging'* the psychiatrist not to admit her to hospital were that she was thinking, *'Well I've got no bus fare to go and see him in hospital, you know, because I had no money'*.

Celia describes details of the experience as if in the recent past when in fact it occurred over 30 years ago and this is the only time during our encounters that she cries, clearly indicating

that it was a traumatic experience that remains fresh in her mind. She would ‘*avoid going*’ to see the psychiatrist as she ‘*didn’t trust them*’ because;

‘...I’d rather not go in hospital again because he did imply at one time when I went before when I was ill. He said, ‘If you go in hospital...’. He said ‘you’d have trouble getting your children back,’ so it put me off that. I thought ‘I’ll never go in hospital again,’ you know. Not that, yeah. So that’s why I didn’t say anything, you know, because I didn’t want to end up going in hospital again’ (Int.2, p.7).

This results in less support as she is unable to talk to anyone about her experiences and it is within this context that she achieves bringing up her family, her specific personal achievement. She is also proud of her work record earlier in life, evidenced by her specific identification of ‘*working when younger*’ on the personal profile as one of her best achievements in life.

Meritocratic achievements

From a meritocratic perspective Celia had many paid jobs and despite being a ‘*nervous*’ person she is successful in obtaining work consistently from the age of 15. She had a number of different jobs until she started to have children, when she would like to have gone back to work but could not get support. Her desire to work is reinforced by her added note in a returned transcript that points out that when she left her husband, she got her ‘*children into a nursery*’ and got a job and paid for it herself.

When she got a job during her divorce around age 30, she was unable to sustain it due to a continued lack of support;

‘Well they sacked me for being late in the morning because I was taking my little boy to nursery and I kept blaming the nursery and I’d get in work late, about ten minutes, quarter of an hour, and they sacked me for that, you know, yes, so that’s why I left’ (Int.2, p.4).

When she was in hospital she maintained optimism and had a goal to get work but her goal was thwarted when she found herself '*much worse*' than before;

'Well when I was in hospital I thought, 'Well I'll get a part-time job and I'll be alright,' but when I got out of hospital it was different because I didn't have any tablets and I felt very low, you know' (Int.2, p.9).

However, she was successful at an interview but barriers were put in place due to the diagnosis of '*paranoid schizophrenia*'. Celia had not been aware that she had a psychiatric diagnosis;

'Yeah, it was the first time I'd heard it. So I said 'I didn't know that.' I said 'I'm not,' so he shown me this letter and the Doctor had wrote it and it had 'paranoid schizophrenic' on it and it was underlined like that, you know, across. So he said 'There it is in black and white,' you know, 'So you are'. So I said 'Well I didn't know' (Int.1, p.11).

However, she was given '*a trial on a temporary basis*' but her success was short lived as the headmistress told her, '*We've got somebody more suitable that's been in the job longer*' and she was '*sacked*'.

The knowledge of the diagnosis helped Celia make sense of the struggles she had in getting work in the past and the reason for her failure. This realisation removed her motivation particularly when she was told;

'We definitely can't get you a job,' and I was only 50. She said 'It's impossible to get you a job' you know, and sent me back to the income support' (Int.1, p.5).

It was also a great shock given that around twenty years had gone by without this knowledge and she went to see her community psychiatric nurse, very upset;

'I was crying I was that upset, you know, and she just brushed it off, you know, and she said 'They all have labels'' (Int.1, p.12).

Not achieved/Lost

Not being able to work more is something Celia feels is lost not because of her mental health problems as she '*was never off sick*' but because of the diagnosis and treatments. As she struggled to find a job, she claimed benefits but did not lose her desire to work. One promising interview where they '*seemed interested...filling in agreements and things*' resulted in disappointment when after a phone call, '*he couldn't get rid of me fast enough...He seemed to be horrified*'. Later she successfully achieved a part time job as a dinner lady, '*when they interviewed me for a dinner lady...they said right away 'You can start,' you know*', but despite this achievement her success is tainted by insult when she is told '*I don't think we can give you a job because you're a paranoid schizophrenic*' and '*People like you should be on invalidity*'.

In hospital the effect of treatments made her '*weak*' and '*shaky*' and she '*couldn't remember anything*'. As well as these added problems caused by the ECT, she heard voices once she left hospital. It appears that the physical effects of treatment and an inability to interact with her children due to being withdrawn led to her being in a worse position to achieve a manageable family life;

'Well I think it must have affected the children really because I was very quiet a lot of the time, you know, and I didn't...You know, with hearing these voices and that, I used to just switch off, you know, a lot of the time' (Int.1, p.19).

The poor relationship with her mother is also implicated in her experience and she attributes '*domestic violence and also my mother*' as the causes of her '*breakdown*'. Although when she left hospital Celia did not really go out '*mixing with people*', this is similar to her earlier life;

'But I never could go out really because, you know...I had no-one there to mind the children or anything, you know...So I could never have a night out or anything' (Int.1, p.19).

Present and future

For Celia the past remains very much in her present and her yardstick remains how she felt at the time when she got out of hospital 30 years previously;

'Well I think because I go to the gym I feel a lot stronger as well whereas before I was a lot weaker, you know. That's got something to do with it. You know, I was... Well, when I came out of hospital I was...I struggled to mop the floor and things like that' (Int.2, p.9).

Celia finds medication helpful in managing her mental health problems, but this is something she keeps private from her friends as she views it as irrelevant to her social life. In the future she wants to maintain this and keep her *'health and my strength'* as she now believes that she is *'not as bad as what I was in the past. I'm not half as bad'* and she looks forward to more grandchildren.

Despite feeling that she has not mixed with people or *'found a new partner'*, Celia has now, at the age of 66, largely achieved what she wanted in life, that is, a social life. She goes out for meals and;

'Well, I made quite a few friends, you know, going to the gym and I'm up early every morning and I'm doing...I'm out about quarter to ten each morning, you know, and it passes quick the time at the gym, you know, and I talk to quite a few people as well, you know' (Int.2, p.9).

This is something Celia may have achieved earlier in life if she had been able to get some support for childcare and been able to work which is what she wanted;

'I would like to have worked more, you know. I would have liked to have a break from the children, you know, but I wasn't able to. Mind you, I enjoyed the children, but I would like to have had a job' (Int.1, p.16).

Chapter Eight

Vinnie's story

'Well they say life's what you make it, but I tried to make it the best Elizabeth and I think life's been unfair to me'.

The context text

Vinnie was 63 years of age when I met him and over the course of around six months that the research process took, developed a good relationship with him. Vinnie agreed that I could contact him after being asked by the director of the third sector organisation he was attending which is where the interviews were conducted. This seemed to be linked to his efforts to keep his family life separate from his involvement in the research. His motive for becoming a participant was that he wanted to contribute to something that would improve the lot of people with mental health problems and this was an opportunity to do that. Vinnie also expected that it would be helpful to himself, that talking about his problems would be therapeutic, which later he said had been the case.

The experiential text

Vinnie was born in 1944, the youngest of three children. He was brought up in a religious household his own father being *'brought up strong church'* and both his father and grandfather were ministers of the church. His upbringing was strict and he occasionally *'got the belt'*. Vinnie found school difficult as he was considered *'thick'* and was bullied. He also experienced much ill health such as pneumonia and flu. He was always tearful; he had coordination problems, and often received detention. By the time he finished school, at age 15 he achieved no qualifications, and started work in a shop having, *'left school on the Friday and I started work on the Monday'*. At age 16, Vinnie's tearful behaviour was put

down to too much drinking and he was prescribed '*phenobarbitone*'. At this point in his life Vinnie was always worried that he was never going to get anywhere, that he would never have a girlfriend or work and would '*die young*'.

Vinnie spent his late teenage and early 20s as a '*Teddy boy*', out '*playing darts or pool and drinking every night*'. He became quite a heavy drinker which his dad was very disapproving of and often pointed out that he would '*never get anywhere*'. Vinnie believed his father and felt that he was a '*Jack the lad*' and would be a '*dead leg*' all his life. During his early 20s however, Vinnie became engaged and with his fiancée's influence, took the opportunity to '*quieten down*'. As marriage was something Vinnie thought he would never achieve, he saw this as an opportunity to prove himself, make something of his life, and they started a family straight away;

'Because [name] come along, that's my first daughter, just 10 months after we were married. You know, we had family right away and I just couldn't...drink and that because I'd got to prove to myself what I can do now and make something of my life' (Int.1, p.3).

A few years later, aged 28 his on-going emotional and physical problems were identified as part of a long term physical illness, an illness that ten years later was to be recognised in the medical profession as a genetic disorder. This enabled him to make sense of his learning difficulties and emotions earlier in his life;

'It can cause lots of things in early life and as I've looked back over me life that's what it's been, the [illness], although it wasn't recognised because they've only started research into it over the last few years we found out' (Int.1, p.5).

This also helped him make sense of the problems his mother had earlier in his life.

With a growing family and the desire to ensure that his '*kids never went short*', Vinnie focused on work and income. His long hours meant that he was '*tired all the time*' and this interfered with his relationships;

'What I did at work all me life I more or less had to work overtime and got every bit of overtime they did just to exist and I think because of the pressures of work and working, say, 12 hours a day for most of me life, 12 hour nights, 12 hour days, shifts, I think that's told on me because I didn't have a family life at home with her. I never saw my kiddies grow up, [name] or [name] because I was always at work' (Int.1, p.9).

As well as the long hours, Vinnie '*found it hard*' being in management as he strove to do a good job arriving for work even when in poor physical health. He did not dare to '*skive*' off because he was always frightened of losing his job;

'You had to be on the ball all the time. I even went to work ill I went to work with a collapsed lung...I collapsed at work' (Int.1, p.10).

This had led, '*three or four times*', to an ambulance being called and he was found on one occasion to have pneumonia. He was always '*a bag of nerves*', '*very grumpy, a nowty bugger*' and used to '*rant*' at his staff. Despite his job Vinnie and his wife found it '*very hard, very very hard financially*' and they ran into '*money problems*';

'Even though money was coming in once a month, before I finished work it had gone. The first few days and there was nothing left' (Int.2, p.9).

Vinnie took another job in management but '*it was a bad spot they picked and the job never took off*' and he was made redundant. He took various '*odd jobs*' for 12 months after which he got a job he wanted and he was '*over the moon*'. This lasted two years after which he was made redundant again as the '*profits were low*'. After this job '*crashed*' he '*cracked up*' and cried for three days then tried to hang himself at work, but was found in the process by a colleague. This caused a lot of friction between Vinnie and his wife who was angry,

but he was *'trapped with no doors'*. He was around 42 by this time, and did not return to work again, resulting in further financial difficulties;

'I couldn't cope with anything. I could not cope. I mean I couldn't cope with getting the bills paid, I got into serious problems with the bank, you know, with bills and like things weren't being paid and we started to live beyond our means because I was not working and only, you know, I was getting...What do they call it?. Sick pay it was called then' (Int.1, p.6).

Six months after the second redundancy Vinnie was admitted to a *'mental hospital'*. He felt that he was being spied on by the Department of Social Security (DSS). His family life suffered and his eldest daughter *'couldn't cope'* with his illnesses. She left home at age 17 and had a baby. Over the following years, Vinnie tried to kill himself many times because there was *'no future'* for him, and he saw a number of psychiatrists. He had *'ECT. treatment'* and *'loads of tablets'* but *'none of it's worked'*. His daughter became addicted to drugs selling her *'kids toys to buy drugs'* something her young daughter had *'to live with'*. This led eventually to Vinnie and his wife becoming his Granddaughters legal guardian, something he is proud of;

'Now I've given her a second chance in life and I feel good for that. Oh, it makes me feel so good...because I can give her a proper life...I feel good that I can give her that chance. It makes you feel real good and she's responding to it. I know she argues, a teenager and that, but it makes me feel good inside that I'm doing something for her and she's coming on well at school and everything and so I'm doing a good job' (Int.2, p.14).

As he continued to struggle with his mental ill health he took many overdoses and also found relief using self-injury, cutting himself and making himself bleed, *'It feels like pop and it's a release...it's something's coming out, you know, and it's like a relief'*. Rowing with his wife also helped as it;

'...gets the anger out of me...I say things that try to hurt her, which is wrong because she does everything for me, but I can't help it...it's the only way I can express myself is to perhaps verbally abuse her or something like that and shout and rage' (Int.2, p.8).

When Vinnie worked he coped with the stress by *'smoking a lot'*. More recently being outside, gardening and appreciating wildlife has helped him. He continues to wonder though if anyone is watching him through binoculars when he is in his garden. He likes reading though this is affected by his concentration which also limits his ability to contribute to a voluntary job he is involved in;

'If I go meetings within half an hour and it's just sort of goobeldy gobble, you know, I lose concentration. I can't store it in. After so long it just gets as though...well, I don't know what they're on about. Even now, nearly 64, me concentration' (Int.2, p.3).

He tries his best, but *'life'*, Vinnie says, *'has been unfair to him'*.

The narrative text

Vinnie's timeline (Table 14.) maps his common experiences, achievements and feelings associated with other significant events. His stated achievements and goals taken from his personal profile and interviews are also shown (Table 15.).

Table 14. Vinnie's timeline

Year Circa	Age	Common experiences	Achievement	Feelings	Other significant experiences
1944	Born				
1949	5	Starts school			
1958	14			tearful, can't concentrate	Corporal punishment Behaviour problems, detention, 'thick' bullied at school
1959	15	left school	shop job 1	tearfulness and low mood, worried	Drinking
1960	16		shop job 2	Tearful all the time	starts phenobarbitone
1963	19		Different jobs		
1967	23	Married			Starts with physical symptoms
1968	24	had child			
1969	25		management job (MJ) 1		
1975	31	mum died had child	Voluntary work?	Fear, upset, worried	Collapsed at work, Off sick
1977	33		MJ 2	Can't sleep, bad tempered Pressure, grumpy	Diagnosed with genetic disorder Work stress
1981	37		Takes various short term jobs		
1983	39		MJ 3		
1985	42	Becomes a Grandad		Rages	made redundant Admitted to psychiatric hospital, ECT teenage daughter leaves home + has baby
1986	43			Useless	Unemployed
1987	44		New job	Happy. Stressed	
1989	46			Relief Useless, can't cope 'Cracked up'	made redundant attempts to hang himself genetic disorder recognised
1990	47		becomes guardian of granddaughter	'Nervous wreck', people spying on him	Not looking after himself Self-injury Overdoses
2002	56		climbs Ben Nevis	Proud	Finds out details about genetic condition
2004	60			Nightmares, fear of decision making, Lost confidence	Starts attending third sector organisation starts counselling
2007	63			feels lost, can't concentrate, blame, worried. resigned, embarrassed	discharged from psychiatric services physical health problems Research interviews

Table 15. Vinnie's stated achievements and goals

Personally valued achievements	<ul style="list-style-type: none"> Reaching management in the retail trade Foreman in industrial work Getting married Bringing up a family Working hard to own my own house Being a good parent Keeping house in good order Teaching children right from wrong Being married for 40 years Being good at decorating and gardening Climbed Ben Nevis for charity Getting to point in life where I am now (being alive)
Not achieved/lost	<ul style="list-style-type: none"> Going on holidays Doing domestic jobs Going for a better job Worried about effect of 'spoilt' upbringing of granddaughter Not being more independent Concentration (and memory) of books read Earnings Knowing I could have done a caring job e.g. nurse Confidence, can't think straight prevents doing things
Future	<ul style="list-style-type: none"> Driving again Make more decisions myself Be normal Have a cottage by the sea Granddaughter have a nice boyfriend Do things with my wife, just the two of us Help people A good family Carry on coming to organisation Do my gardening Love my wife and family

Personally valued/defined achievements

Marriage was Vinnie's first significant and best achievement in life as he did not think he had really achieved anything before this. Getting married and bringing up a family was 'a good achievement' because it 'surpassed his expectations' having never believed he would make anything of himself and it proved his dad wrong;

'When I met [name]...I quietened down going out with mates and that every night...I thought 'Well it's time in my life that I can prove that I can do something for once in my life,' because I never achieved anything at all or proved anything,

you know, because my dad said 'You're always in trouble you and your mates' (Int.1, p.8).

'Working his way up to management' in order to 'earn more money' and 'support his family' showed he was capable in his role as a husband and father, in addition to being a 'good parent', 'teaching right from wrong'. These personal achievements appear to be motivated to a large extent by the need to prove his father wrong;

'...to prove what I could do really. To prove to me...Because my dad said 'You'll never get anywhere,' he said 'just boozing all the time' (Int.1, p.2).

'Bringing up a family' and 'keeping house in good order' are important in his view of achievement even though he 'blame myself the way [name] turned out a lot of it', but he is able to compensate for his daughters problems by making 'sacrifices' by bringing up his granddaughter and being her legal guardian;

'I might be losing myself in terms of what we could have been doing, but I don't believe in reincarnation or anything like that but if I come back...it makes me feel good what I'm doing for her. She'll realise in the future what I've done for her, given her this chance in life' (Int.2, p.14).

His marriage has been severely tested by his behaviour; behaviour he cannot really understand and for which he is full of remorse;

'I don't know what I did, the next thing she was on the floor...she said I'd hit her. I just lost control of everything. I don't know what I'd done or anything. I can remember to this day the day it was. You know, it was a Thursday afternoon and I just decked her one. I don't know why. I didn't hurt her. That's when she said she was going to leave me. I don't believe in men who hit women...but that day...but I felt that down in that day and something snapped inside me and it happened and I regret it to this day and for the rest of my life I'll regret it. She didn't have any bruises or anything...and she went down on the floor and that's when I took a massive overdose and just got me tablets and, you know, took 13 tablets, took a full week's of worth tablets' (Int.1, p.18).

Such destructiveness however provided some short term relief in getting his anger 'out', but, in the long term this adds to his belief that others would be better off without him;

'There's no way out. I can't go up, down, left or right, so I'm going to end it all. I thought, you know, '[name] be better off without me. She can marry again to perhaps somebody worthwhile' (Int.1, p.13).

It is in this context that being married for forty years is an achievement but it is the responsibility for his granddaughter that has ensured its success more recently;

'I think we'd have split up the last few years. It's only through [name] now I think we stick together to be honest' (Int.1, p.18).

Although he considered himself to be *'no good to anybody'*, climbing Ben Nevis for charity provided an opportunity to discover that other people had *'faith'* in him demonstrated in the offer of sponsor money;

'She sponsored me £20...so I thought 'People must have faith in me for once,' and it made me feel good. Very good. It was hard and it was a challenge but I made it. That's something I have done in my life, you know, an achievement. I got a certificate for it and that. I've achieved something to help others too and it made me feel really proud, do you know what I mean?' (Int.1, p.16).

This faith has also recently been shown to him again having been offered a voluntary role at the organisation he attends. This draws on some of the management skills he used in his working life but does not place any of the pressures he had on him to achieve in the past.

Meritocratic achievements

Vinnie's charity work in raising money to help others in his climbing Ben Nevis and his voluntary work is a personally important aim;

'I'd like to be able to help people less fortunate than myself...but I worry about people like that because I know they need help and they need care and they're not like people like me' (Int.1, p.13).

However this quote demonstrates his view of himself as different to other people as he is not *'mentally backwards like others'* and separates himself from those *'less fortunate than himself'*. This is perhaps because of his own caring roles and how he sees himself, not as a

recipient of care despite his long term use of services, but as someone with responsibilities for caring for others. This is also perhaps reflected in his evaluation of himself as someone who *'could have done a caring job'*;

'I'd have liked to have done what you've done now. I mean I was 30 year old and I didn't even know there were male nurses. I'd never been in hospital or anything...but I'd have liked to have done something like you do now or be a community worker helping people out there I think...the care I could give to them to try and help' (Int.2, p.15).

This appears to be something that is more in keeping with his own instincts but which was perhaps suppressed by his traditional upbringing and expectations regarding the roles of men.

His meritocratic achievements regarding work roles feature significantly in his personal achievements. Once he has proved his father wrong by making something of himself having achieved a job and family, his expectations are raised in relation to the possibilities of what he can achieve: the potential to get a better job, earn more money and aim to buy his own house. His view of wealth appears consistently in his views of achievement, for example;

'I think if you had wealth in them days you got on better than working class. I think the working classes in my year affected a lot of people. You know, perhaps say if you were born with a silver spoon in your mouth, as they say, you perhaps got on better. I don't know, it might just be me, but for working class kids, a lot of them, they had to leave school and get a job because their parents needed the money, but those who could afford it 'Oh well, we'll pay for you to go to college,' or 'we'll pay if we have to go to university' (Int.1, p17).

Status and work are integral to his mental health in terms of the need to be a provider, and because being able to provide is so important any perceived threat to maintaining work becomes a threat to his mental health;

'I was worried about me job all the time and if I got made redundant or I lost me job, you know, because we didn't make the targets. I was becoming a nervous wreck going to work although I loved me job. A nervous wreck' (Int.1, p.4).

In addition, this anxiety thwarted his aspiration to earn more as he could not risk failure. Avoiding failure is the only way he could see to prevent a potentially worse situation for himself;

'I thought 'Better to stay as I am and cope with it than going somewhere else to improve yourself and not being able to cope with it'...I was frightened of trying to improve myself in case I couldn't cope with it' (Int.1, p.11).

This dissonance that Vinnie appears to experience sets him up to fail in his aspirations to seek higher earnings and results in the realisation of one of his worst fears;

'But that did cause a lot of me problems and I think it caused me to...Well it started with me bringing about these money problems because there's nothing worse than debt I don't think...which way are you going to turn' (Int.2, p.9).

Work stress was a hindrance to his mental health but it was preferable to being without work a circumstance that leads to attempted suicide one day at work;

'...after that it crashed. I cried for three days after that. I just went to pieces and I thought my life had finished. One day I also tried to hang myself. I went to the garage. He said 'What are you doing, [name]?'...I tried to take me own life anyway' (Int.1, p.12).

Following this immediate crisis, the redundancy went on to provide brief respite 'a release' when 'all the pressure seemed to go off me from work'. But the long term implications of a reduced income maintained his feelings of 'uselessness' and these feelings became unpredictable;

'I was seeing this doctor...I said 'Oh no, Dr [name], I can't say to you and you can't say to me whether you'll be in the job this time next year'. I said 'I can't predict it'...I get in them states where there's no way out. I said 'I just feel trapped...well I'll take my life next week.' It was just a thing on the spur of the moment like that, but your mind goes a blank and there's no way out so you don't bother thinking of family or anything...Four or five times I took overdoses' (Int.1, p.13).

Not achieved/lost

Vinnie's mental health problems prevented him from earning more and finance is frequently referred to in his narrative of his measure for what he has lost;

'I've not in achieved in life what I wanted to be, no way...by a long way. I mean I would have liked to have paid for me house, retire, have money, perhaps go abroad perhaps once or twice a year and have everything' (Int.1, p.14).

His main aim was always to be wealthier;

'Well, I would have liked to have been more wealthy and whatever, big cars and that...control of people, the boss and all that...I'd have liked to have earned more money' (Int.2, p.14).

Because finance was important to ensure his *'kids never went short'* his inability to sustain work is catastrophic as everything was going well until his *'breakdown'* a defining point that altered the course of his life;

'I made a mess of it at the start but, you know, as you go on you improve and I mean it was smashing until I had my, you know, illness or breakdown and lost everything from since then, you know' (Int.1, p.3).

This is perhaps because it puts him back to a place he was early in life and proved his dad right after all and he cannot function;

'I didn't keep myself, I didn't bother having a bath for two or three weeks on end. I thought the world was finished with me, 'nobody wants me.' I thought 'I just can't carry on.' I had visions of people watching me when I was out, that I was being spied on' (Int.1, p.6).

His experience of paranoia regarding the DSS perhaps represents his fear of having no money; that the government will remove his income particularly after he is discharged from psychiatric services after more than 20 years, which happened around the time of our second interview. This was a blow as his association with specialist mental health services has ensured an entitlement to *'Disability Living Allowance'* (DLA) providing a reasonable income, an issue with implications for his mental health. He is discharged because he is

told they *'cannot help him'* and *'he will have to learn to live with it'*, something he has spent his life trying to do. One of the consequences of this has been the loss of his independence as he has to rely on his wife, his *'staff'* for decision making, reinforcing his view of himself as *'useless'*;

'You have to make sure your bills are paid and you have to make sure that, you know, your electric bill or you'll get into trouble...that I can't cope with. I feel sorry that she has to do it' (Int.2, p.8).

Present and future

The importance of work for Vinnie in his concept of a future is evident, where life is over when there is no prospect of work;

'...there was no future for me, even now there no future for me, I'm 65 next birthday so I'm not going to get a job now'. I'm nearly 65 now, my life's over more or less' (Int.1 p.13).

However not working at age 65 is socially acceptable. The social stigma of unemployment is gone which perhaps removed the pressure he felt. This results in having more energy, energy that can be used for fighting any suicidal feelings now he has a new motive;

'So I should have missed all this, but there's nothing to say if I get to that stage that I won't do it again. I fight it now. As I say, for [name] sake I fight it' (Int.1, p.19).

In addition he appears more able to resign himself to his situation with a realisation that more money will not solve his problems;

'I always say I think there is hope. I always thought...I mean I used to worry a lot about money, but now...we're not well off and we cope now. There was a hell of a lot of worry about money, but even now financially, you know, we're not too bad, but it's not going to make me feel any better. I thought it would at one time. I thought financially it'd make me feel better, but it doesn't' (Int.2, p.12).

This resignation is similarly applied to his feelings about the DSS as he now thinks, *'spy on me all they like, I've been getting it for 20 years...and I thought 'stuff them'*.

Although he is glad he was unsuccessful in his suicide attempts, it confirms for him his view of himself as a failure;

'I'm frightened of failure now. I'd like to build a summer house...failure. The first time I took an overdose it was failure' (Int.2, p.9).

This failure is something he *'can't deal with'* again, as he can't *'disappoint'* his wife. However, it creates some ambivalent feelings because he wants to fail at suicide. He hopes to have another ten years to see his grandchildren succeed, a reflection of his own success because;

'They're part of me. I feel it's part of me that's showing what can be done. I mean if could get another 10 years just to see them do well it would mean everything to me because they're part of me' (Int.1, p.19).

His avoidance of failure contributes to his mental health but keeps him from doing what he would like;

'I mean I'd like to do voluntary work, you know, but...I wouldn't want people dependent on me because some days I'm alright and some days I can't even go out of the house if I'm down, so I couldn't do it and I wouldn't like to let people down. I mean there's some days I can't do anything at all, I just stay in' (Int.1, p.14).

There are other barriers he perceives as well; his likelihood to make a *'mess of it'* and also in relation to his desire to work with children. He feels that as a man, it would be seen as suspicious and he cannot face that;

'I'd like to work with handicapped children or unwanted children...but it's a stigma today. And that frightens me to do it... 'Well, what does a man want to go and work with children for?' I mean I love kids when they're small and I don't like to see kiddies suffer today, but it's just that stigma now that I couldn't do voluntary work for them because you've always got that stigma that 'why does a man want to work with children?'' (Int.1, p.15).

Vinnie can see what he has got to be *'thankful'* for, a *'meal, family, clean bed'*. His interest in social history provides a relative comparison that enables him to see what he has achieved. He speaks at length about conditions in the 19th century, child mortality and the

relative improvements that have put his life into perspective. His dramatic polemic, spoken passionately on the state of the country, immigration, closure of health services where *'people will be on the streets'*, the extent of rape and sexual abuse, is perhaps illustrative of his on-going fears and his difficulties in seeing people let down.

His more recent goals relate to things he may be able to achieve such as gardening, rather than wishing for things that he could not conquer. Although he has felt at times his family would be better off without him, he is glad he is not dead because he would have missed seeing the achievement of his children and grandchildren, something to live for;

'I've got something to live for now with grandchildren growing up and they're all pretty bright and I want to see what achievements they have...seeing what achievements I didn't make in life' (Int.1, p.19).

Vinnie says he would like to *'be normal in the future'* and;

'I've come to terms with it. That's all I can really say now and I do my best. I try things and I do my best...I try to do my best. I know things I'll never be able to do again, but I find helping others since I was ill' (Int.1, p.15).

However, he still takes each day as it comes;

'At one time I used to go to bed and thought 'well perhaps I'll have a better day tomorrow'...now I don't even think it. I take each day as it comes now. If I have a good day, very good, I'm happy with it, and if it's a bad day I've had them before and got over them, I just go on' (Int.1, p.7).

Chapter Nine

Lucy's story

'I've always believed in a happy ever after, and that's kept me going'.

The context text

Lucy was 57 when I met her. I was put in touch with her through one of the other participants and she invited me into her home to conduct the interviews. Lucy made apologetic reference to what she seemed to believe was poor accommodation, possibly feeling some shame that had accompanied her from early life when *'We had a scruffy house and I was the butt of all the jokes'*, although choosing to tell the story at her house may illustrate an element of trust in me. She requested that I give her copies of anything I published as she was aware that in the past a psychiatrist had published information based on her in the Lancet without her consenting to it. Lucy seemed to imply that part of her reasoning for agreeing to participate, despite previous bad experience, was that I was not a doctor but a nurse, and also I suspect, because I was female.

The experiential text

Lucy was born a twin, the youngest of 10 children in 1951 and lived in an inner city with her siblings and parents. Her upbringing was horrendous due to living in poverty;

'We had no food, no shoes, scruffy, nits in our hair, impetigo. People wouldn't sit next to me. I really smelt. Dirty, filthy, ingrained shit on us. We really smelt. We had a scruffy house and I was the butt of all the jokes...no shoes to fit you, pumps in winter and plastic sandals in summer' (Int.1, p.10).

This led to bullying at school which resulted in an unhappy and *'very, very lonely'* childhood which she would escape through her fantasy life. As a seven year old, Lucy fantasised;

'I used to wish I could go to the dentist and the dentist put me under anaesthesia, this used to be my fantasy when I was a little girl...and I'd wake up and I wouldn't be me anymore, I'd be somebody else...like a princess or somebody like that' (Int.1, p.7).

In order to be accepted and popular at school she established a *'terrible reputation'* for herself pretending to be sexually experienced. She was *'bright'* but the teachers were *'not interested'* in her as she was *'poor and scruffy'*. She would be sent *'outside to clean the blackboard duster against the wall'*. People like her were *'just marked out for factories'* and her *'thirst for knowledge'* went unnoticed.

Life at home was also difficult because she experienced violence;

'I was so unhappy. There was violence in my house. We didn't know what was going to happen next. I'd two brothers paranoid schizophrenic, one sister paranoid schizophrenic and one brother and one sister manic depressive, you know, and these were violent men. You know, they just used to hit you round your head and they'd be horrible teasers, terrible' (Int.1, p.8).

Lucy's brother *'used to wake us up in the night saying we had bubonic plague...he said he was pregnant to a man and all that was crazy'*. A sister and a brother killed themselves but the stigma of this meant her family tried to hide it saying instead her brother was *'murdered'*. Lucy also felt *'stigmatised'* by her mother who *'she didn't love'* but *'felt guilty'*. She was in her 40s when Lucy was born and Lucy was *'ashamed'* of her because she was *'old, poor, scruffy'*. Her mum was beaten up by her dad and he would *'sleep with other women'*. The family were *'outcasts'*, considered *'weirdo's'* and blamed for anything that went wrong;

'...people don't come to your house and you don't have friends. Because people used to call us the Adams family, weirdoes, you know, and anything that happened in the area we got the blame...It's stigma. It's like being a pariah, outcast. You know, I was always the last to be picked in school for the games, you know, and I mean having no friends it's very, very lonely and horrible and to feel dirty and unclean all the time it was as if I was unclean' (Int.1, p.9).

This resulted in a childhood which was;

'Horrible. It's all black. When I think of my life as a child I think it's in black and white. There was absolutely no colour in my life' (Int.2, p.1).

Lucy left school aged 15 with no qualifications and *'barely able to read or write'* but found work in a factory. Her older siblings *'all married.... to get away'* and Lucy also needed to *'escape'* from the abuse she experienced so *'at the age of 15 I ran away from home and didn't come back and I slept on the streets'* with *'dossers and tramps'*. She returned home only after hearing that her mother had died suddenly. On her way home she was *'raped by a man in a lorry'*. At home she found herself blamed for her mother's death because they said, she had died of a *'broken heart'* when Lucy had left. Her Dad spat at her at the graveside and neighbours *'threw stones at her in the street'*. They were *'cruel bastards'* and she was threatened with being sent to *'an approved school'* but her sister came to her aid;

'They was going to send me to a approved school too, but me sister [name] and me twin brother pleaded with me dad; and me sister [name] was living in a nurse's home and she said she'd come back and look after me' (Int.1, p.16).

She moved in with her sister, but soon after this at age 16 Lucy became pregnant and unknown to her family she went to live in an unmarried mother's home. She gave birth but she did not really know what to do with the new baby who was like *'a tiny tears doll'*. At this point she moved in with another sister and became a child-minder while her sister went to college; *'so at the age of 17 I had five kids, my own baby and four children'*.

From ‘*about probably the age of 15*’ Lucy had developed a belief system in ‘*witchcraft*’ and at age 18 she moved into a shared house where there was a witch’s coven. Here she had a frightening experience;

‘I was 18. I lived in this house and there was a witchcraft coven going on and they used to do things to me and terrify me with spirits in the night and take me money from me. I escaped and went to the police and the police got the Doctor. I must have been so distressed the Doctor came up’ (Int.1, p.11).

Her complaint to the police was not taken seriously and she was seen by a psychiatrist who, unknown to her at the time diagnosed her as having paranoid schizophrenia. Two years later, she received a letter asking her to visit the psychiatrist where she received an apology because the people from the coven had been convicted;

‘...he gave me an apology to say he’s sorry he classified me wrong because he got the people who was doing it to me. They went to prison, you know, years later. No-one’d believe me, you see’ (Int.1, p.11).

Lucy believed that this happened because ‘*My name was [name] and that was it, we was bastards*’ and she also believed that because of this the psychiatrist ‘*stigmatised me because of my brothers that were paranoid schizophrenic*’. The apology she received was accompanied by her being ‘*re-classified*’ as having a ‘*minor personality disorder*’ and she was glad to know she was not a ‘*paranoid schizophrenic*’.

Around this time, at the age of 20 Lucy got married to a man who would ‘*spend all the money in the pub*’, gave her ‘*venereal disease*’ and was ‘*cruel*’ to her son. He was also violent and she got no support;

‘He used to follow me around. He broke my nose and my family always used to take his side you know, that I was causing trouble. He was a horrible man, evil’ (Int.1, p.6).

During their marriage they had two children, but after two years together she decided to leave him which was difficult because *'there was no women's aid'*, but she moved into a battered wives refuge, and divorced him through the courts. During this time she tried to improve her reading and writing and spent a lot of her time in the library with her children again trying to quench her *'thirst for knowledge'*.

Lucy joined the women's movement around the age of 24, and encouraged by other women she had met there, she went to college and undertook numerous courses over the next ten years as she wanted to *'be somebody'* and to *'fit in with other people'*;

'It's because I joined the Women's movement and I went on study groups at [name]. You know, they was left wing people and they just brought me on and I just realised I had to get myself more educated' (Int.2, p.3).

She was also helped by a second husband *'a very, very middle-class man who helped to educate me'*. He was the first man she had met who treated her with respect; *'I was in love with the fact he treated me like a person'* but he was *'a very, very cold man...I didn't love him when I married him'*. She remained married for ten years but after that she *'forced him out'* and got divorced.

Lucy worked *'intermittently'* over the years but she gave up work when she had children as she thought it important *'to be at home for when the kids come home from school'*. Much of her work was voluntary work as she was a *'perpetual student'*. She was an *'anxious'* mother but did her best and developed many skills such as cooking, skills she finds are passed over by others at the women's centre who make negative assumptions about her abilities;

'I mean in work a woman said to me...she was a young woman and she said 'Would you like to learn how to bake?' to me and I was appalled because I've been baking all my life. The very fact she didn't ask me what I'd done with me life really, really

devastated me. You know, I can cook. I taught myself how to cook. I don't cook the way chefs prepare it, but at the end of the day I'm a really good cook. They can't take that away from me. Now it really hurt me that' (Int.2, p5.).

The women's centre however has remained a source of support, but the thing that has helped the most is '*...the spirits. I've got a strong flame inside me and it never goes out. My own pilot light*'. Lucy said that doing a crossword in the morning '*forces the rubbish from me head*' and cooking can also distract her. In addition, '*I read self-help books*' and '*If all else fails I just go to bed and wait while it passes*'.

In the future Lucy would like to write a book. She does not want to be a '*victim*' any more but a '*survivor*'. In the end, what makes the difference for Lucy is the mood she is in on a particular day, reflected in the colour of her hair: red on a good day, brown on a bad day. If things are going smoothly, she is in control, and there are no shocks, rows or conflict, life is '*alright*'. Her optimism carries her through as she has always believed that there will be a '*happy ever after*';

'I've always believed that there's a happy ever after and that's all that's kept me going, you know; and something always turns up for me because I think if you don't hurt anybody and don't harm people, I think you get back from life...and I'm always thinking there's somebody up there watching over me' (Int.1, p.20).

The narrative text

Lucy's timeline (Table 16.) maps common events, achievements and feelings associated with other significant events. Her stated achievements and goals from her personal profile and at interview are also shown (Table 17.).

Table 16. Lucy's timeline

Year circa	Age	Common experiences	Achievements	Feelings	Other significant events
1951	Born				
1958	7			black, no colour fear and shame	Violence at home
1966	15	Left school	Started work in a factory	Unhappy	Establishes belief system in witchcraft ran away from home
1967	16	mum died got pregnant		Guilt, couldn't love anything, lonely	raped Came home moved in with sister went to unmarried mothers home
1968	17	had baby Moved in with sister		Timid and meek	Looked after sisters children
1969	18		different jobs	Distressed	assaulted when living in witches coven police call psychiatrist diagnosed with paranoid schizophrenia
1971	20	gets married	Cleaning work volunteer work (VW) 1	Relief	apology for previous diagnosis; reclassified as personality disorder
1973	22	Has two children Divorced		anxiety attacks	experiences violent marriage lives in refuge
1975	24				Short term Psychotherapy
1976	25	Married			
1978	27		Certificate at poly		
1981	30		Diploma Management committee	Emotional problems	
1986	35	Divorced	College course		
1987	36		2 A levels College course VW 2		
1988	37	Became a grandma	College course 3 certificates		
1991	40		Started degree		Physical health problems
1996	45		VW 3	Upset	Niece reminds her of killing her mother, family exclude her
2001	50		VW 4		
2004	53		VW 5 Training certificate (TC) 1	Terrible, tearful, hurt	Assumed to be a service user rather than volunteer
2005	54		TC 2		
2008	57			Panic attacks, out of control, failure	research interview

Table 17. Lucy's stated achievements and goals

Personally valued achievements	It depends how I feel at the time My children Run a marathon Good cook Can grow flowers and herbs I can read Tarot cards Intelligence, can pick things up easily and quickly Good sense of humour I like to think I can influence people to make changes in their lives by empowering them
Not achieved/ Lost	'nothing' ability to earn money to improve living circumstances. Lost self confidence Not being good enough, being a failure
Future	To move into a better house To have a garden in which to grow things To be happy and contented. To write a book For her daughters problem to be resolved Waiting for something exciting to happen

Personally valued/defined achievements

Lucy's mood on any particular day dictates her sense of achievement;

'Well, for example, if the sun's shining and me life's alright, you know, and I'm happy, you know, achievements seem to be more important to me, whereas if when I get the blackness on me, somebody could give me a thousand pounds or I could get a top job and such won't make me happy' (Int.1, p.1).

This seems to have a symbiotic relationship with her environment, *'the state of the house'* as when the house is clean, her *'mind is nice'*, and perhaps illustrating the relative nature of her sense of achievement;

'Achievement for me wouldn't be a car or a top job or a trip abroad. Achievement would be to cook a nice meal that I'm satisfied with' (Int.1, p.2).

The identification of her *'sense of humour'*, *'intelligence'* and her ability to *'empower people'* as personal achievements reflects her largely conceptual ideas regarding personal

achievement and perhaps represents attributes that she has in spite of her upbringing and problematic experience. Such measures enable achievable goals and perhaps ensure she can create a peaceful domestic environment that was always unattainable as a child. More ambitious achievements she can relate to by proxy where her children's achievements are her achievements, because they '*excelled her expectations*', all having achieved professional jobs.

However, Lucy's children are one of the more confusing aspects of her story, how many she has and when they were born. I only discovered the existence of one of her children, whom she had had adopted, because she told me that she had just had a phone call from her when I arrived for the second interview. Inquiries about this area of Lucy's life did not provide any clarification only further confusion and it has not been possible to work out exactly where different births fit into her chronology from the information she shared.

From the point of view of the people she chooses to spend her time with at the women's centre, her '*normal*' achievements are viewed as exceptional but this attitude to her doesn't affirm them, only infuriates her;

'When I first went there they asked me had I kids and I said 'Of course I've kids,' and they was amazed that I'd brought me kids up myself to full adult-hood and that they've all gone off and done things. You know, I'm just a normal, fucking woman. It's abnormal, for me, to have your kids taken into care and to do drugs and things like this. I can't understand it. And I can cook. I looked after a husband, I've had to cook and manage a budget myself for years and people are amazed I've actually done that' (Int.2, p.14).

Meritocratic achievements

When Lucy was at home with small children, paid work served a practical purpose and she took many different types of work. Her role as a mother at home took priority for her but during the time she had the support of a husband she did undertake many voluntary jobs.

Although she has a long list of meritocratic achievements which can be seen in the achievement column in table 16, their lack of importance to her is shown by their omission from her personally valued achievements, as she did not identify any of her qualifications as personal achievements, only the process of acquiring the knowledge that led to them;

'...because I wanted an education. I got in with the women's movement at the age of...1975 I joined the women's movement and I just got myself enlightened and I wanted to learn. I wanted to learn more. I was hungry for knowledge. I'd learnt nothing at school' (Int.1, p.5).

She judges herself for this however and feels like she is not good enough *'a failure'* and considers herself *'just lazy'* and *'not ambitious at all'*.

The drive for knowledge appears to be a consistent goal for her from when she was at school despite discouragement. She started degree study although it remains unclear whether she finished it as she says;

'I wasn't ready to do the degree because I could barely read and write, but most of me friends were pushing me you see because I'm bright and articulate in me speech, but me written work...Well, as you can see I'm rubbish' (Int.1, p.5).

She appears to give herself little credit for having taught herself to read and write and her subsequent development has been motivated by the women's centre. Her role there is as a volunteer and she has contributed to various organisational roles but she has been treated like a user of the service by younger workers perhaps contributing to some confusion in how she sees herself;

'I see all these people coming and they rely on me and I don't think it's fair but then again I do offer myself to people as like a willing slave, a nutter. A nutter for people to use' (Int.2, p.13).

This causes some resentment for her but she says nothing;

'You know, there are people who I see I'm more qualified at, more committed at, but then again I don't really want a job. I'd refuse it if it came, but it would be nice to be offered a job and just to be acknowledged. It'd be lovely that' (Int.2, p13).

This lack of recognition perpetuates her perception of herself as a 'waste of space'.

Not achieved/lost

The assumption about her lack of skills is a perpetuation of her experience of negative expectations earlier in life. However, she accepts this as punishment because of her guilt;

'I was being punished. I felt as if I deserved it. I felt as if I deserved everything that happened to me in my life, all the bad things because I felt responsible for me mother's death and that's what my father told me, that's what the rest of my siblings told me' (Int.1, p.17).

This acceptance means that the 'depression' she has experienced 'all of my life' is not conceived as a loss as it describes the life she has lived, in which she considers herself to have lost 'nothing' due to her mental ill health. This is despite her recognition that she was left unable to 'feel' or 'bloody love anything'. These feelings eventually led her to try psychotherapy but she found that she did not want the change it offered as she likes herself how she is;

'What happened there was I worked out that they were just trying to make me feel...you know, knock me edges off, I like me edges' (Int.1, p.19).

Because 'you need money to do things' she is unable to 'decorate me house...and pay somebody to do it properly and get carpet laid, and me door put back on...that window pane there'. The barrier to this is not being accepted as mentally ill which prevents her from improving her income as having a mental illness would make her eligible for DLA.

For a recent application Lucy tried to see a psychiatrist but was disappointed;

'I mean, to be honest, I tried to see a psychiatrist, was it last year or this year? My doctor wrote off the psychiatrist just as if there's nothing wrong with me...and she refused to see me' (Int.2, p.5).

As she has been treated as mentally ill before, she feels that this is unfair;

'I'm just not sick enough for help, yet I'm not normal enough to be treated properly...I'm in a Catch 22 situation' (Int.2, p.5).

This has left her feeling bitter and cynical leaving only a sense of self-preservation;

'Yeah, I've learned to play it. I won't do it...with people I was genuinely fond of, but if they...I wouldn't steal or anything like this, but if I committed a crime I'd probably use it. You know I could use it to my advantage and get some extra money from the DHSS. I mean that's very blunt, isn't it, using it to my advantage. I mean I know it's horrible that, but that's the truth, that's the way I feel' (Int.2, p.8).

Present and future

Although Lucy cannot get professional validation of a mental illness, she has benefitted in her life from being mentally unwell, being a *'little bit batty'*, suggesting that being seen as having mental health problems has provided her with a tool that has helped her through life. She sees them as opportunities, or as assets. Lucy's mental health problems have made her *'more experimental'*, given her more *'freedom to be funny'*, allowed her to *'take more risks'* and be *'flamboyant'* in her dress sense. They have made her who she is although;

'I think if I had it all over again what I'd do. I'd have stuck at things because I see myself as an intelligent, articulate and capable woman' (Int.2, p.13).

The *'spirit'* inside her gives her hope for a better future which she thinks has come from a God that she can believe in;

'I think it's come from God...who you call God and I call God, you know, the higher being, I think it's come from there. I've learnt it over time. I've always felt alienated from society. I always felt different from society, but everybody feels different because everybody is different. I mean everybody's unique. I'm not the only unique woman on this earth. You're unique and everybody's unique' (Int.2, p.10).

This overrides her bad days when she feels *'fat and old and ugly'* but this is changeable as *'it depends on my mind'* particularly when she feels she lacks *'control'*;

'I don't really know. I mean like I'd love to go upstairs and, you know, take control of the situation, but I can't, so I feel impotent in my life. You know, the rest of my life's out of my control at the moment' (Int.2, p.1).

This situation refers to the contact made by her adopted daughter and this exacerbates feelings of anxiety regarding her role as a mother;

'Well I've lived some days I've wanted to kill myself. For example I'm, on some anti-anxiety tablets because a few weeks ago this Madeleine McCann popped in my head and I've not done this for a long time...put myself in her mother's place and I started to imagine that one of my own kin was going to get themselves killed, my grandson. Oh, it was horrible. I couldn't sleep. I was having...sweating and me chest was pounding; smoking more...So I went to the doctor one day and told him I couldn't get these, you know, unwanted thoughts out of me head about death and things happening to me kids. Anyway, he just gave me these tablets. I'm having 'em for a month' (Int.1, p.21).

These feelings however coexist with her optimism, as she feels that she has *'always had the ability to bounce back'*. She is able to see beyond her immediate needs and problems to a better time in the future;

'Yeah hope. I mean even if I was on the executioners block I still would not believe that I was going to get executed. I think something'd turn up last minute, touch wood'. You know, I've got a spirit in me that flames up' (Int.2, p.10).

Her life is better because she finds it easier to live with herself and accept herself, not because her mental ill health has improved to any great extent but that;

'I think I'm a better person now than when I was younger. I like myself a lot better now and I've come to terms with myself now' (Int.2, p.9).

The fairy tale life of her childhood remains as she waits for *'something exciting to happen'* and;

'I always believe in happy ever after. It's kept me going and I believe in happy ever after now. I know that one day I will feel happy. You know, it's a bit like a fairy tale and I believe there's going to be a happy ever after for me' (Int.2, p.7).

Chapter Ten

Emma's story

'I think if I could get an education, then my mental health issues wouldn't have been a waste of time'.

The context text

Emma did not want to meet at her home as she was 'ashamed' of her 'hoarding'. We therefore arranged to meet at the university premises where I work, which was significant for Emma as she placed high value on education, comparing herself to Rita in the film *Educating Rita*.

Emma's trust of me seemed to be established on our first meeting when I said to her that I knew nothing about dyslexia and dyspraxia (which she told me she had) and if I did anything unhelpful she must feel free to point it out to me. She was overjoyed that I had said this and it seemed to establish a bond between us. She was very talkative and articulate, questioning both of herself and me. I appeared to have more in common with Emma than other participants being unmarried and having no children although she also described herself as 'gay'. Emma seemed to be on a quest of self-examination and understanding, but seemed consumed with self-loathing and frequently made reference to her inadequacies and failings. She was aware of her gregarious public persona that was the antithesis her inner self.

Emma said that she wanted to hold her story in her hand, feeling that this would validate it, and make it real. She said that she could 'exorcise' herself by being involved in the research. She expected that talking about her problems would be therapeutic, as talking to

me as a researcher rather than a therapist would mean her story would be listened to and not *'therapised'*.

The experiential text

Emma was her parent's first child, born in 1956. Her mother had *'post natal depression'* as she had a baby every year for the next 11 years after Emma was born. Her father was *'an emotional cripple'* who did not want to know anything about his children's emotional state or take responsibility in case *'it upset him'*. He beat her regularly and from the age of 6 she wanted to be *'dead'*, believing that she was *'no good'*;

'I was no good. I didn't do enough work in the house. I was responsible for my mother's illnesses. I was responsible for when my dad was late. Felt responsible. He said I was responsible, but I felt responsible also' (Int.1, p.12.)

She sought attention by offering help *'oh, I'm not getting any attention, so I'll clean the pots. I'm not getting any attention, so what shall I do mum? Can I help you mum?'*. Her mum would be *'upset about my dad'* and Emma became a confidante as each would *'sound off'* to her about the other. This resulted in becoming a *'parent to her own parents'* as well as parent to her siblings whom she then *'abused'*. She was never happy;

'I can't ever remember a happy time when I was a child. I abused all my brothers and sisters in one way or another...not only did I feel guilty for my actions, but I felt guilty for being the eldest and not being good' (Int.1, p.5).

Emma always wondered why she was *'so different from other children'* and why *'did I not have any friends'*. She was *'bullied dreadfully'* at home and at school including by *'teachers'* because of her *'dyslexia'* and *'dyspraxia'* unrecognised at the time;

'I understand because I had dyspraxia I couldn't play netball. I tried to play netball. I didn't get it. I used to run one way when I saw the ball running the other way. I didn't get it. I was bullied for that' (Int.1, p.18).

Her dad's response to this was violence towards her;

'I'd get bullied at school and if I came home crying, my dad'd hit me for crying because...I shouldn't be soft. And I remember in [name] Avenue and [name] Road he beat me up that much and he gave me a stick and he kicked me out of the house to tell me to go and hit this person, to stand up for myself' (Int.1, p.10).

Her *'fantasy'* as a *'child'* was that she would have a *'white wedding'* and a *'picket fence house'* and she would have *'6 children and they would go to university'*. But Emma knew that having a family was not an option for her as she would surely abuse and blame them for her unhappiness;

'But I couldn't have children. Not because I couldn't have children, but I couldn't have children because I know that I would have abused them...because I was such an angry person. I would have shook 'em to death or fucking suffocated them or...I would have...The worst abuse is the mental abuse. I would have blamed them for my unhappiness' (Int.1, p.25).

Emma has been *'an outcast'*, with *'school, neighbours, friends, siblings, father, work colleagues'* for as long as she *'can remember'*. She wanted to be *'normal'* and *'for people to love her'*. Her early puberty before age 11 and the masculinity of her *'hairy'* body added to her bullying. She wanted to be a *'ballerina'* but was *'fucking ostracised for being ridiculous'*.

Emma left school when she was 15, without any qualifications and unable to *'read and write'*, and subsequently worked in many different jobs from factories to care work. She never stayed long in a job as she got *'bored'* or *'bullied'*.

She believed for some time that she was a *'man in a women's body'*, dressed in a *'masculine'* fashion, wearing *'three piece suits with a shirt and fucking tie and a bleeding hat and overcoat and men's shoes'* and did *'male type jobs'*. She had a *'loud booming voice'* had allowed her *'body hair to grow'* and she felt that she was a *'disgusting ugly dykey dyke'*. She went to see a psychiatrist and only *'a blood test'* confirmed she was *'all*

woman' and so she reverted back to 'women's clothes'. She ate 'chocolate' in order to 'feel nice' and to 'survive' and this led to an 'eating disorder', something that became 'part of the jigsaw'. As well as an 'eating disorder', she hurt herself but kept this private;

'I was a very sophisticated nutter. I used to hurt me feet so you can't see it. I used to batter me head. And the eating disorder...I didn't think it was an eating disorder, but I used to eat' (Int.1, p.10).

She did not think she would live long;

'No, I didn't think I'd live. I would have thought that I would have been dead because I used to put myself in really dangerous situations. I mean going to Australia to commit suicide is quite a big one, so I didn't think that I would live' (Int.1, p.24).

A psychiatrist she had seen in her early 20s suggested to her GP that she should have psychotherapy, something that was not told directly to her as 'my doctor put it upon himself that I didn't need it...he ignored me because I'd go very well dressed'. She was 38 before she found this out because 'No fucking doctor told me nothing about that'. She then spent two years having psychotherapy which motivated her to start college, where she achieved one happy moment, discussing literature;

'...that was the only one time that I've ever been happy, because it was a feeling that I have never in my life experienced and I couldn't wait to go to college' (Int.1, p.8).

She had three long term relationships, 'marriages' the first with a man who was an 'emotional cripple like my dad', and the latter with women, both of whom were 'nutters', one of whom she loved and who died.

Emma describes herself as 'an obsessive hoarder' and she finds it difficult 'to enter and leave through the front door at times'. She is 'in constant fear that somebody will discover what a complete nutter' she is and 'take my home away from me'. She lives with the

'shame 24/7'. Emma is scared of having 'new relationships' and making new friends and has 'dropped everybody' apart from one person so that she does not have to 'give' all the time. She feels unable to succeed;

'I just think that I just existed and the governments paid to keep me in these last 10 years, 15 years, and I've contributed fucking jack shit all because I haven't had the education...I know I can't blame anybody for that, but I can't seem to get the education that I need to move on because I do believe genuinely...I have an awful lot to offer, but unfortunately it's suppressed' (Int.1, p.5).

Education was always the solution;

'So if I'd have had a bit of education, I might not have been such a nutter because I would have found another way how to express myself' (Int.1, p.26).

The narrative text

Emma's timeline (Table 18.) maps her common experiences, achievement and feelings associated with other significant events. Her stated achievements and goals from interview and personal profile are also shown (Table 19.).

Table 18. Emma's timeline

Year circa	Age	Common experiences	Achievement	Feelings	Other significant events
1956	born				
1957	1	Sibling born			
1958	2	Sibling born			
1959	3	Sibling born			
1960	4	Sibling born			
1961	5	Start school Sibling born			
1962	6	Sibling born		Unhappy, Wishes to be dead felt no good, evil	Beaten by father Bullied at school Mothers 'post natal depression'
1963	7	Sibling born		Guilty, suicidal	Told she is stupid
1964	8	Sibling born		Suicidal Low self-esteem, worth	Parenting siblings and parents
1965	9	Sibling born		Suicidal Overeating chocolate	Memory about Hiroshima
1966	10	Sibling born		Suicidal Unhappy	
1967	11	Sibling born			
1970	14		Volunteer work		
1971	15	leaves school	lots of different jobs	Hurting feet Battering head Overeating Shaky	
1976	20	long term relationship (LTR) 1	volunteer work	Believed she was a man	
1980	24			Lonely, suicidal	Travelled in Australia
1988	32	LTR 2			
1992	36		Care assistant		
1994	38		learns to read and write		Loses carer job start Psychotherapy Finds out dyslexic and dyspraxic
1997	41		Window cleaner Taxi driver		Stops work
1998	42		college courses best actress award	Happy	
2000	44		Volunteer work		
2003	47	LTR 2 ends LTR 3			Caring for siblings Travels in Europe
2004	48			Shame, fear, hoarding	DIY; Loses water and heat, hoarding,
2005	49	LTR 3 ends		Heartbroken	Partner dies
2006	50			Eats till sick	gastric bypass
2008	52		Lived to age 52	Shame, fear, tearful	research interview

Table 19. Emma’s stated achievements and goals

Personally valued achievements	That she has lived to the age she has Being able to read and write Passing driving test Being genuine and being who she is, true to herself Award for being best actress
Not achieved/Lost	Ability to pass written assignments and exams Any career development due to lack of education To have children or foster children
Future	To speak other languages To be computer literate To be able to open a letter without being anxious To be a ‘number’ and pay tax (have a job) To be a psychodrama teacher To be a well-rounded healthy human being.

Personally valued/defined achievements

For Emma ‘*happiness*’ would be her achievement;

‘...it is an achievement to be happy and content with your life because I believe, in my philosophy, that money never buys you anything. What you’ve got around you really necessarily doesn’t...As long as you’re warm, you’re relatively healthy, because you can still be happy if you were unwell...warm, somewhere where you might feel safe’ (Int.1, p.4).

She finishes the above statement by saying ‘*So I must be a very sad lady!*’ an illustration that she does not consider herself to be warm healthy or safe. Adult education is the only thing that brought her any experience of happiness;

‘You know, only one time that I ever was introduced to happiness was my first year at college when I went back to school and what happened was...It was like Educating Rita, that film Educating Rita, where she’s talking. It’s like she’s talking with all these students in a café understanding things and sharing things and then he’s saying ‘I don’t want you to be like other students,’ and her not getting that, completely not getting that, and then she becomes like these students, up her own arse’ (Int.1, p.5).

Despite identifying this as the only time she has happiness, her ‘*one*’ true happy moment is conflated with two other events connected by their content regarding education and literature; the first, when she won the best actress award at college;

'That's why I know that that was the only one time that I've ever been happy, because it was a feeling that I have never in my life experienced and I couldn't wait to go to college and I couldn't wait and the fact that I won best actress...It didn't occur to me that I would ever win anything!' (Int.1, p.8).

And the second, discussing literature with her nephew;

'...he read it and he went 'I can't believe how brilliant it is!' So we discussed a book and that was a happy day' (Int.1, p.27).

This link between happiness and education is key to her mental health because *'I think that if I could read and write that I'd keep me mental state good'*. Reaching 52 is an achievement because she had *'lived a dangerous life'*, and she *'thought I would have been dead by middle thirties. Thirties, middle thirties'*. But she survived;

'My survival techniques must have been to make sure that I was adequate for everything that I could do. I could do anything' (Int.1, p.5).

Meritocratic achievements

Emma did make some progress in learning to read and write which was motivated by recognition of her learning disabilities when she started college;

'Well, once they named it, it gave me the impetus to further my education because prior to that I wanted a job that I wanted to like and love. So I went to adult learning at [name] in [name] and I went there and the woman went 'I think you're dyslexic,' and I made some enquiries about that and did some research about it and from then I self-taught myself to read' (Int.1, p.3).

But Emma remains angry it was not noticed at school;

'...it makes me dead angry to think that nobody noticed that I failed in everything else and I knew that. So if I'd known that, surely that would have given them a clue I wasn't as thick as they thought I was!' (Int.1, p.3).

Her aspiration has been to achieve an education which is where happiness lay, so the lack of access to education exacerbated Emma's mental ill health. Nevertheless, she was

successful in getting lots of jobs between the ages of 15 and 42, the most successful being those that she could organise around her mental ill health;

'And when I taxied that was great because when I taxied I only worked three days a week, 12 hour shifts, so I could work on it and most jobs that I've had after [name] were only three days a week. I'd work 12 hours so I'd have enough to pay me rent or whatever I needed to pay for or whatever and then if I'm poorly I could relax the other four days' (Int.1, p.20).

She stopped work at age '42 when I haven't worked since' but she does 'voluntary work, lots of other little bits and pieces'.

Not achieved/lost

Over the years Emma has attempted to achieve qualifications. She has completed an 'A' level and a counselling course, but she is unable to write the assignments;

'I went to [name] college and I did a two year course on performing arts. However, because I could never finish the assignments I did it twice and I still didn't finish the assignments, so that was a bit heart breaking. And I did an 'A' Level in Theatre Studies and I failed and that was dreadful as well' (Int.1, p.3).

Despite the link she makes between mental ill health and lack of education, she contradicts this saying;

'I genuinely believe if my mum and dad had more time for me and made me happy, it wouldn't have made no difference whether I could read or write' (Int.1, p.18).

And;

'Yeah, I wanted to be normal because I wanted people to love me and I never felt loved. Now I'm saying it out loud, it was me mum and dad I probably wanted to love me' (Int.1, p.11).

This places the love of her parents above education and she defends them;

'I can't blame me dad and mam for this as well, but I'd say before one's 6 it was definitely their responsibility. They should not have given me that much responsibility...but because they had no time because they had a baby every year' (Int.1, p.6).

However, her clear recollection of an event before she was eleven years old demonstrates her anger with them, her voice is raised, she speaks more rapidly and her tone is one of outrage. She saw a news report about the threat of a nuclear bomb and recalls her distress;

'In '64, round about that time there was talk about another war because I used to remember hearing my mam crying about the fact that if they set off an Hiroshima bomb again, all the babies were going to get killed and all the babies are going to die and I saw images on the TV then of all these poor little children who was completely deformed and they were talking about deformity when they grew and I remember crying, crying so much that my pillow was wringing wet with tears and I was dreaming that I would have to murder, kill. If the bomb goes off in England I would have to kill all my brothers and sisters, then my mum and dad and then me in the end because I could not stand and watch them suffer the effects of Hiroshima. Now as a 52 year-old woman, my god how much responsibility must I have had at that age! To think that my dad couldn't have looked after me and my mum couldn't have looked after me and couldn't protect me and the fact that I would have had...it would have been left to me to kill them all out of their misery. How bad is that?'(Int.1, p.9).

She lost '*...just having a family life*' because of the choice she felt she had to make but maintains her perception of herself as a parent, illustrated in her correction of herself, '*my children, my brothers and sisters*', which is said without emphasis of any kind.

Present and future

Despite Emma's anger and emotional pain of feeling responsible for parenting everyone, at the same time it became something that gave her a reason to live. The cause of her problems is also a solution to them. The worse her siblings are, the better she is because she has to look after them;

'At the moment I'm relatively strong because I've got three kin that need me, so as soon as they stop I go down again' (Int.1, p.17).

Although she is '*half an inch from being normal*' her hoarding is '*completely out of control*'. She is a '*con artist to myself over-eating, under-eating. It's like I'm a raw wound*'.

Her previous relationship choices she recognises as mirroring her relationship with her dad;

'Well, three long-term marriages that I had, I understand now that I was just trying to re-live living with me dad because they was very much like that and that's why I'm so scared. I'm so scared to start a relationship now' (Int.1, p.25).

And it affects her ability to form relationships;

'It just resonates in my ears that's why my house is a mess...so I don't invite anybody in because I really need to love me and I need to live my life' (Int.1, p.9).

She wants *'to be a liver! I want to live, just live the precious present'*.

Chapter Eleven

Discussion of findings: a collective text

Introduction

The previous seven chapters presented the biographical narratives of seven people who demonstrate sophisticated interactions between experience, personal interpretation and events, framed within individual world views that do not show any universal sequence (Shanahan & Macmillan, 2008). Instead, the biographies illustrate the personal nature of choices and decisions in the context of individual lives. What can be extrapolated from the individual stories is their wider relevance that will be drawn together here in a collective text and developed as a discussion of the findings. The interpretation in the collective text presented in this chapter was influenced by life course theory which avoids age distinctions and instead focuses on historical and geographical location, social ties to others, human agency and timing of events and roles (Elder & Giele, 2009).

We know from the existing literature (chapter two) on the long term experience of mental illness and experience of recovery that people;

- Experience fear, hopelessness and isolation because of stigma and rejection
- Keep things secret to seem normal and avoid stigma
- Experience social disadvantage
- Self-help through establishing control and routine
- Draw on complex models to explain mental ill health which is a mixture of personally meaningful and medically defined
- Experience trauma and fear from illness, hospitalisation and treatments
- Take a long time to feel recovery is possible
- Make reference to life history when making sense of mental health issues and indicate ambiguity in relation to starting points
- Take an active role in their recovery and adapt to any impairment experienced
- Benefit from occupational engagement
- Learn to cope better with change, time and persistence

Studies largely focus on ‘what’ questions, whereas this study with a focus on ‘how’ questions adds details. Although the research questions in this study focus on the effect of long term mental ill health on achievement and the effect of mental ill health in the present, the answers to these questions are not easily addressed as separate delineated issues. Rather, the present has appeared to be a part of all that is past in the way other authors have suggested (Bluck & Habermas, 2000; Miller, 2000) and so the answer to one question becomes an implicit part of answering the other. There are no ‘resolutions’ as has been suggested as the end of a life history narrative, only the beginning and the ‘*muddle*’ (Atkinson, 1998, p.1) with hope emerging as they look to their futures.

The memories participants draw on retrospectively are significant in that they are likely be communicating the centrality of the issues remembered in their personal identity at the time of retrieval (Bluck & Habermas, 2000; Rubin & Bernsten, 2009). This also highlights the importance of life context when attempting to synthesise several complex theoretical positions into a single entity where the unifying framework is a person’s life (Davidson & Strauss, 1995).

The Beginnings explores the relevance of early life in the participants’ experiences of mental ill health and its relationship to their achievements. This includes the sociocultural influences of their perspectives as well as its implications for the ambiguity of starting points in mental ill health. Adult life develops this further with an exploration regarding what the narratives tell us about how their aspirations were influenced and how this is linked to their relationships and their agency, in particular in shaping their subsequent opportunities. Their efforts to make sense of their experiences are then explored. Self-protection is identified as a motive for their choices examining the idiosyncratic nature of

how this was achieved which includes privacy and secrets and avoidance of failure. Multiple prolonged stress further highlights the meaning taken from experiences implicating traumatic responses and how different choices and reactions lead to the consequences of the consequences. The prolonged nature of their mental health issues suggests a process leading to emotional exhaustion which co-exists alongside hope, where they are better and worse at the same time.

The Beginnings

The place of experiences that occurred in childhood or early adulthood are clearly implicated in the narratives of the participants, either in making sense of what happens to them or in the formulation of an explanation for how they come to be as they are and this is consistent with existing literature (Hensley, 2002; Walen, 2002; Nyström et al., 2002; Tryssenaar et al., 2003; Hedelin & Jonsson, 2003; Nehls & Sallmann, 2005; Thompson et al., 2008; Erdner et al., 2009). In this study, some of these memories are prior to the age of 10, and thus outside the empirically recognised 'reminiscence bump' (Demiray et al., 2009), a period aged 10-30 where memories of novel and distinctive events that form identity are most commonly drawn. The experiences and memories drawn on in the biographies include bereavement, poverty and abusive and/or other formative relationships all of which are situated within the sociocultural conditions that framed their expectations, aspirations and opportunities for achievement.

All the participants were born between 1930 and 1956 and five participants, (Peter, Louise, Jon, Celia, and Vinnie) were born before the end of the Second World War in 1945, the culmination of two decades of poverty and insecurity for a sizeable minority of the population (Carnevallia & Strange, 2007). Although socioeconomic deprivation in

childhood is known to have long lasting detrimental effects into later adulthood (Drakopoulos et al., 2011) this is not evident for Peter who was '*happy go lucky*' and feels only pride at his mother's and his own achievements despite her having been a single mother with seven children, who herself had been born in the '*workhouse*'. It is possible that this assessment of his childhood is relative to what came after and that his serious mental health problems later overshadowed any prior sense of distress. This would be in keeping with autobiographical reasoning where narratives of the present, past and anticipated future cannot be divorced from each other but are integrated with the life already lived (Bluck & Habermas, 2000; Miller, 2000). In addition, Peter is part of a unique cohort directly affected by the Second World War in which he wanted to be a part, to '*save his country*'. These shared cultural values of the society at the time, despite his social deprivation may have contributed to his resilience in the face of adversity (Gallo & Matthews, 2003; Keyes, 2009). His experience of poverty may also be tempered by the fact that his experience was not unusual in the community he lived in, unlike Lucy whose experience of poverty in the 1950s singled her family out as '*weirdo's*' and '*outcasts*', resulting in social exclusion by teachers, peers and the community. Families subject to discrimination have a disproportionate share of negative life events, and economic hardship often exacerbates their distress (George & Lynch, 2003). Lucy's subsequent inability to read and write was a clear disadvantage with regard to her future opportunities. This is similarly mirrored in the experience of Vinnie and Emma who also struggled to learn and were bullied for their difference, both finding out much later that they had unrecognised learning difficulties.

Family or school environment is more likely to lead to bullying than any personal characteristics (Arseneault et al., 2010) and Vinnie, Lucy and Emma did not have the

benefit of policy initiatives supporting children and families available in recent years (Kurtz, 2003). Their experience is nevertheless consistent with the literature which shows more likelihood of bullying when experiencing difficulties such as maltreatment (Vinnie, Lucy and Emma), parental depression (Emma) and violence (Lucy and Emma) (Arseneault et al., 2010). These experiences are also risk factors for mental health problems in childhood (Bayer et al., 2008) along with parental illness and/or death as experienced by Louise, Lucy and Emma, separation/divorce as experienced by Jon, controlling parenting style and harsh discipline as experienced by Vinnie, Lucy and Emma, and physical health problems as experienced by Peter and Vinnie. Until relatively recently, bullying was considered a normal part of interaction between young people and therefore believed not to be harmful (Arseneault et al., 2010) but evidence shows that bullying and abuse has a significant impact on childhood mental health in terms of distress, anxiety, depression and social isolation with these experiences having long term physical and psychological effects into adulthood (Moeller et al., 1993; Edwards et al., 2003; DeFrain et al., 2003; Downs et al., 2006; Arseneault et al., 2010; Johnson et al., 2010).

The occurrence of separation, harsh discipline and physical ill health for Peter, Jon and Vinnie, however are not experiences specifically drawn on in relation to understanding their mental health and they are not memories that appear to have been consciously interpreted as detrimental. However, poverty, health problems, abuse, violence, multiple bereavement or loss and separation are all experiences that can be considered chronic stressors and all but Celia (though she does allude to a poor relationship with her mother) appear to provide evidence of such experiences in some form in their narratives in relation to their early life. Emotional pain associated with childhood adversity has been perceived as adaptive (Zanarini et al., 1997; Holm & Severinsson, 2008) and Lucy and Emma attempted to

protect themselves as children from their parents/families abuse of power through their fantasies, strategies for survival which serve the function of giving hope (Holm et al., 2009). By the time the participants left school they seem to have had not dissimilar expectations, attitudes shaped by their personal and sociocultural environment that impacted on their aspirations.

Aspirations

Children from poorer families tend not to achieve the same academic outcomes as wealthier families though worse outcomes are also found for children from wealthy families who are subject to pressure to excel and the likelihood of being home alone (Nuru-Jeter, 2010). The latter scenario appears to have no relevance in this study, the former however appears to be consistent with the participants' experiences. It would appear that their aspirations were guided by their association and expectations of being '*working class*'. As Peter points out, in the late 1940s, '*there were no opportunities in those far off days for the likes of us. Those were for wealthy families*'. Vinnie echoed similar thoughts regarding wealthy people from around 1960 when the '*working class...only finished up working in factories*'. Lucy suggests that school did not challenge such views with teachers having low expectations and '*we was the ones just marked for factories*'.

Despite apparently disadvantaged beginnings whether because of childhood deprivation, loss or abusive relationships, all participants found work even though only Jon had any qualifications. This is not necessarily unusual however, as a recent study found that two thirds of people (3581) aged 50+ have been found to have finished their education before the age of 16 (Netuveli et al., 2008). The participants in this study had expectations to get jobs and work regardless of their early deprivation or limited opportunities. It does not

interfere with their drive to find employment and as Lucy says, even up to 1966 '*in them days you could just go to a factory turn up at the gates, get a start that afternoon or the next day*'. Jon alone appears to have had the resources for further study, but the pressure for this comes from his own ambitions to achieve and his desire to please God and he left school with a '*technical certificate*'.

Although Jon appears to be different in relation to his opportunities, personal ambition is also evident for Vinnie, Lucy and Emma, all having a sense of what they wanted in terms of their education or work, consistent with recovery literature that showed the place of personal goal setting (Smith, 2000; Matusek & Knudson, 2009; La France & Stoppard, 2006; Patching & Lawler 2009; Armour et al., 2009). For example, in Vinnie's case he knew he did not want to be an '*assistant all his life*'. Jon and Vinnie's motives to support their families were integrated with their drive for promotion, consistent with the established recognition that the male role is culturally defined by work status and providing for the family (Wilkins, 2007; Almeida & Wong, 2009). Perhaps this also explains Vinnie's dissonance in trying to please his father when he would have preferred a caring job more often associated with female roles (Eagly & Steffen, 1984; James, 1998). For Jon and Vinnie their work ethics are reflected in their definitions of achievement; Jon's desire to be part of the elite, and Vinnie's aspirations be a manager. These ambitions continued to shape their attitudes for many years as did Lucy's '*thirst*' for knowledge and Emma's desire for education. In contrast, Peter, Louise and Celia were happy to just get work and earn enough money to support their families. However some potential gender differences emerge when they reach their early 20s.

Adult life

Peter, Louise, Jon, Celia, Vinnie and Lucy were married between the ages of 20 and 22, during the years 1952-1971 with Lucy and Jon each being married and divorced twice. Celia also divorced and Louise separated, though now is widowed as is Peter. Vinnie remains married. Since the 1960s it has been suggested that marriage was a disadvantage for women's mental health yet advantageous for men, though this relationship is not straightforward (de Vaus, 2002). No firm conclusions can be drawn from this study, however as there are examples of both the benefits (Peter, Vinnie and Lucy's second marriage) and the disadvantages (Louise, Jon, Lucy's first marriage). Any relative protection that marriage might have provided for the women was negated by violence (Celia and Lucy), and infidelity (Louise and Lucy) and Louise sums up her marriage by saying, '*what was most detrimental to my mental health? My husband*'. For Jon too, his marriage has a symbiotic relationship with his mental wellbeing as on the one hand it met a central requirement in his life in pleasing God, and on the other it never met his needs or expectations in relation to spiritual compatibility, and it results in the stressful decision to divorce on more than one occasion.

Divorce itself is highly problematic being classed the second most stressful life event that can happen after the death of a spouse (Holmes & Rahe, 1967) an event that was also experienced by Celia and twice by Lucy. However, marriage, divorce and children clearly limited the work opportunities for Louise, Celia and Lucy whose priorities became childcare. Women's experience was a particular focus of a number of studies reviewed (Chernomas et al., 2000; Hedelin & Strandmark, 2001; Hedelin & Jonsson, 2003; Nehls & Sallman, 2005; Broussard, 2005; McKay, 2010) in recognition of their particular challenges.

Relationships have been found to have particular significance in influencing lives (Ritsher et al., 2007; McKay, 2010). Lucy found that her second marriage served a purpose in providing the stability and respect that she had never had before and it is perhaps what guided her choice given that she *'didn't love him'*. Her husband's support gave her a chance to join the women's centre which provided new opportunities and relationships that led her to realise that she could achieve more, and this motivated her to begin studying. For Emma it is her choice of undergoing therapy that helps her realise she can aspire to an education though this comes only as a result of her own resourcefulness and persistence having been let down by others who ignored a GPs recommendation 20 years earlier;

'No fucking doctor told me nothing about that and the only reason that I got that information was because the nurse didn't think that I would read my notes' (Int.1, p.14).

She was *'so afraid'* that the doctor thought she was *'normal'* that she *'begged him, I cried 'Please, please'. I knew instinctively that that would help'*.

As with the women in the McKay (2010) study, occupation was important to Emma but despite undertaking therapy she was unable to consistently *'contribute'* or maintain employment to realise her goal to be *'a number'* as a member of the workforce. As Leete (1989) described, being part of a workforce made life easier because it was normal and gave a sense of belonging to a community. However, the relationship between mental health and work is complex. For Peter, it was helpful and protective for his mental health, but for Vinnie it was both necessary for his mental health and at the same time detrimental. The dichotomy between the overwhelming demands of work and its benefits has been recognised with participation in work being found to have value beyond any other aspects of life and a means of self-empowerment (Strong, 1998; Young & Ensing, 1999; Goodwin & Kennedy, 2005; Van Niekerk, 2009). In addition, the negative impact that failing to get

work has on mental health is recognised (Provinchir et al., 2002; Van Niekerk, 2009) a situation Celia found herself in on a number of occasions. The importance of trying to prevent any deterioration in their mental health had an impact on the types of work or work roles the participants aimed for. Choosing to avoid certain types of work or work roles enabled them to avoid failure and stress which appears was one strategy for self-protection. This resonates with the work of Maslow where needs are understood as hierarchical, the first of which, physiological need, has to be met before the next level can be addressed (Huitt, 2007). The second level need, the need to maintain safety is congruent with efforts related to self-protection. This need has to be met before growth needs can be acted on leading to higher levels such as the realisation of one's potential (self-actualisation). Clarke et al. (2009) found that goal attainment was difficult when symptoms were distressing, but when achieved contributed to improved likelihood of moving toward recovery. The goals for success with the participants in this study were to make sure they did not place themselves in a position that was unachievable; anticipating that this would be worse, so protecting their mental health at times appears to have become a priority over realising any ambitions.

Self-protection

The notion of self-protection appears to have a relationship with the issue of control found as part of the theme coping strategies in the literature where daily structure and goal setting provided a sense of self-empowerment (Leete, 1989; Walen, 2002; Sholtis, 2002; Erdner et al., 2002; Hensley, 2002; Tryssenaar et al., 2003; Roe et al., 2004; Hutchinson, 2004). This type of control is evident in the present lives of the participants where making the effort to go out provides a structure that gives them purpose and gets them '*out of the house*'. In the past other strategies seem to have been developed by the participants that serve to protect

themselves and maximise their chances of success in relation to everyday functioning and also psychological peace of mind. One of these strategies appears to be avoidance of failure, a strategy that can reduce fear and maintain confidence (Van Niekerk, 2009). Failure would adversely affect mental health because they could not cope with stress and this fear led to avoidance. Vinnie was *'frightened of failure'* and *'trying to improve myself in case I couldn't cope with it'*. Louise wanted to train to be a nurse but had to protect herself from failure as she *'didn't want to try and fail'* so achieved the *'next best thing'* a career she loved.

Chernomas et al. (2000) conceptualised fear of stress as a barrier to success. In contrast, the participants in this study indicate that their fear related to failing because failure was seen as a cause of stress. This fear therefore resulted in choices that enabled avoidance of failure and the accompanying avoidance of stress that shaped their choices (agency) to ensure self-protection. Such self-protection may have compromised their achievements from a meritocratic perspective but it appears to have maximised their chances of success in other areas of their lives ensuring that they did not have additional stressors to cope with. This strategy is shown to be a long term solution, for example Jon has stopped driving to avoid *'the contingency of a breakdown or possible accident'* and;

'Jettisoning those things which are superfluous and complicated and difficult it's a way of improving my life and the stress attached to it' (Int.2, p.4).

One of the more apparently destructive methods of self-protection is self-injury. Self-injury did not emerge as a theme in the existing literature about long term mental ill health, but it often used to obtain relief and escape from unwanted emotions, thoughts or situations (McAndrew & Warne, 2005; Holm & Severinsson 2008). This appears to include cutting, overdose, and harmful eating behaviours, in evidence in the narratives of Vinnie and

Emma. Vinnie found cutting himself a relief as other forms of self-injury and expressions of anger. Emma used chocolate to *'feel nice'*, and describes her *'eating disorder'* as *'part of the jigsaw'* where she *'found ways to survive'*. Self-injurious behaviour however can be misunderstood or not socially accepted (Rayner et al., 2005) and often takes place in private as Emma confirms;

'I was a very sophisticated nutter, I used to hurt me feet so you can't see it' (Int.1, p.10).

Such privacy is a choice that appears to provide self-protection in avoiding adverse consequences and to maintain control over life. For Jon this is related to his belief that his *'weakness'* would disappoint people and so to maintain his self-respect he keeps his thyroid problems a secret. All of the participants refer to keeping their thoughts private consistent with the literature which showed concerns about being trusted and the stigma of mental illness (Leete, 1989; Karp, 1994; Chafetz, 1996; Repper et al., 1998; Lundin, 1998; Walker, 1999; Chernomas et al., 2000; Hedelin & Standmark, 2001; Tryssenaar et al., 2003; Hutchinson, 2004; Lester & Tritter, 2005; Broussard, 2005). Both Jon and Lucy voice such concerns. Jon says, *'...they might feel nervous if you tell them you've got mental difficulties'*, and Lucy feels; *'...no-one trusts people who are mentally ill. People think you're mad'*. Keeping silent may limit the the disabling effects of social disadvantage (Leete, 1989; Champ, 1998; Erdner et al., 2002; Tryssenaar et al., 2003; Nehls & Sallman, 2005; Lester & Tritter, 2005; Erdner et al., 2005).

Even though some decisions that the participants made are separated by 20 years of social change they show consistent motives. Peter and Celia both withheld information in order to ensure they did not risk losing their children by their own incarceration in a mental hospital, and such a fear is also alluded to more recently (Walker, 1999; Hogg & Warne, 2010).

Celia avoids the risk of losing her children by avoiding the doctor who she *'doesn't trust'* and who told her hospitalisation would result in *'trouble getting your children back'* and she keeps her feelings to herself. This also avoids the risks of feeling vulnerable to the pressure of authoritative professionals and not being believed (McGrath, 1984; Tryssenaar et al., 2003). This is also reaffirmed by Lucy who maintains her silence and illustrates a particular distrust of people who are professionals;

'I mean I've been honest with you. I'm not honest with them...I only tell the doctors what I want to. I mean me sister doesn't tell the doctor anything, you know, because they're professional people' (Int.1, p.19).

Though Peters experience spans many years from the early 1950s this fear remains real and impacts on later decisions, such as in 1992 when he saw the Ministry of Defence psychiatrist;

'But I never told them about my feelings about hurting anybody because I still had that fear that they would keep me in forever' (Int.1, p.12).

This fear of revealing such intimate information was not restricted to the psychiatrists. He did not feel able to confide in those closest to him, his work colleagues, his wife nor his children as he wanted to protect them. Lucy's experience of not being believed and labelled *'paranoid schizophrenic'* colours her views today and she remains afraid of misinterpretation;

'I wouldn't tell anybody because of the things I do, you know. 'Cos I like going in the woods and dancing naked and I do and I like that, but the doctors'd say that that's strange' (Int.1, p.14).

Although the choice to maintain privacy ensures personal reassurance and is self-protective, it creates additional emotional strain, as Peter indicates;

'I have friends plenty of friends, but they don't know what's inside and what it's doing' (Int.2, p.8).

It is possible that this is shaped by cultural expectations in relation to what others are assumed to find acceptable (Karp, 1994; Lundin, 1998; Chernomas et al., 2000; Hedelin & Strandmark, 2001; Broussard, 2005). Likewise the need to be '*normal*' like other people (Leete, 1989; Karp, 1994; Chafetz, 1996; Repper et al., 1998; Walker, 1999; Chernomas et al., 2000; Tryssenaar et al., 2003; McCann & Clarke, 2004; Lester & Tritter, 2005; Broussard, 2005), a value expressed by Jon, Vinnie, Lucy and Emma that indicates perceived exclusion from mainstream society (Van Niekerk, 2009). When Celia did not know she was labelled as schizophrenic, she believed she could succeed in competitive employment, but finding out about her diagnosis changed her views. She knew her capabilities and had managed her experience for many years congruent with recovery literature (Sullivan, 1994; Marin et al., 2005; Davidson et al., 2005b), though she had not interpreted her experiences as mental illness and learning about the diagnosis took away her motivation.

This need to maintain silence about experience is something Louise learned at age 21, when she was forced to keep the distress of having a still born baby to herself after she was told she was upsetting the other patients. Experience of bereaved mothers who learned to '*shut up*' and be silent in order to hide their grieving from a world that did not or would not understand it is documented in the literature (Hentz, 2002). Similarly, such silences as maintained by the participants in this study may not necessarily be a coping strategy, but may illustrate an honouring and awareness of the deeper experiences of loss (Hentz, 2002). This may explain the lack of reference to any detail in some cases in relation to the loss or whereabouts of the participants own parents. Privacy and secrets therefore implicates hidden internal struggles (Poirier & Ayres, 1997) further evidence of which is provided in the interviews when it is said for example, '*I've not told anybody else*' (Jon) and '*I should*

have never taken...our love life away...I used to crack on I was asleep...you're the first to know about that..' (Peter). The private emotional work the participant's had undertaken is also implicated in their attempts to make sense of what they were experiencing.

Making sense

People draw on a variety of models to make sense of their experiences (McGrath, 1984; Karp, 1994; Lewis, 1995; Chafetz, 1996; Ritsher et al., 1997; Chernomas et al., 2000; Hedelin & Strandmark, 2001) and this is also the case in this study. These are drawn from those culturally available and/or personally relevant and formal diagnosis may or may not be implicated in this. All the participants used colloquial language to describe their mental health, referring to concepts such as *'lunatic'*, *'nutty'*, *'insane'*, *'potty'*, *'whacko'*, *'daft'*. For some, mental illness was also determined as analogous with physical illness, for example, Jon who was *'mentally aware physically'*. This is congruent with some of the literature (Hutchinson, 2004; Ritsher et al., 2007) as is their difficulty finding a language to articulate their experience which results in many apparent contradictions (Karp, 1994, Ritsher et al., 2007). For example, Peter says of PTSD, *'it's not an illness'* but he also says;

'...with an illness like this which I have got and quite a lot of other people've got it's not an illness because I know there'll be no absolute cure...It's not an illness to me, it's a curse' (Int.1. p.21).

Formal diagnosis was not available as an explanation until the age of 60 for Peter, 50s for Louise and Celia and 40s for Jon and Vinnie. Prior to this they found their own way to explain and manage their experiences. All the participants attribute the origins of their experience early in their life long before any psychiatric diagnosis, diagnosis that specifically helped with developing this understanding only for Peter. Although Peter

views his early life as happy and adulthood as difficult, there was no real turning point or transition regarding mental ill health because it was insidious;

'I didn't realise I had mental health problems then. I only took it for granted that these headaches I was getting was part and parcel of all getting older or things like that' (Int.1, p.15).

Explanations for mental distress tend to mirror medical models as the dominant cultural discourse (Casey & Long, 2003; Stickley & Timmons, 2007). All the participants appeared familiar with concepts of psychiatric diagnosis though not all were clear about the place of this in their own lives and there were many ambiguities. All participants could be identified as describing on-going symptoms: nightmares, low mood, suicidal thoughts, anxiety, inability to concentrate or complete complex tasks and feelings of worthlessness. From a medical perspective it could be argued that Peter is recovering from PTSD, Louise from bipolar disorder, Jon from clinical depression, Celia from paranoid schizophrenia, Vinnie from clinical depression and anxiety, Lucy from personality disorder and Emma from eating disorder and depression. However, the narratives demonstrate less straightforward interpretations. As Lucy says, *'You become ill when people start making you doubt your own reality. That's when you become ill'*, and distinguishes between *'emotional'* and *'psychiatric'* problems saying; *'No. I've not got a personality disorder I don't think. I think I am disturbed and damaged, emotionally damaged'*. Emma, in answer to a question about her understanding of her mental ill health replies, *'I always wanted to know what was after the moon and after Venus and it's exactly the same. I didn't understand why I was odd'*. This raises questions regarding the utility of psychiatric diagnosis for individuals and it appears from the evidence in this study that there is little place for these in the participants' narratives other than for Peter who similar to the findings of Erdner et al. (2005), was relieved to be given a diagnosis which reassures him that he was not a *'lunatic'*.

Within current evidence there appears to be a general assumption that there is a starting point for mental illness consistent with a medical model that provides parameters for measurement (Karp, 1994; Hedelin & Strandmark 2001; Nyström et al., 2002; Hedelin & Jonsson, 2003; Roe et al., 2004; Lester & Tritter, 2005; Thompson et al., 2008; Erdner et al., 2009). This is challenged however by findings that implicated early life and biography in explaining mental ill health (Karp, 1994; Repper et al., 1998; Chernomas, 2000; Hedelin & Strandmark, 2001; Erdner et al., 2009). Indeed, for Molan (2007), assigning beginnings to something as elusive as state of mind is itself strange. This indefinable quality was also reflected in the narratives of participants in this study. However, a ‘before’ and ‘after’ seems to have more clarity in adolescence (Wisdom & Green, 2004; Leavey, 2005). Peter can broadly identify childhood as before mental illness, a time when he was ‘*happy go lucky*’. Similarly, Jon identified early adulthood as a defining point, rather than much later when diagnosis was offered;

‘I mean 1964 was the year when it happened and a great change dates from then, you know’ (Int.1, p.3).

The meaning of mental ill health and personally significant stressors appears to result in reinterpretation which can sustain self-theory (Wang & Conway, 2004), such as Louise’s overwhelming experience of still birth and other bereavements which dominate her narrative over any affect that living through war time had. It has been argued that in times of change especially when fundamental assumptions about the self are challenged individuals focus on their lives as a whole rather than specific memory, linked to self through emotional or motivational significance (Bluck & Habermas, 2000). Likewise, narratives become more complex with retelling and change with reinterpretation (Clandinin & Connelly, 2000). This suggests that autobiographical memory is important in the construction of experience of long term mental ill health, and the holistic perspective

enabled by a biographical approach has shown that chronic stress or ‘multiple prolonged stress’ is evident in the participant’s lives.

Multiple prolonged stress

The individual narratives demonstrate that as well as the usual demands of everyday living, such as earning a living and parenthood, common struggles we all share (Dinan, 2005; Borg & Davidson, 2008), participants were facing additional emotional pressures relevant to their personal life experiences that they tried to alleviate by developing various strategies. These strategies often led to further tensions in their relationships or further tensions in having to keep things to themselves. This created challenges and is implicated in the choices they made or felt compelled to make in relation to what they could achieve. However, from the data generated it appears that certain experiences were experienced in a traumatic way.

Vinnie’s suicide attempt was a product of his mental ill health but also created new mental health challenges with which he has had to contend as ‘*now I see sort of flashbacks and things of things I’ve done*’. The traumatic experience of hospitalisation and treatment is evident in the existing literature (Lovejoy, 1984; Unzicker, 1989; McKay, 2010), confirmed by Celia in this study. The explanation for this impact however is complex and part of the wider context of people’s lives. When Celia talks of her hospitalisation around 1973, her distress is triggered by her memory of begging for her son not to be admitted to the children’s hospital and her own hospital admission. The significance of this period of her life is demonstrated as a reference point for how she feels now, even though it was 37 years previously;

‘Well I think because I go to the gym I feel a lot stronger as well whereas before I was a lot weaker, you know. That’s got something to do with it... Well, when I came out of hospital...I struggled to mop the floor and things like that. I couldn’t. You

know, I was out of breath and I was ill with it, you know, but I mean I feel a lot stronger, you know, doing the exercise' (Int.2, p.10).

Similarly, Louise uses the present tense, saying *'it cuts deep'* to describe the distress caused by her husband's infidelity, regardless of this occurring 30 years prior to the telling of her story as well as the detailed recall of her still birth. These narratives appear to suggest that events are re-experienced in some way, consistent with existing literature (Hedelin & Strandmark, 2001; Hedelin & Jonsson, 2003; McCann & Clarke, 2004) and this is a characteristic of trauma (APA, 2000). This study showed that some experiences that can ordinarily be considered traumatic such as accident, still birth, witnessing violent death, bereavement, and rape contributed to persistent stressors present in participant's on-going lives. One such illustration is in Lucy's interview;

'Can I just take you back to something that you said a few minutes ago that you brushed over very quickly? Forgive me if you don't want to go there and that's fine, but you said you'd been raped by a lorry driver? [Silence]. No, okay. Do you want to stop?' (Int.1, p.18).

In the silence Lucy puts her palm out towards me indicating 'stop', whilst her body is suffused with silent tears. People often cannot find the language to communicate trauma (McKay et al., 2004). Such stressors remain private and therefore contribute to their personal on-going emotional labour.

It has been found that an accumulation of stressors can result over time in PTSD like symptoms (Scott & Stradling, 1992; Scott & Stradling, 1994; Scott & Stradling, 2001a; Scott & Stradling 2001b; Marsh, 2003), and this can happen if what might be considered more ordinary stressors are prolonged (Ravin & Boal 1989; Scott & Stradling, 1992; Scott & Stradling, 1994; Alonzo, 2000; Scott & Stradling, 2001a; Scott & Stradling, 2001b; Marsh, 2003; Aldwin & Levenson, 2004; Alea et al., 2004; Friedman et al., 2007;

Hathaway et al., 2009; Bovin & Marx, 2011; Barskova & Oesterreich, 2011). The stress and emotional work evident in the participant's narratives in this study is clearly prolonged. The energy required to meet demands particularly when mentally unwell is hard work (Hentz, 2002; Sholtis, 2002; Deegan, 2003; Morisey, 2003; Weingarten 2005; Woodgate, 2006) and can result in excessive stress and emotional problems (Provinchir et al., 2002; Van Niekerk, 2009). The stress is prolonged because of the subsequent consequences of the consequences of mental ill health, because as well as daily hassles, long term mental ill health is a consistent and chronic stressor, important because there is no respite (Kraaij et al., 2002; Brown, 2007; Almeida & Wong, 2009).

Consequences of the consequences

There is evidence in the narratives of this study that the chronic nature of the stress experienced led to emotional exhaustion. Although this is less evident in the narratives of Louise and Celia, they share experiences of prolonged stress and the repeated stories in their narratives, as with the other participants, may indicate their significant emotional work (Price, 2011). Emotional exhaustion is not a theme discovered in the literature reviewed however, though there are brief references to how exhausting and what hard work recovery is in autobiographical accounts (Sholtis, 2002; Deegan, 2003; Morisey, 2003; Weingarten 2005) and this is true even from an early age (Hentz, 2002; Woodgate, 2006). It also includes bereavement which is itself emotionally exhausting (Tedeschi & Calhoun, 2007). This suggests that the participants' emotional work has been going on for an exceptionally prolonged period of time and it has various effects. For example, reduced emotional reserves to care is illustrated by Peter in his attitude to personal risk taking;

'It means couldn't care less what happens...the fear is there of being whatever...but after a while you get where you say 'Bugger it. If you're going to get it, you're going to get it no matter' (Peter, Int.2, p.13).

Lucy alludes to extreme behaviour that redresses her inability to feel, an emotional numbing;

'It's like when my mother died I died too and for myself to feel alive I had to do these crazy, over-the-top things to feel alive. I just never felt inside' (Int.1, p.18).

Peter, Vinnie, Lucy and Emma all declared surprise that they had '*got this far*' as at times in their earlier lives they thought that they had '*no future*'. This suggests a sense of a foreshortened future similar with other reported findings (Repper et al., 1998; Hedelin & Strandmark, 2001; Tryssenaar et al., 2003; Erdner et al., 2005; Thompson et al., 2008). A sense of a foreshortened future is another characteristic of trauma (APA, 2000) which appears to form part of the experiences of long term mental ill health. Evidence for this association is additionally provided by the apparent presence of emotional exhaustion.

Retaining emotional reserves is shown to be an on-going battle;

'I thought by doing what I did would give me the energy to stay and keep me going to work...After a while I thought 'No, I'm exhausting myself and I'm exhausted now.' Must keep my strength I realise now...that I should never have taken...our love life away...there are times during the night I used to crack on I was asleep...but I thought you need all the strength you've got [name] to keep going, 'keep going during the day to keep your family together' (Peter, Int.1, p.20).

And;

'This is what is very exhausting. It is very, very exhausting'...you burn a lot of energy up and it's energy that's a waste. It's a waste' (Peter, Int.2, p.11).

Emma loses the strength to maintain the same effort;

'All my life I've genuinely believed I can achieve anything that I want to and I still believe that, but I'm tired now. I've been on that treadmill for a long time. I still believe it, but I'm just too tired' (Emma, Int.1, p.5).

And;

'So my achievement from being very young to probably up to me thirties or maybe up to me forties, I have been [name], whereas I'm so tired now that I don't go out in the clothes that I want to go out in and I don't dance in the street like I used to do and I don't say 'Hey!' to people in the street' (Emma, Int.1, p.8).

Similarly, Lucy sums up thinking about her life as ‘...*drained emotionally, drained and very tired. The way I feel at the moment. Really shattered. It really does shatter me*’.

The indications of emotional numbing and emotional exhaustion in the narratives suggest experiences are the result of excessive stress because they are also characteristics of stress burnout (Maslach & Jackson 1986; Schaufeli & Greenglass, 2001; Kristensen et al., 2005). Stress burnout is also linked to reduced personal accomplishment (Wessells et al, 1989; Freudenberger, 1989; Smith, 1992; Smith & Gray, 2001; Brotheridge & Grandey, 2002; Kristensen et al., 2005; Huynh et al., 2008). The participants did not achieve all they wanted as they were challenged by mental ill health and in some cases the effects of treatment, being unable to participate properly in everyday activities due to lack of confidence or concentration and fear. In addition, from a meritocratic perspective, participants all retired early from paid work. All but Peter had stopped work by their 40s, some never having had stability in this respect, which is consistent with studies that show frail mental health and depressive symptomology being associated with early retirement and reduced participation in the labour market (Rice et al., 2011; Drakapoulous et al., 2011). However, efforts to maintain work earlier in life showed some success when work was organised around personal needs. For example, Emma worked more successfully in jobs that she could organise around personally sustainable patterns, where she could work shifts that enabled her to work hard for several days then spend days in bed as with her taxi job.

Stress burnout could be suggestive of deterioration with ageing, however it appears that this is not the case as the narratives suggest there are areas of life where things have got better

and there is a sense of hope, indicating a complex picture of being better and worse at the same time.

Better and worse at the same time

The emotional labour through the life course that suggests a process leading to stress burnout is not an end point but an on-going process that implicates the ever changing circumstances (Plummer, 1983; Denzin, 1989; Featherstone & Hepworth, 1989; Davidson & Strauss, 1995; Holstein & Gubrium, 2000; Shanahan & Macmillan, 2008; Elder & Giele, 2009). This includes the ambiguity of mental illness, that is, whether participants accepted diagnosis or not. It became apparent that 'better' was made not in reference to a discrete illness, but to changes occurring as the participants lived through time. Time is implicated in finding explanations for experience that remained on-going through life, without an endpoint (Chapman, 2002; Weingarten, 2005; Henderson, 2005). Participants adapted as their opportunities, social roles, circumstances and personal and practical resources changed and this is incorporated into their thinking. This is illustrated by Celia, who when asked of her mental health 'would you describe it better, worse, the same?' she says;

'Well, I made quite a few friends...going to the gym and I'm up early every morning...and I talk to quite a few people as well...I go with a friend and we go in the café afterwards and usually I get home about two o'clock...each day except on Friday we usually go up town' (Int.2, p.10).

Similarly, Peter is better because the pressure of worrying about hurting his wife has gone, but he is worse because he is '*a bleeding wreck. Still am more so now. I'm lonely now*'. In a similar way Vinnie is better because he feels less pressure to work and as suggested in the individual chapter, it is socially acceptable not to work once past age 65. But he also emphasises that he is '*worse*'. Emma says she is '*not well*' at the moment, as well as saying;

'That's why I know I'm well. You wouldn't think that I was well now. You'd think that...The doctors and everybody around me used to think I was very well before, but I was really a nutter before and I'm not a nutter now. I'm scared to death of starting to live again because I'm that close...I'm that close to being normal! Half an inch!' (Int.1, p.21).

Her narrative is a good example of the contradiction inherent in being both better and worse at the same time. She says that when her siblings are particularly unwell as they were at the time of the interview, she is better due to having to look after them. But, her hoarding is worse indicating she is worse;

'Well, the hoarding's always been with me all my life. This is the worst it's ever been' (Int.1, p.21).

But her noticing this means she is better;

'When I open my front door I have to climb over one box...over another box...and in me kitchen I've got loads of bin-bags all over the place, but...that's when I'm very poorly I wallow in that and I don't see that, whereas now it's driving me mad!' (Int.1, p.21).

But she also says;

'I'm crying. Crying a lot...very, very low. Very...very unhappy. Very unhappy. I'm just very unhappy that I am a great person and I can't do nothing with me life!' (Int.1, p.16).

All this serves to demonstrate that simplistic measures of wellness do not capture the paradoxical complexity of experience (Miller,1994; Warelow & Holmes, 2011) such as being both sick and well (Deegan, 1992). Vinnie says *'it's just the same'* as well as *'it's worse'* as does Lucy. Louise is *'content'* now because all her family are well. Her adverse experiences have occurred already and *'nothing worse can happen'*. This is consistent with literature that shows older people experience significantly fewer adverse events than younger people, except in relation to death of a spouse (Ensel et al., 1996; Henderson et al., 1998). It is clear from the participant's timelines shown in the individual chapters that

fewer events occurred in their later years compared to their earlier lives. Louise worries in her anticipation of adverse events and given her previous experiences she is fearful of loss, but now not afraid of her own death of which she has no fear.

One of the changes that enabled participants to feel better was helping others as this enables a focus on abilities rather than disability (Leavey, 2005). Peter, Vinnie and Lucy all participate in voluntary work to help others, a mutually beneficial activity that also contributes to their own wellbeing (Ritsher et al., 1997). This form of self-help has also been supplemented by reading material of various sorts over the years, which Peter, Louise, Vinnie, Lucy and Emma in keeping with others, also found helpful (Spaniol et al., 2002; Borg & Davidson, 2008). Self-help is implicated in the existing literature that found control through routine and structure with daily goals (Leete, 1989; Hensley, 2002; Walen, 2002; Sholtis, 2002; Tryssenaar et al., 2003; Roe et al., 2004; Hutchinson, 2004) which for the participants in this study appears to lead to a sense of hope in later life.

Hope

The presence of suicidal thoughts, feelings and actions provide evidence of hopelessness at times in the participant's lives, with some evidence of emotional numbing and sense of a foreshortened future. Peter felt hopeless as he found no help, and his wife was still gone;

'So I left all that behind. I went there as an outpatient and all that...Then after about 2 or 3 years it come back again, all the tears, silent nights, you know, the kids had finally left the last lad had finally left... 'I've done it. I've done it. I've lost me missus, me kids have all left home. There's just me'. I lost interest then. I got rid of all me birds. I was well known for keeping birds finches and all that but I just gave them away. I just thought 'Oh, sod it' (Int.2, p.10).

It is difficult to say whether such hopelessness co-existed with hope earlier in their lives, but hope is evident in their present as older people. There is a vast literature on hope (Herth

& Cutcliffe, 2002a), though interestingly it did not emerge as a major theme in the literature review but formed part of the possibilities for change and learning (Chafetz, 1996; Tryssenaar et al., 2003; Roe et al., 2004). However, there have been very few studies of hope in older people (Herth & Cutcliffe, 2002b). The only direct reference to hope the participants made in this study was in relation to their future as they see it now. Hope in later life is not well understood but the deployment of strengths appears fundamentally related to development across the lifespan (Isaacowitz et al., 2003) and this can be equated with the personal efforts implicated in the literature that lead to adaptation, learning and functioning (Young & Ensing, 1999; D'Abundo & Chally, 2004; Lamoureux & Bottorff, 2005; Weaver et al., 2005; Ridge & Ziebland, 2006). Dreams and aspirations can be maintained despite prolonged adverse life experience (Repper et al., 1998) and people can become happier in the long term (McKay, 2010).

Despite the occasional '*blue day*' now, Peter, and also Jon, share a view to '*Never give up hope*', to meet a new partner. Vinnie is able to see his relative success now he does not feel pressured in the same way;

'I always say I think there is hope...I mean I used to worry a lot about money, but now...we're not well off and we cope now' (Int.2, p.12).

For Lucy it is her continuation of the lifelong attitude to adversity and she is optimistic;

'Something good always turns up...I still hope that something'll turn up, a solution to me problems, because it always does. I mean if I've no money, something always turns up...You know, it's for a reason and I believe in the higher being will not put me through this without a reason' (Int.2, p.10).

This reference to a higher being occurs briefly across several narratives when participants grapple with explaining how they made sense of what was occurring. In the same way as

Lucy implies above, this appears to be to reassure them that their difficult experiences have not been for nothing as Louise says;

'You've got to pick yourself up, you know...I thought, well it's been a waste of time all this making myself ill if I'm not going to do anything with my life from now' (Int.2, p.6).

Relationships with animals also provides hope and plays an important part in the mental health of Peter, Celia and Lucy with Celia's dog providing structure to her day and a reason to get '*out into the fresh air*' (Walen, 2002; Erdner et al., 2009). Peter now finds that animals replace children in relation to his feelings of responsibility that he feels keeps him alive;

'When you've got animals of any kind they've got to be fed otherwise you joss it or whatever...Especially with birds they need a lot of attention and that's where I was before you came...I was feeding them, you know. They've got to be fed no matter how...I felt bleeding awful today, but I'd gone to bed at whatever, cried me bleeding eyes out for, you know, whatever, but no, they have to be fed otherwise I could lose some tomorrow' (Int.2, p.14).

It appears that the participants need to find reasons to carry on.

Conclusion

The findings in this study develop knowledge by focusing on the specific perspective of later life with people aged between 52 and 76 with more than 20 years duration of mental ill health that started before the age of 45. This implicates the longest term experience from a largely unheard perspective. Therefore this study adds to existing knowledge in the following ways;

- Early life, relationships, sociocultural conditions, life context and personal preferences shaped attitudes to achievement
- Personal views of achievement relate to family and relationships, work, education and skills, leisure, and personal development with some variations
- As well as usual life demands, mental ill health itself e.g. attempted suicide or the effects of managing feelings are additional stressors

- Participants anticipate what may cause them stress and make choices to avoid this in order to protect their mental health
- Efforts at self-protection can contribute to experiences of stress for example in relation to keeping thoughts private to avoid stigma and increase chances of success
- Starting points for mental ill health are ambiguous and past life, in particular childhood, becomes a resource for making sense of subsequent distressing experiences
- Work is both protective and detrimental for mental health
- Marriage is both protective and detrimental for mental health and opportunities for support
- Considerable duration of mental health problems and individual stressors experienced over time produce characteristics that match those of trauma and stress burnout
- In later life people are better and worse at the same time with co-existence of stress burnout and hope because of changed social and personal circumstances
- In later life hope is evident and goals for the future focus on issues relating to health and wellbeing, family and relationships, and leisure with some variations

Participants in this study have faced prolonged stress in multiple ways through the whole of their lives both in relation to events that happened to them, but also in their personal responses, interpretations and the meaning they took from these and the consequences of this. This process involved significant emotional labour as they grappled with making sense of their mental ill health in the context of their lives, keeping much of their experience to themselves.

This study has shown that subtle changes occur over prolonged periods of time. Therefore these changes are more likely to become clearer when people are older. However, because of changing sociocultural and personal circumstances, these changes are not one directional and are the result of complex idiosyncratic reasoning, choice making and life context over time. In discussing the implications of the study for health and social care, the next chapter will focus on the findings of better and worse at the same time, which includes developing our understanding of prolonged stress and the coexistence of hope in later life.

Chapter Twelve

Discussion of implications

Introduction

This study has provided an in-depth exploration of how mental ill health is experienced through the life course. In doing so, the exclusion of people who are older from research about experience and recovery in relation to long term mental illness has been revealed. Consequently there is a near absence of any understanding of the experience of people with long term mental health problems from early life into older age.

One of the main challenges in this thesis has been in weaving together the concepts of ageing through time and the accompanying mental ill health so commonly epitomised as a definable illness and an abnormal state (Janoff & Bulman, 2004; Aldwin & Levenson, 2004; Tedeschi & Calhoun, 2007; Sheikh, 2008; Barskova & Oesterreich, 2009; Robert-McComb et al., 2011). This study makes a unique contribution to the knowledge of ageing and mental ill health by adopting a frame of reference that focuses on strengths in a population of people rarely if ever perceived in this way (Bowers et al., 2005; Collier & Yates-Bolton, 2011). The discussion of the collective text illustrated how life history shaped narratives in relation to growing older with mental ill health explicating the similarities and variations. The consequences of mental ill health are shown as having additional consequences that over time become enduring life stressors.

This chapter focuses on the implications of the long term issues that lead to being better and worse at the same time, that is, stress burnout as a result of prolonged stress coexisting with

feelings of hope. These findings provide a new perspective on long term mental ill health that builds on previous literature because these findings have only become apparent when examining experience over particularly long periods of time. The concept of ‘multiple prolonged stress’ has been named as prolonged duress stress syndrome (PDSS) (Scott & Stradling, 2001a), but to date has had little attention in the academic literature and has not been discussed in the context of existing mental ill health.

Whilst there is very little evidence to inform policy and practice in relation to ageing and mental ill health, the findings of this study do not have exclusive relevance for any one health or social care service but have universal application for any person who needs to understand older people and mental ill health, either in a professional or personal setting. The findings can be interpreted to assist and inform those involved in either policy, practice, research or education and this chapter will summarise issues relating to the effect of living with long term mental ill health on achievements and its effect in the present followed by a more focused discussion regarding the implications of the study for health and social care.

Living with long term mental ill health to older age: its effect on achievements

A recovery frame of reference drew attention to strengths and abilities and the term achievement in this study was used as a proxy for positive aspects of life for people with long term mental ill health as they progressed to later life. Recovery in this discussion refers to contemporary recovery that focuses on recovering a life that is meaningful to the individual rather than recovery from mental illness as a definable medical condition (Deegan, 1988; Deegan, 1993; Anthony, 1993; Spaniol et al., 1997; Reeves, 1998; May, 2000; Jacobson & Greenley, 2001; Brown, 2001; Deegan, 2001; Bledsoe, 2001; Turner,

2002; Repper & Perkins, 2003; Rethink, 2005; Campbell, 2007). Making sense of mental ill health through an eclectic mix of concepts mirrored previous literature where explanation seeking through personal theorising was evident (Lovejoy, 1984; Unzicker, 1989; Karp, 1994; Lewis, 1995; Chafetz, 1996; Ritsher et al., 1997; Chernomas et al., 2000; Fekete, 2004). This provides the context within which the participants defined their achievements.

The participants' achievements as they saw them could be categorised as relating to work, family and relationships, education and skills, leisure and personal development. These might be considered common experiences we all share (Dinan, 2005; Borg & Davidson, 2008) and show that the minds of people with long term mental ill health are occupied with everyday things most of the time, not mental ill health (Ritsher et al., 1997). However, the context to the perception of these achievements in relation to mental ill health are contextual and can be illustrated through the variations to the categories of achievement which included:

- being genuine to self (Emma)
- it depends how I feel at the time (Lucy)
- not feeling bitter about things that have happened to me (Louise)
- helping people (Peter and Vinnie)
- managing not to get put away in an asylum (Peter)
- managing with little money (Celia)
- doing everyday things other take for granted (Peter)
- surviving to the present (Peter, Vinnie, Emma)

Despite this focus on strengths a sense of loss also emerged from the narratives. What was felt to be lost could be categorised as relating to work, health and wellbeing family and relationships, and education and skills. The variations in relation to what was felt to be lost were identified as:

- a sex life with wife (Peter)

- not being able to participate properly in activities (Peter)
- mental fitness and loss of concentration (Jon, Vinnie)
- inability to travel (Peter, Jon)
- inability to use mind and too shaky after ECT (Celia)
- not being more independent (Vinnie)
- loss of confidence (Vinnie, Lucy)
- being a failure (Lucy)
- Nothing (Lucy)

The participants protected their mental health as a priority, maintaining their safety consistent with Maslow's hierarchy of needs (Huitt, 2007) as protecting mental health over realising ambitions appeared to be more important. Lucy's additional feeling that she had lost nothing validates the 'depressed' life she has lived. Reduced personal accomplishment from a meritocratic perspective appeared to be a result of the choices participants made rather than an adverse outcome of long term stress, though personal perspectives of achievement were not related to meritocratic achievements alone.

The following quote, reproduced exactly as Peter wrote it on his personal profile illuminates how important perceptions of personal biography are in interpreting the present, given that it is written by someone who has lived with the severe consequences of trauma for nearly sixty years;

*'My life more so my early life was a life of out and out poverty. We slept six to a bed it was a flock mattress on the stone floors. I was always on the outside of the bed so I copped for everything when the kids turned over what clothes I had covering me went with them and the fights started but we as a family mam and 7 of us all had our own job to do we had to there was very little to eat so we did these jobs to get money for mam my job was chop firewood put it in bundles and sell them to the neighbors 1st bundle after that I used run errands for the neighbours ½ per errand, on Friday night I youst to have a round I go round were the Jewish families lived I would prepare fire for them and light the candels fore them for that I got 1 ½ penny which I would give to my mam. Then mam would go to the shop and bring home a loaf and brawn. By god I can taist it know.
THAT WAS MY ACHIEVEMENT'*

This illustrates that what remains significant for him in his present as an older person.

How mental ill health affects life in the present

The findings in this study provide evidence that the participants have life histories that may mean that they are vulnerable to the effects of stress, as it was sustained over a long period of time. Stress had been experienced in some form for all the participants since they were children or young adults but sustainability of prolonged adversity is not well understood (Zautra, 2009) and what is experienced as stressful is idiosyncratic. As Turnbull (2011) states;

‘What happened to you in adulthood was related to what happened to you as a child. The lightning bolts meaning and impact depended on the personal CV of the individual it was striking and puncturing’ (p.319).

The sense of achievement in having lived to later life appears to be accompanied by a sense of emotional numbing, evident in the decreased sensitivity to risk taking that Peter, Lucy and Emma indicated as well as emotional exhaustion congruent with stress burnout. However, participants are better and worse at the same time because in later life, stressors change, improving in some ways as well as presenting new challenges, for example Peter’s loneliness. The finding of being better and worse at the same time has important implications for the development of knowledge because people with mental illness have been consistently theorised as different from ‘healthy’ subjects in the literature (Tedeschi & Calhoun, 1995; Jeste et al., 2003; Janoff & Bulman, 2004; Aldwin & Levenson, 2004; Tedeschi & Calhoun, 2007; Sheikh, 2008; Barskova & Oesterreich, 2009; Robert-McComb et al., 2011).

The removal of stress associated with early retirement appears to contribute to an improving situation for mental health as participants grow older, as they are not pressurised by others expectations in this respect once in their 60s. This may have implications for the growing body of evidence that shows that mental health improves with ageing when measured on non-clinical samples using measures of depressive symptomology (Nilsson & Persson, 1984; Henderson et al., 1998; Jorm, 2000; McMunn et al, 2004; Rice et al., 2011). The mental health of people with long term mental health problems can also be expected to improve because of the changes in circumstances and priorities as people age in this respect.

Hope emerges in the narratives of later life which implicates reciprocal relationships in relation to helping others as well as continued personal aspirations. McKay (2010) found with the oldest participants of the published studies that women with persistent mental illness were happier in the present and that their future had turned out better than expected. However, although this is shown in this study, Peter also states that he '*wouldn't swap my experience because it's made me what I am now*' and both he and Vinnie additionally refer to there being '*no future*' now, indicating continuing contradiction and reinterpretation suggestive of continued stress. The participant's future is better than expected in that their sense of a foreshortened future earlier in their lives has not borne out and they have exceeded their expectations. Because of the stage of life that the participants have reached it appears that past experiences have become their biography and their whole lives a resource for reinterpreting their experiences.

The future goals that the participants stated showed a stronger emphasis on health and wellbeing in later life which may indicate an awareness of older age as a risk factor for

physical ill health (Woodrow, 2002; Jacoby & Oppenheimer, 2003). Although physical ill health did not emerge in the participants' narratives in this study, reference to physical health was made in conversations (recorded in field notes following our meetings), such as diabetes, chest and eye problems. This is therefore an important issue that cannot be ignored as physical health care has been a particular concern in mental health care in recent years (DH, 2006b). This is because it has been established that people with long term mental illness have a lifespan 20-25 years shorter than the general population due to physical health complications and lack of interventions or access to appropriate treatment (Jeste et al., 2011).

As well as health and wellbeing, future goals in later life relate to leisure, family and relationships, with some variations. For example, as a 52 year old, Emma's future goal includes becoming a member of the workforce, but for the others it is clear that this aspect of life has lost its importance. Other variations, which appear to be related to coping with or resolving the sense of loss they experienced, include:

- take each day as it comes (Louise)
- help people (Peter and Vinnie)
- make more decisions (Vinnie)
- be normal (Vinnie)
- move to a better house (Lucy)
- wait for something exciting to happen (Lucy)

Mental ill health in the present therefore has a relationship with the stage of life that the participants feel they have reached. Having got further than they thought they would enabled them to consider the possibilities for the future and a sense of hope is therefore possible.

The wider issues that can be extrapolated from this study that have implications for health and social care relate to age equality, recovery and long term conditions.

Implications for health and social care

Age equality

The foundations of this thesis rested on the lack of knowledge we have about ageing with mental illness because of apparent exclusion from mental health policy and age discrimination common in practice (Bytheway et al., 2007; Age Concern, 2008; Beecham et al., 2008; DH, 2008; DH, 2009a; Mental Health Foundation, 2009; RCP, 2009b; DH, 2009b; CPA, 2009). Health and social care policy has created underlying tensions in the care of older people that places concepts of active, healthy, person centred and individualistic approaches against issues of passivity, decline, loss and categorisation (DH, 2008). Likewise policy has also focused on older people in the context of long term care needs associated with disability, frailty and continuing chronic conditions such as stroke and dementia (DH, 2005d; DH 2008b). Old age appears to have become synonymous with ill health and disability in a culture that has come to use the term 'old old' to refer not only to the over 85s but to people over 65 who are chronically ill and/or disabled regardless of their chronological age (Neugarten, 1974; Komp, 2009). This study provides evidence of what it means to age to later life with mental ill health and develops current knowledge by extending the adult voice without assumptions regarding what older age may mean. The evidence generated in this study can be used to review current health and social care provision to older people with long term mental ill health to later life.

Mental health services are now removing age defined services and beginning to include all adults in line with equality legislation and associated service requirements (Healthcare Commission, 2009; Equality Act, 2010; National Mental Health Development Unit, 2011a & b). New mental health policy takes a lifespan approach which recognises the importance of preventative interventions in early life (DH, 2009c; DH, 2011). This approach is validated by the findings in this study which confirms and extends previous theoretical positions relating to the relationship between early life deprivation and adult mental health (Moeller et al., 1993; Edwards et al., 2003; DeFrain et al., 2003; Downs et al., 2006; Arseneault et al., 2010; Johnson et al., 2010). This study has additionally shown that narratives will continue to change as reinterpretation occurs depending on life context and the personal meaning of events that takes precedence in participants' memories.

As older people are now included directly in mental health policy for the first time, the lifespan approach of the new mental health policy theoretically provides an opportunity to develop sensitive approaches to people with long term problems to older age. However, it has not continued forward the aim of the NSFOP (DH, 2001a) of rooting out age discrimination. This omission potentially makes people who are older vulnerable to authoritative professionals (McGrath, 1984; Tryssenaar et al., 2003) as age discrimination is more pronounced in mental health services than other areas of health care (Anderson, 2011) and challenging it remains a priority (Joseph Rowntree Foundation, JRF, 2011). This study provides evidence that suggests that any changes that have occurred by later life are not simply explained by being older. In implementing mental health policy, continued vigilance is needed in relation to attitudes towards older people when there is a tendency to view older people with compassionate ageism (Friedan, 1993) and consumers of care, rather than as citizens with aspirations (Bowers et al., 2005; JRF, 2011).

The risks of drawing erroneous conclusions when old age is perceived as explanatory of differences (Riley, 1973; Riley et al., 1988) remains a risk that may misinform people about mental ill health in later life. In the Hedelin & Strandmark (2001) study focused specifically on elderly people, alienation, fear and hopelessness in older people with depression was found with participants that appear to have experienced depression from early life. These participants were between the ages of 71-92 in 2001 therefore one potentially important issue in interpreting results is that they were born between the years of 1909 and 1930 and so some had lived through two world wars. Hedelin & Strandmark (2001) however question only whether the women's advanced age and life stage could have influenced the meaning depression had for them. In addition, they showed decreased aspiration, pessimism, inability to look forward or learn, but this was also found in studies of younger people (Repper et al., 1998; Tryssenaar et al., 2003; Erdner et al., 2005; Thompson et al., 2008). Together these studies therefore include perspectives from people of a wide age range so their findings may not be explained by being older (Kraijl et al., 2002). However Tryssenaar et al. (2003) also found better coping with ageing and in a development of the Hedelin & Strandmark (2001) study, a reanalysis of data found fight, pride and recognition of strengths (Hedelin & Jonsson, 2003). These apparent contradictions may be explained by the finding in this study that people are better and worse at the same time, reflecting the fact that more than one process is occurring as people age when complex interactions between events, learning and changing circumstances occurs.

Some previous studies had not excluded older people directly but passively by recruiting participants in mental health services likely to serve age specific populations (Davidson & Strauss, 1992; Karp, 1994; Sullivan, 1994; Young & Ensing, 1999; Smith, 2000; Davidson et al., 2005; Sells et al., 2005; Marin et al., 2005; Jensen & Wadkins, 2005; Roe, 2005).

The studies that state specific age limited inclusions without justification can be considered directly age discriminatory (Roe et al., 2004; Roe, 2005; Piat et al., 2009; Erdner et al., 2009). If 64 year olds are accepted as participants in studies alongside 18 year olds, which all the studies allow but rarely comment on, then life stage is important and there is no reason to exclude people older than age 64.

Others perceptions of the needs of older people may not match those of older people themselves (Heikkinen, 2000; Dadswell, 2005; Strauss, 2008). Heikkinen (2000) found that no sense of being old emerged until after the age of 85 when the physical body became an explicit concern and physical props such as walking aids affected how others perceived them. Similarly ageing did not emerge as relevant in the narratives in this study. Because of this observation, near the end of interview two, I specifically asked about the relevance of their ageing experience. The participants were unable to provide an answer and looked confused, and Peter said;

'I still feel as though I'm 21 at times...You only age on the outside, do you know what I mean, due to appearance, but when you look in a mirror you don't see your age, you just see who you are. It's other people that notice it, you don't notice it' (Peter, Int.2, p.12).

This is also important because life expectancy has now increased to 82.1 and 78.1 (females and males respectively) (Office for National Statistics, 2008-2010) and confusion may arise when perceptions of middle age have increased to 63 (Institute for Fiscal Studies, 2008), whilst conceptualisations of older person have decreased to the age of 50 (DWP, 2005).

Traditionally, the age of 65 has been used as an arbitrary measure helpful for organisation of services (Heikkinen, 2000; Bytheway et al., 2007) but older age can only be accepted as

a proxy measure for objective differences such as biological changes (DH, 2008). However, it seems clear from the few studies that recruit from public and primary care settings (Karp, 1994; Lewis, 1995; Schrieber, 1996a & b; Thornhill et al., 2004; Lester & Tritter, 2005; Broussard, 2005; LaFrance & Stoppard, 2006) that older people are generally not coming forward and volunteering as research participants. For example, the three recovery studies that specify an inclusion criterion of over 18 years of age only attract adults up to the age of 51, 55 and 57 respectively (Davidson & Strauss, 1992; Patching & Lawler, 2009; Matusek & Knudson, 2009). More evidence is needed from adults who are older regarding long term mental ill health as this study shows that subtle differences are found that seem to be visible only over very long periods of time. However, it has been found that older people find it difficult to participate in public consultations (Bytheway et al., 2007) and have few opportunities to share opinions (JRF, 2011). This in itself is an equality issue and therefore unheard voices should be sought out (Bytheway et al., 2007). One way of achieving this could be for researchers to adopt proactive recruitment procedures of people who are older to ensure that their valuable long term experiences do not become lost in the milieu of health and social care. This is particularly pertinent regarding the implications for developing our understanding of recovery.

Recovery and long term conditions

The National Service Framework for Long Term Conditions (DH, 2005d) has had little influence on mental health practice though the influence of poor mental health and wellbeing is recognised as a pivotal factor in determining the quality of life and recovery outcomes for people with long-term physical health conditions (Czajka, 2010). Recovery underpins key policy and practice guidance documents for mental health services (DH, 2001c; DH, 2003b; DH, 2005b; DH, 2006c; Sheppard et al., 2008; DH, 2011). As older

people are becoming included in adult services they are increasingly likely to gain access to recovery approaches and interventions previously denied them, but understanding the particular needs of people who have lived to later life with long term mental ill health remains undeveloped.

As most mental health care takes place in primary care (Lloyd et al., 1996; DH, 1999; Rethink, 2005; Cummings & Kropf, 2011) and people of working age with long term mental ill health are recognised as a neglected majority (Rethink, 2004; Sainsbury Centre for Mental Health, 2005), older people with long term mental health problems can be considered the neglected minority of the neglected majority as they remain invisible (McKay, 2010), despite having special needs (Jolley et al., 2004). The participants in this study talked little about health care services in their narratives though it was clear that Peter, Louise, Celia, Vinnie and Emma had some experience of specialist mental health services at times in their lives, with Jon and Lucy having had contact with psychiatrists at some point but relied largely on primary care.

Duration

The considerable duration of mental ill health for some people in the published literature appears to have been overlooked as potentially important, unlike the medical research about schizophrenia referred to in chapter one which makes a distinction between onset for the first time in later life and long term mental illness to older age. People who are older potentially provide the most comprehensive picture in relation to issues of recovery given that they have longest term experience.

Inclusion in this study included at least 20 years duration of mental ill health that started before age 45. Whole lives are implicated however with participants all showing in excess of 46 years of experience. Similarly, the existing literature indicates extensive duration of mental ill health for many people (Leete, 1989; Champ, 1998; Lundin, 1998; Chernomas et al., 2000; Erdner et al., 2002; Nyström et al., 2002; Lester & Tritter, 2005; Broussard, 2005) though only three studies defined long term. Long term was defined as at least 5 years (Thompson et al., 2008), in treatment for 2 years (Erdner et al., 2009) and over 15 years duration (Tryssenaar et al, 2003). In existing studies the participants with extensive duration of mental health problems were included alongside people with one year experience. People with relatively shorter experience may be affected by a sense of biographical disruption, that is, the effects of the onset of disruptive symptoms on everyday life (Bury, 1982, Williams, 2000). This may have more relevance in adolescence when there is a more defined sense of a before and after (Wisdom & Green, 2004; Leavey, 2005), and Peter and Jon continued to make this distinction when in their 70s. Chronic illness disrupts an anticipated future, events that have not yet occurred, that are not yet part of a person's biography. Likewise as new experiences occur narratives are reconstructed (Williams, 2000). Therefore, the sense of biographical disruption at the onset of health problems becomes ones biography when reflected back on from later life may be reconstituted as a different narrative as one's whole life becomes a resource for reinterpretation.

Severe and persistent mental illness has been conceptualised as a minimum of one year (Manderscheid et al., 2010). When such concepts are placed in context alongside the participants in this study whose experience implicate up to 63 years, it would seem to confirm that there is a need to recognise such a population of people as having potentially

special needs (Jolley et al., 2004). This is important when chronic mental illness associated with severe disability is viewed as a separate sub group from mental health consumers who function well in the community and who use personal and professional support systems to manage their mental health problems (Rubin & Panzano, 2002) both of which have elements that describe the participants in this study. The needs associated with long term mental ill health to older age may be neglected when the needs associated with different life stages are conflated. This implicates the need to consider duration of mental health problems and life stage rather than chronological age. Chronological age seems to have become shorthand to explain any change (Collier, 2011a) and is indicative of how ageing fallacies are perpetuated (Riley, 1973, Riley et al., 1988). A useful distinction might be made between long term and life time mental ill health which could replace the term ‘graduates’ which has become less popular and considered offensive (Wrigley et al., 2006b).

Recovery has become a philosophy that underpins much contemporary mental health care. This philosophy relates to having positive expectations and a focus on strengths and abilities (Anthony 1993; Deegan 1993; 2001; Jacobson & Greenley 2001; Reeves 1998; Rethink 2005; Roe et al., 2004; Spaniol et al., 1997; Turner 2002; Brown 2001; Campbell 2007). However, practitioners are unsure whether they are managing chronic conditions or promoting collaborative approaches aimed at recovery (Lester & Gask, 2006) and this confusion is perpetuated though conflation between the concept of recovery from mental illness as a medical condition, and recovery relating to the philosophy that includes individually perceived definitions that can include the rejection of psychiatric labels (Onken et al., 2007).

This study has confirmed previous evidence that explanations for mental distress do not necessarily rely on psychiatric diagnosis. Diagnostic practices seem to have limited utility for the participants in this study and played an almost independent role in their lives for all but Peter. For the participants diagnoses are vague or not properly remembered and both the experience of mental ill health and the event of being told a diagnosis is shown to be something to be made sense of, an event which can become a distressing memory as in Celia's case and congruent with other research and autobiographical accounts (Lovejoy, 1984; Unzicker, 1989; Weinberg, 1997; Champ, 1998; Casey & Long, 2003; Nehls & Sallmann, 2005; Moeke-Maxwell et al., 2008;). Perhaps for some people giving a diagnosis becomes an intervention for managing their stress, for others, depending on how it is done or what it means to a person it becomes another stress to compound the rest.

Mental illness however has become an organising principle of mental health culture (Diamond, 2000). Psychiatric classification medicalises emotion and distracts us from the meaning for personal experiences of mental ill health particularly when people's emotions are invalidated and seen as confirmation of the presence of illness (McGrath, 1984; Leete, 1989; Chernomas et al., 2000; Sayce, 2000; Sholtis, 2002; Tryssenaar et al., 2003; Lester & Tritter, 2005). The emotional needs of people needing intervention for their mental ill health remain at best tacit and unrecorded and at worst invisible and unaddressed (Morton, 2010; Cummings & Kropf, 2011). This may be because mental disorder has been theorised as a maladaptive response (Robert-McComb et al., 2001) with undesirable methods of coping (Rose, 2000; Wang et al., 2009; Johnson, 2010).

It has been questioned whether any distinction can be made between pathology and the stress of everyday life (First et al., 2004). Psychiatric explanations for mental distress can

destroy the links between acute experience and former life experience, redefining people in terms of diagnosis and illness (Diamond, 2000) and dismissing experiences as pseudo stress (Dinan, 2005). The meaning or context for experience is not routinely investigated in psychiatric practice which increasingly aims to value the technical and outcomes based approaches (Morton, 2010).

Mental disorder has also been conceptualised as the opposite outcome to personal growth following traumatic experiences (Tedeschi & Calhoun, 1995; Janoff & Bulman, 2004; Aldwin & Levenson, 2004; Tedeschi & Calhoun, 2007; Sheikh, 2008; Barskova & Oesterreich, 2009). The recovery literature showed that people who already had mental health problems described their development and personal growth beyond illness and diagnosis, what they were achieving despite mental health problems and that they changed and learned over time (McGrath, 1984; Leete, 1989; Chafetz, 1996; Ritsher et al., 1997; Lundin, 1998; Champ, 1998; Walen, 2002; Hensley, 2002; Sholtis, 2002; Tryssenaar et al., 2003; Hutchinson, 2004; Roe et al. 2004). This is suggestive of personal growth related to positive psychological change that has been found to occur in response to traumatic experience (Tedeschi & Calhoun, 2004; Calhoun & Tedeschi, 2006; Tedeschi & Calhoun, 2007; Sheikh, 2008; Barskova & Oesterreich, 2009; Sherr et al, 2011). This suggests that what mental health service users have been describing in their recovery stories is post-traumatic growth as a consequence of their long term mental ill health and life experiences. This study suggests that as well as continued experience of psychological challenges, the passage of time resulted in a change in circumstances, personal resources and perspectives that led to learning effective strategies for survival. The participants therefore demonstrate a symbiotic existence of mental health problems and growth and cannot therefore be said to show outcomes of disorder or growth. Some of the more destructive self-protective

strategies shown by participants in this study may therefore be considered a reflection of them as inherently more stressed individuals rather than maladaptive and undesirable. The presence of two apparently opposing states existing at the same time is an example of the philosophical concept of antimony (Kant, 1929) where contradictory perspectives and apparently mutually exclusive approaches on the same issue are both necessary in order to understand (Davidson & Strauss, 1995).

Past and present

This study suggests that emotional needs may be implicated in an inequity in diagnostic practices. Lucy was given a diagnosis of personality disorder when she was around 20 years old and despite having never been treated or to her knowledge, cured, this diagnosis is presumably still recorded somewhere in her clinical notes from around 1976. This knowledge remains part of her present and she now needs to capitalise on this to increase her income with access to DLA. However, she cannot do this as professionals appear to place no importance on this aspect of her past. The event has been consigned to history and she has been told that there is nothing wrong with her. She is left in the present with the effects of her distress at the injustice of being '*not sick enough for help, yet...not normal enough...I'm in a Catch 22 situation*'. Janet Russell (aged 60), who was diagnosed with schizophrenia in her 30s similarly illustrates this here and now imperative by professionals where the past is expunged;

'In 2000 I was told that I had never been ill because if I had I could not have recovered to the extent I did. Ultimately it had taken the medical profession 31 years, 6 consultants, and enough drugs to knock out the population of London to conclude that there was nothing wrong with me' (Russell, 2007, p.24).

Approaches for people seeking mental health care often rely on the here and now in understanding mental ill health, with past experience being a summary of risk factors such

as past experience of attempted suicide or violence, evident in assessment documents or recorded as past medical history (Kraaij et al., 2001). The error with this approach is illustrated in Peter's story when the psychiatrist told him he was not interested in his past, only his future, an affront that resulted in Peter asking the psychiatrist to leave his house. Vinnie experienced distress when mental health professionals focusing on the present discharged him because they said, he would have '*to learn to live with it*', something he continues to do as he always has. The additional strain caused by this approach could be addressed through life story work which has been shown to change attitudes, increase socialisation, understand behaviour and improve relationships (McKeown et al., 2006). At present this is currently represented only in relation to dementia, learning disability and older people living in care home settings. Biographical approaches may help inform interventions in nursing care where exploration of life histories and the meaning of events and experience can lead to meaningful engagement. This could be done through the use of a personal profile such as that used in this study which provides basis for discussion congruent with recovery principles.

In addition, in order to improve sensitivity to the meaning of narratives in later life and the context of older people's lives the quality of research might be improved by stating birth cohorts instead of age, for example, 'born before 1950' or 'born between 1995 and 2002'. This subtly changes the focus which may draw attention to the influence of birth cohort and sociocultural influences in interpreting findings. Stating birth cohorts may also provide a tool for those evaluating research conclusions. This study would have required participants to be born before 1955, nevertheless, older age (over 50) and parameters for duration and onset of mental ill health in this study ensured long term experience to later life that drew attention to subtle changes that happen over time.

Physical health

Although physical health in later life is not a strong part of the narratives in this study, it is a particular concern for mental health policy (DH, 2006b) because of the premature mortality rate in people with long term mental illness (Jeste et al., 2011). Long term stress increases the risk of serious physical health problems (Holmes & Rahe, 1967; Boscarino, 2004) and people with depression have been found to be at significant risk of coronary heart disease (Lawson et al., 2003). This study suggests that mental ill health is a context that creates an on-going consistent stressor and this may be particularly important for people with long term mental ill health when older age is also a risk factor for physical health issues (Woodrow, 2002; Jacoby & Oppenheimer, 2003). Attention to the stress of mental ill health therefore may also have an important role to play in understanding the physical health needs of people with long term mental health problems.

Strengths and limitations of the research study

The findings of this study can only be evaluated in the context of its strengths and limitations and the implications of this for the quality of the study. This discussion will be based on the cabinet office framework for assessing the quality of qualitative research which examines defensibility of design, rigour in conduct and credibility in claim (Spencer et al., 2003). For the purposes of this discussion this will be presented as; research design and credibility, participants and recruitment, data collection, and interpretation.

Research design and credibility

Having been so immersed in the study as the researcher I can only hope that the reader finds the study believable, reasonable and convincing (Atkinson, 1998; Roberts 2002). There are a number of strategies that were adopted in the study to try to meet these

principles. These were decisions that aimed to listen to and hear the participants' stories (Casey & Long, 2003; Jensen & Wadkins, 2007) and keep the narratives whole as far as possible in maintaining their perspective (Bornat et al., 2000). This was achieved through utilising a personal profile (CV) to capture an individually relevant framework for inquiry, returning transcripts for checking (Atkinson, 1998; Roberts 2002), developing a framework to provide opportunity for their stories to be presented in their words (Wengraf, 2001; Reissman, 2002; Carson & Fairbairn, 2002) and interpreting sparingly (Matusek & Knudson, 2009)

Personal profile (CV)

A strategy for keeping focused on the participants relevancies was achieved in introducing the use of a personal profile that was an adapted CV. Previous life history templates have included social and medical history (Chafetz, 1996), photographs (Thompson et al., 2008; Erdner et al., 2009) and charting house moves as the focus for transition and upheaval (Sunnqvist et al., 2007). Similarly with these methods, the personal profile met the aim of providing a concrete reference point for the participants' stories, but for this study had a specific remit in recording life's achievements congruent with the research questions. The personal profile appears to have benefits for research methods that aim to be congruent with principles of recovery as it was helpful in drawing together principles of citizenship, achievement and personally relevant issues from the participant's perspective. This provided a rich source of information on which to base personally focused questions.

Returning transcripts

Returning transcripts was done in accordance with suggested good practice in biographical research (Atkinson, 1998; Roberts, 2002) but this practice raised questions in relation to the

ethical risks and benefits. The aim of this strategy is to improve research credibility; however, the process appeared to be arduous for the participants, taking an inordinate amount of time for little gain to the research. Jon in particular said it was very difficult reading over his story again and he did not return any checked transcripts. Indeed only five out of the 13 transcripts were returned, some without any changes. There is a risk that while researchers consider interview transcripts as data for checking, the participant's lives and experiences are being presented back to them in written form probably for the first time which potentially presents them with a new challenge. These issues reflect the nature of the researcher participant relationship as a human relationship where people engage with a person rather than a research project (Reissman, 2002; Ferrarotti, 2003).

This relationship was respected and acknowledged in part by offering participants a copy of their interview transcripts to keep for themselves. This resulted in comments by both Peter and Emma who said that they wanted to '*hold their story in their hand*' with Peter additionally intending his copy to be given as a legacy for his children who do not know the extent of his mental ill health. The therapeutic value of research is well established (Cook & Bosley, 2001; Dickson-Swift et al., 2009; Clark, 2010), and this study was no exception. Engaging in the research relationship seemed to be an important event in the participants' lives, hence it was included in their timelines. This appeared to be both in the immediacy of the moment, for example on one visit, Peter said '*I felt bleeding awful today until you came...*', but it also appeared to show a deeper meaning for participants as Peter said to me many times that I had '*saved his life*'. The importance of the potential lasting impact of the event of the research interview was also illustrated when Emma passionately expressed the value of just being listened to and not '*therapised*' as, in being involved as a research participant she had achieved what others have said they needed which was just to have their

story heard (Tryssenaar et al., 2003; Nehls & Sallman, 2005). In addition, the participants trust in this process was illustrated in their disclosure of information that they had never told anyone about before. This draws attention to the responsibility that researchers have when given intimate knowledge of the lives of others in researching sensitive subjects (Lee, 1993).

Participants and Recruitment

There are some questions to consider about what the participants in this study contribute to knowledge regarding ageing with mental illness and its effect on achievement and life in the present. Research regarding ‘graduates’, that is, people living into later life with persistent mental health problems has relied on a measure of later life of the age of 65. The experience and recovery studies had less consistent measures usually defining specified types of mental illness and sometimes age. The participants in this study were not recruited on the basis of having a diagnosed mental illness and were not all over the age of 65. Louise and Celia fit the traditional description of graduate, perhaps because they had been introduced to the study by a psychiatrist, although Peter also fits the traditional definition and he recognised a description of himself in my recruitment poster. Emma however misunderstood the poster but was instrumental in shaping the decision to include people younger than 65 when she telephoned me. Her misunderstanding forced me to consider the definition not only of older adult but also the nature of long term. This highlights the risk of missing valuable contributions to research evidence when researchers make assumptions, as I did at first, and which much of the current literature appears to do, about relevancies of age as an inclusion criteria.

However, over the age of 50 as a stage of life and an inclusion criterion in this study was justified on the basis that we needed to hear this voice due to previous exclusion. This ensured that the experience the participants brought to the study was focused on a period of time that facilitated the use of biographical method when looking back over their life.

The flexible recruitment process implemented in this study however, has provided an opportunity to discover a previously hidden population of people who do not necessarily reflect usual researcher definitions but self-identify with having long term mental health problems (Young & Ensing, 1999; Broussard, 2005; Strauss, 2008) and show considerable mental health challenges.

Data collection

The data collection was influenced to a certain extent by my own anxiety as a research student. I found that my own goals and strategies influenced my approach in a much more controlling way than I had anticipated or intended. The need for interviewees being determined not to lose control has been recognised (Wengraf, 2001). For me this was related to an anxiety to maintain a thread of coherence that made sure I was answering the research questions. There were times when someone would make reference to something significant in the interviews only for me to say, *'can we come back to that later'* and I often questioned myself about whether a question that I wanted to ask was relevant to the research or whether it was a clinical question. The effort to manage my anxieties and follow this process was problematic as it prevented a free flow of ideas from the participants as they were drawn back to other issues. This illustrates the reflexive nature of the research process and could also be considered an example of the asymmetry of power in a research interview (Mishler, 1986). If repeating the study, I would follow the suggestion

that life history interviews start with the single question ‘tell me about your life’ (Wengraf, 2001) and only then follow this up with prepared questions if a person was not talkative or if their concentration was limited.

Interpretation

By including only seven people, the detailed exploration of vast amounts of data was possible and conveying the richness and depth of the life stories was achieved by developing several layers of interpretation, that is, interpreting narratives, reconfiguring participant stories and developing a collective text. Narrative analysis will always have some indefinable quality and gaps in reproducibility (Patton, 2002) due to the reflexive nature of narrative method. The listening, noticing, writing, listening and editing process adopted was dependent on what I independently observed, though over-reading helped organise my thinking and provided a method of interpreting sparingly as I had no fixed theoretical position in mind and hoped to be guided by the emerging data. The context, experiential and narrative text framework also forced me to constantly reflect on whose words I was representing and as a result enabled me to remain as faithful to the participant stories as possible whilst recognising the need to interpret them for a research audience (Denzin, 1989; Poirier & Ayres, 1997).

Conclusion

The context of the participants’ lives in this study confirms the potential for having special needs in relation to pursuing their aspirations and achievements as regards work, family and relationships, education and skills, leisure and personal development. From the perspective of later life, future goals incorporated resolving some of their losses, continuing with activities already achieved and forming new hopes and dreams.

This chapter has discussed the implications of the findings in relation to age equality, recovery and the nature of long term, suggesting that there is a difference between long term and lifetime mental ill health. Based on these key points the next chapter will make some recommendations in relation to health and social care.

Chapter thirteen

Recommendations and conclusion

Introduction

This study was an exploratory study that utilised biographical methods as a sensitising tool in an area of knowledge poorly understood (Plummer, 1983). This approach has illuminated some potentially important issues for health and social care. This chapter will complete the thesis by drawing some conclusions in relation to what can be recommended in relation to policy, practice and education and will also provide a commentary on the possibilities for future research. In addition, some personal reflections will be made before a final conclusion that gives the final words to the participants.

Recommendations

Policy

The voices of adults with long term mental ill health across the whole spectrum of perspectives in relation to life stages have not been adequately heard in research and consequently the evidence for policy decisions is brought into question. This needs to be addressed as the Equality Act (2010) makes it unlawful to discriminate against people with ‘protected characteristics’, of which age is one.

Over the last ten years, positive change has resulted from the NSFOP (DH, 2001) in rooting out direct age discrimination but indirect discrimination remains a concern and continues to be a challenge for the future (JRF, 2011). However tackling age discrimination has not been included in current mental health policy introduced in 2011 that includes older people for the first time. Although this study does not directly investigate age discrimination,

challenging age discrimination is at its fundamental core. The evidence it has developed is important in influencing attitudes towards older people and how older people are cared for in mental health services. As the new mental policy will have implications for adults of all ages within the remit of mental health teams, practice development initiatives could continue the work achieved through the rooting out age discrimination standard but with a focus on indirect age discrimination. In addition, mental health policy may need to re-examine its commitment to tackling age discrimination in order to meet its obligations for age equality and quality of care for older people. This is particularly important when rehabilitation, adult and old age psychiatry remain in conflict about who should be providing a service for older people with long term mental health problems (Abdul-Hamid et al., 2011). This may also contribute to developing sensitivity towards the potentially unique needs of people who have lived with life time duration of mental ill health to older age.

Practice

This study has demonstrated the importance of the emotional experience in prolonged stress in life time mental ill health and this perspective could offer mental health nurses new knowledge with which to develop their skills. The risks in relation to here and now approaches that psychiatric models may encourage in practice are in contrast to the historical and temporal nature of memory and its relationship to personal meaning making which, as demonstrated in this study, has a direct effect on mental ill health as it is experienced in in later life. Service models that focus on mental illness as the organising structure are at risk of overlooking how living with mental ill health long term becomes a stress in itself. The findings of emotional exhaustion, emotional numbing, re-experiencing events in some way and a sense of a foreshortened future indicative of trauma and stress

burnout when duration is long suggest that the use of stress inventories and trauma histories could contribute to comprehensive assessments in practice. This understanding could also be enhanced through the development of biographical approaches in practice. A personal profile such as that used in this study would be a practical tool by which this could be achieved congruent with recovery approaches. The personal profile (CV) proved to be an effective tool in capturing people's positive achievements and its use in practice environments in documenting service user stories and life context could promote the desired culture of recovery values.

This study found hope was evident in the present for older people who have experienced life time mental ill health but hope is not well understood in older people (Herth & Cutcliffe, 2002b). Hope is implicated in recovery, and recovery principles are integrated into mental health care approaches. With older people now becoming more likely to be included in adult mental health care services, knowledge about hope and recovery in this population will help practitioners develop their understanding in this respect for people who may not routinely be considered in this way because of assumptions that might be made about older people. This would contribute to a practice culture that is affirming of older people's strengths and therefore in keeping with the principles of contemporary recovery.

Research

The personal profile (CV) developed as a research tool that was congruent with biographical methods and recovery values, served as an anchor for memories and a basis for informing personalised interviews. It proved to be an effective tool that has not been utilised in health research previously. It is therefore recommended that this tool is developed further particularly as a method for mental health research which aims to be

rooted within contemporary recovery principles, as it captures positive achievements and a sense of citizenship. As a visual tool it is also useful for people who may find concentration difficult.

The principles of equality are also an important area for consideration in future research. If such principles are applied to research and how we accumulate evidence regarding older people with long term mental ill health then there are several actions that researchers might consider taking. As it has been found that older people find it difficult to contribute to public consultations (Bytheway et al., 2007) researchers should consider proactive recruitment approaches for the inclusion of people who are older.

Proactive recruitment procedures would improve the quality of research by ensuring that it does not directly or indirectly discriminate on the basis of age and will contribute to the trustworthiness of research findings. The quality of research in this respect could also be improved by reference to birth cohorts instead of chronological age when inclusion criterion is necessary and justified. For example 'born before 1950' or 'born between 2002 and 2007'. This would increase the researchers' sensitivity to potential cohort issues when interpreting findings and encourage critical thinking about their justification for age inclusions. This may also sensitise practitioners to the potential difference between long term and life time mental ill health. The latter is perhaps a more accurate conceptualisation of older people with long term mental ill health who have previously been categorised as graduates given that this study suggests that there is a tendency to refer back to childhood in explaining this.

As well as useful practice tools, stress assessments and trauma histories could inform research with a view to developing a comprehensive understanding of the nature of long term mental health problems to later life. The sustainability of prolonged stress is not well understood (Zautra, 2009) and people with life time experiences of mental ill health may offer a perspective that can assist in developing our understanding of sustainability. As stress is also implicated in physical ill health, research concerning the presence, meaning and effect of stress in relation to physical health issues could potentially contribute to understanding premature mortality for people with long term mental illness to later life.

Research should be undertaken to examine the presence of hope in older people with long term mental health problems. This would also inform the recovery agenda and its application to older citizens who happen to have life time mental health problems and how they might be helped to achieve their future goals. This would contribute to a better understanding of the needs of this population.

To begin to understand these needs more fully future projects need to include establishing the number of people registered in primary care with long term mental health problems to older age. This has already been suggested by Bawn et al., (2007) but has not been acted on. This continues to be important as this study shows there continues to be an invisible population of people whose needs are marginalised and poorly understood. The needs of this population remain largely to be discovered.

Education

All of the issues recommended above and discussed in this thesis have implications for pre-registration and post qualifying education of professionals. An audit of the teaching of age

discrimination in higher education establishments would provide evidence on which to make further recommendations. This is particularly pertinent given the recent failings found in older peoples care (Care Quality Commission, 2011) and student nurses demonstrate a need for this education due to stereotyped attitudes and beliefs that can remain unchallenged (Collier, 2007c). The teaching of hope and recovery in relation to people who are older and who have long term mental health problems could itself help tackle ageist attitudes. In addition the teaching of stress and trauma issues as illustrated in this study may contribute to critical debate regarding the understanding of prolonged mental distress.

There appears to be a substantial body of evidence that raises questions about the utility of psychiatric diagnosis for individuals. Teaching people with mental health problems about the philosophical underpinnings to different types of knowledge would mean they are not misinformed about what they have to accept (Fekete, 2004). This would be in contrast to current approaches for psycho-education that seem to be aimed at persuading people about one model for mental illness, that they are mentally ill, which has been my experience and which I have seen mental health nursing students continue to perpetuate. Narratives in health care are not well understood or respected because nurses are looking for truth (Price, 2011) but an alternative model of psycho-education that discusses types of knowledge would be more in keeping with recovery approaches that base themselves on empowerment and choice agendas.

Personal reflections

Kenyon (1996) states;

'My story is a story from a particular point of view, moreover a point of view that changes with time, experience and the very telling of my story as I create discover and am created by my world' (p.669).

This is true for me as a mental health nurse, academic and research student. This study has made me think differently about people with mental health problems, in particular long term mental health problems. My original research proposal in 2005 was related to identifying the prevalence of psychosis in older people, particularly 'graduates'. As my work developed I found that the medical perspective became less relevant. My publications (Collier, 2005a; Collier, 2006a; Collier, 2007a; Collier, 2008b; Collier, 2010a; Collier, 2011a) written and presented as the thesis developed were attempts to clarify my thinking and proved to be a helpful way of focusing my attention on the key issues which made me more sensitive to the meaning of mental ill health for people's lives. My conference presentations (Collier, 2005b; Collier, 2006b; Collier, 2007b; Collier, 2008a; Collier, 2008c; Collier, 2010b; Collier, 2011b) also helped reassure me that this was an important study, particularly as a summary of one of these was published in *Mental Health Practice* (McMillan, 2008) entitled, 'A beautiful biographical approach'.

Intellectually I am in a very different place from when I began this thesis in 2005. I was concerned at the outset that I did not set myself up as the expert, as I felt to consider 'lay knowledge' somehow inferior to my professional knowledge would be paternalistic. I considered that my knowledge and the participant's knowledge was just of a different type (Hogg, 2008). However the power inherent with being a nurse and researcher remained evident in how participants perceived the relationship, for example Louise showed deference to my supposed knowledge asking in her interview '*do you think I've got bipolar*

disorder? I now feel that the people I met as patients in my career as a practitioner who were patient and kind to me were in a better position to know what they needed, I just had all the power.

Some of the more practical lessons I have learned include;

- To take spare batteries
- To use an external microphone
- To ask to use a room without animals
- To plan for things to take a long time
- Not to panic and just keep swimming

Conclusion

This study has put mental ill health at the forefront of investigation in people who happen to be older. In using a holistic approach that life history method offers, sensitivity to the experiences people face temporally and contextually and their effects has been established. It has become apparent that the explanation for any differences in relation to the experiences of mental ill health between people of different ages is to be found in the passage of time that provides opportunity to learn and change.

Long term mental ill health appears to create an environment whereby the priority becomes to survive, which results in choices to avoid the possibility of failure in order that people protect themselves from unnecessary additional stress, given that there are other external sources of stress that they have to contend. This is dealt with by keeping silent, which, whilst self-protective, nevertheless potentially exacerbates the stress further. The process of making sense of all of this is an on-going process which over time implicates feelings of emotional exhaustion. The changed sociocultural and personal environment becomes part of an autobiographical reasoning that sustains self-theory. This creates a situation where

people with long term mental ill health feel better but also worse at the same time, where personal growth co-exists alongside stress burnout and is coupled with a renewed sense of hope in later life. This provides a potential explanation for the inconsistencies in the existing literature as it has found that there is a process of emotional labour driven by usual life demands, events and experience of mental ill health both as a result and a cause of ongoing stress. This also points to the need to reconsider the nature of long term when the whole biography becomes a resource for interpretation and long term becomes life time.

Although definitions of older age are arbitrary, there is still a population of people growing older with mental health problems who continue to risk being invisible through misunderstanding, misjudgement and ageism by nature of ageing and being older. The findings in this thesis confirm the need to be more aware of this invisible population of people particularly those who may not match or fit diagnostic criteria particularly as such classifications have been developed with younger people and threshold for diagnosis are not the same for older people (Beekman et al., 1999). It is still the case that we do not know how many people with long term mental ill health to older age there are, and even though people in touch with specialist mental health services can benefit from this access most people will only be seen in primary care settings (Lloyd et al., 1996; DH, 1999; Rethink, 2005; Cummings & Kropf, 2011). Ageist attitudes and indirect age discrimination is insidious (Collier, 2005a; Bytheway et al., 2007; DH, 2008) and practitioners continue to need education and policy initiatives to critique personal awareness in order to reduce the risks of age discrimination (DH, 2008). People need to become sensitive to their own attitudes toward ageing as well as the larger cultural influences on reading others texts and lives (Ray, 1998).

This thesis will finish with the words of the participants who contributed so generously to this study, as they think about their futures;

Peter *'I have that allokepic feeling now. If your numbers up your numbers up. Dare I say, well tomorrow is another day?'*

Louise *'I'm happy and I'm contented you know. Yeah I'm quite happy now. As long as my family are well that's all that matters to me really'.*

Jon *'I would like to be remarried I'd like to make up the broken relationships with all my family'.*

Celia *'I just want to keep healthy you know. My health and my strength. And family to be alright'.*

Vinnie *'A good family. All I hope is...I want to be able to just carry on coming here. I'd like to do me gardening and that, love me wife and family'.*

Lucy *'Just carrying on like this in the same vein. Just waiting for something exciting to happen'.*

Emma *'I want to be a liver! I want to live, just live the precious present'.*

Appendix 1

Key words and subject headings of scoping search

Key terms used	Additional search terms and Subject headings
Experience	mental health
Perspective	psychosocial rehabilitation
Subjective	Psychiatry
Ageing	client characteristics
Life course	dual diagnosis
Biography	Involvement
Biographical	daily activities
Narrative	coping behaviour
Story telling	social support
life cycle	interpersonal interaction
Lifespan	employment status
Life history	quality of life
Longitudinal	well being
Duration	psychological stress
Graduates	patient history
Mental illness	client satisfaction
Serious mental illness	Gerontology
Long term mental illness	Older
Severe mental illness	demographic characteristics
Enduring mental illness	user views
Chronic mental illness	user involvement,
Persistent mental illness	Meaning
Ongoing mental illness	
Achievement	
Life satisfaction	
Success	
Recovery	

Appendix 2

Exclusion criteria for literature review

Biological ageing
Physical health
Staff focused
Reviews
Treatment and intervention evaluations
Cognitive functioning and dementia
Family or carer perspectives
Illness management
Evaluation of services
Methodological validation
Mental health service utilisation
Aetiology
Discussion papers
Prevention initiatives
Forensic
Prevalence studies

Appendix 3

Table of hits for different databases in scoping search conducted 8/3/10

Database	Initial search hits	Relevant abstracts retrieved
PsycINFO	3096	99
Medline	3450	7
Amed	114	4
Assia	60	7
BNI	344	19
Cinahl	104	13
PsycEXTRA	81	1
AgeInfo	61	1
Total	7210	151

Appendix 4

Key words and subject headings for focused search

Subject headings	Mental illness	Experience	Subject headings
Mental disorders Mental disorders (chronic)	Mental illness	Experience	Life experiences Work experiences
Psychosis Recovery (disorders)	Serious mental illness	Perspective	Keyword
Chronic mental illness Psychiatric patients, Chronicity (disorders)	Long term mental illness	Subjective	Keyword
Severity (disorders) Schizophrenia Psychiatric diagnosis	Severe mental illness		
Experiences (events) Involvement Rehabilitation	Enduring mental illness		
See long term See mental illness	Chronic mental illness		
Key word search	Persistent mental illness		
Keyword search	Ongoing mental illness		

Subject headings	Achievement	Life course	Subject headings
Achievement	Achievement	Ageing	Aging
Life satisfaction Personal satisfaction	Life satisfaction	Life course	Life span
Achievement Success	Success	Biography	Biography Biographies Autobiographies
Recovery	Recovery	Biographical	Biographical data Life experiences Narratives
		Narrative	See biographical
		Story telling	Story telling
		life cycle	Life span Life histories
		Lifespan	Life Span Life cycle Life change events Attitude to life
		Life history	Life review History Life history review
		Longitudinal	Longitudinal studies Prospective studies Resilience (psychological) Depression (emotion) Post-traumatic stress disorder
		Duration	Key word
		Graduates	Key word

Appendix 5

Permutations of search terms: Focused search conducted 26/5/10

		Medline	Psyc INFO	BNI	AMED	Psyc EXTRA	Assia	Cinahl
1	Mental illness terms	773475	413351	45716	45680	18544	2562	19014
2	Experience terms	356458	293020	8624	12210	8815	40696	42931
3	Achievement terms	217748	854221	806	4114	5506	25607	11851
4	Life course terms	1185904	182282	1146	9047	8184	16005	149388
5	1 and 2	47313	59361	2415	3535	1666	487	799
6	1 and 3	177822	16585	434	1928	1296	247	69
7	1 and 4	137392	56221	214	1716	2212	188	1720
8	1,3,and 4	5534	2624	3	102	117	23	63
9	1,2 and 4	11949	12508	12	157	400	47	104
10	1,2 and 3	1732	3380	58	186	108	61	69
11	1,2,3 and 4	573	684	1	6	23	11	9
	Total retrieved	10	50	8	10	2	24	24

Appendix 6

Age inclusions in experience of mental illness literature

Author	Age inclusion criteria*	Age characteristics of sample*
Chafetz, 1996 ; Broussard, 2005 ; Thompson et al., 2008	over 18	X
McCann & Clarke, 2004	'young adults'	X
Roe et al., 2004	18-55	20-39
Karp, 1994	X	20s – 50s
Erdner et al., 2002	30-63	X
Erdner et al., 2005	X	21-57
Erdner et al., 2009	26-65	X
Lester & Tritter, 2005	X	19-61 (mean 38)
Nehls & Sallmann, 2005	X	19-65
Ritsher et al., 1997	X	29-52
Repper et al., 1998	X	25-65
Lewis, 1995	X	20-70
Thompson et al., 2008	X	38-51
Nyström et al., 2002	X	38-55
Tryssenaar et al., 2003	over 35	37-64
Hedelin & Strandmark, 2001	X	75-92
Hedelin & Jonsson, 2003	X	71-92
Total ranges	18-65	19-70 [71-92]**

*X means no information given

**range for the two studies focused on elderly people

Appendix 7

Age inclusions in recovery in mental illness research

Paper	Age inclusion criteria*	Age characteristics of sample
Davidson & Strauss, 1992	Over 18	20-55
Hsu et al., 1992	X	34-39
Sullivan, 1994	X	Mean 39 sd 9.5
Young & Ensing, 1999	X	26-59
Smith, 2000	X	38-60
Spaniol et al., 2002	X	30-53
Roe, 2005	18-55	20-39
Jensen & Wadkins, 2005	X	19-64
Davidson studies, 2005	X	29-55
Bradshaw et al., 2007	X	37 mean
Borg & Davidson, 2008	X	26-54
Armour et al., 2009	X	25-54
Piat et al., 2009	18-64	Mean 43.6
Ridge & Ziebland, 2006	over 18	<30->66
LaFrance & Stoppard, 2006	X	22-66
Schrieber, 1996a & b	X	32-69
Lamoureux & Bottorff, 2006	Over 19	19-48
Matusek & Knudsen, 2009	Over 18	24-57
Weaver et al., 2005	X	14-63
D'Abundo & Chally, 2004	X	17-46
Thornhill et al., 2004		30-70
Patching & Lawler, 2009	Over 18	24-51
Total age range	18-64	17-70

*X means no age inclusion criteria given

Are you over the age of 65?

Have you lived with emotional ('nerves') or mental health problems (e.g. anxiety, depression, hearing voices), since before you were 45?

I am a research student at Salford University looking for people willing to talk to me about the effect that living with emotional or mental health problems has had on their life?

Could this be you?

For more information (with no obligation) please contact;

Elizabeth Collier
Lecturer in Mental Health
University of Salford
Allerton building
Frederick Road Campus
Salford
M66PU

Telephone: 0161 295 2729

Email: e.collier@salford.ac.uk



Please display until Nov 07

Appendix 9

Ethics and governance permissions

LREC asked that the anticipated length of the interviews should be added to the information sheets and that the sentence ‘anonymised information, including direct quotes from my interview can be used in teaching and publication at a later date’ that appears on the information sheet be added to the consent form.

Permissions were granted as follows:

Salford University research governance and ethics Sub-committee approval achieved 8/1/07.	Code RGEC05/85
LREC Approval granted 2 nd January 2007	Code06/Q1402/75
BSTMHT Governance approval achieved 26 th March 2007	CodeBSTMHT469
Research passport received 3 rd April 2007	
PCT Governance approval received 5 th March 2007. Research passport received. 5 th March 2007	Code RMG/06/106

Annual progress reports were provided to each organisation.

Appendix 10

Information sheet given to participants

Information for participants

My name is Elizabeth Collier. I am employed as a lecturer in mental health at the University of Salford. I am also a registered mental health nurse (RMN). This research will be conducted as part of an educational qualification (PhD).

The research is about people who have experienced mental ill health from before the age of 45, and who are now aged over 65. The research will ask you to;

- Complete a written description (personal profile) about your personal biography, with the researcher or alone if you prefer
- Answer questions about how your mental ill health has affected your achievements through life and have these conversations tape recorded. It is anticipated that this could take up to 2 hours in total (in 1 or 2 interviews as preferred).

When making a decision you should also consider the effect that talking about the past would have on you and whether you feel able to do this. Your contribution to the research will be anonymous, and any information you provide, including the tape recordings will be kept in a safe, secure place. You will be asked whether you will consent to the use of this anonymised information, which may include direct quotes, being used in teaching and published articles at a later date.

Although I do have some previous research experience, this project will supervised by a more experienced researcher. I have permission from the local research ethics committee, Bolton, Salford and Trafford Mental Health Trust and Greater Manchester primary care trust to conduct the research.

For more information please contact me on 0161 295 2729, or email e.collier@salford.ac.uk, or write to me at; University of Salford, School of nursing, Frederick Road Campus, Salford M66PU.

Appendix 11

Consent form

Participant code. ___

CONSENT FORM

Title of Project: A qualitative study on the effect of long term mental ill health on the achievements and goals of older adults

Name of Researcher: Elizabeth Collier

Please initial box

1. I confirm that I have read and understand the information sheet for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.
2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my medical care or legal rights being affected.
3. I understand that data collected during the study, may be looked at by responsible individuals from the university of Salford, from regulatory authorities or from the NHS Trust, where it is relevant to my taking part in this research. I give permission for these individuals to have access to such information.
4. I agree for the interview to be audio taped
5. I agree to take part in the above study.
6. I agree that anonymised information, including direct quotes from my interview can be used in teaching and publication at a later date.

Name of Participant

Signature

Date

Name of Person taking consent
(if different from researcher)

Signature

Date

Researcher

Signature

Date

When completed, 1 for participant; 1 for researcher

Appendix 12

Personal profile

Date completed.....

Personal Information

Participant code.

Gender

Nationality

Ethnicity

Date of birth

Please indicate by underlining whether you are;

Single, divorced, separated, co-habiting, married,
civil partnership, widowed

Accommodation type e.g. care home, private residence,
council, private rented....

How do you/have you
measured success and
achievement in your life?

What would you say is the
best achievement in your
life?

How would you describe
other best achievements?

What do you think you have been good at through your life e.g. good cook, good parent, musical skills, anything

What are your wishes/goals for the future? Please include things that seem small.

Hobbies and interests

Now	In the past	

Employment

Job title	Approximate Year

Other experience e.g.
Volunteer work, military
national service; anything

Nature of work	Approximate years

Appointments held e.g. in
public office
or responsibilities
undertaken

Education;
include
approximate year

Schools	Colleges

Universities	Subject studied

Summary of any qualifications and approx. year

Other Awards received

Additional personal achievements not previously mentioned

Any other comments about your life

Appendix 13

Worked example of personalised interview guide.

Participant number 3 (Louise); Interview. 18th June 2008

Have you ever filled in a CV before? How did you find it?

You left school at age 15 in 1950 is that right? Can you tell me about that? Was that usual?

What were the circumstances? Did you want to stay on?

You don't put any qualifications. Did you take exams at school? Usual for time it happened?

You mention working as a part time cleaner. Was this age 23-39? (the time when you have not identified any work)?

You finished work in '92 when you were 57. Can you tell me why you finished work then?

You say that you have measured achievement as trying to be a decent person. Can you tell me what you mean by this?

You also say knowing that your family love and respect you. Can you tell me more about this being an achievement?

If not covered – why sons and grandchildren and great grandchildren are your best achievement.

You say being able to cope and work as a nursing auxiliary is a best achievement. Can you tell me more about why this is an achievement?

Can you tell me (anything more about) at what stage of your life did mental ill health become significant? (what were you doing at the time)? What was happening?

When you were younger, what would your attitude to mental illness be do you think?

Can you identify where your attitude came from? How did your upbringing affect your outlook?

So when it happened to you how you did understand what was happening to you?

What were your beliefs/explanations about what was happening to you?

Were you given a diagnosis? How did this come about?

Did you agree with the diagnosis? How did you feel about it?

What effect did it have at the time?

You identify your children etc as your best achievement. What were your particular challenges? What effect did your mental health problems have on this?

I notice that you are widowed? Can you tell me about your experience of this. How were your MH problems affected by this or how did it affect your MH problems

You say that you have been your best as a parent. Can you tell me what this means to you?

You refer to not feeling bitter about the things that have happened to you. Are there any other things other than those you have mentioned?

Do you think that you have achieved all the things you wanted to so far?

Do you think that your mental health problems stopped you from achieving anything you wanted to?

What part have your hobbies played in your mhp- helped?

Can you identify any positive aspects to your experience of MHP?

What has helped most?

What has helped least?

How do you think your mental health problems affected your family?

Do you think your life experience is particularly different from other peoples from the same era?

Are there any other effects that your mental health problems have had on your achievements in life that we've not talked about?

Is there anything else you would like to say about yourself and how you have lived with mental health problems?

Nb clarify if it comes up; the effect of the illness or the diagnosis?

Interview2

Clarifying questions from first interview

How did feel after doing the first interview?

You refer to having a breakdown in the first interview. Can you tell me more about what you mean by a breakdown

You also said that you had a bad time after you had a hysterectomy. Can you tell me more about what you meant

You said that you told your husband that he could come to your house as long as he wasn't drunk – had that been a problem in the past? You also refer to 'what he did' are you able to tell me what this refers to?

You describe one of your motivations for managing your mental health problems was to stay out of (name), Can you tell me why you feel like this?

Did you ever feel disabled by your mental health problems?

You describe different aspects of mental health problems over the years, but can you identify what you thought the future when you were ill in the past? Has it been the case?

What is your experience of mental ill health now ? it better worse, same? Why do you think that is?

You said that you seem to cope better more now – can you say how and why?; Do you think you manage the effect of mental ill health better now than in the past? Why do you think that is?

How do you think has the passing of time/aging affected your perspective?

Has it changed for better or worse during your life?

Do your hobbies help your mental health? Can you explain.

What would you want to say to others – SU, professionals,

Does it stop you doing anything you would like to do now?

Are there any positive aspects to your mental ill health now?

Is there anything which you have always been interested in that you would still like to be able to do in the future?

Is there anything you have always wanted to do but not had opportunity?

Is there anything else you would hope for your life now?

You say on your CV that your goals for the future are to keep well and try to be strong.

Can you tell me how you will do this

Do you have any other personal goals for the future?

How do you think your mental health issues will affect this?

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