LIVING WITH LONG-STANDING MENTAL ILL HEALTH IN OLD AGE: A QUALITATIVE SYSTEMATIC REVIEW AND NARRATIVE INQUIRY

Victoria Jagne
BA (Hons.), MSc (Ed), MSc Psych

PhD

University of York

Social Policy and Social Work

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Abstract

Introduction: Mental ill health in older adults is very common across all care settings, however it is often unrecognised due to the nature of the symptoms and the fact that many older people live alone. It is estimated that over 20% of older people (aged 60 years or over) suffer from serious mental health problems (WHO, 2017). This study therefore sought to examine older adults' subjective experiences of living with long-term mental ill health.

Method: The literature study synthesised and interpreted findings from 19 studies covering a heterogeneous population of people aged 55-90+, representing a wide range of mental disorders at different stages of progress and treatment, across nine countries (Australia, Canada, Hong Kong, New Zealand, Norway, Sweden, Taiwan, UK, USA) and using a range of qualitative methods. The overall literature search process was conducted between October 2014 and January 2015. An updated literature was undertaken in January 2019 which re-ran the original searches, limited to January 2005–January 2019. A subsequent empirical study using narrative methods focused on a more homogenous population of older people aged 75-92, all resident in the same county, with one or more of the four most common mental disorders (psychotic, anxiety, mood and personality disorders) at different stages of progress and treatment and treated at different mental health institutions.

Results: The qualitative systematic review of international literature found that the experience of living with long-standing mental ill health in old age is characterised by ambiguity. There are sources of suffering, imposed by mental ill health itself, by treatments for mental ill health and by co-morbid disease. The combined findings of both part of the study suggest that mental ill health presents, at the least, a disruptive potential in the life story of older adults, a disruption which is characterised by threats to bodily integrity, challenges to everyday living, spoiled hopes and fear of death. At the same time, partly because mental ill health is often only the latest in a series of adverse life events, inner resources of fortitude and hopefulness combine with family, professional and social support (Wallace, 2001) to produce a form of resilience which represents continuity in the life narrative and which mitigates the worst effects of disruption, even at an advanced stage of mental ill health among older adults.

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Declaration

I declare that this thesis is a presentation of original work and I am the sole author. This work has not previously been presented for an award at this, or any other, University. All sources are acknowledged as References.

I received ethical approval for this study from the Social Care Research Ethics Committee: REC reference: 16/IEC08/0021
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The final list of documents (included as appendix in this thesis) reviewed and approved by the Social Care Research Ethics Committee is as follows:

1) Recruitment Poster
2) Participant Interview Guide
3) Participant Consent Form
4) Participant Information Sheet Long Version
5) Research Protocol

Signature: vjagne

Printed name: Victoria Jagne

CHAPTER ONE

1.1 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. The current study focuses on older people aged 55-90+, with experience of one or more of the four most common mental disorders (psychotic, anxiety, mood and personality disorders). These disorders have a significant negative impact on people's social functioning, employment and educational opportunities, family life, and health across the lifespan (George, Duran, & Norris, 2014).

The study reports the methods and findings of a research inquiry which investigated older people's experiences of living with long-term mental ill health. The thesis begins with a systematic review (Chapters 2 and 3). The review aims were to identify research which looks at experiences of living with long-term mental ill health in adults (aged 55 to 90+). Chapter 4 presents an empirical study (narrative inquiry) focused on a more homogenous population of older people aged 75-95, all resident in the same county, with one or more of the four most common mental disorders (psychotic, anxiety, mood and personality disorders**)** at different stages of progress and treatment, treated at different mental health institutions.

In this Introduction, I set out the background to both parts **(Part One - Qualitative Systematic Review; Part Two - Narrative Inquiry)** of the study which I conducted to answer the overarching research question: 'What are the subjective experiences of older people of living with long-term mental ill health?' I explain the research problem and the aim of my study and indicate the research questions which guided my inquiry. I make some observations on the nature of mental ill health in older age and on specific features of ageing in modern society. I close with a chapter-by-chapter summary of the structure and contents of the thesis.

1.2 Background to the Study

It is well-documented that the population of much of the developed world is aging. On the one hand, this represents a success story in terms of reducing deaths from infectious and a number of systemic diseases, most notably cardiovascular disease. On the other hand, it also presents a challenge to provide adequate health services to a population with rapidly increasing longevity, as well as an opportunity to develop policies that can assist in promoting good physical and mental health. A number of researchers have asked whether we are ready to meet the challenges of an aging population (Doyle *et al.*, 2009; Connolly, 2012).

Mental ill health is a leading cause of disease burden globally and as a result of both population growth and ageing, this burden has been increasing over time (Whiteford et al., 2013). Mental ill health costs England 22.8% of the total burden, compared to 15.9% for cancer and 16.2% for cardiovascular disease (World Health Organisation, 2008). The wider economic costs of mental illness in England have been estimated at £105.2 billion each year. This includes direct costs of services, lost productivity at work and reduced quality of life (Centre for Mental Health, 2010).

The number of older adults living with mental health problems in the UK. is growing. A study conducted on behalf of Age UK found that the scale of mental health issues facing the older population is considerable, with 7.7 million people reporting symptoms of depression and around the same number (7.3 million) saying they have experienced anxiety (Age UK, 2016). Figures from the Office for National Statistics (ONS) (2016), indicate that older people are expected to make up a growing proportion of the UK's population over the next 30 years. While the population overall is projected to grow by 12.7% from 2016 to 2046, the population aged 65 or over is forecast to grow by 55.1% and those aged 75 or over by 101.9%. In other words, the number of people aged 75 or over is expected to double in the next 30 years.

The fastest growing age group is those aged over 80 years, with numbers expected to increase almost eight-fold by 2100 (United Nations, 2016). In 2016, 1.6 million people, or 2.4% of the UK population, were aged 85 or above. With increased life expectancy and continued healthcare advances, these numbers are anticipated to greatly increase over the next few decades, rising to 3.2 million (4.4% of the population) in 2041.

Mental ill health in older age is very common across all care settings, however it is often unrecognised due to the nature of the symptoms and the fact that many older people live alone. The Department of Health has estimated that 40% of older people in GP clinics have a mental health problem, rising to 50% of older people in general hospitals and 60% of those in care homes (Burns & Warner, 2015). For example, in a 500-bed general hospital on an average day, older people occupy 330 of the beds, of whom 220 will have a mental health disorder of some kind, 80 will have dementia, 80 will have depression and 60 will have delirium (NHS, 2017). In fact, a report from the King’s Fund (The King’s Fund and Health Royal Society for Public Health, 2019) suggests that by 2026 ageing will be the sole driver for increasing the numbers of people with any form of mental disorder. These demographic changes present many challenges, one being the increased demand on health and clinical services (WHO, 2017).

Mental health has an impact on physical health and vice versa. For example, older adults with physical health conditions such as heart disease have higher rates of depression than those who are medically well. Mental disorders induce functional disability, disturb rehabilitation, burden the health system and impair life-quality of old patients and their relatives. Good mental health in older age is just as important as physical concerns. Indeed, poor mental health in old age will inevitably contribute to physical deterioration. Therefore, mental health problems in old age should be treated as vigorously as physical health problems in that age group. Serious mental health problems seen in older people include long-term conditions persisting from earlier in life as well as depression occurring for the first time in old age which can both precipitate and exacerbate the condition. Alzheimer's disease and other dementing illnesses predominantly occur in older age groups. Whereas depression is an affective or mood disorder, dementia is a biological based dysfunction in cognitive or intellectual functioning. Dementia is not a normal part of aging but a syndrome (a group of related symptoms) associated with an ongoing decline of brain functioning (Wilson, 2017). Some form of dementing illness affects 5 to 10 % of the population over 65 (Costa et al., 1996). It is estimated that one million people in the UK will have dementia by 2025 and this will increase to two million by 2050 (Prince et al., 2013).

Mental disorders behave differently in older adults (Wisdom et al., 2008) and their progress may be influenced by the presence of coexisting diseases of old age (comorbidity) (Bartels, Miles, Dums, & Pratt, 2003; Bartels, 2004; Flanagan, Miller, & Davidson; Baumann, 2009; Corrigan, 2006; Palinkas et al., 2007; Pratt, Bartels, Mueser, & Forester, 2008; Pratt, Van Citters, Mueser, & Bartels, 2008). Although there is an extensive literature reporting clinical and epidemiological research into older people and mental ill health, little is known about the experience of having a mental disorder in older populations from the individual's point of view. There is continuing concern though, that older people's specific needs, both physical and psycho-social, are not sufficiently considered independently of their chronological age, when prescribing treatment and care for mental disorders (Karel, Gatz & Smyer, 2012). For this reason, this thesis seeks to explore the subjective perceptions of older people of living with long-term mental ill health.

1.3 Aims and Objectives of the Research

The exclusion of older adults from most community surveys of mental ill health has probably led to the relative underestimation of mental health problems in older people. Also, mental health problems are under-identified by healthcare professionals and older people themselves, and the stigma surrounding mental illness makes people reluctant to seek help. The invisibility of older 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.

Given the current state of knowledge, the aim of this research inquiry was to investigate the experiences of older people of living with long-term mental ill health. My specific focus of interest was the experience of people aged 75 and older, since this appears to be a hidden population whose experiences are largely unknown. Individuals aged 75 and older are rarely represented in mental health research or policy documents. In this qualitative systematic review, for example, only two of nineteen studies selected for review (from an international sample of 262 papers) were of patients aged 75 and older.

1.4 Research Questions

The fundamental purpose of this research is to gain knowledge of, and to understand, the impact of long-term mental ill health on the lives of older people. 'What are the subjective experiences of living with long-standing mental ill health described by men and women aged 75 and older?' What happens when an older person develops symptoms and signs of mental illness? What is it like to receive a diagnosis of mental illness and to go through what can be complicated treatments which older people often find it difficult to tolerate? Having completed active treatment for mental disorder, what is the experience of everyday life living with the after-effects of mental ill health? What if treatment is not indicated? Answers to such questions have rarely been sought from older people themselves.

The research questions which guided this study are:

(i) What is the impact of a mental health diagnosis on older people?
(ii) How does living with long-term mental ill health affect achievement?
(iii) How are decisions about treatment made?
(iv) What is the impact of mental health treatment on the life of the older person?
(v) What is the impact of long-term mental ill health on the person's daily life?

1.5 Study Methods in Outline

In the framework outlined by Robson (2002)) the purpose of this research is predominantly *exploratory* rather than *descriptive* or *explanatory.* Important aspects of exploratory enquiry are that it seeks to find out what is happening, particularly in little understood situations; to seek new insights; to ask questions and to assess phenomena in a new light. I conducted a qualitative systematic review, therefore, of older people's experiences of living with mental health illness in order to investigate the gap in the literature and to produce new knowledge concerning older people's experiences of living with mental health illness. This qualitative systematic review will be referred to here as *Experiencing Mental Ill Health* and will be reported in Chapters 2 and 3 of the theses. I followed this qualitative systematic review with an empirical study, using narrative methods, of a population of people aged 75 and older and living with mental health ill health in a semi-rural county. This study will be referred to as *Mental ill health Stories* and will be reported in Chapters 4-9.

1.6 Overview of Mental Ill Health

The principal aim of this study was to explore older people's experiences of living with long-term mental ill health. Defining mental ill health can mean different things to different people, so some clarification is required at this point. Mental ill health, mental illness and mental disorder have been used quite loosely and with comparable lack of precision. In this thesis mental ill health will be used post diagnosis. The broad term 'mental ill health' is often used as an umbrella term that includes both mental illness and mental health problems. A mental illness is a disorder diagnosed by a medical professional that significantly interferes with an individual's cognitive, emotional or social abilities. There are different types of mental illness and they occur with varying degrees of severity. Examples include mood disorders (such as depression, anxiety and bipolar disorder), psychotic disorders (such as schizophrenia), eating disorders and personality disorders.

According to Dr Geraldine Strathdee, the former National Clinical Director for Mental Health, NHS England (2013-2016)

> *… Mental ill health, like physical ill health, often has its roots in the interaction between the individual's genetic, biological, neurodevelopmental and other fundamental attributes. Like so many healthcare conditions, it is the complex interaction between the individual and the environment in which she or he grows up, works in, lives in, that can protect against, or trigger, the development of mental illness. (Strathdee, 2015)*

Most psychiatric professionals define mental disorders by using the Diagnostic and Statistical Manual of Mental Disorders (DSM-5). Published by the American Psychiatric Association (2013), this manual is an efficient and practical/clinical tool for assigning funding in the bureaucratic governing structure of United States politics. While DSM-5 categories might be better at explaining the individual differences among various mental disorders, they are also too rigid for a social understanding of disability. Not everyone with the diagnosis of schizophrenia has the same experience with their impairments, and few people *fit* completely into one category.

The first formal definition of mental disorder appears in DSM-III as a result of a deep conceptual review. This definition emerged to meet various needs of psychiatry at that time, in particular to serve as a starting point for an evidence-based and a theoretical classification of mental disorder and to justify the removal of homosexuality from classifications and counter the arguments of antipsychiatry (Telles-Correia, 2018). A definition was elaborated in which the main condition for a mental disorder to be present was the presence of the criteria of distress and disability (less permeable to theoretical differences and to moral, cultural, and religious values than the concept of psychiatric or psychological dysfunction). The criteria of harm (distress and disability) remained as paramount in the definition of mental disorder in DSM-IV and the importance of these criteria also led them to make part of the specific diagnostic criteria for most disorders listed in DSM-IV. Nevertheless, in DSM-5 a major and barely discussed change occurred. The concept of dysfunction takes precedence, appearing at the beginning of the definition, possibly being considered its main criterion:

> *A mental disorder is a syndrome characterized by clinically significant disturbance in an individual's cognition, emotion regulation, or behaviour that reflects a dysfunction in the psychological, biological, or developmental processes underlying mental functioning. Mental disorders are usually associated with significant distress or disability in social, occupational, or other important activities…* (APA, 2013*).*

Harm criteria are no longer a basic requirement, but a frequent occurrence that might or not be present. This could lead to the inclusion (in psychiatric diagnostic manuals) of situations that are not associated with distress and disability as happened in the past, potentially re-exposing psychiatry to the danger that entities considered psychological or biological dysfunctions, according to certain theoretical currents (easily permeable to moral and social values), may be considered mental disorders (Wakefield, 2013).

The problem of considering a mental disorder to be mainly a dysfunction (as in DSM-5) may arise in both perspectives: as a biological dysfunction or as a psychological dysfunction (Bolton, 2008). According to Kim (2007), mental manifestations, regardless of the physical or neurological core, only represent a mental disorder if they are regarded as inadequate, non-adaptative, or causing harm (considering the sociocultural background and circumstances of the patient). That does not mean that we cannot try to find the physical or neurological correlates of these mental manifestations. However, in psychiatry, separation of disordered from non-disordered is not dependent upon neurological biomarkers. This means that clinical concepts are precursors to biological concepts. Thus, mental disorder cannot only be defined by a physical or biological dysfunction (Kim, 2007).

The notion of biological causality remains a major orienting principle in efforts to understand the nature of mental ill health. A useful convention was adopted, however, by segregating ‘organic’ from ‘functional’ mental disorders. This dichotomy is based upon an aetiological distinction - the presence or absence of a biological abnormality or dysfunction that fully accounts for the condition. Specific examples include anxiety, depression, dementia, and schizophrenia. Nonetheless, the two broad concepts often associated with mental ill health are `disorder`, implying a deviation from the `norm`, and `illness` which implies analogy with physical illness.

The Mental Health Act (MHA) (2007) defines mental disorder as “any disorder or disability of the mind”. This definition provides a single, simple definition rather than specifying categories of disorder, which changes the way the MHA (1983) defined mental disorder. Categories of disorder are abolished, and this amendment complements the changes to the criteria for detaining service users. All mental health disorders are treated in the same way. Mental disorder can include: any mental health problem normally diagnosed in psychiatry.

1.6.1 Mental health problems and illness

Mental health is “a state of well-being in which the individual realises his or herown abilities, can cope with the normal stresses of life, can work productively and fruitfully, and is able to make a contribution to his or her community.” (World Health Organisation, 2013a). Mental illness, also called mental or psychiatric disorder, is a diagnosable condition that significantly interferes with an individual's cognitive, emotional or social abilities.

A mental health problem also interferes with a person’s cognitive, emotional or social abilities, but may not meet the criteria for a diagnosed mental illness. Mental health problems often occur as a result of life stressors and are usually less severe and of shorter duration than mental illnesses. These often resolve with time or when the individual’s situation changes. However, if mental health problems persist or increase in severity, they may develop into a mental illness.

The definition of mental health in the national ‘No Health without Mental Health’ policy is that it is a positive state of mind and body, feeling safe and able to cope, with a sense of connection with people, communities and the wider environment. Levels of mental health are influenced by the conditions people are born into, grow up in, live and work in (Department of Health, 2011). The World Health Organisation (WHO) (2009) conceptualise good mental health as a state of wellbeing, in which people realise their own abilities, can cope with the `normal` stresses of life, can work productively while able to make contribution within their community. The WHO (2009) claim the essential dimension is contained within their constitution suggesting health is a state of complete physical, mental and social wellbeing and not merely the absence of disease or infirmity.

1.6.2 Serious mental illness

There are a number of different definitions of serious mental illness in the literature. The International Statistical Classification of Diseases and Related Health Problems 10th Revision [ICD-10] is the official classification system for diagnosis used by the majority of United Nations member states for epidemiological and quality assurance purposes and to compile national mortality and morbidity statistics (World Health Organisation, 2007).

1.6.3 Definition of ‘Long-Term’ or ‘Long-Standing’ Ill Health

Under the Equality Act 2010, a mental health condition is considered a disability if it has a long-term effect on your normal day-to-day activity. Long-standing health problem or disease is a health problem that has lasted or is likely to last for at least 6 months. The main characteristic of a long-standing problem is that it is permanent and is expected to require a long period of monitoring, observation or care. Within the mental health context, your condition is ‘long-standing’ or ‘long-term’ if it lasts, or is likely to last, twelve months (King’s Fund, 2012). ‘Normal day-to-day activity’ is defined as something you do regularly in a normal day. This definition includes things like using a computer, working set times or interacting with people (King’s Fund, 2012). There are many different types of mental health condition which can lead to a disability, including: depression, bipolar disorder, obsessive compulsive disorder and schizophrenia.

1.7 Structure and Contents of the Thesis

Chapters 2 and 3 report the methods and findings of a literature review, formed from a substantial synthesis of qualitative studies which investigate older people’s experiences of living with long-term mental ill health. In this thesis it is referred to as Experiencing Mental Ill Health, for convenience and to distinguish it from the empirical narrative study which is also reported here.

In Chapter 4, I describe and justify the research design of an empirical study, given the brief title *Mental Ill Health Stories*. I detail the sampling and recruitment procedures and present brief biographies of the study participants.

In Chapter 5, I report and reflect on the methods chosen to generate, analyse and interpret the narrative data generated in Mental Ill Health Stories. I begin with some commentary on epistemological matters concerning qualitative research data before going on to a detailed account of the primary method of data generation used in the study, the Biographic-Narrative-Interpretive Method or 'BNIM' (Wengraf, 2008, 2001). I go on to describe and explain at length the methods used to transcribe the interview data and subject them to a two-stage narrative analysis based on the concept of the illness trajectory (Corbin & Strauss, 1988) and on a reading of participants' illness narratives (mental ill health stories) in the light of their life histories.

In Chapters 6-8, I report and interpret findings from the narrative study which relate to the pre-diagnostic, diagnostic and treatment periods of the participants' experiences of mental ill health. I present the findings with interpretive commentary in the light of relevant literature. I begin with analysis of the participants' stories of the first signs or symptoms of mental ill health and their help-seeking behaviour (Chapter 6). I go on to report their experiences of receiving and reacting to the diagnosis of mental ill health (Chapter 7) and conclude by reporting their experiences of treatment (Chapter 8).

In Chapter 9, based on close analysis of the life history elements of the interview transcripts, I interpret the 'mental ill health stories' to suggest that the overriding features of situating self in life with mental ill health among the participants in this study are hope and hardiness, together forming a kind of resilience which appears to be psychologically protective and which fosters a determination to continue living positively. I go on to consider the data in the light of analytic questions which help to situate the private individual experiences of the participants in a wider social context.

Chapter 10, in this concluding chapter I attempt to draw out the significance of findings from both the qualitative systematic literature review and empirical investigation, for our understanding of older people's experiences of living with mental ill health. I review and reflect on the identification of a research problem, the formulation of a research question and the principal approaches adopted by way of investigation. I consider the strengths and limitations of the chosen research methods (qualitative systematic review and narrative inquiry) and discuss the challenges of comparing findings from two parts of the study which attempt to answer the same question, but which use different methods. I summarise the key findings across both parts of the study and conclude the chapter, and the thesis, with some observations on the transferability of the findings to wider populations.

CHAPTER TWO

PART 1: SYSTEMATIC REVIEW (EXPERIENCING MENTAL ILL HEALTH)

2.1 INTRODUCTION

I designed and conducted a systematic search and review of qualitative research literature which investigated older people's experiences of living with mental health illness. Reports of research studies traditionally begin with a review of existing literature in the field. A literature review sets the context for a research study, revealing gaps in existing knowledge which the study intends to fill. Scholarly expectations in the field of social science research about the rigour with which such a review is conducted have been rising in the last decade. Researchers are expected to replicate the research process itself in respect of the literature search; that is, to develop a search question and a search strategy which includes methods of searching, retrieval and analysis of the sample of literature retrieved. The result of this analysis should be a critical review, not just a descriptive or narrative summary, which provides appraisal of the quality of existing work.

To make the most effective use of research findings, approaches to synthesising the results of many studies on the same topic have increasingly found favour and, in quantitative research, sophisticated methods of meta-analysis have been developed which aim to produce a definitive set of findings from a wide range of work. In qualitative research such an approach is deemed to be an essential part of increasing the usefulness and relevance of findings (Sandelowski et al 2007). There has been debate about whether the approach is epistemologically appropriate for qualitative research (Campbell et al 2011; Graham & McDermott, 2005; Sandelowski et al 2007). This approach is termed variously 'meta-study', 'metasynthesis', or 'research integration'. It is an approach to the literature, which is more than a critical review, but an attempt to integrate findings across studies in order to arrive at new understandings.

My reading of methodological literature in the field of qualitative reviewing and synthesis (Booth et al., 2013; Campbell et al., 2011; Sandelowski & Barroso, 2007; Zimmer, 2006; Britten et al, 2002; Paterson, 2001; Barbour, 2001; Noblit, 2018; Noblit and Hare 1988) led me to conceptualise the review of the literature to be reported in the study as a 'qualitative systematic review'. This seems to me, the most accurate rendering of a pragmatic combination of methods and concepts to be found in a field with ever changing, and sometimes conflicting, terminology. There is continuing methodological debate about what exactly constitutes a synthesis, for example. My purpose was not specifically to develop the methodology of qualitative meta-synthesis, or rigidly to apply one set of techniques. Rather, I took a flexible and eclectic course (Johnson et al 2008), applying methods from different sources to examine in detail the findings of qualitative research which reports older people's experiences of living with long-term mental ill health.

In this chapter I present the methods used to search and review relevant primary research. I present the analysis and interpretations of the review findings in the next chapter.

2.1.2 Inclusion and exclusion

The criteria for inclusion were:

1. peer-reviewed qualitative research studies from January 1997 to January 2015;
2. research that included interviews with persons with mental ill health as participants;
3. literature in English language only;
4. studies that included reference to mental ill health and to older adults (explicitly or implicitly);
5. reports of primary qualitative research focused on older people with experience of mental ill health;
6. studies which included participants aged 55 years and over (considered 'older adults').

Studies which determined the relationship between attitudes to ageing and depression and/or anxiety were included. This may not be the main focus of the research, however, if studies reported on the relationship between the two constructs they were included within this review.

Exclusion criteria:

1. bachelor, and taught MSc dissertations;
2. existing reviews;
3. studies specifically focusing on adolescent experience and post-partum experience;
4. studies specifically assessing methodological instruments or approaches;
5. discussion, narrative reviews or studies with no data collection and systematic reviews or meta-analysis were excluded from this review;
6. biographical or auto-biographical accounts of living with mental illness from the perspective of a single person with mental ill health;
7. lacked an empirical basis i.e. absence of a discernible research methodology;
8. were reviews of the literature on lived experiences in mental ill health and only explored circumscribed experiences in mental illness (such as receiving a diagnosis) rather than ongoing lived experiences.

In addition, inaccessible international dissertations, and book chapters that had not been peer reviewed were excluded.

2.2.1 Systematic Literature Search

The question that guided the search for relevant studies was, “What qualitative research literature is available which reports experiences of living with mental ill health of adults aged 55 and over?” Studies were identified through searching electronic databases, manual searching of purposively sampled journals and follow-up of references. Studies were retrieved if they were reports of primary qualitative researched, focused on older people with mental ill health and written in English.

The purpose and methods for study identification and retrieval for meta-study are contested in the methodological literature. One approach is to identify and retrieve all studies relevant to the search question. But there is debate over the extent to which a search needs to be *comprehensive* (covering all possible sources of material) and/or *exhaustive* (retrieving all material that is relevant to the research question). Most authors agree that both are necessary but there are dissenting voices (Barbour 2001; Booth et al. 2013) arguing that methods could appropriately be modelled on sampling for primary qualitative studies. For example, purposive or theoretical sampling and the concept of “data saturation” could legitimately be applied to samples of papers. From this perspective, the intention is not to identify all literature on a particular topic; rather, it is to identify specific groups of papers with characteristics relevant to the phenomenon being studied (Booth et al 2013). This is the approach taken in this study. The goal was explicitness of methods rather than completeness of sampling (Edwards et al 2000,1998).

A three-stage process of literature searching was undertaken comprising:
i) electronic searches of bibliographic databases; ii) manual searching of purposively selected journals; and iii) follow-up of reference lists. A summary of each stage can be seen in Box 2.1., p. 26.

At each stage of searching abstracts were retrieved if the title included reference to mental ill health and to older adults (explicitly or implicitly) but were excluded if it was clear from the title that the paper was about mental ill health-related health promotion or screening. Titles were also excluded if they were clearly not full reports of primary research: for example; conference abstracts, editorials or commentaries or news reports. If it was not clear from the title or the abstract that the study reported primary qualitative research about older people and mental ill health, then the paper was retrieved and read against the inclusion criteria. Papers were included in the provisional bibliographic sample if they reported qualitative studies of older adults which investigated accounts of individuals’ experiences of living with mental ill health.

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. There were many terms excluded from the searches that had no relationship to experience of mental illness, for example, biological ageing or carer perspectives, staff focused treatment and intervention evaluations, reviews, discussion papers, prevalence studies, and mental health service utilisation. If it was not clear from the title or the abstract that the study reported primary qualitative research about older people and mental ill health, then the paper was retrieved and read against the inclusion criteria.

Box 2.1 Summary of three-stage literature search

Stage 1: Electronic database search Stage 2	Stage 2: Manual search selected journals	Stage 3: Follow-up references from papers included at
↓	↓	↓
214 papers identified papers identified	95 papers identified	48
↓	↓	↓
12 papers included (2 duplicates)	**4 papers included**	**3 papers included**
↓	↓	↓
202excluded	91 excluded	45 excluded

2.2.2 Stage 1: Searches of electronic bibliographic databases

The overall search process was conducted between October 2014 and January 2015. An updated literature was undertaken in January 2019 which re-ran the original searches, replaced the British Nursing Index database with Social Care Online database, limited to January 2005 – January 2019.

Electronic database searches of English-language papers, 1994-2019, relating to the experience of long-term mental illness included Social Care Online, CINAHL, Medline, Psych Info, Psych Extra, ASSIA, AMED and additionally, one focused specifically on old age, Age Info. 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. Age Info 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. Subject and key word searches were conducted of eight electronic databases (Box 2.2 p.27) using a range of terms representing *old age, mental ill health, mental illness, experience, chronic illness.* An early 'scoping search' using the keywords 'living adj2 mental illness' combined with 'age$ or elder$ or older$' yielded twelve reports, from 156 records returned, of a qualitative study exploring the experience and meaning of living with mental ill health in old age. These reports met the inclusion criteria and were included in the provisional sample.

Box 2.2 Electronic Databases searched and hits for different databases

Database	**Years**	**Initial search hits**	**Relevant abstracts Retrieved**
PSYCINFO	1994 – 2019	344	19
MEDLINE	1994 – 2019	3450	8
AMED	1994 – 2019	114	5
ASSIA	1994 – 2019	60	8
SOCIAL CARE ONLINE	1994 – 2019	3096	99
CINAHL	1994 – 2019	104	15
PSYCEXTRA	2004 – 2019	81	1
AGEINFO	2000 – 2019	61	1
Total		**7210**	**156**

Subsequent searches were more detailed, including subject headings and a qualitative 'filter' (Wilczynski et al 2007) designed to maximise the retrieval of qualitative studies. This search strategy can be seen in Box 2.3 (P.31). The search was conducted in January 2015 and yielded 214 records. One hundred and fifty-three titles referred to aspects of chronic illness unrelated to older people, thirty-nine titles referred to older people, eight titles referred to people with mental disorders, and just fourteen titles referred to older people with ill health. Abstracts were obtained for these fourteen articles. Nehls et al., 2005 was a study of women aged 19 to 65 (mean age 40), living with a history of physical and/or sexual abuse substance use and mental health problems rather than of older adults' experiences. Broussard (2005) was a study of women's experiences of bulimia nervosa (aged 18 -36 years), not a study of older adults with mental ill health. Neither of these papers met the inclusion criteria and both were excluded from the review sample. The remaining twelve abstract met the inclusion criteria and were included in the review sample.

2.2.3 Stage 2: Manual searching purposively sampled journals

In this phase, the intention was to widen the field of search beyond electronic bibliographic databases in the hope of locating relevant qualitative studies. A scoping search was conducted for potentially relevant journals accessible through the Bodleian Libraries catalogue. I looked for journals concerned with mental illness or ageing, and for journals concerned with social science or qualitative research. I excluded journals concerned with recovery or suicide following a mental illness as the focus of the review is on living with mental illness rather than dying from the illness. 49 journals were located, and the contents lists searched covering a period of 21 years 1994-2015, where available (see Box 2.7 p.41).
45 journals located in the catalogue were accessible electronically and contents lists were searched on-line. Four journals were accessible in print versions only. Library visits were required to scrutinise contents lists for these journals and to photocopy potentially relevant abstracts and articles. Relevant print articles were subsequently scanned into electronic format.

Articles were screened by title (contain reference to mental illness AND older people) and then by abstract (contains clear reference to the study being concerned with some aspect of older people's experiences of living with mental illness; clear indication of qualitative methods; written in English). Ninety-five titles in four of the manual selected journals contained reference to older people and mental illness. Abstracts were sought if the title included reference to mental illness and to older adults (explicitly or implicitly) but the articles were excluded if it was clear from the title that the paper was about health promotion or screening or if there were clear indications that the article was not a full report of primary research; for example, conference abstracts or editorials/commentaries. Twenty citations were excluded on the basis of title screening. From the remaining 75 citations a further 55 were excluded after reviewing the abstract (50 were reports of studies using quantitative methods, four were not research reports and one was a survey of a population of older people without mental health). The full report was retrieved if a) the abstract contained clear reference to the paper being a report of primary qualitative research investigating older people and mental illness or b) the report was a mixed methods study investigating older people and mental illness which the abstract suggested contained a qualitative component; or c) if it was not clear from the abstract whether the paper was i) a research study or ii) a qualitative research study. Twenty reports were retrieved. Four papers met the inclusion criteria and were included in the review sample. Two of the papers retrieved by manual searching were also located in the electronic search (Hedelin & Jonsson, 2003; Hedelin & Strandmark, 2001).

A provisional bibliographic sample of 16 qualitative research reports was obtained by the combination of electronic and manual searching. Only two of the studies retrieved focused exclusively on people aged 75 or over (Hedelin & Jonsson, 2003; Hedelin & Strandmark, 2001). These were different interview-based studies by the same research group. One study investigated mental health phenomena through21 older women's lived experiences of mental health and depression, using the phenomenological approach in collecting experience-based and person-centred descriptions (Hedelin & Jonsson, 2003). The second study was a phenomenological investigation, specifically focused on the perceived meaning of living with mental health in old age, using a purposive sample of 16 women between the ages of 71 and 92 (Hedelin & Strandmark, 2001). 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.

Because so few studies concentrated on the target age group for this review, I decided at this stage to accept authors' implicit definitions of older people (the age range of participants in the provisional bibliographic sample was 51-99) and to make this qualitative systematic review a study of older people living with mental ill health.

2.2.4 Stage 3: Follow-up of references

Reference lists of the eleven papers included in the sample from electronic and manual searches were also scrutinised for titles which met the screening criteria of containing reference to older people and mental illness. Forty-eight citations were identified in this way. Thirty-one citations were inaccessible (not in library catalogue; print versions only available; reference details incomplete or inaccurate). Sixteen citations were excluded after reviewing the abstract because they were reports of quantitative studies or were not research publications. Three studies (Erdner et al., 2002; Martinsson et al., 2012, Mckay, 2012) met the inclusion criteria and were included in the bibliographic sample.

2.2.5 Evaluation and reflection on search strategy and methods

Initial literature searches using electronic databases were rudimentary as I began to retrieve skills unused for some time and to develop new competence in searching systematically. Studies retrieved during early searches were all clinically orientated (diagnosis, treatment) quantitative studies or were epidemiological studies concerned with matters of incidence, prevalence, public health. None of these studies were about patients' experiences. Recognition that the patient perspective, the main focus of my planned empirical study, was absent from these studies propelled my searches in a different direction.

Discussion with a healthcare librarian and reading more widely (Barroso et al 2003, Paterson, 2001, Wilczynski et al 2007; Wong, 2006) revealed that indexing of qualitative studies in electronic bibliographic databases is limited and varies between databases, making identification of qualitative studies difficult.

Box 2.3 Example of search including ‘filter’ for qualitative research
Search conducted on CINAHL

1. *HEALTH SERVICES FOR THE AGED/ or *"AGED, 50 AND OVER"/ or *AGED/ or *AGED, HOSPITALIZED/ or Aged.mp.
2. elder$.mp. [mp=title, subject heading word, abstract, instrumentation]
3. geriat$.mp. [mp=title, subject heading word, abstract, instrumentation]
4. gerontol$.mp. [mp=title, subject heading word, abstract, instrumentation]
5. old$.mp. [mp=title, subject heading word, abstract, instrumentation]
6. 1 or 2 or 3 or 4 or 5
7. exp psychiatry/
8. PSYCHIATRY/
9. exp Attitude to Illness/ or exp Mental Health Patients/ or exp Aged/ or exp Adaptation, Psychological/ or exp Adult/ or exp Patient Attitudes/ or exp Thematic Analysis/ or severe mental illness.mp. or exp Ongoing mental illness/
10. Psychological stress.mp. [mp=title, subject heading word, abstract, instrumentation]
11. 7 or 8 or 9
12. exp chronic mental illness/
13. chronic illness.mp. [mp=title, subject heading word, abstract, instrumentation]
14. 12 or 13
15. experience$.mp. [mp=title, subject heading word, abstract, instrumentation]
16. (living adj2 mental illness).mp.
17. (living adj chronic mental illness).mp.
18. 15 or 16 or 17
19. 6 and 11 and 14 and 18
20. qualitative studies/
21. ethnographic studies/
22. phenomenological research.mp. [mp=title, subject heading word, abstract, instrumentation]
23. ethnonursing research/
24. grounded theory/
25. exp qualitative validity/
26. purposive sample/
27. exp observational method/
28. content analysis/ or thematic analysis/
29. constant comparative method/
30. field studies/
31. theoretical sample/
32. discourse analysis.mp. [mp=title, subject heading word, abstract, instrumentation]
33. focus groups/
34. phenomenology/ or ethnography/ or ethnoological research.mp.
35. (qualitative or phenomenol$ or ethnon$).tw.
36. (grounded adj (theor$ or study or studies or research)).tw.
37. (constant adj (comparative or comparison)).tw.
38. (purpos$ adj sampl$).tw.
39. (focus adj group$).tw.
40. (emic or etic or hermeneutic$ or heuristic or semiotics).tw.
41. (data adj1 saturat$).tw.
42. (participant adj observ$).tw.
43. (heidegger$ or colaizzi$ or spiegelberg$).tw.
44. (van adj manen$).tw.
45. (van adj kaam$).tw.
46. (merleau adj ponty$).tw.
47. (husserl$ or giorgi$).tw.
48. (field adj (study or studies or research)).tw.
49. (lived adj experience$).tw.
50. narrative analysis.tw.
51. discourse$ analysis.tw.
52. human science.tw.
53. life experiences/
54. convenience sample/
55. exp cluster sample/
56. or/20-55
57. 19 and 56

This was confirmed at a later stage when author searches of papers included in my final sample yielded all but one of the reports, I had located by manual searching but which had not been identified during electronic searches. Running electronic searches using a qualitative 'filter' designed to maximise the yield of qualitative studies (Wilczynski et al., 2007) did prove fruitful, however.

An updated literature was undertaken in January 2019 which re-ran the original searches, limited to January 2005 – January 2019. Social Care Online (2005-2019) was electronically searched using the same process and a further twenty studies were deemed potentially relevant and accessed in full. Twelve of the Twenty studies did not meet the inclusion criteria (see Appendix 1). In order to reduce any effects of publication bias the authors of the included studies were contacted to increase access to unpublished studies which might meet inclusion criteria for this review. Nine authors were approached of whom five responded. Four studies were suggested, and one met the criteria for inclusion in the review. The remaining three studies were excluded and are reported in Appendix 1.

My aspiration throughout this phase of searching was to locate and retrieve a collection of relevant qualitative research reports that would be deemed sufficient in number to conduct a meta-synthesis. Deriving from the meta-ethnographic method pioneered by Noblit & Hare (1988) meta-syntheses typically include relatively small numbers of studies. Noblit & Hare, working in the field of education research, recommended the approach with between four and six studies which used similar methods to each other. Researchers who developed the method in health and social sciences argued that meta-methods could be used successfully with studies which used a range of different methods (Campbell et al 2011). Campbell et al's sample was four studies, though their study was specifically to test the methodology across different study designs. Meta-syntheses in teenage motherhood (Graham & McDermott, 2005) and in chronic leg ulceration (Briggs & Fleming 2007) included fewer than 20 studies.
Research teams working in the fields of motherhood and HIV (Sandelowski and Barroso 2003) and chronic illness (Paterson, 2001) conducted meta-syntheses of larger numbers of studies (56 and 246 respectively). Paterson recommend a minimum of 12 studies for a meaningful meta-synthesis. With 19 relevant studies

retrieved and limited time for additional searches, I decided to begin review of the reports and postpone further searching.

Literature searching for this review was conducted systematically and with an attempt to be comprehensive, using a variety of methods. Ultimately, a sample of reports was obtained which represented a useful and workable sample for meta-study or, in what became my preferred phrase, *qualitative systematic review*. Experienced meta-study researchers note that even the most rigorous search will miss some relevant articles (Paterson, 2001). It should also be noted that while the search process was rigorous and methodical, it was not tidy. The account given here does not reveal the false trails, the frustrations, the subtle shifts in thinking, or the surprises, satisfactions and rewards, which characterised the whole experience.

The provisional bibliographic sample can be seen in Table 2.1 (p.44). It is described as provisional because the analytic process to be used (Sandelowski & Barroso, 2007) allows for later exclusions (see Locating and Extracting Findings below, p.36). The 19 research papers reviewed were published between 1996 and 2019 the majority of which (16) 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), Australia (1), Canada (1), Hong Kong (1), Norway (2), New Zealand (1) Sweden (3), United Kingdom (3) and Taiwan (1). Congruent with the expectation for qualitative studies that seek to provide in-depth understanding rather than generalisability from large sample sizes (Silverman, 2017), numbers of participants are relatively low with between 4 and 61 participants included in all but one study which surveyed 166 people (Ritsher et al., 1997). The age range of participants was 51-92.

2.3 Evaluating papers and extracting findings

The aspiration for this review was to produce a meta-synthesis of qualitative research which reported older people's experiences of living with long-term mental ill health. A range of articles and books on meta-methods inspired this approach to the qualitative literature review (Britten et al 2002; Campbell et al 2011; Graham & McDermott, 2005; Paterson, 2001; Sandelowski et al 2012; 2007, 2003) and it was from among this group of authors that a framework was chosen for review and analysis of the sample of reports selected for this qualitative systematic review. Sandelowksi and colleagues produced a series of papers from the late 1990s onwards documenting and reporting on their attempts to develop the methodology of qualitative meta-synthesis or, as they came to call it, 'research integration studies'. Their project culminated in the publication of a handbook which became a source to guide my approach (Sandelowski & Barroso, 2007). While this has proved a useful framework for my analysis, I have found it necessary to adapt the method and to introduce analytical techniques from other sources. Table 2.2 (p.46) summarises the analytic method used in this review, comprising the application of six key stages in Sandelowski & Barroso's framework, with the addition of a method for presenting the summarised findings derived from Noyes and Popay (2007) and a working hypothesis derived from the findings.

2.3.1 Quality assessment

Each study was quality assessed following approaches used by Steeman et al. (2006) and Thomas and Harden (2008) for the systematic assessment of methodological quality of qualitative studies, in order to maximize the validity and reliability of the review's findings. I evaluated the quality of each included study using a pre-established, structured rating instrument (Methodology Checklist: Qualitative Studies - National Institute for Health and Clinical Excellence [NICE], 2009) that focused on five key areas: (1) clarity of reported aims; (2) study design; (3) methods (data collection, ethical issues and researcher reflexivity); (4) rigour of data analyses; (5) validity, relevance and critique of findings. I paid particular attention to the adequacy of sampling techniques and the apparent rigor of data analyses to ensure that any identified accounts and themes relating experiences of living with mental ill health and/or attributes were derived from a transparent analytic strategy and that presented themes were credible in representing the personal experiences of participants living with mental illness.

Studies were given categorical ratings to reflect the extent to which the validity of their findings was likely to be threatened by their methodological quality (Table 2.3 p.47). In accordance with the quality checklist that I employed (NICE, 2009), studies were assigned ‘category A’ ratings if they fulfilled all stated criteria or if any unfulfilled criteria were judged very unlikely to alter their findings and conclusions. Studies were assigned to ‘category B’ if they fulfilled most key criteria (more than 50%) on the checklist, showed clear evidence of rigour in data analysis and if, overall, any unfulfilled criteria were judged unlikely to alter their findings and conclusions. Studies assigned to ‘category C’ were those for which key methodological criteria (adequacy of reported sampling techniques, data collection and/or rigour in data analysis) were unfulfilled and where the validity/relevance of findings was therefore unclear. Studies in this category were excluded from the synthesis if, in addition, data analyses were deemed to lack any clear rigour and there was insufficient evidence that bias had been controlled.

Five studies were assigned a ‘category A’ status following methodological quality assessment (see Table 2.3 p.47) but the majority of included studies were assigned a ‘category B’ status, implying adequate rather than strong methodological quality overall. The most common reason for studies failing to earn category A status was lack of clarity in reporting around sampling and/or data collection methods. Three included studies were assigned a category C status on the basis of my methodological assessment (Ogden, 2017; Curtin et al., 2018; McCann et al., 2004). In all three, while there was some lack of clarity regarding the validity of findings, this was primarily linked to inadequate reporting of recruitment and sampling strategies. Additionally, in all three there was evidence of sufficient rigour in the analysis of qualitative data with no clear evidence of potential biases. Although all studies showed at least some evidence of rigour in data analysis and validity/relevance of findings, they varied in the extent to which they fulfilled other methodological criteria in each of the key areas addressed by the quality appraisal checklist employed. Variation was most evident in the clarity with which sampling techniques and data collection methods were reported. Only eleven of the articles clearly reported the roles of the named researchers with regard to data collection, analysis and write up. The remainder either lacked clarity on this or did not report researchers' roles. Only half of the papers (10/19) adequately described how ethical issues in the study were addressed. With the exception of Ogden (2017) and Curtin et al. (2018) all articles clearly reported the implications of their findings but eleven did not present an adequate methodological critique of their studies or findings.

2.3.2 Locating and extracting findings from included papers

Findings, or results, from qualitative research reports form the raw data for a qualitative research integration project. It is important therefore to identify and locate all statements in a report which constitute the findings from the research. Findings were defined in this project, following Sandelowski & Barroso (2007 p.214), as 'the data-driven and integrated discoveries, judgements or pronouncements which researchers offer about the phenomena, events, or cases under investigation'. The following types of statement which appear in research reports are not findings within this definition and were not extracted (see Box 2.8 p.42 for detailed explanation of the rationale for these decisions):

- direct quotations from interview data offered in support of findings
- statements which indicate that they are portions of interview data, even though they are not direct quotations
- statements which offer the authors' views on the clinical, educational or research implications of the results
- statements which refer to findings from other studies or from academic literature.

The structure and style of qualitative research reports are not standardised and frequently adopt a format which Sandelowski & Barroso (2007) call 'amended experimental report'. This is a reference to the standardised format for reporting in scientific studies, which is often modified in qualitative research reports. The effect of such modifications, and its significance for a research integration project, is that findings, or results, may be reported in sections of a report other than those headed ‘Findings’ or ‘Results’. Reports must be read closely and thoroughly, therefore, with the working definition of a finding held in mind, in order to be sure of locating all the findings reported.

The process for extracting findings was guided in this project in two ways. First a process of ‘initial appraisal’ was undertaken whereby each report was read in detail and re-structured according to a detailed framework. This process gave an initial sense of what material in the report could be said to constitute its findings. Second, following Sandelowski & Barroso’s (2007) recommendation, a set of decision rules was written, based on the definition of a finding stated above, to guide the extraction of findings more clearly. Decision rules reflected the complexity and subtlety of locating findings and were flexible enough to allow for inevitable ambiguities and include specific exceptions (see Box 2.8 p. 42). For example: “Statements that indicate they are portions of interview data, even though they are not direct quotations, are not findings and should not be extracted. These may begin, ‘One participant said that...’ or, ‘One participant described…’” (Decision Rule 4 of 7). Applying this rule led to the judgement that, in the following statement from one of the studies, the first two sentences were classified as findings, whereas the third sentence was classified as supporting data and was not extracted as a finding:

> Participants described past life experiences and attribution of meaning to their lives. Relationships were often the focus of attribution of meaning. For example, one participant described the development of her relationships with God and others and how she was helping others in her church congregation.

To enhance validity of the process of extracting findings two researchers (myself and a professorial colleague) independently extracted findings from three papers selected at random from the bibliographic sample of nineteen qualitative research reports. Each researcher used the written decision rules as a guide to extraction. There was nearly 90% consensus across all three reports. That is, approximately 9/10 of the findings extracted were extracted by both researchers. There was a variation of 10%, representing findings which were extracted by one or the other researcher but not by both. Reasons for this variation included: simple oversight, competing interpretations or violation of a decision rule, or persistent ambiguity regarding status as a finding where the decision rules did not prove an effective guide. Of 25 statements initially extracted as findings by one or other researcher, but not by both, it was agreed to include 19 as findings and to exclude the remaining six (one was extracted as a simple oversight and five contravened a new decision rule). Discussion of these inconsistencies led to the writing of one new decision rule (number 7, Box 2.8 p.42) and to creating an exception to an existing decision rule (number 1, Box 2.8 p.42). In line with Sandelowski & Barroso's prescription all the reports were then re-read in the light of the new decision rules.

The outcome of this process of locating and extracting findings is confidence that the data set created for this research integration study, or qualitative systematic review, is genuinely constituted from the findings of the research reports included in the sample. Four hundred and fourteen findings were located from 19 reports and were extracted to word processing files. Subsequently, all findings were copied into one-word processing file in preparation for the stage of analysis described in Sandelowski & Barroso's framework as 'Grouping Findings'.

2.3.3 Grouping Findings

Findings were grouped by topic, in a process analogous to thematic analysis. 'Topics' are recurrent patterns, subjects, themes or motifs which are recognised through the close familiarity with the findings engendered by the previous stages of initial appraisal, locating, extracting and editing. For example, the topic of 'empowerment' was observed to recur in the findings following repeated readings. In order to group all findings on this topic a search was conducted of the findings file using the Find (Ctrl+ F) facility in Word. The text was searched on 'empower`, which also retrieved 'empowerment' 'empowering', 'empowered' and 'power'. Synonyms or closely related concepts appeared while searching the text on these key words and further searches were conducted on these new terms. In the case of empowerment, the concept of 'autonomy' was related, and the text was also searched on this term (plus ‘autonomous’). At the same time notes were made of topics which might overlap or link with empowerment; for example, *passivity, patient-physician relationship, control, making choices, making decisions, information-seeking*. This process was repeated for each of the identified topics.

Findings were initially grouped into 15 topics. Table 2.4 (p.52) shows which topics featured in each of the papers. Findings on the topic of relationships with family and friends appeared in all 19 reports; findings on the topic of assertiveness only appeared in two reports (assertiveness was the major topic of this particular study). In a second phase of identifying topic groupings, I re-read all the study reports alongside the topic groupings identified in the first phase in order to check face validity, and with the intention of noting any potentially significant omissions from the original list. This process resulted in the identification of four additional topic groupings: age/ageing, alone-ness, meaning and limited time. The findings were interrogated again to locate findings in each of these topic areas.

2.3.4 Abstracting Findings

The grouped findings comprised a data set of approximately 20,000 words. In order to reduce the data still further in preparation for synthesis the grouped findings were explored to discover further patterns, overlaps, comparisons and redundancies. Sandelowski & Barroso’s framework refers to this process as ‘abstracting’ the findings. This means that the findings are summarised, abridged, reduced to a form which represents their essence. Authors’ original words are used except where findings are rewritten, according to decision rules, to maximise clarity. Findings are rewritten to ‘render them more parsimoniously’ and to produce a ‘set of statements that concisely but comprehensively captures the content of all the findings and preserves the context in which they appeared’ (Sandelowski & Barroso 2007 p.159). In the process of abstracting, redundancies and repetitions in the grouped findings are eliminated and finding statements are refined to make them inclusive of the researchers’ ideas conveyed in the findings. It is important to preserve any contradictions and ambiguities in the findings (Sandelowski & Barroso 2007). Abstracting the findings produced a data set of approximately 6000 words in eight topic areas (bodily signs and symptoms, disability, treatment, empowerment, states of mind, stigma, learning and management of illness, relationships). All the previously identified topic groupings, from both phases of topic identification, were incorporated in the dataset from which the abstracted findings were derived.

2.4 Summary

In this chapter I have presented the rationale and purpose for conducting a qualitative systematic review to investigate older people's experiences of living with mental ill health. I have explained in detail, and evaluated, a three-stage method used to search for relevant primary research studies. A five-stage model was used to review the studies, following Sandelowski & Barroso (2007), whereby the published reports are appraised; findings are located, edited, grouped and abstracted to produce a dataset for subsequent analysis.

In the next chapter I present analysis and interpretation of this dataset, comprising findings from a sample of 19 qualitative research reports which investigated older people's experiences of living with mental ill health.

Box 2.7 Journals searched electronically & manually

Age and Ageing
Ageing Research Reviews
Ageing and Society
Aging & Mental Health
Aging & Amp; Mental Health
Aging & Amp; mental health: an international journal
Archives in Psychiatry Nursing
Australian And New Zealand Journal Of Psychiatry
American Journal of Geriatric Psychiatry
American Journal of Psychiatry
Biological Psychiatry
Bipolar Disorders
BMC Medicine
BMC Psychiatry
BMC Public Health
Canadian Journal of Community Mental Health
Canadian Medical Association Journal
Community Mental Health Journal
Critical Public Health
European Archives Of Psychiatry And Clinical Neuroscience
Geriatric Nursing
Gerontologist
Gerontology
Hospital and Community Psychiatry
International Psychogeriatrics
International Journal of Geriatric Psychiatry
Irish Journal of Medical Science
Issues in Mental Health Nursing
Journal of Affective Disorders
Journal of the American Geriatrics Society
Journal of Emergency Nursing
Journal of Intellectual Disability Research
Journal of Medical Ethics
Journal of Occupational Therapy
Journal of Psychiatric and Mental Health Nursing
Journal of Psychiatric Research
Journal of Social Psychiatry
Perspectives in Psychiatry Care
Psychiatry Research
Qualitative Health Research
Qualitative Social Work
Schizophrenia Bulletin
Social Psychiatry and Psychiatric Epidemiology
Social Science & Medicine
Sociological Forum
Sociology of Health and Illness
Social Work In Healthcare

Box 2.8 Decision Rules for Extracting Findings from Qualitative Research Reports for an Integration Study

A finding is defined as: ‘a data-driven and integrated discovery, judgement and/or pronouncement researchers offer about the phenomena, events, or cases under investigation’ *(*Sandelowski and Barroso 2007; 2003).

1. **All findings or finding-type statements which meet the definition above should be extracted in the first instance, wherever they appear in the report and irrespective of repetition.**

Exceptions/ambiguities? Finding-type statements which represent examples of findings expressed during the analytic process and which do not reappear as findings elsewhere in the report. These represent findings-in-progress rather than actual findings and should be excluded.

E.g. McCann & Clarke, 2004 Table 1 p 202 ‘Example of the revealing of one essential theme in an interview’

The illness means a time of unrest and distance from the ingrained social pattern and a reorientation to new demands.

This is a finding-type statement, but it does not appear as a reported finding elsewhere and it is relatively clear from the context in which it is presented that it is derived from one particular stage of the analysis (‘holistic reading approach’).

2. **If in doubt, extract and discuss.**

3. **Direct quotations from interview data are not findings and should not be extracted**

‘Participants dealt with suffering through the basic social process of enduring. *As one participant said, "You don't manage pain, you endure it."* The first sentence is a finding, the second is not.

Exceptions/ambiguities? Statements which include one or two words in quotation marks but where the reporting voice is really the author’s e.g.

‘Strategies for decreasing pain fostered hope for "relief of pain" and to "not suffer more" because participants felt they were able to do something about their pain’. This is a finding.

4. **Statements which indicate that they are portions of interview data, even though they are not direct quotations, are not findings and should not be extracted. May begin ‘one participant said that...’ or ‘one participant described…’**

‘Participants described past life experiences and attribution of meaning to their lives. Relationships were often the focus of attribution of meaning. *For example, one participant described the development of her relationships with God and others and how she was helping others in her church congregation.’*

The first two sentences are findings. The third is not.

5. Statements which offer authors' views on the clinical, educational or research implications of the results are not findings and should not be extracted

'In this study, participants described their suffering as pain from severe mental illness, other diseases, loss of physical function, feelings of helplessness, and dependency. *Because of the nature of mental illnesses, preventing or eliminating suffering may not always be achievable. Therefore, fostering and encouraging enduring are also important focuses for research and practice.*'
The first sentence is a finding. *The next two sentences are not findings.*

6. Statements which refer to findings from other studies or from academic literature are not findings and should not be extracted

'Participants described enduring as work that requires strength and willpower. *Fagerhaugh et al. (1980) defined "pain work" in their study of terminally ill patients as the healthcare professionals' role in helping patients endure their pain.* The findings of this study emphasize that the participants also had `"pain work."'

The first and third sentences here are findings, *the second sentence is not a finding*.

Exceptions/ambiguities? 'By offering a framework for the interpretation of events and situations, strong religious and spiritual beliefs often deepen a sense of meaning (Idler, 1987; Pollner, 1989; Ellison, 1991; Pargament,1997), a finding corroborated by the geriatric population we Interviewed' (Mulholland & Jackson, 2018: 324).

This may be included as a finding because, although it begins with reference to another study it offers a statement which confirms that the same findings occur in the study being reported. Such findings may be re-written (Sandelowski & Barroso), being careful to preserve the authors' original words and intentions. The present example could be re-written as follows:

'Strong religious and spiritual beliefs offered a framework for the interpretation of events and situations which gave participants a deeper sense of meaning'

7. Finding-type statements which gloss over the substantive meaning of the finding by the authors' use of evaluative or emotional language may be re-written using more neutral language and then extracted as a finding

E.g. Repper et al, 1998: '*the findings of this study are a reminder of the incredible ability of older hospice patients to endure suffering'*

In this sentence the word 'reminder' invites the reader to locate themselves, with the author, in a supposed state of pre-existing knowledge whereby it is known already, independently of this research, that older people are stoical; and the word 'incredible' represents a value judgement about such a quality.

The finding may be re-written to represent the substance of its meaning as a finding simply by using more neutral language

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Table 2.1 Provisional bibliographic sample and location source

Report	**Source i.e. located by….**
Allan, J. and Dixon, A. (2009), “Older women’s experiences of depression: a hermeneutic phenomenological study”, *Journal of Psychiatric and Mental Health Nursing* 16, 865-873.	Electronic search
Chafetz, L. (1996) The experience of severe mental illness, a life history approach. *Archives in Psychiatric Nursing* 10(1):24-31.	Manual search
Curtin A., Martins D., Schwartz-Barcott D. 2019. Coping with mental health issues among older Hispanic adults. Journal of Gerontological Nursing, 40(2), 123-128	Electronic search
Curtin A., Martins D., Genere A., Perez D., Cabrera E., Viveiros N., Schwartz-Barcott D.(2018). Perceptions of Mental Health Among Hispanic Older Adults: Findings Among Immigrants from the Dominican Republic, Colombia, and Guatemala. Journal of Gerontological Nursing, 44(11), 44-50	Electronic search
Erdner, A., Nyström, M., Severinsson, E., Lützén, K. (2002) Psychosocial disadvantages in the lives of persons with long term mental illness living in a Swedish community. *Journal of Psychiatric and Mental Health Nursing* 9(4), 457- 463.	Follow up search (Erdner et al., 2009)
Erdner, A., Andersson, L., Magnusson, A., Lütszén, K. (2009) Varying views of life among people with long-term mental illness. *Journal of Psychiatric and Mental Health Nursing* 16(1), 54-60.	Electronic search
Hedelin, B., Jonsson, I. (2003) Mutuality as background music in women’s lived experience of mental health and depression. *Journal of Psychiatric and Mental Health Nursing* 10(3), 317-22.	Manual search
Hedelin, B., Strandmark, M. (2001) The meaning of depression from the life world perspective of older women. *Issues in Mental Health Nursing* 22:401-420.	Electronic search + Manual search
Lai, D.W.L., Chan, K.C., Xie, X.J., Daoust, G.D. (2019). The experience of growing old in chronic mental health patients. Aging & Mental Health.	Electronic search
Martinsson, G., Fagerberg, I., Lindholm, C. and Wiklund-Gustin, L (2012), “Struggling for existence - life situation experiences of older persons with mental disorders”, available at: http://dx.doi.org/10.3402/qhw.v7i0.18422	Reference follow-up (Byrom et al., 2017)
McCann, T.V., Clarke, E. (2004) Embodiment of severe and enduring mental illness; Finding meaning in schizophrenia. *Issues in Mental Health Nursing* 25(8), 783-798.	Electronic search

Report	Source i.e. located by….
McKay, E. A. (2010). ‘Rip That Book up, I’ve Changed’: Unveiling the Experiences of Women Living with and Surviving Enduring Mental Illness. *British Journal of Occupational Therapy*, *73*(3), 96–105.	Reference follow-up (Collier et al., 2013)
Mulholland, F., & Jackson, J. (2018). The experience of older adults with anxiety and depression living in the community: Aging, occupation and mental wellbeing. *British Journal of Occupational Therapy*, *81*(11), 657–666	Electronic search
Ogden, L. P. (2017). “To fill the emptiness”: The importance of work in life history narratives of older adults with schizophrenia-spectrum diagnoses. *Qualitative Social Work*, *17*(4), 556–576.	Electronic search
Repper, J., Perkins, R., Owens, S. (1998) ‘I wanted to be a nurse...but I didn’t get that far’: women with serious on-gong mental health problems speak about their lives. *Journal of Psychiatric and Mental Health Nursing* 5(6), 505-513.	Manual search
Ritsher, J.E.B., Coursey, R.D., Farrell, E.W. (1997) A survey on issues in the lives of women with severe mental illness. *Hospital and Community Psychiatry* 48(10), 1273-1282	Manual search
Thompson, N.C., Hunter, E.E., Murray, L., Ninci, L., Rolfs, E.M., Pallikkathayil, L. (2008) The experience of living with chronic mental illness: a photo voice study. *Perspectives in Psychiatric Care* 44(1), 14-24.	Electronic search
Tryssenaar, J., Chui, A., Finch, L. (2003) Growing older: the lived experience of older persons with serious mental illness. *Canadian Journal of Community Mental Health* 22(1), 21-35.	Electronic search
Wang, J.Y. (2011), “Service users’ personal experience and interpretation of mental illness: oriental narratives”, *International Journal of Social Psychiatry,* Vol. 58(4), 425-432.	Electronic search

Table 2.2 Summary of analytic techniques applied to extracted findings from research reports

Initial Appraisal	Reports read and appraised
Locating Findings	Definition of finding Decision rules Locating findings wherever they appear in report Separating findings from supporting data Optimising validity by independent location of findings by another researcher in a randomly selected sample of reports (n=3)
Extracting Findings	Creating a Word file for each report into which identified findings are copied
Editing Findings	Reading extracted findings and editing where necessary to make sense for readers unfamiliar with original report, but staying as close as possible to original wording and preserving sense and context
Grouping Findings	Identifying recurring 'topics' (similar to thematic analysis) based on close familiarity with findings Optimising validity by independent researcher checking grouped topics for face validity against findings for whole sample
Abstracting Findings	Summarising findings across topics and research reports, collapsing similar topics together, representing the essence of the findings in fewer words, while preserving the original context of the reports
Descriptive Summary of Findings	Presenting abstracted findings in narrative format
Working Hypothesis	'To live with mental ill health in old age is to live in a perpetual state of ambiguity'

Table 2.3 Summary data from bibliographic sample of living with mental illness / Methodological Quality Rating

Report	Participants*	Aim and methods	Study Setting	Methodological quality rating**
Allan, J. and Dixon, A. 2009 (NEW ZEALAND)	4 older women, 65 years and over, with a diagnosis of depression, were clinically well (not depressed); and were able to recall and discuss their experiences of depressive illness. Aged 69–82 years	Aim: to explore how older women understood their depression and the meanings they attached to these experiences. Methods: Hermeneutic phenomenology, Heidegger's approach.	Recruited from an outpatient mental health unit.	A
Chafetz, L. 1996 (USA)	43 participants (55.8% were male) with long-term severe mental illness. Age: not indicated	Aim: to explore participant's perception of their experience of severe mental illness. Methods: qualitative descriptive study utilising life chart interview and data from clinical records. Interviews were audio-taped and transcribed using content analysis.	From four settings that targeted specific subgroups of severely mentally ill: out-patient clinic, a day treatment service, an intensive case management programme and a long-term subacute facility.	B
Curtin A., Martins D., Schwartz-Barcott D. 2019 (USA)	11 women and 6 men with mental health issues of stress, anxiety and depression. Aged 65-83 years	Aim: to understand how older Hispanic adults who have migrated from Guatemala, Dominican Republic and Columbia, living in a low-income Community, cope with the mental health issues of stress, anxiety and depression. Methods: An inductive, qualitative, descriptive research design, including interviews.	Recruited from a free clinic for uninsured residents of a low income, urban, predominantly Hispanic, community in New England.	B
Curtin A., Martins D., Genere A., Perez D., Cabrera E., Viveiros N., Schwartz-Barcott D. 2018 (USA)	11 older women and 6 older men from the Dominican Republic, Colombia, and Guatemala. Aged 65-83 years	Aim: to understand older Hispanic immigrants' perceptions of mental health issues, especially those related to stress, anxiety, and depression. Methods: An inductive, qualitative, descriptive research design, including interviews.	Recruited from a free clinic for uninsured residents of a low income, urban, predominantly Hispanic, community in New England.	C

Report	Participants*	Aim and methods	Study Setting	Methodological quality rating**
Erdner, A., Nyström, M., Severinsson, E., Lützén, K. 2002 (SWEDEN)	4 people diagnosed with long-term mental illness. 2 women and 2 men. All living in the community with contacts with both psychiatric care and social services. Aged 51-63 years	Aim: to gain an in-depth knowledge of how persons with mental illness experience their everyday situation. Methods: ethnographic, inductive study- three open-ended interviews, at 1-week interval. Interviews transcribed using content analysis.	Recruited from Swedish community.	B
Erdner, A., Anderson, L., Magnusson,A., Lütszén, K. 2009 (SWEDEN)	8 participants (5 women and 3 men) with long-term mental illness. Aged 56-65 years	Aim: to explore views of life among people with long-term mental illness. Methods: Ethnographic framework – data generated through photographs, interviews and participant observations. Hermeneutic methodology used to derive key themes in transcribed interviews.	Recruited from three-day centres for people with long term mental illnesses living in the community.	B
Hedelin, B., Jonsson, I. 2003 (NORWAY)	21 women with mental health problems, especially depression. Aged 71-92 years	Aim: to obtain a deeper understanding of mental health phenomena through older women's lived experiences of mental health and depression. Methods: phenomenological study – qualitative interviews transcribed and subjected to interpretive phenomenological analysis.	Local community based.	A
Hedelin, B., Strandmark, M. 2001 (NORWAY)	5 older women diagnosed with long-term depression. Aged 75-92 years	Aim: to gain a deeper understanding of depression in older women by investigating and describing the meaning of depression from a life-world perspective. Methods: phenomenological study using qualitative interviews. Hermeneutic methodology used to derive key themes in transcribed interviews.	Local community based.	A

Report	Participants*	Aim and methods	Study Setting	Methodological quality rating**
Lai, D.W.L., Chan, K.C., Xie, X.J., Daoust, G.D. 2019 (HONG KONG)	61 participants (33 male and 31 females) previously been clinically diagnosed with a mental illness by a psychiatrist before being referred for mental health care or support services. Aged 55-75 years	Aim: to understand how people with mental illness prepare for aging and explore their motivations and challenges to adopting healthy aging lifestyles and practices. Methods: qualitative narrative interview approach.	Recruited from community and institutional settings in Hong Kong.	B
Martinsson, G., Fagerberg, I., Lindholm, C. and Wiklund-Gustin, L. 2012. (SWEDEN)	7 older persons, 2 men and 5 women, currently receiving treatment or under examination for, mental disorders by primary health care or psychiatric care. Aged 71-75 years	Aim: to illuminate the meaning of the life situation as experienced by older persons with mental disorders (excluding dementia disorders). Methods: Interviews using the lifeworld approach. Text was analysed using a phenomenological hermeneutical research method, inspired by the philosophy of Paul Ricoeur.	Recruited from one urban and four rural districts in Sweden.	C
McCann, T.V., Clarke, E. 2004 (AUSTRALIA)	9 adult participants (5 men and 4 women) diagnosed with schizophrenia. Age: not indicated	Aim: to explore adult's experience of living with schizophrenia. Methods: phenomenological study utilising unstructured interviews transcribed and subjected to phenomenological analysis.	Recruited from larger qualitative study carried out in the community, in regional and rural South Wales.	C

Report	Participants*	Aim and Methods	Study Setting	Methodological quality rating**
McKay, E.A. 2010 (SCOTLAND)	5 women living with enduring mental illness. Aged 52-74 years	Aim: to examine the experiences of five women living with enduring mental illness. Methods: narrative inquiry, specifically the life history interview, as a primary tool for examining women's lives. Participants were interviewed in their own homes and the interviews were tape-recorded. Two interviews were conducted with each participant, ranging from 3 to 4 hours in total duration.	Recruited from a community in the Glasgow area.	A
Mulholland, F., Jackson, J. 2018 (IRELAND)	5 community-dwelling people (4 females and 1 male) with diagnoses of anxiety and/or depression. Aged 67- 89 years	Aim: to understand the occupational experience of Irish older adults with anxiety and depression so as to inform therapeutic programmes. Methods: qualitative research design with a phenomenological framework. The interviews were analysed using thematic analysis.	Recruited from a heavily populated urban environment in Ireland.	A
Ogden, L. P. 2017 (USA)	8 participants (3 women and 4 men) with diagnosis and current treatment of a schizophrenia-spectrum disorder. Aged 56–73 years	Aim: to develop an understanding of the importance and meaning of vocational histories, present-time employment status, and vocational goals for older adults who were in treatment for schizophrenia-spectrum diagnoses. Methods: The theory of cumulative adversity and advantage focused 35 semi-structured interviews and 43 field observation points that developed life history narratives.	Recruited from three sites: an inpatient psychiatric hospital, a day treatment program and a residence for older adults with serios mental illness (SMI).	B
Repper, J., Perkins, R., Owens, S. 1998 (UK)	14 women with serious ongoing long-term mental health problems (primarily schizophrenia. Aged 55-65 years (mean age = 50.7)	Aim: to explore the lives of women with serious ongoing mental health problems and their experiences of services, to develop understanding of the context and impact of mental distress. Methods: exploratory and qualitative approach based on grounded theory. Data generated through focus groups, transcriptions thematically coded.	Nottingham Rehabilitation and Community Care Service, through a range of services for people with long-term mental health problems.	B

Report	Participants*	Aim and Methods	Study Setting	Methodological quality rating**
Ritsher, J.E.B., Coursey, R.D., Farrell, E.W. 1997 (USA)	166 participants (107 women and 59 men) with various severe mental illnesses. Aged between 54-58	Aim: to explore issues of living with severe mental illness, personal relationships, professional relationships and healthcare. Methods: relational theory approach comprising open-ended interviews.	Recruited from a mixture of ten rural, urban, suburban psychiatric rehabilitation centres of Maryland communities.	B
Thompson, N.C., Hunter, E.E., Murray, L., Ninci, L., Rolfs, E.M., Pallikkathayil, L. 2008 (USA)	7 participants (2 men and 5 women) diagnosed with bipolar disorder, depressive disorder, or anxiety disorder. Aged 52-55 years	Aim: to explore if photo-voice methodology can be used to enhance the level of empathy professionals feel when meeting a patient who carries a psychiatric diagnosis in any setting. Methods: qualitative descriptive study utilising individual in-depth interviews and photo-voice methodology.	Recruited from a group of outpatients from one of the authors' caseload. Conducted at a Midwestern teaching hospital's psychiatric outpatient clinic.	B
Tryssenaar, J., Chui, A., Finch, L. 2003 (CANADA)	15 older individuals with various severe mental illnesses. Average age: 65 years	Aim: to describe, from the consumers' perspective, the complex factors involved as persons with serious mental illness grow older in the community. Methods: qualitative descriptive study approach data generated through individual semi-structured interviews.	Community sample	B
Wang, J.Y. 2011 (TAIWAN)	10 voluntary participants who have mental illness and live in different areas of Taiwan. Gender: not indicated Aged between 51-62 years old	Aim: to examine service users' experience and interpretation of mental illness. Methods: Semi-structured, in-depth interviews. All interviews were audio-taped and transcribed.	Recruited from different settings: four from the same long-term psychiatric hospital, three lived with their own families and another three were in the same halfway house.	B

*** Descriptions of participants based on that presented in each study. Not all studies reported full range of demographic and clinical characteristics of their sample.**

**** Methodological quality ratings: A - Any unfulfilled criteria very unlikely to affect validity of findings and conclusions.**

B - Some criteria fulfilled those not probably unlikely to alter findings/conclusions.

C - Few or no criteria fulfilled. The conclusions of the study are thought likely or very likely to alter.

Table 2.4 Cross Comparison of Study Reports by Topic (Grouped Findings)

Topic

	Assertiveness	Bodily Symptoms	Control	Diagnosis	Disability	Fear	Information & Decisions	Isolation & Loneliness	Learning & Management of Illness	Mental Impact	Relationships (Family & Friends)	Relationships (Healthcare Professionals)	Spirituality & Hope	Stigma & Rejection	Treatment
Article															
Allan et al., 2009		*	*			*		*		*	*	*		*	
Chafetz, 1996		*		*	*	*			*	*	*	*	*	*	*
Curtin et al., 2019				*						*	*	*			*
Curtin A., Martins D., Schwartz-Barcott D. 2018			*							*	*	*	*		*
Erdner et al., 2002		*	*	*	*		*		*	*	*	*		*	
Erdner et al., 2009						*	*	*		*	*	*	*		*
Hedelin et al., 2003		*	*					*		*	*	*			*
Hedelin et al., 2001		*		*		*	*	*	*	*	*	*		*	*
Lai et al., 2019	*		*				*	*	*		*	*	*		
Martinson et al., 2012			*	*		*	*	*	*	*	*	*		*	
McCann et al., 2004										*	*	*			*
McKay, 2010			*	*					*	*	*	*	*	*	
Mulholland et al., 2018		*	*		*	*		*	*	*	*	*			
Ogden, 2017		*	*	*		*		*		*	*	*	*		*
Repper et al.,1998		*		*					*		*	*		*	*
Ritsher et al., 1997	*		*	*					*		*	*			*
Thompson et al, 2008		*					*	*			*	*	*		*
Tryssenaar et al., 2003			*		*	*	*		*	*	*	*			*
Wang, 2011				*	*					*	*	*	*		*

CHAPTER 3

'EXPERIENCING MENTAL ILL HEALTH': ANALYSIS AND INTERPRETATION OF FINDINGS

3.1 INTRODUCTION

Older people in the studies reviewed for *Experiencing Mental Ill Health* reported a range of complex impacts arising from their experience of mental ill health which related to a) the bodily signs and symptoms of mental illness; b) decisions about whether to have treatment and experience of undergoing treatment; c) the extent to which they felt empowered; d) disability which is a common framework for interpreting the effect of mental ill health; e) the states of mind induced by the experience of living with mental ill health; f) the effects of mental ill health on their relationships with partners, families, friends and health professionals; g) stigma: 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; h) learning and management of illness and personally constructed complex ways of coping that result in strategies for control and organisation as a method of self-care.

The findings are presented here at two levels of analysis: descriptive and interpretive. The first, descriptive, level stays very close to the language of the original reports in order to preserve the credibility of interpretations which are made of the studies' findings at the second, interpretive, level of analysis. The only exceptions to this fidelity to the original authors' language are where findings have already been edited or rewritten (Sandelowski & Barroso, 2007) according to the decision rules referred to in the previous chapter or where the narrative flow and clarity of meaning required the insertion of some linking phrases.

3.2 Descriptive analysis of findings

3.2.1 Findings relating to Bodily Signs and Symptoms

Older people in these studies experienced changes in their bodies which they attributed to mental illness, to the effects of antipsychotic medications and to age related changes associated with normal ageing or with comorbidities. Bodily experiences included fatigue, nausea and vomiting, appetite loss, feebleness and pain in different parts of the body were common complaints as was severe giddiness. There was a close interrelationship between mental and physical pain (Allan & Dixon, 2009; Chafetz, 1996; Ritsher et al., 1997; Repper et al., 1998; Hedelin & Strandmark, 2001; Martinsson et al., 2012; Tryssenaar et al., 2003; Hedelin & Jonsson, 2003; Curtin et al., 2018; Thompson et al., 2008; Erdner et al., 2009). Others spoke of the side effects of antipsychotic medications, such as weight gain, decreased libido, and facial hair, which adversely affected their health and sense of self and femininity. Older people expressed a belief that long-term medication use had caused premature aging (Tryssenaar et al., 2003).

Older people could feel severely buffeted, worried and anxious by these experiences but at the same time put in place strategies to manage the situation. Fatigue was managed by taking time to rest and by maximising available energy (Hedelin & Strandmark, 2001; Hedelin & Jonsson, 2003). Medication for pain in and antipsychotic medications was augmented not only by non-pharmacological means of pain relief but by a strategy of endurance based on finding hope and on adjusting to pain emotionally (Repper et al., 1998; Ogden, 2017).

Religious faith and the support of caring families provided essential underpinning support for the effectiveness of these psychological pain-relieving strategies (Chafetz, 1996; Curtin et al., 2019; Erdner et al., 2002; Lai et al., 2019; Martinson et al., 2012; Mulholland et al., 2018 and Repper etal.,1998). Adaptation to unwanted changes in physical appearance was achieved by simply avoiding the sight of the changed body or by reconstructing the difficulties to emphasise a positive side. For example, loving attention from family members

sometimes compensated for the psychological pain (Ritsher et al., 1997).
The experience of, and strength of reaction to, bodily change appeared to be heterogeneous according to age, stage of mental illness and comorbid disease. For some, effective pharmacological treatment which had minimal impact on the body or on the person's life proved to be encouraging and made things easier. For others, physical changes could be overwhelming ("excruciating") (Allan & Dixon, 2009; Ogden, 2017; Mulholland & Jackson, 2018; Wang, 2011), diminish physical and emotional strength unbearably, provoke revulsion and self-abhorrence, undermine a sense of normality and transform life into a hopeless and lost situation (Mulholland & Jackson, 2018).

3.2.2 Findings relating to Disability

Disability is a common framework for interpreting the effect of mental ill health (Sayce, 2008) 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 (Erdner et al. 2002; Tryssenaar et al., 2003; Curtin et al., 2018; Wang, 2011; Mulholland & Jackson, 2018).This includes invalidation of opinions resulting in being disbelieved, not taken seriously and without a voice (Ogden, 2017; Tryssenaar et al., 2003; Wang, 2011) as well as leaving people open to the pressure from authoritative professionals (Tryssenaar et al., 2003). This was contrary to what was needed which was to have their story heard (Tryssenaar et al., 2003; Curtin et al., 2018).

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).

3.2.3 Findings relating to Treatment

Thirteen of the studies reported older people’s experiences relating to treatment. Decisions about treatment, including whether or not to have treatment, were affected by interpersonal, intrapersonal and social factors. Relationships with the healthcare personnel and with family members affected treatment decisions. For example, the approach to decision making was seen as a collaborative venture, by women undergoing treatment for depression (Hedelin & Strandmark, 2001, Allan & Dixon, 2009), in which women saw their role as to be informed about the available treatments but to leave the final decision to the medical team on the basis of a trusting relationship. This was seen not as a choice to opt out of decision-making but as a preference to view oneself as only one part of the decision-making process. It is important to note that these women were receiving treatment as part of a research study and were highly motivated towards taking an active part in the management of their disease.

For older people in other studies, making decisions about treatment was sometimes felt to be burdensome and they expected healthcare providers to make decisions for them, based on their superior knowledge. On the other hand, older people who did want to be consulted, or wanted to decide against treatment, and who were ignored or unsupported in their decision, regarded their healthcare providers as paternalistic (Hedelin & Strandmark, 2001; Hedelin & Jonsson, 2003). Such attitudes and behaviours on the part of healthcare personnel caused ruptures in their relationships with older people. Whatever the decision, encouragement from family members was important.

Important intrapersonal factors in decision making about treatment includedthe ability to exercise personal control. In some studies, (e.g. Lai et al. ,2019; Martinson et al., 2012; Erdner et al., 2009, 2002; Thompson et al., 2008; Hedelin & Strandmark, 2001) some older people tried to get as much information and knowledge as possible in order to make independent decisions, whereas others chose not to be informed or to seek control and to let other people make decisions for them. For older people, making decisions about treatment, and living with their consequences, was experienced as difficult in the light of comorbid conditions. They sometimes chose to forego treatment (Chafetz.1996) explicitly in the context of their age, or age-related health problems and social circumstances. Careful thought preceded decision-making. Readiness to undergo treatment showed itself in bargaining about the price to be paid in side-effects in proportion to the beneficial effect of treatment (Chafetz, 1996; Ritsher et al., 1997; Ogden, 2017). More broadly, willingness to undergo treatment was influenced by older people's values and their perception of their whole life situation.

Decisions about treatment were influenced by social context, that is, the general attitude to mental illness treatment in old age. Those in advanced old age felt that their age was a factor taken into account by health professionals in deciding treatment options, which in some cases meant limited access to various methods of therapy. Suspicions about being treated less carefully owing to old age exacerbated feelings of abandonment and uncertainty. Contrary to these unmet expectations of high-quality treatment, some older people were challenged by their peers on the value of undergoing treatment at all at that stage of life.

Findings from these studies revealed a number of strategies employed by older people for managing the process of undergoing treatment for mental illness. Strategies included placing trust in the health professionals; seeking comfort through prayer; maintaining an active life; concealing the illness from anyone outside the immediate family; keeping a sense of control by being well-informed or, on the contrary, remaining passive and allowing healthcare professionals to be responsible for decisions about treatment and care; adapting and adjusting constructively to side-effects of treatment and residual disabilities. Maintaining an active life included, for some women undergoing depression treatment, sustaining a role as primary caregiver to others.

Treatment effects for older people in the Swedish studies (Erdner et al.,2002, 2009) were experienced against a complex background of bodily disabilities and limitations resulting from the mental disorder disease, from the effects of ageing (including comorbid disease) or from ageing impaired by mental illness. The effects of mental ill health and its treatment seemed to produce the greatest limitations in daily life, however, to the extent that life became "disintegrated": that is, more or less fully occupied with travelling to undergo treatment, residing away from home for the duration of the treatment, then coping with the side-effects of treatment, not only on the body but on social life and relationships. These experiences provoked existential, as well as physical and emotional, suffering.

Despite these difficulties, older people with mental illness felt that it was possible to endure their experiences and to accomplish the tasks required of them in order to face the illness and its treatment. Illness experience presented an unexpected consciousness of the personal power and strength to have gone through a tough period of illness and treatment which forced them to reappraise their life. Despite its difficulties, the value of having undergone treatment was appreciated as time went on. In the anticipated future there was a reorientation and re-entry to ordinary social life, but with a new experience added.

3.2.4 Findings Relating to States of Mind or Feeling Associated with Living with mental illness

Fifteen of the studies reviewed contained findings relating to states of mind or feeling which accompanied older people's lives with mental ill health. They expressed a range of negative and positive emotions including uncertainty, fear, anxiety, insecurity, depression, despair as well as confidence, hope, safety, reassurance and peace. Older people described fear and worry when they were first diagnosed with a mental illness. An unsympathetic attitude from the physician at this early stage meant a violating experience leading to anxiety, sleep disturbance and feelings of dejection. There was uncertainty about the relative roles of mental illness, other illnesses and of age itself in producing symptoms and disabilities. Lack of information about the disease was discouraging and became a source of fear of progressive disease and death.

Uncertainty was described as living in a “shadow land” (Hedelin & Strandmark, 2001). When older people wanted information but could not acquire it, they felt insecure and out of control. Symptoms such as appetite loss, nausea and vomiting caused them to worry about nourishment and about their dependence on others. They feared the physical side-effects of treatment and worried about what would happen when side-effects appeared.

It was not only the impact of the mental illness on the body which caused negative emotions. Relationships with relatives, friends and health professionals, in many ways, sources of support could also produce anxiety and fear: for example, fear of rejection by family and friends or fear of retribution by physicians in response to assertive behaviour. Fear was a recurring theme in the studies 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 (Ogden, 2017) and most commonly, fear of illness and revisiting distressing experience (McCann & Clarke, 2004; Wang, 2011). This resulted in living fearfully in a restricted world (Curtin et al., 2018), because of abuse experiences (Thompson et al., 2008), alienation (Hedelin & Strandmark, 2001), fear of losing children, or rejection resulting from stigmatising public perceptions and discriminatory judgements (Allan et al., 2009; Repper et al., 1998; Hedelin & Strandmark, 2001; Mckay, 2010). Fear of death was also evident (Erdner et al., 2009), as was terror of gaining weight (Mckay, 2010).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; Erdner et al., 2009; Martinson et al., 2012;). In addition, grief is experienced as a result of wasted years. 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; Mckay, 2010). There is also emptiness and lost feeling associated with depression (Allan & Dixon, 2009) as well as a lack of love and care in early life (Martinsson et al., 2012).

Thoughts about the future hovered between hope and despair. Hope was important as a way to endure mental ill health and arose in the treatment phase from absence of signs of the mental illness along with positive information from the doctor. Despair arose from feeling abandoned and uncertain about how future life would be affected by the mental illness. There were fears of becoming dependent on help for daily living and expressions by couples of a nagging worry about their future together. A contradictory finding in the face of anxieties about the future is that, in regard to expectations of how much time was left, older people had realistic presumptions about future time and mostly met the probability of a foreshortened life with no fear (Erdner et al., 2009). Death itself was sometimes feared and sometimes viewed as a release, but the process of dying was feared as older people anticipated excruciating symptoms, confinement to bed and dependence on others (Erdner et al., 2009).

Resources and strategies for replacing feelings of uncertainty, own fear and anxiety with feelings of confidence and assurance included older people's chosen attitudes, as well as specific behavioural strategies. Attitudes included: acceptance of pain; acceptance, without fear or sadness, that a long and eventful life was coming to a natural end; hoping for relief of pain, an end to suffering and life after death; endurance of suffering; trusting in a higher being, confidence in God, belief in fate. Faith brought comfort, security, assurance, peace, tranquillity, serenity, lack of fear and thankfulness. Having a good understanding of their mental ill health, effective treatment and strong relationships with family, friends, healthcare providers and other patients also played a role in boosting feelings of safety and confidence.

Behaviours to combat negative emotions included: adjusting to pain by consciously diverting the mind from it; deciding to undergo a treatment; "binding" anxiety by focusing on others and praying for them; screening off or setting aside the experience of threat; denying that the mental illness still existed; compensating for the threat by making lifestyle changes; remaining distanced from the illness by not talking about it; and presenting a picture of the self to family members and caregivers as safe, happy and unafraid.

3.2.5 Findings Relating to Being Empowered

Eleven of the studies reviewed contained findings relating to empowerment. A continuum was evident in which older people were empowered or disempowered to varying degrees according to their own attitudes and actions or the attitudes and actions of others. Participants in the studies were empowered by an attitude which represented an internal locus of control, through their self-directed assertive behaviour or through the supportive actions of others.

Self-empowered attitudes included a feeling of responsibility for one's own health, and the unexpected consciousness of the personal power and strength to have endured a tough period of illness and treatment. Self-empowered behaviour included employing a range of assertive strategies in encounters with physicians, such as: information seeking, insisting on comprehensive and efficient treatment and management of their illness and, as a last resort, changing to a different physician if they were not satisfied (Allan et al., 2009). Participants felt empowered by health professionals when they felt listened to and believed in, when they were given a choice to take part, or not to take part, in discussions and decisions about treatment. A contrary finding, seen in just one study (Hedelin & Jonsson, 2003) is that the invitation to make a treatment decision in the face of multiple health problems was seen as burdensome rather than empowering. It was seen as ironic that such a complex decision should be left to a patient, despite the physician's clearly superior knowledge.

Participants were disempowered by an attitude which represented an external locus of control, by their passive behaviour or by negative attitudes and actions of healthcare providers. Extreme feelings of disempowerment were reported by some participants from the point of diagnosis as life was perceived as suddenly and wholly surrendered to the trust of healthcare personnel (Wang, 2011). This was experienced as a disintegration of the life situation. Passive behaviour on the part of older people was seen as disempowering when it was enforced, rather than actively chosen, because they felt a lack of options due to their poor health. Passivity was not always disempowering; sometimes it was a route chosen by older people to get what they wanted. Healthcare providers reinforced feelings of disempowerment when participants felt they were being neglected on the grounds of their age.

3.2.6 Findings Relating to Relationships

More than one third of all the abstracted findings relate to study participants' relationships: with their life companions, family, friends, communities and healthcare providers. All the studies reviewed contained findings about relationships in the context of living with mental illness.

Intimate relationships with spouses changed as a result of living with mental ill health and adaptation to change was needed in order for couples to maintain the quality of their life together. Couples interviewed together about the experience of living with mental illness (Ritsher et al.,1997) expressed a deeper sense of closeness but noted that living with the disease required them to be together every day. Couples agreed that open communication was essential to adjust to changes in their normal intimacy patterns. Being able to confront their problems and talk about them together helped them to overcome denial and move toward acceptance. Facing facts and talking about options seemed to make life easier to manage.

Increasing disability and dependence made some older people worry about the strain put on their partners and created anxiety about the spouse's future life alone. At the same time as awareness of vulnerability, however, there was a strengthened relationship between some spouses which resulted in feelings of confidence in meeting future challenges together.

Changing relationships with family members had both positive and negative aspects. Participants identified caring family members as helping them with uncertainty and alleviating struggles in daily life by giving consolation, comfort and confidence. They expressed a need to remain close to family members and enjoyed the more frequent visits which resulted from their illness. Even where geographical distance precluded regular visiting, many participants considered family support, most often from their adult children, as being vital to their survival. They also valued contact with grandchildren, which gave them a sense of engagement with a world outside of their own limited life space. Relationships with the family were interpreted in new ways. Families’ capacity for loving care appeared to be unexpectedly great and this was seen as something that would not have been disclosed if the person had not contracted mental illness. The strength to handle life with a mental illness, derived from supportive family relationships, gave illness a new meaning and transformed it to a positive experience. In addition to receiving support from their families, participants sought to protect family members from the mental illness, and relieve their sense of being a burden, by not letting mental ill health dominate in conversation; putting things in order and by praying for them.

Where misunderstandings arose concerning various changes caused by mental ill health, taking up an undramatic attitude toward the disease, and talking openly about mental ill health, reduced misunderstandings and fantasies. Some participants, however, hardly ever talked to their families about their situation. Though they expressed a need to share their experiences with other people, and talked with other patients, they expressed sorrow that family members so seldom asked about their health. This made them feel even more alone with their experiences of mental ill health. Loneliness was experienced, too, through widowhood or being the only survivor among family and friends. But solitude also brought positive feelings of independence and an appreciation that certain aspects of daily life could run more smoothly.

Participants frequently found support in their friends and social networks, including fellow sufferers. They also used their friends’ health and state of life as a comparison to measure how they were doing, a process of “downward comparison” (Wang, 2011). They usually compared their own situation favourably, no matter how bad they felt it to be, with their perceptions of others". Church communities offered a good deal of support to older people living with mental ill health. People felt connected to their church communities through prayer; both being prayed for and praying for others, including their healthcare providers; through a sense of belonging to something that had lasted for generations and through individual friendships. Church also played a significant role in socialisation (i.e. having a social life) for many older people, particularly those living alone.

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 eight key areas of life that participant 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 (Ogden, 2017; Martinsson et al., 2012; Erdner et al., 2002; Hedelin & Jonsson, 2003; McCann & Clarke, 2004; Mulholland & Jackson, 2018; 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 (Erdner et al., 2009).

For some it was important to talk to other patients with mental ill health about their disease, the prognosis and their psychiatric professional's comments on their progress. Sometimes, though, there was ambivalence about whether to involve other people. Some participants chose not to disclose their mental ill health to friends and relatives beyond the immediate family because they feared relationships would be negatively affected, believing that people prefer to stay away from mental ill health sufferers (Erdner et al., 2009).

Relationships with healthcare providers were reported both positively and negatively. Healthcare professionals were said to be important by being available. Their efforts to treat older people with candour, honesty and thoughtfulness led to feelings of security and hope. Positive relationships with physicians and psychiatrists were marked out by a sense of trust. Some older people described their relationships to their physicians as close, like a friendship. Successful encounters with physicians and other healthcare providers were comfortably paced. Older people were affirmed in such encounters by being believed in and listened to. Being invited to participate in discussions and decisions about treatment was experienced as a respect for autonomy which was supportive and affirming.

Relationships were damaged or ruptured, in contrast, when older people felt unsupported in their autonomous decisions (not to have treatment, for example). If the life situation aroused feelings of abandonment and uncertainty about how illness would affect future life, suspicions about being treated less carefully owing to old age added to those feelings. Unreasonably long waiting times and vague information from the physician were interpreted as a consequence of low priority because of age. When evident signs of a mental illness were neglected and explained as age-related it was felt to be insulting and unacceptable. Experiences of information being withheld and suspicions about dishonesty led to distrust of healthcare professionals.

3.2.6 Findings Relating to Learning & Management of Illness

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; Mulholland & Jackson, 2018; 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; Lai et al., 2019). 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.

The process of learning, whether embracing a strange world (Chafetz, 1996), changing personal attitudes and responses to own experiences (Allan & Dixon, 2009; Ogden, 2017; Mulholland & Jackson, 2018; Wang, 2011), going easy on oneself and accept oneself (Ritsher et al., 1997), or going through the trial and error of treatments (Tryssenaar et al., 2003; Mulholland & Jackson, 2018; Thompson et al., 2008), is lengthy and can be a journey of fear (Mulholland & Jackson, 2018).

Experiences preceding diagnosis such as emotional pain early in life or significant losses are found in two studies (Repper et al., 1998; Ogden, 2017). Similarly, no starting point could be identified for women suffering from depression (Allan & Dixon, 2009) 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 (McCann & Clarke, 2004). 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). Control is achieved through creating an environment of structure and routine (Erdner et al., 2002; Tryssenaar et al., 2003; Lai et al., 2019) and with determination and desire to win (Chernomas et al.2000; Lai et al., 2019). Similarly, setting goals for self-improvement gives something to look forward to and is motivation for getting up each day (McKay, 2010).

Coming to terms with experiences or illness can result in changed self-image or challenged identity (Allan & Dixon, 2009; Ogden, 2017; Mulholland & Jackson, 2018; Wang, 2011) and for some pride was reclaimed in survival (Erdner et al., 2009), though over time this all results in emotional exhaustion (Erdner et al., 2009). 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.

3.2.7 Findings Relating to Stigma

Stigma is a key theme for Chafetz, (1996) but is also significantly reflected in other studies referred to within the theme of fear and also reflects shame (Erdner et al., 2009). Its effect could impede participation in social life (Hedelin & Standmark, 2001; Tryssenaar et al., 2003) resulting in attempts to pass as normal or less bizarre (Allan & Dixon, 2009; Chafetz, 1996; Repper et al., 1998; Tryssenaar et al., 2003; Wang, 2011; Mckay, 2010). 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 (Allan & Dixon, 2009; Ogden, 2017; Hedelin & Strandmark, 2001; Mckay, 2010). Feelings of failure were reinforced by stigma imposed by others (Ogden, 2017), however involvement in the workforce, a 'normal' activity, decreased stigma and made life easier by being accepted as part of a community (Tryssenaar et al., 2003).

3.3 Interpretive analysis of the findings

3.3.1 A working hypothesis: ambiguity

A positive-negative dichotomy relating to a range of reported experiences was detected in the findings from the studies reviewed. Close familiarity with the findings as a whole suggested the working hypothesis that to live with mental ill health in old age is to live with perpetual ambiguity. This hypothesis was investigated in the hope of producing more penetrating insights by exploring what Sandelowski and Barroso (2003b) call "dimensions of contrast" in the findings, or what Elofsson & Öhlén (2004) represent as "dialectical experiences." Such contrasts were presented by authors using the stylistic phrasing "on the other hand . . ." or, "on the one hand . . . and/but on the other . . ." or, as a variant, "at the same time." For example:

> The patients interviewed said in their narratives that they were well informed about their mental illness and their prognoses. Although there were struggling with their mental disorders, a key ingredient for many was the notion of encouragement and support from their primary care physicians, despite their lifelong battle with a debilitating disease. On the other hand, they spoke about a feeling that mental ill health might still run their lives and lead to "death" (Erdner et al., 2009).

The theme of ambiguity is represented by other linguistic and conceptual devices as well. Metaphors of darkness ("shadow land," Tryssenaar et al., 2003), fracture ("disintegration," Hedelin & Strandmark, 2001) and the concept of liminality (living on a threshold of "betwixt and between," neither one thing nor the other; Erdner et al., 2009) presented the experience of ambiguity at the heart of living with mental illness in old age. Examples of this condition of profound ambiguity were found across the disease spectrum and the age range, including untreated mental disorder, active treatment for various mental disorders and the post-treatment state following therapy or hospitalisation for advanced mental illness.

Even where specific findings presented an experience, say, of unequivocal suffering, for example, a complex of background bodily disabilities and limitations resulting from the mental illness disease (Erdner et al., 2002, 2009) or spousal rejection (Ritsher et al., 1997), other findings produced a similarly unequivocal account of a positive aspect of living with mental illness; for example, the comforts provided by religious faith (Ogden, 2017). Sometimes a single experience carried both positive and negative connotations; for example, a diagnosis and treatment brought painful challenges to body image but at the same time renewed loving attention from the family (Tryssenaar et al.,2003). Exploring dimensions of contrast across the findings as whole, therefore, confirmed the ambiguity hypothesis.

3.3.2 An ‘imported concept’: biographical disruption

I also interpreted the findings from this review in the light of the concept of biographical disruption in chronic illness (Bury 1982). Sandelowski and Barroso present the use of “imported concepts” as an interpretive device in the synthesis of qualitative findings (2007). My reading of this is that review findings can be usefully investigated in the light of concepts established in related fields of research. Bury articulated six features of the experience of rheumatoid arthritis which combined to disrupt normal life. Biographical disruption has since been investigated in relation to a range of disease and illness states (Green et al., 2007; Hopkins, 2004; Rajaram et al., 1997; Richardson et al., 2006) and in some research the concept has been contested and modified (Carricarburu & Pierret 1995; Faircloth et al., 2004).

Because mental illness is increasingly regarded as a chronic illness, the review findings were explored in the light of Bury’s categories in an attempt to determine the extent to which living with mental ill health in old age represented a biographical disruption,conceptualised as comprising: i) the experience of pain and suffering, and the fear or anticipation of death; ii) the disruption of normal relationship rules of reciprocity and mutual support; iii) re-examined expectations; iv) disrupted assumptions, with a focus on new attention to the body; v) fundamental rethinking of biography and self-concept and vi) mobilising resources as a response to disruption (Bury 1982).

3.3.2 (i) Pain, suffering and death.

Pain, suffering and death were apparent across the review findings. Physical pain was typically experienced in the later stages of mental illness (McCann et al., 2004) or as a side-effect of treatment (Repper et al., 1998; Ogden, 2017). Some older people were able to put strategies in place, in addition to taking prescribed medication, effectively to manage pain; for others, pain was excruciating and overwhelming. Psychological pain comprising uncertainty, anxiety and fear ran through the whole experience of living with mental illness, from diagnosis through to treatment. Fear of death was also evident (Erdner et al., 2009), as was terror of gaining weight (Erdner et al., 2009; Mckay, 2010). With regard to death, these findings suggest that death in itself was not feared by the very old, especially when it completed a fulfilled life, but the process of dying, and leaving loved ones behind, was very much feared.

3.3.2 (ii) Disruption of normal relationship rules of reciprocity and support.

With the exception of some startling examples of alienation in personal relationships brought about by the experience of mental ill health and its treatment (Lai et al., 2019) and some evidence of social withdrawal (Hedelin, 2003), findings from these studies suggested the reverse of this kind of disruption, indicating rather a biographical flow (Faircloth et al., 2004). Relationships with family, friends and other support networks were at the least maintained, and were sometimes enhanced, during the experience of living with mental illness. Such relationships provided a vital means of continuing support, physical, emotional and practical, for the studies' participants. Support did not always flow one way; the relationships could also involve reciprocity, with the mental illness sufferer offering practical (Tryssenaar, 2003) and spiritual (Curtin at al., 2018) help to family and community members.

Relationships between patient and healthcare provider also proceeded smoothly in most cases. Physicians were seen as friends and as partners in decision-making (Tryssenaar, 2003; Hedelin & Jonsson, 2003). Older people confidently sought information, or chose to remain in ignorance, according to their own perceived needs. There could be disruption though, when participants made a decision against treatment (Hedelin & Strandmark, 2001; Chafetz., 1996). This ruptured the unwritten contract whereby physicians offer treatment, sometimes recommend it, and patients accept the treatment. When older people decided against treatment the healthcare providers' response was sometimes unsupportive.

3.3.2 (iii) Re-examined expectations.

Study participants reported changes in their expectations of present and future life, from alterations to daily activities necessitated by limitations caused by disease or treatment. Variation in changed expectations could be seen even within one study population (Thompson et al., 2008). For some participants in this study mental illness caused minimal disruption to their daily plans, whereas for others the effects of the disease and treatment, fatigue in particular, had a big impact on daily life. A positive finding in relation to re-examined expectations was also reported by Tryssenaar, (2003) to the effect that a mental illness diagnosis helped couples to set new priorities and more meaningful goals for themselves.

3.3.2 (iv) Disrupted assumptions, with a focus on new attention to the body.

Mental illness, inevitably though variably, brought a disruption of taken-for-granted assumptions about the body and forced a reappraisal of its capabilities and its relation to the self. Older people in these studies experienced changes in their bodies which they attributed to mental illness, to the effects of antipsychotic medications and to age related changes associated with normal ageing or with comorbidities. Bodily experiences included fatigue, nausea and vomiting, appetite loss, feebleness and pain in different parts of the body were common complaints as was severe giddiness (Erdner et al, 2002; Tryssenaar et al., 2003). A combination of mental illness, treatment and old age itself, led to the familiar body becoming transformed into a disobedient body, a vulnerable body, an unreliable body, a body forced to endure (McCann et al., 2004). For some participant's effective treatment, with limited side-effects, softened the impact of mental illness on the body and permitted the maintenance of an active lifestyle (Chafetz, 1996; Tryssenaar et al., 2003).

3.3.2 (v) Fundamental rethinking of biography and self-concept.

Some participants in these studies had a strong self-concept which was not challenged by their disease but rather became a resource underpinning their adaptive response. Women with mental ill health who were self-empowered and assertive (Erdner et al., 2002) or whose existing religious faith gave meaning to their illness (Erdner et al., 2009) reveal biographical flow (Faircloth et al., 2004) rather than biographical disruption. For others, the psychosocial effect of treatment was to place them into a state of "liminality" which became a permanent, immutable state, leaving them in a condition of no longer knowing who they were (Lai et al., 2019). Faircloth et al., 2004 describes liminality as the ambiguity one feels in the middle of a ritual of transitioning from one status to another. An individual belongs to neither the status he has left nor to the one he is entering. Having a life-threatening illness not only involves tests, doctor visits, and medications, but also living with the illness. Individuals in these circumstances experience liminality, a grey zone where experiences no longer fit into typical categories and where two opposite feelings (E.g. fear and fearlessness) can reside at once. It is a sort of paradoxical zone where patients are living but yet dying.

3.3.2 (vi) Mobilising resources as a response to disruption.

Bury (1982) writes that "the disruption of friendship and community involvement arises not only because of functional limitations . . . but also because of the embarrassment which such disabilities create" (p 175). There is certainly evidence in the studies reviewed that functional limitations and embarrassment acted to disrupt both family and social relationships (Ogden, 2017; Martinsson et al., 2012; Erdner et al., 2002; Hedelin & Jonsson, 2003; McCann & Clarke, 2004; Mulholland & Jackson, 2018; Thompson et al., 2008) though this could be temporary (Erdner et al., 2009).

At the same time, study participants engaged in a wide range of coping strategies (McCann et al., 2004; Tryssenaar et al., 2003) in which they marshalled their inner resources as well as activating their community networks (church, fellow patients) to support them.

I conclude that the findings from the studies reviewed do reveal elements of biographical disruption, both to the life course and to the sense of self, in the lives of older people with mental ill health. But the effects of disruption were modified by the maintenance, in some cases the enhancement, of family and other support systems and by the inner resources brought to bear by participants on their changed situation. Disruption was sometimes softened, too, by experiences of biographical flow (Faircloth et al., 2004) in which participants responded to their illness in a way which revealed continuity with their former selves.
The central finding of this review, the experience of profound ambiguity at the heart of suffering from mental illness in old age, pertains also to the application of the interpretive concept biographical disruption: older people experienced both disruption and continuity in their lives with mental ill health.

3.4 Summary

The analysis and interpretation of findings in the studies reviewed suggested that the experience of living with mental ill health in old age was characterised by profound ambiguity. On the one hand life comprised a sense of disintegration, diminished identity, suffering and social retraction. At the same time these experiences were balanced by sources of comfort and strength found within the self and among relationships with family, friends, healthcare providers and community.
These findings (of ambiguity) have been echoed in studies of older people living with disease other than mental illness (Elofsson & Ohlèn, 2004) and in a mixed population of people (aged 19-61) living with mental illness (Lester et al., 2005).

Although it might not be inherently surprising or novel to find that older people experienced, for example, a high degree of uncertainty when living with a mental disorder, or that daily life comprised a fractured set of realities, the detailed

accounts of what their experiences meant for them, and the ways in which they responded, have been clearly identified by this method of systematic review and shown in the description and interpretation presented here.
The findings from this review reveal the multidimensional nature of older people's experiences of living with mental illness, throwing into sharp relief both the sources of suffering endured and the resourcefulness and resilience (Nygren et al., 2007) older people bring to managing a changed life.

The studies reviewed revealed both positive and negative findings relating to clinical practice. Some health professionals, for example, established strong caring relationships with older people who have mental ill health. In some cases, physicians even came to be seen as friends by their patients. But, sometimes, it was reported that older people felt discriminated against on grounds of their age. It is not clear from the findings why such feelings arose or if discrimination, in fact, took place. What does seem clear is that older people appreciate and value a facilitative and empowering approach, which is respectful of their unique personalities and life circumstances, to discussions about their diagnosis and about available treatments. At the same time, some older people's wishes to receive direction and guidance from people they perceive to be the experts should be respected. Ascertaining older people's wishes in this regard requires careful and individualised assessment (see Chapter 8 for a consideration of this in relation to findings from my empirical study).

Healthcare professionals also may need to introduce flexibility into healthcare systems and processes in order to take account of older people's particular needs. For example, the debilitating effects of mental illness treatments and of comorbid conditions may have implications for the timing of hospital attendance for treatment and follow-up, and for support of older people during their hospital visits. Finally, for healthcare professionals who are predominantly in younger age groups, a leap of imagination may be needed to enable genuine empathy with people whose life situation may be one of profound existential challenge.

I undertook this review because I discovered that very little primary research has been conducted in this important field and, significantly, only 3 qualitative studies of older people's experiences of mental ill health were identified in the United Kingdom. There is scope for more research which investigates the subjective experience of living with long-term mental illness in old age. Considerable duration of mental ill health is implicated in this review but those with the longest experience, often in excess of 20 years, are not singled out for discussion despite the unique nature of this noted in the medical literature discussed in chapter two. 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 the empirical study. I followed up this systematic review, therefore, with an empirical study, using narrative methods in a series of face-to-face interviews with a population of people aged 75 and older living in a semi-rural county. In the next two chapters I report the purpose, design and methods of this study.

CHAPTER 4

PART 2: EMPIRICAL STUDY 'MENTAL ILL HEALTH STORIES'

4.1 INTRODUCTION

In this and subsequent chapters I report the background, purpose and conduct of a narrative study which I carried out to follow up my literature-based study with empirical research in a UK population of older people with long-term mental ill health. I will refer to this study by the brief title *Mental Ill Health Stories*. In this chapter, I describe and justify the research design and present the approach taken to ethical considerations. I detail the sampling and recruitment procedures and present brief biographies of the study participants. In order to preserve participants' anonymity all names used are pseudonyms and identifying details have been changed. In the next chapter I give an account of the methods used to generate data for the study and of the methods chosen for data analysis.

4.2 Background and purpose of the research

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 literature (chapter 2 and 3) 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. It is such gaps in the literature that have led me to the identification of the aims and research questions for this study. *Mental Ill Health Stories* is an exploratory, descriptive investigation of older people's experiences of living with long-term mental ill health. Since older people's subjectivity is missing from research on older people and mental ill health (see chapters 2 and 3), I chose to use a method which would privilege participants' own accounts of their mental ill health experiences and their lives, told in the form of a story or series of stories. Frank, (2013) argues forcefully that stories of illness are told to be heard, not to be analysed. If the reason for eliciting the story is an avowedly therapeutic one, then I would agree with this. Where stories are sought for research purposes, though, the story has a wider purpose than the celebration (Atkinson, 1997; Atkinson & Delamont, 2007) of the teller's experience. Its purpose is to produce knowledge; therefore, analysis and interpretation of the story are required (Thorne, 2009).

Having said this, social research is not conceived and conducted in a moral vacuum and a motive force behind this study is to enable the voices of a hidden population of mental illness sufferers to be heard. I assumed *pacé* Vincent (1999) and Asquith (2009) [see Introduction] that the current life experience of people over 75 with mental ill health, and probably with comorbidities as well, would, indeed, be characterised by suffering. My research has a partly moral purpose in seeking to describe this suffering and present it to audiences whose knowledge would thereby be increased and who would be motivated to work towards reducing suffering in this population. Though Riessman urges caution in the enterprise of research as empowerment (2008, p199).
Without distracting from the moral purpose, these assumptions must be open to challenge by a subtler understanding of social reality and of the possibilities for eliciting any kind of 'truth' through the medium of a face to face research interview (Wiggins & Potter, 2017). It would be naïve to assume that I can present the 'voices of older people' directly and unmediated. Even raw interview transcripts (*pacé* the oral history work of Studs Terkel) represent an artefact that is co-constructed, the output of an interaction between interviewer and informant (Gubrium & Holstein, 2009; Silverman, 2017) which is then rendered in particular ways by the act of transcription (Riessman, 2008). Interviewing is not an epistemologically neutral act. And it is not morally neutral. The job of the interviewer is to listen, try to understand and to 'retell it afterwards', in a balanced and non-judgemental way (Bourdieu 1993, p 61).

4.3 Research design

A social movement is underway which reveals a shift from the world in which doctors and nurses were divided from patients on the basis of their superior knowledge and expertise, a world in which decisions were made *for* patients, not made *with* them (Boote et al 2002). Some older people appear to regret the passing of that world and still want to have important decisions made for them (Boote et al 2002) but there appears to be forceful societal change developing in which consultation and shared decision-making is becoming the dominant characteristic of the relationship between healthcare providers and the public (Allsop et al, 2004; Brown & Zavestoski, 2004). Such 'consumer involvement' is increasingly encouraged (Tritter, 2009) or even mandated, in all parts of the research cycle.

Against this background, I sought ways to gain the views of people affected by mental ill health about the purpose and methods of my study. Drafts of my research proposal were reworked following comments received from members of Consumer Research Panels (CRP) in a South East England County. Consumer Research Panels are groups of consumers – meaning mental ill health patients, carers, and other people affected by mental ill health – who work with mental health researchers in a variety of ways with the intention of improving the relevance, quality or conduct of a research study. CRP's gather together people affected by mental ill health who wish to be involved in mental health research, and who can provide an easily accessible, expert resource for researchers and also a forum through which to pursue consumer-led projects. I also consulted with a Mental Health Partnership Group in a county where I plan to conduct the study. Overall, there was a strong sense in the feedback received that panel members affirmed the purpose of the research, though most of the CRP members were not in the target population of people aged 75 and older. I received particularly helpful commentary on draft interview questions from a 78-year-old man with schizophrenia. He warned that one or two of the questions sounded like those of a younger person who did not understand the world in which an older person had grown up. I was mindful of this advice when designing the interview method for the study.

I also sought the views of senior clinicians at the chosen research site, a Mental Health

Centre in a semi-rural county. Discussion with the Lead Clinician for the Mental Health Research Network led me to a decision whereby the study population would be comprised of people aged 75 and older suffering one or more of the four most common mental disorders in the United Kingdom: psychotic, anxiety, mood and personality disorders. Presentation of my research proposal at a weekly multi-disciplinary and multi-professional meeting of clinical staff brought an enthusiastic response and the promise of help with recruitment which was richly fulfilled.

Early formulations of research questions focused on the experiences that older people have of living simultaneously with mental ill health and with one or more diseases characteristic of old age (e.g. chronic respiratory disease, cardiac disease, diabetes). Over a period of time (see commentary below on ‘emergent thinking’) the questions became modified to focus more broadly on the experience of living with long-term mental ill health. Ultimately, the final research question for the study became: ‘What are the subjective experiences of living with long-term mental ill health described by men and women aged 75 and older?’

Early influences on the research design were a combination of Robson’s (2002) explication of the distinction between fixed and flexible designs and Lincoln and Guba’s (1985) ideas about naturalistic inquiry. Fixed designs are appropriate to questions looking for cause and effect, for measurement and so on (randomised controlled trials and other experimental designs). Flexible designs are appropriate to more open-ended questions in which phenomena are loosely or ill-defined at the beginning. For Lincoln and Guba ‘the naturalistic inquirer is almost always in the position of not knowing what he or she doesn’t know’ and so ‘it would be foolish to expect the naturalist (sic) to be able to describe a design in anything other than broad brush process strokes before the study is undertaken’ (1985, p298). Of course, as Lincoln and Guba make plain, it is important that a clear design is ultimately discernible.

A particularly important feature of these ideas was that, in an exploratory inquiry, the research design is allowed to emerge over a period of time (as a result of reading, thinking, discussion, and writing) rather than be predetermined. It was clear from the outset that a qualitative (or flexible, or naturalistic) design was appropriate to this study. But the initial research questions for the study, focused on self-reported experience of participants, are answerable by a number of qualitative methods, including grounded theory, phenomenology, ethnography, narrative inquiry. After much reading, thinking and discussion, I chose to use narrative and biographical methods.

There are at least six reasons why narrative emerged as my first choice from among the family of qualitative methods: i) my experience of life history interviewing; ii) the growing interest and expertise in narrative methods in the university department of my doctoral registration; iii) my intellectual interests in the structure of stories and in language; iv) other stakeholder interests in hearing patient stories to influence service development from the user perspective; v) attractiveness of a field in which there is a diversity of approach; vi) exciting and stimulating encounters with narrative researchers and narrative research.

Finally, the overall approach to the narrative inquiry reported here was strongly influenced by Clandinin & Connelly's (2004) conceptualisation of the 'three-dimensional narrative inquiry space' focused on the dimensions of time, place, personal and social context. Methods of data generation were strongly influenced by the Biographic-Narrative-Interpretive Method of interviewing (Wengraf, 2001).
These approaches are described and analysed more fully in the next chapter.

4.4 Ethical considerations

Ethical approval for the study was obtained from the Social Care Research Ethics Committee through the Integrated Research Application System (IRAS) and was granted in June 2016 (see Appendix 2).The primary ethical considerations in the proposed study concerned the perceived benefits of the study to be balanced against the risk of harm, conceived principally in terms of the potential for causing emotional distress by talking about mental ill health. The protection of individuals' privacy was also deemed to be important as was their physical and emotional comfort during the interview. The research proposal and protocol submitted for ethical review can be seen at Appendix 3.

4.4.1 Perceived benefits of the study

Mental ill health research has a high public profile in the United Kingdom, in particular through the activities of Mental Health Research UK (MHRU), a UK charity dedicated to raising funds for research into the causes of mental illnesses. Much of the research activity brought to the awareness of mental health patients and the public is concerned with development of more effective treatments with fewer side-effects. There is a powerful incentive for individuals suffering from mental ill health to take part in such studies. I made it clear to potential participants that taking part in my study would not have a direct benefit on their health or any impact on their treatment. This was achieved by providing written information, supplemented by discussion, in which the purposes and methods of the proposed study were expressed as clearly as possible (Participant Information Sheet at Appendix 4).

4.4.2 Privacy/confidentiality

It is important in any research interview in which people are asked to reveal their personal thoughts, feelings, ideas or experiences that participants are able to be assured that their recorded statements are kept private and confidential. (Exceptions to this occur in oral history interviewing where it may be mutually agreed that interviews are made available to a wider audience). Participants in this study were assured of confidentiality and that participants will remain anonymous in all publications and disseminated material arising from the study. In practice this meant that only the researcher had access to the research data. In addition, it meant taking steps to ensure that all personal and interview data were stored securely, in locked filing cabinets and password protected electronic systems. Permission was sought specifically from each participant to record the interview on digital audio recording media. Audio recordings were transferred to computer at the earliest opportunity following the interview and were password protected. Transcripts of interviews were made anonymous, as were any statements made by participants during interviews which are reported in the research findings. Written consent to participation in the study was sought and gained from each participant (Consent Form at Appendix 6).

4.4.3 Discomfort (physical) during interviews

Participants in this study were older men and women who by virtue of their inclusion in the research were living with diseases, that is, the objective presence of pathology, of various kinds. The extent to which they would be suffering illness, that is the subjective experience of symptoms, at the time of recruitment to the study and participation in interviews was unpredictable. Several recruits, having agreed to participate, withdrew before interview as they became too unwell to take part. Measures to minimise any physical discomfort to participants during the process of the interview included: i) reassurance that participation is entirely voluntary and that the participant may withdraw if feeling unwell enough to participate (or, indeed, for any other reason) either before or during an interview; ii) negotiating the venue for the interview with each individual (in the event, all participants chose to be interviewed in their home); iii) participants were invited to consider how best they might be helped to manage their participation in the interview in the event of their becoming tired. In this research, only one participant found it necessary to terminate the interview (after 57 minutes) due to breathlessness caused by her asthma. We began the interview with an agreement that she could stop talking when she felt unable to continue. She paused for a few moments after about twenty minutes, while her husband made a cup of tea, and then voluntarily resumed the interview. 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).

4.4.4 Distress (emotional) during or after interviews

Talking about painful experiences can be therapeutic but it can also be distressing. It was important that people who were being asked to talk about their experiences were made aware that either of these reactions may occur. On the one hand, positive feelings may come from being listened to, and possibly seeing experience in a new light as a consequence; on the other hand, negative feelings of renewed pain may arise as distressing experiences are re-told and imaginatively re-lived. Participants in this study were informed about these important matters in the information leaflet they received before agreeing to take part in the research (see Appendix 5). The following extract from the research protocol (Appendix 3) submitted for ethical review demonstrate the approach taken in the study:

> Should the recollection of painful experience during the interview become distressing the interviewer (VJ) will honour the person's experience by pausing the interview and giving the participant time to express their feelings if they so wish. If the participant is too upset to continue the interview, then the interview will be terminated. Participants will be assisted to make the decision that best meets their own needs. Should this situation occur the researcher (VJ) will use skills gained from many years of counselling work in health and education to comfort the participant. If distress persists beyond termination of the interview participants will be referred to the adult mental healthcare team for further support. At all times the participant's needs, will take priority over the demands of the research.

During the interviews one participant became tearful on two occasions while recalling being given her diagnosis. Three participants became tearful on talking about the deaths of their wives (all from various mental disorders in old age). I responded to this with attentive listening and expressions of sympathy. In all cases the distress evoked by their memories appeared to be transitory. There was no sign of residual emotional discomfort at the end of the interviews. If at any point the researcher became aware of any potential risk issues (e.g. suicidal ideation), she paused the interview, determined the immediacy of risk through open discussion with the participant, and acted as agreed with the ethics committee. Specifically, if risk was significant and urgent, the interviewer would contact immediately emergency medical/social care services, and subsequently inform the relevant parties. Alternatively, if risk was significant but non-urgent, the interviewer would discuss available support options with the participant, and if they gave consent, inform the relevant agency who could then facilitate support-seeking as appropriate.

4.4.5 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 practicing Psychotherapist and Counsellor, 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 are satisfied with the process and had the opportunity to ask any further questions.

4.5 Study population and sample; study site and recruitment

4.5.1 Study population

The study population comprised men and women aged 75 and older, resident in a semi-rural county, who have been diagnosed with one or more of four common mental disorders: psychotic, anxiety, mood and personality disorders. The age group 75 years and over was chosen because, although the population defined as aged 65-100+ is heterogeneous, the incidence of age-related physiological changes is reported to increase sharply between the ages of 70 and 75 (Bartels 2004). This means that a cut off of 75 years is likely to reflect more fully the complex intersections of mental ill health, comorbidity and old age (Hedelin et al., 2001) than a cut off of 65 years, the conventional beginning of 'old age' throughout most of the 20th century in western industrialised societies. The four common mental disorders were chosen on the advice of senior mental health staff at the research site.
My initial plan had been to follow Hedelin et al (2001) and recruit widely and openly from among the target population, irrespective of mental health site. I accepted the clinician's advice, choosing to regard it as at least a useful 'limiting and distributing device' (Kitwood, 1980) which would facilitate recruitment.

4.5.2 Study sample

Factors which influence decisions about sampling size in flexible designs/qualitative research include (Morse 2015; Robson 2002): i) the nature of the topic (fewer informants are needed if it is obvious and clear; conversely more informants are necessary if the topic is challenging and difficult to grasp); ii) the quality of the data (fewer informants are needed if data are ‘on target’ and are ‘rich and experiential’); and iii) the study design and methods (more data are acquired per participant with repeat interviews so fewer informants are needed; semi- structured interviews yield fewer data per person than in-depth interviews so more informants are needed). Morse (2015) recommends approximately 30-50 *interviews* (note, not informants) for ethnographic and grounded theory studies.

Taking account of the above recommendations and placing them in the context of a biographical/narrative approach based on in-depth interviews which are likely to yield a lot of data, it was proposed to recruit up to 40 informants to the study, ideally 10 from each of the four mental health groups targeted. Inclusion criteria comprised:
i) men or women aged 75 or older; ii) diagnosed with one or more of four targeted mental disorders: psychotic, anxiety, mood and personality disorders; iii) be well enough to take part in at least one interview, in English and lasting approximately 1-2 hours in length or otherwise provide relevant data (e.g. diary/journal).

As the study plan unfolded, I decided to reduce the number of planned recruits from forty to twenty. In the time available to conduct the study it was deemed impractical to attempt to interview forty people. In addition, it was thought acceptable by my doctoral research advisors to reduce the number of recruits for empirical study in light of the extensive work already conducted as part of my doctoral studies in the form of a qualitative systematic review, forming the first part of this thesis.

4.5.3. Inclusion and Exclusion

The inclusion criteria for this study were as follows:

1. Aged 75 years or older
2. Diagnosed with one of four targeted mental disorders: psychotic, anxiety, mood or personality.
3. On-going experience of mental ill health
4. Experience of mental ill health from for at least 20 years
5. Be well enough to take part in at least one interview, in English and lasting

approximately 1-2 hours in length or otherwise provide relevant data (e.g. diary/journal).

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.

4.5.4 Study site and recruitment procedure

The study was based at a local Mental Health Clinic and supported by consultant psychiatrist, the Lead Mental Health Nurse and the Research and Development Directorate. The local Mental Research Network team also supported the study and facilitated initial access to clinicians.

4.5.5 Recruitment procedure

In building on the advantages of recruitment outside mental health services 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 were utilised. These involved: A poster (see Appendix 7) sent to all local libraries; displayed in local leisure centres; displayed in third sector (non-statutory) mental health support organisations; sent to local GP practices for display in their surgeries; posted on the Mental Health Foundation, Mental health groups and Age UK websites. I also discussed the research with adult Community mental health teams; local later life community psychiatric nursing teams and later life Psychiatrists, Clinical Psychologist and Counselling Psychologist in a semi-rural county.

Creswell (2012) discusses the importance of selecting the appropriate candidates for interviews. He asserts that the researcher should utilise one of the various types of sampling strategies such as criterion based sampling or critical case sampling (among many others) in order to obtain qualified candidates that will provide the most credible information to the study. Creswell also suggests the importance of acquiring participants who will be willing to openly and honestly share information or 'their story' (p. 133). It might be easier to conduct the interviews with participants in a comfortable environment where the participants do not feel restricted or uncomfortable to share information.

The recruitment process focused on meeting people who could contribute to the aims of the research and answer the research questions. Out of the 15 people who responded to the posters, one man with schizophrenia (and other chronic health problems) agreed to take part in the study and arranged an interview date which he postponed on two separate occasions owing to his own and his wife's illness. I also identified eligible patients from mental health clinics with the assistance of clinical and administrative staff. I attended relevant clinics and clinicians introduced the research to patients during the course of a routine consultation, supplying them with a single sheet of A4, written by me including my photograph, which explained the study in outline (included at Appendix 5). If patients were agreeable, I then spent a few minutes with them before they left the clinic, explaining the study in more detail and giving them the opportunity to ask questions. With their agreement, I gave them longer written Patient Information Sheet (see Appendix 4) and invited them to think about participation in the study, discussing with family and friends if they wished, before making the decision.

Potential participants were also informed that the study was not intended to provide direct clinical benefit to participants but that it is hoped the findings will influence care for future patients. It was particularly important that it was made clear to participants that this study was not a clinical trial investigating the benefits of particular treatments. A decision to participate was not sought at the time of first contact with the Researcher but participants had at least 48 hours in which to make such a decision. We agreed that I would contact them by telephone, after at least48 hours had elapsed, to discuss any further questions and record their decision about participation.

In five clinic visits during the period July 2016-November 2016, fourteen eligible patients were invited to talk to me about the research. It is important to remember that the first contact was made by clinic staff (consultant, psychiatrist or specialist psychologist) so that patients would have the opportunity to decline to see me, if they so wished. Clinicians introduced the research to patients during the course of a routine consultation, supplying them with a single sheet of A4 short participant information sheet, which explained the study in outline (included at Appendix 5). Three patients declined, though one of these agreed to take the more detailed Patient Information Sheet and gave permission for me to phone her at home. She subsequently declined to take part in the study, confessing that she had not even read the Information Sheet.

Of the eleven people with whom I discussed the study in outline while they were in the outpatient clinic four people subsequently declined, or were unable, to take part in the study. One man with post-traumatic stress disorder declined because he was newly diagnosed and ‘still in shock’ that what he was ‘suffering from all along has finally been given a name’. He indicated that he might write something for me (see Research Protocol, Appendix 3) but did not contact me again and it may be surmised that, out of politeness, he did not want simply to refuse all participation. Another man with depression and anxiety agreed that I could phone to discuss participation but on each of two occasions was too unwell even to have a conversation with me. Another man diagnosed with paranoid schizophrenia, the oldest potential recruit at age 93, agreed to take part and arranged an interview date but was subsequently admitted to hospital urgently with cardiac problems. One woman with anxiety disorders agreed to talk to me in more detail about the study but declined to take part as, when I telephoned, her husband had just been admitted to hospital with a serious illness.

Three deviations from the recruitment protocol arose from practical and ethical decisions made in the field. One patient was recruited who fell slightly outside the lower age range for inclusion (she was 74 years old at the time of recruitment). This was a pragmatic decision the reason for which is explained in my contemporaneous field notes:

> *Clinic visit August 12th 2016*
> *3 eligible male patients (age 76, 79, 78). One female aged 74 (75 years by the time of the interview). Very tempted to be flexible on*

> *age criterion today because I have so few women (only one so far) and because if all 4 agree today that is my numbers achieved and won't need to come again. Since it's best part of a day each visit that is an important consideration.*

The second deviation was that I accidentally recruited a man who did not, strictly speaking, meet the inclusion criterion of having one of the four major mental health disorders. I had assumed that all the patients attending the clinic on August 18th 2016 were patients with some form of depression or anxiety. Hence, the discussions with clinic staff about their eligibility focused on the age criterion rather than the mental disorder criterion. Because I had no access to patients' notes before and after meeting them, I did not realise until after recruiting him to the study that this person, whom I thought had depression or anxiety, did, in fact, have Alzheimer's (details derived from participant's own narrative. No questions were asked directed at seeking this information). Identifying depression in someone with Alzheimer's can be difficult, since dementia can cause some of the same symptoms such as feelings of low self-esteem and confidence, tearfulness and appetite, concentration and memory problems (Prince et al., 2013). Since depression is very common among people with Alzheimer's, especially during the early and middle stage and because of the close relationship between the two, I decided to retain him in the study.

The third deviation was that the spouse of one participant specifically requested, at the recruitment meeting, that she be interviewed as well because she wanted her experience as a carer to be heard and, she said, in his presence, that her husband was not 'gifted with words.' Although this deviated from the study protocol, I felt it to be within the spirit of the moral purpose of the research and agreed to interview her separately from her husband, though, again, in his presence. She was not included in the study.

4.5.6 Pilot Study

The pilot interviews were conducted with three older people in their 70s, one female and two males. The pilot study was used to assist the research in determining if there are flaws, limitations, or other weaknesses within the interview design and to allow me to make necessary revisions prior to the implementation of the study (Kvale & Brinkmann, 2018). The participants were identified previously during the initial consultation with the members of Consumer Research Panels (CRP) in a semi-rural county about the research. I was able to interact with the pilot study participants in a relaxed and informal manner where I had the opportunity to learn more about the in-depth experiences of the participants through structured interviews. This informal environment allowed me the opportunity to develop rapport with the participants so that I was able to ask follow-up or probing questions based on their responses to pre-constructed questions. I found this quite useful in my interviews because I could ask questions or change questions based on participant responses to previous questions. The questions were structured but adapting them allowed me to explore a more personal approach to each pilot participant interview. According to Gunaratnam (2009), the strength of the general interview guide approach is the ability of the researcher "…to ensure that the same general areas of information are collected from each interviewee; this provides more focus than the conversational approach, but still allows a degree of freedom and adaptability in getting information from the interviewee" (Types of Interviews section, para. 1). The researcher remains in the driver's seat with this type of interview approach, but flexibility takes precedence based on perceived prompts from the participants.

The pilot interview, which lasted for an hour and 20 minutes, showed that the questions were capable of eliciting rich data on the thinking and practice of the interviewee. It was also effective in highlighting several ways in which the interview schedule could be improved both through the interviewee feedback and the experience of actually doing the interview.

4.5.7 The study participants

Twenty people, ten men and ten women, agreed to take part in the study and were interviewed in their homes. Details of the interview method are reported in Chapter 5. The participants 'demographic and biographic details are summarised in Table 4.1 (p.103). One quarter of the participants (5 people) was aged over 85, the oldest (female) being 92 and the youngest (female) 75. Ten participants were married (two for the second time: one following bereavement, the other divorce); nine were widowed and one (in addition to the remarried divorcee) was divorced. Eight of the participants were living alone at the time of interview, eleven with a spouse or partner and one with an adult child. Of the ten men interviewed five had been widowed (one of them twice); of the ten women participants four had been widowed. One man and one woman had been divorced. Five men were living alone at the time of interview and three women.

None of the participants were in paid work but one man (Richard Burns) was actively pursuing creative and business interests at the age of 91, undeterred by his mental ill health. Several others were actively occupied in a variety of ways: for example, with hobbies (John Murray, Louis Green) or with family concerns (Judith Pinkett, Sam Shaw). A brief biographical sketch of each participant, drawn from what they said about themselves during the interview, concludes this chapter. A summary of their disease characteristics (age at diagnosis, treatments undergone, reported side effects and comorbidities, and other experiences of mental disorders) is presented in Table 4.1 (p.103).

4.5.8 Brief Biographies (all names are pseudonyms, listed in alphabetical order by first name)

Barbara Vine (f. Paranoid Schizophrenia, interviewed Jul 23rd 2016)
Barbara was born in 1932. She worked in the stores department of a local factory. She has two daughters and a son, all living nearby and giving her a lot of help and support. She also has close friends with whom she still manages to socialise. Barbara’s schizophrenia developed over a period of time but was not aware of it as it was something that she ‘didn’t know much about’. She has been a mental hospital inpatient and had medication, from which she suffered some transitory side-effects. At the time of interview, she felt that her osteoarthritic knees impede her daily life more than her mental ill health. Barbara’s husband committed suicide after severe depression during the 12 months preceding our interview.

Christine Mendelson (f. Severe Depression, interviewed August 25th 2016).
Christine was born in North East, in 1940, one of eight children. She had rheumatic fever as a teenager, which affected all aspects of her life. She had heart surgery in 1963 (which 'changed her life') and again in 2003. Christine married and came to South England in 1967 and worked in various part-time jobs and later as a school secretary. They had two children, with one of whom Christine has lived since the death of her husband in 1995. She had a stroke while pregnant with her second daughter, and still has a dense right hemiplegia. She feels that if she'd had physiotherapy at the time it might have helped her to recover function. Christine's mental illness was detected by her GP who referred her to a psychiatric hospital. She was admitted and was diagnosed with Severe Depression and Anxiety in 1999. She was treated initially with medication then electro-convulsive therapy (ECT) and long-term psychotherapy, which she resisted at first as she felt it will not help her case. Christine feels very satisfied with her treatment and has no after-effects. She takes Zoloft daily along with other medications for blood clotting, hypertension and osteoporosis.

Clive Holmes (M. Adjustment Disorders/Major depressive disorder, interviewed August 13th 2016).
Clive was born in England in 1940. When he left school, he joined the merchant navy and worked his way up the ranks to command of a ship. He left the navy aged 26 and joined a general management trainee scheme in industry. He gained a series of promotions over the years, taking him to various towns and cities in the United Kingdom as a factory manager. He took up the opportunity of private health screening offered by his company and discovered, at the age of 53 that he had prostate cancer, a disease which killed his father and his younger brother. This changed Clive's emotional state, he became withdrawn, agitated anxious. As the days went on, more changes became evident, 'sudden, uncontrollable bouts of crying, followed by periods of silence; he would go long periods without talking'. It affected his work, his concentration was short, and he couldn't do even the simplest tasks, his work mates didn't know what was happening, 'they have never seen him like this, this wasn't the person they knew and worked with'. He thought he was the only one in the world going through this and couldn't tell or talk to anyone until a friend told him they too were going through the same illness, 'there was someone else'. He finally sought help from a private psychiatrist and was diagnosed with adjustment disorder with major depressive disorder. He was prescribed medication and received counselling. He

maintained contact with his friend who also gave him the answers to his questions. His friend gave him the strength and the support he needed.

Doris Snelling (f. Depression/Anxiety disorders, interviewed July 21st 2016)
Doris was born in 1924 in the small semi-rural village where she still lives. She had a very happy childhood living with her parents and three sisters. She left school at 14 and worked in an office until she married at 21. She had a son and a daughter who have both married and divorced and who still live in nearby villages. Her children's marital separations followed quickly on the death of her own husband from cancer in 1996 after 43 years of marriage. Doris talks repeatedly about having had a happy life and that she has no regrets apart from not disclosing sooner that she had signs of mental ill health, which she kept to herself for about 8 years before eventually visiting the GP in Dec 1990. She has had psychiatric inpatient treatment, ECT, medication and counselling and is satisfied that her depression is under control. She is also very satisfied with all the treatment she has received in the NHS. Her attitude to problems is generally to face up to them and accept them and this is now how she approaches having mental ill health.

Henry Hornby (m. Schizophrenia, interviewed July 29th 2016. **Died November 2016**).
Henry was born in Southern county in 1933. He left school at 15 and became an apprentice plumber. He spent some time in the army then returned to plumbing. He worked for many years as a plumber, including a period of self-employment which he did not care for, and finished his working life in general maintenance in his local general hospital. He is widowed with one daughter who lives nearby. He began to experience episodes of low mood and anxiety in his late 60's. In 1994, he collapsed in a toilet after he suffered a 'heart attack sensation' following a family outing to the local pub for lunch. His daughter administered CPR at the scene while waiting for an ambulance. Henry was hospitalized and later transferred into a mental hospital. He was diagnosed with schizophrenia, paranoia and depression. He has had ECT, medication and psychiatric treatment. He seems to find the institutional context (nursing home) he has been in this year (2015-2016) very difficult to adapt to. He repeatedly states that he will manage and be a lot better when he goes home.

John Murray (Acute Stress Disorder/Post-traumatic Stress Disorder, interviewed July 18th 2016)
John was born in a semi-rural town in 1933. His childhood was marked by several periods livingaway from his family, in an orphanage and in an approved school.
He was a sickly child with bouts of pneumonia and influenza. He found school difficult as he was considered to have ‘an intellectual disability’ and was also bullied. He left school at 15 with no qualifications. He joined the army aged 17 and served in Europe. He enjoyed life in the army, but his physical symptoms continued. He subsequently worked as a labourer and in an Aerospace department. He met his wife at the age of 23 and they had three children, one of whom has died. He struggled with emotional and physical problems and often experiencing periods of being tearful all the time, restlessness, memory difficulties, feelings of worthlessness and suicidal thoughts.
His wife died from cancer in his early 30’s. He became a heavy drinker which resulted in him being made redundant. He attempted suicide and was later admitted to a Psychiatric hospital. He was given medications and ECT. He continued to struggle with his mental ill health and tried to kill himself on numerous occasions. A decade later, he was diagnosed with ‘acute stress disorder and depression. He continues to take antipsychotic medicines and also receiving psychotherapy. He keeps himself busy by tendering his garden, which he is now finding tiring.

Josephine Barnes (Paranoid Schizophrenia, interviewed July 18th 2016).
Josephine was born in 1929 and raised on a farm. She became familiar with the world of medical and surgical treatment from a young age having a cleft lip and palate corrected in her infancy. She worked in a factory towards the end of WW2 and in a mill for the next for 30 years. She divorced from her first husband, who beat her, when their two children grew up. She is now married to Roy, a childhood friend. Her daughter died in a car accident at the age of 26. Josephine grieves for her but does not feel bitter about her death. She believes that it was during this time that her mental illness became apparent. Her symptoms became severe and was detained in hospital following an assessment. She was diagnosed with Paranoid Schizophrenia. She received ECT as part of her treatment, had antipsychotic medications and psychotherapy.

Judith Pinkett (f. Bipolar Disorder, interviewed September 7th 2016. Died January 2017)
Judith was born in the North, in 1930. She was the second eldest of eight children and

spent her late adolescence as a primary caregiver to her younger siblings after leaving school at 14. At 16 she went to work, at first in a gift shop, then in the Sweep and finally, until marriage, in a toffee factory. Judith married in 1955 and moved to the South East England in 1956. She had four children, two of whom died aged 16 and 21. Her two remaining live nearby and are, she says, 'very good to us.' Judith has had mental ill health for almost 25 years but would not accept anything was wrong with her. She remembered being a lot more irritable and being very nasty to others, but she put it 'down to her arthritis'. In the past 12 years, Judith has been detained under Section 3 of the MHA (1983) on 3 occasions because she had a 'known bipolar affective disorder with psychotic symptoms. She has now been discharged but still under the care of the same Mental Healthcare Team. She was highly satisfied with all her treatment and care in hospital but a little disappointed at the lack of follow-up when she went home.

Louis Green (m. Persistent Delusional Disorder, interviewed August 30th 2016. Died February 2017) Louis was born in 1928. He was born and raised in South East England . He was a soldier in WW2 and was injured during the war. Louis ended up in a military hospital and eventually returned to the UK as an injured soldier. After his return home, he met and married his wife and enjoyed a varied working life followed by a period of unemployment. He decided to join the Territorial Army. It was not long after his marriage, when his daughter was a baby that Louis started feeling particularly frightened, irritable and angry but he did not know why. The doctor said it was nerves and prescribed some medication. He continued to experience, nightmares, 'seeing and feeling things that were not really there', sweats and dizziness. His wife encouraged him to talk to the doctors again. The doctor asked him if anything happened while he was in the forces and he felt able to tell him about his experiences of injury and death of friends. The process of assessment with military doctors that followed his intervention, eventually led to his diagnosis of persistent delusional disorder, PTSD and the award of a pension. He was not able to share this with his wife however, as she died three weeks before he received the letter. No long after his wife's death, Louis attempted suicide and was admitted to a mental hospital. Louis was devoted to his family, his children and all his grandchildren and great-grandchildren. He had an optimistic nature and did not dwell on his mental ill health. Since his treatment for mental illhealth, he had taught himself to draw and paint.

Mark Davies (m. Obsessive Compulsive Disorder/Anxiety Disorder, interviewed July 28th 2016). Mark was born in 1928, in a semi-rural village close to where he still lives. He left school at 14 and worked in a range of agricultural jobs. Mark married in 1956 and together him and his wife had three children. Mark's wife died in 1984 from lung cancer. He enjoyed close relationships with several women over subsequent years but did not want to remarry. He lives alone but has many friends and an active life. For a number of years Mark had anxiety symptoms and obsessive-compulsive disorder (OCD) traits and didn't 'feel right,' generally suffered with obsessional thoughts that are repetitive, disturbing and often horrific and repugnant in nature. He had thoughts of causing violent or sexual harm to loved ones. The intrusive thoughts caused him a lot of distress – '*the very idea that I was capable of having such thoughts in the first place was horrifying*'. Mark visited his GP who referred him to a consultant psychiatrist. After investigations, he was given a diagnosis of obsessive-compulsive disorder and anxiety disorder. He was shocked at this but fairly quickly came to terms with it and developed a very positive and determined attitude towards recovery. He had ECT, psychotherapy for almost a year and medication, which was very helpful. He is now under the adult mental health team, which is made up of a number of different healthcare professionals, such as psychiatrists and clinical psychologists. Mark's stories about his illness, and his life, are underpinned by his great appreciation of all the help and support he received from his family, friends, neighbours, doctors and nurses.

Mary Willis (f. Agoraphobia/Neurotic Depression/Bipolar Disorder, interviewed October 24th 2016) Mary was born in 1940. She worked as a shop assistant and later a wage officer. She was very adventurous when she was younger. She loved the independence her first car gave her and rode tandems and scooters. She met Jeff in a pub, and they got married a few years later. Doctors told Mary and her husband, Jeff that they will never have children. However, they proved the doctors wrong and were overjoyed when Sarah came along. Mary became unwell about a year later and didn't know what was going on around her and also did not want to go out as normal. She felt disoriented, shortness of breath and dizziness. She couldn't leave the house alone and avoided using public transport or being in crowds for fear of provoking these reactions. She prayed every night she wouldn't get up the next day. It was hard for her to make sense of what was happening. The doctor said it was depression and too much stress. Mary describes always knowing depression and being a worrier. This time she had to go to a psychiatric hospital which frightened her. Mary's mental ill health was diagnosed as agoraphobia and neurotic depression. Her treatment in hospital included antidepressant medications, psychotic medications, ECT and psychotherapy. She has been under psychiatric care for 28 years. She takes 3 types of medication daily for her mental ill health. Mary and her husband have lived in the house they currently occupy for 40 years. Mary feels seeing a psychologist was a start of getting well. As part of her recovery, Mary attended the wellness recovery action plan group at the hospital. She now helps to run the group.

Norah Jarvis (f. Manic Depression, interviewed Oct 31st 2016).

Norah was born in 1937. 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. Norah left school in 1952 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. Norah got married in her early twenties and gave up work when she was eight months pregnant with her first child early 1960s. She really wanted to continue work but was unable to find any support as both her mother and mother in-law worked. Norah’s husband was violent towards her and she tried to leave him, but her mother said that marriage was ‘for better or worse’. At age 24 Norah 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. During the process of their divorce, her husband struck her violently on the head and she started to get headaches, having nightmares, 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. She was sedated and subsequently, she received further medications and ECT without being given any diagnoses. She felt very low when she left hospital and started to hear voices more so than before. She tried to get numerous jobs but failed. She continued to try and find work and in the early 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 ‘manic depressed’, but nevertheless was offered a trial period which was short lived. This was the first time she had heard about ‘manic depression’ 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 at the time of the interview.

Norma Williams (f. Hypochondriacal Disorder/Anxiety Disorders, interviewed September 1st 2016) Norma was born in 1930 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 and moved in with her auntie and uncle. Norma experienced a further bereavement at 4 years old when her uncle died. Norma, 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 Grandmothers dead body in the coffin at their house, which she did not want to do. Shortly after this, at the age of ten, Norma started having panic attacks. At age 15, Norma 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. She was alone, 'crying under the bed clothes' because the nurses told her she was 'upsetting all the patients' and they said, she had plenty of time to have more children. When she went home from hospital her panic attacks intensified. She also had constant pain in her stomach which she was convinced that it was 'stomach cancer'. She felt physically sick and was so bad after this that she had a 'mental breakdown'. One afternoon, when Norma 'was choking' in panic, she 'ran quite a long way' to the GPs where she 'fell in the surgery'. She was prescribed anxiety medication. Norma 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. She was never satisfied working as a cleaner and in her early forties, she got a job as a nursing auxiliary. She was happy working in this job although she had occasional periods of sickness but tried to get on with her everyday life. 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. At the age of 42 Norma 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. In her early 50s, Norma 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. 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 where investigation confirmed a diagnosis of hypochondriacal disorder, an anxiety disorder.

Following this experience, she retired from work. She remained on good terms with her husband during their 12-year separation until his death. Her anxiety continues but she no longer gets panic attacks in the night, but they threaten in the day sometimes. At the time of interview, Norma was continuing treatment with medication and psychotherapy. Her attitude to having mental ill health is fatalistic. ‘It’s there,’ she says, ‘you’ve got to accept it.’

Peter King (m. Panic Disorder/Generalised Anxiety Disorder, interviewed September 11th 2016)
Peter was born in 1941, in North East but moved to South East England with his parents at the age of three. He found school difficult as he was considered ‘thick’ and was bullied. He was always tearful, had co-ordination problems and often received detention. He left school at 14 and began a seven-year engineering apprenticeship.
He then spent two years in the army, which he broadly enjoyed, before returning to engineering. Peter became a heavy drinker in his early 20’s which worried his father. During this time however, Peter became engaged and married a few months later.
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 recognized in the medical profession as a genetic disorder. This enable him to make sense of his learning difficulties and emotions earlier in his life. With a growing family, Peter worked long hours even in poor physical health. This had led ‘three or four times’, to an ambulance being called and he found on one accession to have pneumonia. He was always very grumpy, a bag of nerves and used to be aggressive towards his staff. Peter was made redundant and found very hard financially to support his family. He took another job in management which lasted for two years after which he was made redundant again. After losing this job, he ‘cracked up’, cried for three days and then tried to hang himself at work. This caused a lot of friction between Peter and his wife as he did not return to work again, resulting in further financial difficulties. Peter was admitted to a psychiatric hospital and was later diagnosed with panic disorder and generalized anxiety disorders. He had ECT treatment, medication and counselling. Peter spoke of his distress at the diagnosis but does not dwell on having mental ill health and is optimistic that treatment will be successful.

Richard Burns (m. Complex Post-Traumatic Stress Disorder, interviewed September 26th 2016) Richard was born in the North East in 1924. He intended to become an architect, but WW2 intervened, and he became an engineer instead. He travelled frequently abroad. He lived and worked in the North East for a period, where one of his sons still lives. He has had psychiatric inpatient, drug therapy, psychotherapy and one dose of ECT treatment for complex post-traumatic stress disorder (COMPLEX PTSD). He knows that his mental ill health is serious, but he is unworried and concentrating on developing a new business for the creation and sale of heritage designs, for which he has taught himself to use some new computer software.

Rosemary Jackson (f. Manic Depressive Disorder/Anxiety Disorder, interviewed July 23rd 2016) Rosemary was born in 1928, one of seven children. For reasons she still doesn't understand, she spent about 5 years of her childhood living with nuns in what she called a 'private orphanage', though both her parents were alive. She left school at fourteen to work, first in a bank then, during the war, weaving in a cotton mill. She then left home to work as a nanny, followed by factory jobs in the shoe manufacturing and electrical industries. Rosemary attributes her delay in marrying (at age 37) to her youthful passion for dancing. She had two children (deliberately unwilling to produce the large families typical of her relatives) and continued to work in her own small businesses (chip shop followed by newsagent). Rosemary's husband died in 1986. Her son and daughter live nearby. She sees them regularly enough to do their washing and to help with childcare. Over the years Rosemary has also fostered seven children. In her early 60's she began experiencing unexplained severe body aches and pains, extreme mood swings and persistent suicidal thoughts. This totally consumed her attention and she couldn't even read a book, watch tv or sleep. Her GP visited her and suggested that she will be better off in hospital. The GP referred her to a psychiatrist. She was reluctant at the time but in the end, she knew she needed support. She was diagnosed with excessive manic-depressive disorder (bipolar depression). She was treated with medication, ECT and counselling. Her drug therapy continues. Her attitude to these illnesses is that 'life must go on, and you just bounce back'. She is very satisfied with all her treatment in the NHS and is eager to get back to voluntary work in a local charity shop.

Sam Shaw (m. Delusions & Post-Traumatic Stress Disorder, interviewed September 3rd 2016) Sam was born in Wales in 1934. His dad was a miner but didn't want his sons to follow him and all three boys worked in the aerospace industry. With the help of his older sister Sam saved enough money to buy a house when he got married to Elaine. They have one son (deceased) and a daughter and in 1997 they moved to South East England to be near their daughter and their grandchildren. Two months after their move, Sam suffered a stroke. He recovered from a relatively minor stroke with only minimal left-sided weakness. During his convalescence he became very agitated and began accusing his wife of being an impostor. He also thought that visiting relatives were being impersonated by strangers and that this was all part of a plot to deprive him of his money. He frequently threatened to strike others, although he did not actually commit violence. At times he broke down and 'wept copiously, apologizing to his wife somewhat over-effusively'. He was admitted to a psychiatric unit where an electroencephalogram and a CT scan revealed cerebral abnormalities, especially but not exclusively on the right side. Sam was diagnosed with post-traumatic stress disorder. His symptoms gradually improved on anticonvulsant treatment. He returned home functioning on a somewhat limited level but apparently 'free of delusions. He has repeatedly relapse after discharge because he stops his medications. Since Sam's mental ill health 'is lifelong', he remains under permanent psychiatric supervision.

Sylvia Lawrence (f. Borderline Personality Disorder/Depression, interviewed August 17th 2016) Sylvia was born in 1938 in the small semi-rural town where she still lives. She was one of five children. She worked in a factory when she left school until she married at 20. She had four children, one of whom died from a brain tumour aged 29. Sylvia worked part-time as a cleaner and supervisor in a local hotel and leisure complex and as a school dinner lady. Her husband was a long-distance lorry driver and died from a heart attack in 1999. Sylvia attributes the start of her mental ill health to the stress caused by the death of her daughter and her husband. She struggled with persistent and overwhelming feelings of fear and experiencing excessive anxiety especially in social situations. She became withdrawn, 'painfully shy', socially inhibited and 'felt inadequate'. Sylvia was admitted into a psychiatric hospital where she remained for over a year. She was diagnosed with personality disorder and severe symptoms of depression and anxiety. She was treated with ECT and medication for depression, anxiety and psychotic symptoms. She also received a course of psychological therapy for six months. She feels much better though ‘often fatigued’, but still likes to get out of the house to shop and to visit her dwindling number of friends and her three sisters and brother, who all live nearby.

Trevor Barrat (m. Schizoaffective Disorder/Depression, interviewed September 17th 2016) Trevor was born in 1935. He worked in horticulture for much of his life and ended his career as groundsman at his local city football club. He lived for 20 years with diabetes and was proud of the systematic way he managed his life to maintain health. He took the same approach to life with mental ill health. Trevor’s doctor suspected that he had schizophrenia after complaining of symptoms of agitation, sleeping very little, hallucinations and delusions. He referred Trevor to a psychiatrist. He was finally diagnosed as having a combination of symptoms reflecting two separate mental illnesses, schizophrenia and major depression. He was treated with antipsychotic drugs and counselling. The side effects of his mental ill health treatment gradually abated though he still could not tackle the heavier work he would like to do in his garden. His sons helped with this.

William Morris (m. Post-Traumatic Stress Disorder (PTSD), interviewed September 21st 2016). William was born in 1931 in a large Semi-rural town. He left school at 14, had a few different jobs and then did National Service in the army, where he was stationed in Europe. He didn’t care much for military life. On discharge from the army in 1958 he worked as a postman for a short time before getting a semiskilled factory job as a turner, making engine components. At that time, he moved, with his wife, to the house they still live in, where they raised two sons. William worked at this job until 1988, when he was made redundant. Subsequently, he worked until retiring aged 65 in a local hospital, again delivering the post. Until retiring William had always been fit, but since then has undergone numerous operations. PTSD ‘came as a surprise, without any overt warning symptoms, in 2000’. He began to have ‘visual flashbacks, nightmares and vivid dreams. At times he would be afraid to sleep because of the nightmares he was having. He was diagnosed with post-traumatic stress disorder and treated with medication and psychotherapy. He is hopeful that the treatment will ‘help him regain a sense of control over his life’

4.6 Summary

In this chapter I have explored some conceptual and practical matters informing the design of a narrative study. I have given a detailed account of the ethical principles and practice governing my approach to interviews with potentially vulnerable participants on a sensitive subject. I have explained the method of sampling and the recruitment procedures employed and have introduced each of the study participants. In the next chapter I report in detail the methods used to generate, analyse and interpret the narrative data sought from these participants in relation to their life with mental ill health.

Table 4.1 Demographic characteristics (details derived from participants' own narratives. No questions were asked directed at seeking this information).

Name (Pseudonym)	Age at Interview	Age at Diagnosis	Gender	Diagnosis	Marital Status	Living With	Other Family	Occupation/S	Mental Health Treatment	Comorbid Conditions	Family Experiences Mental Ill Health
Barbara Vine	84	62	F	Paranoid Schizophrenia	W	Alone	2 daughters 1 son grandchildren	Factory	Medication Mental Hospital ECT	Obesity Stroke Osteoarthritis	Husband committed suicide after severe depression
Christine Mendelson	76	59	F	Severe Depression Anxiety Disorders	W	Daughter	2 children	Part-time - jobs School-secretary	Psychiatric hospital Medication ECT Psychotherapist	Heart disease Osteoporosis Hypertension Anorexic	None mentioned Significant past: Death of spouse
Clive Holmes	76	64	M	Adjustment Disorders Depression	W	Alone	1 son 1 daughter grandchildren	Merchant-Navy Factory-manager	Psychotherapy Medication ECT	Prostate cancer Bronchitis	None mentioned Significant past: Wife died of cancer
Doris Snelling	92	59	F	Depression Suicidal Feelings	W	Alone	1 daughter 1 son	School-secretary	Mental Institute Medication ECT Counselling	Rheumatoid & Osteoarthritis	None mentioned Significant past: 2 sisters died Total abdominal hysterectomy @56yrs

Table 3.1 Demographic & Disease Characteristics (details derived from participants' own narratives. No questions were asked directed at seeking this information).

Name (Pseudonym)	Age at Interview	Age at Diagnosis	Gender	Diagnosis	Marital Status	Living with	Other Family	Occupation/S	Mental Health Treatment	Comorbid Conditions	Family Experiences Mental Ill Health
Henry Hornby	83	68 ish	M	Paranoid-Schizophrenia Depression	W	Alone	1 daughter grandchildren	Army Plumber	Mental Hospital Psychiatrist Medication ECT	Heart Condition Orthopaedic	None mentioned Significant Past: Wife died in her 30's
John Murray	83	48	M	Post-Traumatic Stress Disorder Acute Stress Disorder	W	Daughter	2 daughters 1 son (died) grandchildren	In the Army Labourer Aerospace	Mental Hospital ECT Medication Psychotherapy	Orthopaedic	None mentioned Significant Past: Wife died Son died
Josephine Barnes	87	54	F	Paranoid Schizophrenia	M (2nd)	Husband	2 daughters (1 deceased)	Factory Mill	Mental Hospital Medications ECT	Diabetes Hypertension	None mentioned Significant Past: Physically abused by first husband. 1 daughter died In car crush age 26.
Judith Pinkett	74	50	F	Bipolar Disorder Depressive Disorder	M	Husband	4 children 2 deceased	Shop-assistant Factory	Mental hospital Medication ECT	Rheumatoid-arthritis Diabetes (II)	None mentioned
Louis Green	88	61	M	Persistent Delusional Disorder	W	Alone	2 daughters 1 son grandchildren	Army Engineer	Psychologist Mental hospital ECT	Osteoarthritis Diabetes	Wife Died Attempted suicide Head injury (Army)

Table 3.1 Demographic & Disease Characteristics (details derived from participants' own narratives. No questions were asked directed at seeking this information).

Name (Pseudonym)	Age at Interview	Age at Diagnosis	Gender	Diagnosis	Marital Status	Living With	Other Family	Occupation/S	Mental Health Treatment	Comorbid Conditions	Family Experiences Mental Ill Health
Mark Davies	88	73	M	Obsessive-Compulsive Disorder Anxiety disorders	W	Alone	3 children grandchildren	Agriculture	Psychiatrist ECT Medication	None mentioned	Significant Past: Wife died of cancer
Mary Willis	76	58	F	Agoraphobia Neurotic Depression Bipolar Disorder	M	Husband	1 daughter grandchildren	Wage office Shop-assistant	Medication ECT Psychotherapy	Diabetes II Obesity Osteoarthritis	None mentioned
Norah Jarvis	79	31 ish	F	Manic Depression	D	Alone	2 children grandchildren	Clerical work	Psychiatrist Medication ECT	Irritable bowel Osteoarthritis	Significant Past: Violent husband Physically abused
Norma Williams	84	45 ish	F	Hypochondriacal - Disorder Anxiety Disorders	W	Alone	3 daughters (1 deceased) 2 sons	Machine-operator Cleaner Nursing-auxiliary	Medication Counselling Mental Health Unit	Osteoarthritis - hip. Kidney disease	Death of Parents Death of Grandparents Separated from Siblings 2 Miscarriages Hysterectomy
Peter King	75	40 ish	M	Panic Disorder Generalised Anxiety Disorders	M	Wife	2 daughters	Engineering apprentice Factory manager	Psychiatric - Hospital. Medication ECT Treatment Counselling	Learning-disability Genetic-disorder Diabetes II	Significant Past: Attempted suicide (1971). Respite care (1976)

Table 3.1 Demographic & Disease Characteristics (details derived from participants' own narratives. No questions were asked directed at seeking this information).

Name (Pseudonym)	Age at Interview	Age at Diagnosis	Gender	Diagnosis	Marital Status	Living with	Other Family	Occupation/S	Mental Health Treatment	Comorbid Conditions	Family Experiences Mental Ill Health
Richard Burns	91	66 ish	M	Complex Post-Traumatic Stress Disorder	M	Wife	3 children	Engineer	Drug therapy ECT Psychotherapy	Prostate cancer Osteoarthritis Kidney	Significant: Heart attack 1980's
Rosemary Jackson	84	63	F	Manic Depressive Disorder (Bipolar disorder. Anxiety Disorder	W	Alone	2 children	Bank Cotton mill Factory	Drug therapy ECT Counselling	Diabetes II Osteoarthritis Hypothyroid	Significant Past: Death of husband
Sam Shaw	82	71	M	Post-Traumatic Stress Disorder	M	Wife	1 son (deceased) 1 daughter	Aerospace industry	Psychiatrist Medication ECT	Diabetic Heart Disease	Suffered a stroke in 2001
Sylvia Lawrence	76	61	F	Borderline-Personality Disorder Depression	W	Alone	2 sons 2 daughters (1 died)	Factory Cleaner Supervisor	Medication Psychotherapy ECT	Asthma	Daughter's death Husband's death
Trevor Barratt	81	63	M	Schizoaffective Disorder, Depression	M	Wife	2 sons 1 daughter	Horticulture	Medication Psychotherapy	Diabetes II	None mentioned
William Morris	85	66	M	Post-Traumatic Stress Disorder	M	Wife	2 sons grandchildren	Army Postman Factory	Medication Psychotherapy ECT	Asthma	Numerous-operations Hypertension

CHAPTER 5

DATA GENERATION AND ANALYSIS

5.1 INTRODUCTION

In this chapter I report and reflect on the methods chosen to generate, analyse and interpret original empirical data intended to answer the question, ‘What are the subjective experiences of living with long-standing mental ill health described by men and women aged 75 and older?’ I begin with some commentary on epistemological matters concerning qualitative research data before going on to a detailed account of the primary method of data generation used in the study, the Biographic-Narrative- Interpretive Method or ‘BNIM’ (Wengraf, 2008, 2001). I go on to describe and explain at length the methods used to transcribe the interview data and subject them to a two-stage narrative analysis based on the concept of the *illness trajectory* (Corbin & Strauss, 1988) and on a reading of participants’ illness narratives (mental ill health stories’) in the light of their life histories.

5.2 Method of data collection/generation

The phrase ‘data collection’ implies that data already exist, just waiting for a researcher to pick them up, by whatever means deemed to be most appropriate to the circumstances (interview, questionnaire, focus group). In reality, the kinds of data sought for qualitative research studies (experiences, ideas, opinions) rarely exist in a pre-formed state, independently of the circumstances which researchers create to collect them. As already noted, the interview situation itself contributes to the type of data that are produced (Silverman, 2017). The phrase ‘data generation’ more accurately describes this process of constructing, not merely reporting, data (Wolcott, 1994).

In order to generate data for this study I conducted narrative interviews with twenty men and women aged 75 and older, living in a semi-rural county, with one or more of four major mental disorders (see Chapter 4). Interviews took place in the participants’ homes, by their choice, and lasted between 2 hours (longest) and 38 minutes (shortest). All but three of the interviews fell within the optimum length of around 90 minutes for a single interview in narrative research (Hermanowicz 2002; Seidman, 1998). Written consent to their participation in the study was obtained from each person at the time of interview. Interviews were audio-recorded, with permission, and field notes taken during the course of interview, supplemented by immediate post-interview debriefing notes (Wengraf, 2001). My approach to narrative interviewing was informed by reading of cross-disciplinary methodological and theoretical literature in the fields of life history and narrative research (Atkinson, 1997; Bornat, 2002; Bruner, 1987,1991; Bury, 2001; Clandinin and Connelly, 2004; Cole & Knowles, 2001; Elliot, 2005; Frank, 2013, 2000; Riley & Hawe, 2005; Roberts, 2002; Sparkes & Smith, 2005; Stanworth, 2004) and finally determined by the Biographical-Narrative Interview Method (BNIM) (Wengraf, 2008; 2001).

My reading of this method, and application of it in my first interviews, led me to conceptualise a narrative interview as one in which the informant is enabled to tell a story. In my use of the word 'story' I am following Riessman (2008) in not being over precise about the distinctions between 'narrative' and 'story' and Webster and Mertova (2007) in emphasizing the importance of the 'connected unfolding that we call plot' (p.19) as a defining feature common to all stories. This sounds straightforward but it requires a very different approach from, say, a semi-structured interview using an interview schedule based on questions which are designed to elicit a type of information pre specified by the researcher. The story or stories sought in narrative interviewing according to the BNIM method may be whole-life stories or they may be partial life stories, about a particular aspect of the participant's life relevant to the research topic. The interviewer asks the informant to tell the story and then listens to what is said. No interruptions are made, nor guidance given, which would influence the direction of the story towards the interviewer's interests and perceptions; rather, the informant is encouraged, by attentive listening, to keep talking until they have no more to say. Apparent diversions which might seem to contain irrelevancies are tolerated because, like a meandering river which eventually comes back on course, the diversion can produce material that does turn out to be useful and that may not have been generated with a more purposeful attempt to stay on track by interviewer questioning.

5.2.1 Biographic-Narrative Interview Method

I decided to use the Biographic-Narrative Interview Method (BNIM) because it offered a useful combination of openness and structure. I will go on to describe technical details of the method and ways in which it was modified in use during the course of my interviews.

BNIM requires that the interviewer first invites the participant to tell the story of interest, in their own words and without interruption from the interviewer. This is known as ‘sub-session 1’ of the interview. Agreement is gained that the interviewer will take written notes (as well as audio recording) during sub session 1 and that after the respondent has finished speaking and following an interlude in which the interviewer formulates questions based on the written notes, the interview will continue with questions. This is known as ‘sub-session 2’.

The questions in sub-session 2 follow the sequence of topics in the order that the respondent has spoken of them, in order to maintain the ‘gestalt’ (i.e. wholeness) of the interview and to honour the participant’s disclosures: to ignore something they have told you is to disrespect them, potentially to alienate them (Wengraf, 2008). Questions in this sub-session are designed to deepen and enrich the stories told, not to satisfy the interviewer’s curiosity on related topics, even those of relevance to the research question. Such questions may be asked in a ‘sub-session 3’ of the interview which, typically, will take place on a separate occasion (otherwise the interview is likely to go on too long for most participants’ comfort) and may be conducted over the telephone. Questions in sub-session 3 may take the form of a semi-structured interview. Questions in sub-session 2 should be of a narrative kind, asking for more detail on ‘what happened?’ I found that a single ‘story-telling occasion’ (Frank, 2000) comprised of a sub-session 1 and 2 yielded sufficient data from each participant and that it was not necessary (or practical) to conduct a sub-session 3 of any of the interviews.

The strengths of this interview method are that it enhances the possibility that participants will speak of what they want to say, not what they might think the interviewer wants to hear, and that the combination of structure and openness allows flexibility for in-depth exploration. A major limitation of the method in use is that, in my view, it is too tightly structured, and its prescriptiveness can undermine the advantages of an open style of interviewing.

5.2.2. Modifying the method in use

From the first interview I found that I wanted to introduce modification to the method. I call these modifications 'variants.' By 'variant' I mean a decision I made to do something other than that prescribed in the method.

Variant 1. The initial question, intended to stimulate the participant to tell a story or stories related to the research questions, is supposed to be carefully composed and asked precisely as written. Wengraf (2008), fond of acronyms, calls this a 'SQUIN'; that is, a 'Single Question aimed at Inducing Narrative.' I found this to be unworkable. Reading a question, even one you have composed yourself, is not the same as asking it; and speaking it as written, without variation, is difficult in the dynamics of a social interaction (Mishler, 1986). Typically, a pre-prepared SQUIN is quite a long question and I found some people interrupting me, eager to begin talking, before I had finished asking the question, or appearing visibly anxious as though they were going to be asked to do something, they felt unsure of.
My variation was to explain, using the core material from the question, before the interview began what I would be asking and then, at the beginning of the recording, refer back to the question. There is variation across the interviews in my precise wording of this. Mishler and colleagues (1986) argued that this is unavoidable and that it is unrealistic to expect absolute consistency in the interactional dynamic of a comparatively naturalistic interview setting. The content, and form, of the SQUIN changed slightly over the course of the interviews to invite life history as well as illness narrative.

Variant 2. Wengraf recommends the use of a customised notepad for notetaking during sub-session 1. I found this to be too prescriptive and that concentrating on trying to use it diverted my listening attention away from the participant. I only used it on one or two occasions, replacing it with my preferred method of a small notebook with blank pages and landscape orientation which could be held and used more discreetly, leaving me freer to interact with the participant (eye contact, bodily gestures, para-verbal vocalisations) in ways which encouraged talk.

Variant 3. Wengraf recommends an interlude of several minutes in which the interviewer composes questions for sub-session 2 based on the notes taken in sub-session 1. He suggests separation from the participant by some means (inviting them to make a cup of tea; taking yourself to the bathroom). On the one occasion (first interview) that I tried this I could not use the tea making strategy as the participant was not very mobile and it seemed too ridiculous and artificial to take myself to the bathroom for the purpose of note-taking. Consequently, I remained seated and with the agreement of the participant spent several minutes (about five) looking through my notes and composing questions. A long silence between individuals in a face to face interaction is uncomfortable. Hence the participant, after an interval of a couple of minutes, began to make comments about the interview and his hopes that it would be of use. I found this distracting, because I had to make a verbal response while trying to think about my questions.

My variation in subsequent interviews was to compose questions more spontaneously, based on reference to my notes (variant 2). This allowed a flexibility and a freedom of exchange which enhanced the interpersonal qualities of the interview, making it seem more like a conversation (McCormack, 2000; 2004) putting the participant, in most cases, more at ease and more ready to talk.

The risk of this strategy was to damage the ‘gestalt’ of the interview. For example, sometimes I began sub-session 2 with a question which followed up a story that had closed, rather than opened, sub-session 1. In the BNIM method, not only is the interviewer supposed to begin questions on the topic which the participant first spoke about, but the questions should be in a forward direction only. That is, you are not supposed to return to a topic that you have not asked about after a topic that you *have* asked about. I found this to be too rigid a prescription. On occasions where I began a sub-session 2 in the way described above, I found opportunities

later in the interview to return to earlier stories, to encourage a deepening of the narrative, and thus maintain the gestalt of the interview. Although I have been concerned throughout the study with the technical aspects of conducting narrative interviews, I was also aware that the foundation of a successful interview is in the relationship forged with the interviewee. Life experience, maturity and social skills, as well as previous experience of conducting life history interviews, all played a significant part in helping me to establish and maintain a relationship of trust with the participants in the study, beginning at our first encounter in the outpatient clinic or on the phone for participants who responded to the adverts. It was this relationship which encouraged participants to talk to me in detail about their lives.

Using extracts from my field notes and reflective journal, shows the developments in my thinking about the BNIM interview method, focused on the use of the Single Question aimed at Inducing Narrative (SQUIN) over a formative three-week period preparing for and conducting the first interviews. These extracts show the key transition made from focusing exclusively on eliciting stories of participants ‘experiences since receiving a mental disorder diagnosis to incorporating an additional interest in their life story/biography before getting mental ill health. This was a key transition because it had become apparent from the first interviews that participants responded differently to the, broadly, similar request to tell the story of their mental ill health. In the first interview (John Murray) the participant spontaneously recounted stories extensively from his life before mental ill health, feeling that he did not have much to say about his experienceof mental illness. The third interviewee, by contrast, (Clive Holmes) presented a detailed and documented medical history, with few references to his life. The second interview (Josephine Barnes) fell somewhere between the others in offering a brief account of her illness, with incidental and occasional reference to aspects of her life before she got a mental disorder.

Reflecting on these differences in the light of my continual puzzling over method it appeared to me that the goal of understanding the impact of mental ill health on older people’s lives would be more likely met by explicitly seeking to generatedata based on their wider life story. In subsequent interviews, therefore, I invited participants to tell as much or as little as they liked about their life story before

they got mental illness in addition to the details of their mental disorder experience. This freedom to choose the amount of detail disclosed, without any direct questioning, maintained the spirit of BNIM inquiry. The data generated in this way provide material which helps to contextualise the experience of mental ill health. The analysis and interpretation of findings chapter, in particular, will provide analysis and interpretation of the ‘mental ill health stories’ in the context of what participants told me of their life stories.

It should be remembered that these are not whole life stories, but partial and selected accounts told on a single ‘story-telling occasion’ (Frank, 2000). Elicitation of whole life stories would be likely to take many hours of interviewing (impractical within the boundaries of this study) and even then, would yield partial accounts as people inevitably select from what they remember on particular occasions and what they wish to reveal to particular hearers. My intention, rather, was to seek a partial account, knowingly, in order to provide a) social ‘lubrication’ for the interview situation and b) context for the illness narrative which was the primary focus of attention.

5.3 Analytic method

5.3.1 Preliminary analysis: Transcription

Transcribing audio-recorded interviews can be seen to lie on the borderline between data generation and data analysis. Turning speech into text is the final act in the production of the interview as ‘data,’ though what is produced is more than simply a written version of the oral event (Czarniawska, 2004 citing Ricouer on ‘discourse’ and the interview as a speech act). If transcription is performed by the interviewer, it is, at the same time, the first act of analysis and interpretation. Sensitised to the theoretical importance of transcription by Elliott (2005) and Riessman (2008), I decided to transcribe the interviews myself. I did not commit myself to an analytic method beforehand but sensed the importance of immersing myself in listening to the interviews while transcribing them. The benefit of such immersion is to allow time for thinking about the data as you perform the task of transcribing them. The task was made

technically easier by use of transcription software (Express Scribe) and although it was time consuming, I regarded the time spent as a valuable investment in a stage of preliminary data analysis.

I conducted two stages of transcription. In the first version, which I called the ‘raw transcript,’ I concentrated on making a verbatim recording of the whole interview, including paralinguistic utterances, and adding marginal commentary on the interview content, on body language and on extra-vocal sounds (e.g. one participant rubbed his hand continually on the arm of his chair, a sound which was clearly picked up by the recorder placed nearby). I made this transcript as soon as possible after the interview (usually within a day or two) and, preferably, before conducting the next interview (I achieved this in all but one case) so that my memory of the interaction was fresh.

In the second version, which I called the ‘worked transcript,’ I concentrated on constructing the interview as a written document, paying attention to the insertion of punctuation marks and paragraphs. The initial impulse for doing this was so that my supervisors could read a transcript. Having had experience of reading long transcripts of interviews which I had neither conducted nor heard, and which were rendered verbatim with no imposition of structure or grammar, I felt that it was important to make the transcript readable.

I also wanted the transcript to reflect the character and personality of the speaker. Consequently, I tried to represent speech patterns, rhythms, accents, idiosyncrasies of grammar and punctuation, as faithfully as possible. I wanted the transcript to sound like the voice of the person I heard, as a way of representing their individuality. For example, many participants frequently used ‘like,’ as a qualifier or as a way of pausing to represent ongoing thought. Many dropped initial consonants or end vowels to blend the definite article with a vowel sound (‘th’ospital; ‘th’army’). Some words were regularly truncated (‘wi’ for ‘with’) and the possessive pronoun given as ‘me’ (sounds like ‘mi’ as in ‘give’) instead of ‘my.’ Plural participles were substituted for singular (‘were’ for ‘was’) and there were frequent glottal stops (‘end o’t’ day’).

McCormack (2000, 2004) makes the ‘lens of language’ a particular feature of her narrative analysis of conversations with a postgraduate student on the theme of leisure. She makes observations about the significance of her own language (diction) and of the implications of pauses in the informant’s speech (signifying hesitancies of thought). I stopped short of drawing such inferences from the particular ways of speaking recorded in the worked transcripts. But I continued to regard the faithful rendering of speech as a way of honouring the individuality of the participant (reflecting the moral purpose driving the research) and of providing a basis for analysis and interpretation of the data. My own positive attitude towards this practice was reinforced by enthusiastic responses from two critical readers (my supervisor and a member of my review panel) of one worked transcript who both felt that the method of transcription enhanced the reader’s ability to engage with the content of the interview and to interact with the person as an individual.

Transcripts were created as analytic tools. They represent my rendering of the data generated in the interview and form the basis of my ‘retelling it afterwards’ (Bourdieu,1993 p.61). Many qualitative researchers choose to return transcripts to participants (Lincoln & Guba, 1985; Riessman, 2008). There is a putative analytic purpose for doing this and a moral purpose. The putative analytic purpose is to request that the participant check the transcript for accuracy, so that the researcher can be sure that the data as recorded represent the data as given. I call this a ‘putative analytic purpose’ because I think, respectfully, that no serious analytic purpose is served by this strategy. On the contrary, returning transcripts can have the effect of distracting from the data. The transcript differs from the interview in being a form of written discourse rather than speech (Czarniawska, 2004 citing Ricoeur). Consequently, participants sometimes focus on their dissatisfaction with their speech as recorded, particularly where it deviates significantly from standard English, to the extent of requesting that the record of their speech is altered so that it sounds, for example, more grammatical (Czarniawska, 2004).

In addition, participants may, when reflecting on the written record of their spontaneous speech, wish to exclude some of the content of the interview. To acknowledge the participant's ownership of the research data in this way is part of the moral reason for returning transcripts. It is, of course, the participant's right to make such requests. However, the researcher does not, I would argue, have a corresponding duty to create a situation in which some of the data may be removed.

I thought long and hard about whether to return transcripts to participants, having made the assumption that I would do so, based on my familiarity with literature on qualitative research methods and ethics. I decided that I would not return transcripts routinely, though would supply them if requested. The reason for this decision lies in the nature of the contract I had established with participants. Essentially, participants agreed to give me their stories on the condition that I would write something about them that would be helpful to other people in a similar situation (see Participant Information Sheet, Appendix 4). I agreed to feedback products from the research (i.e. completed pieces of work) but did not commit myself to return interim work. The Participant Information Sheet states that:

- You can have a copy of the recording to keep if you want one (implication: you have to ask)
- You can have a copy of the transcript and comment on it if you want to (implication: you have to ask)
- I will give you a copy of the final results and I may ask you to comment on preliminary findings (implication: commitment to send final product but permissive on pre-commentary).

The sole commitment in terms of initiating action is that I will send a copy of the final report (probably a summary of the research findings written for a lay readership). None of the participants asked for a copy of the interview transcript. One participant asked for a copy of the audio-recording of the interview, which I duly supplied on a CD (his preferred medium). One participant asked what I 'was going to do with all this' and I explained to her in outline the process of transcribing and analysing the interview and of writing up the research.

5.3.2 Substantive analysis 1: Seeking a narrative method

Narrative research is a family of methods (Riessman, 2008) and it is not always clear that there is an analytic process readymade (unlike Grounded Theory, for example) which can be applied. Narrative data are qualitative data and can be analysed in any of the ways that qualitative data are analysed; by applying coding frames of various kinds to generate themes and categories, which may form the basis of interpretation and/or theorising.

Or, they can be analysed narratively (Bingley et al. 2008). This means that the 'coding frame' is formed out of narrative features that are embedded in the telling of stories: for example; time, place, personal and social context (Clandinin & Connelly, 2004). 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). Some analysts also pay particular attention to the form (language and structure) in which stories are told as well as, or instead of, their content (see Elliott, 2005 on Labov, Gee etc., Frost, 2009).

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).

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). I chose a narrative device to structure analysis of my interview data in the concept of the 'illness trajectory' (Corbin & Strauss, 1988), with a view to answering the research questions. The illness trajectory consists of a temporal arc during which a particular series of events typically occurs (not as straight forwardly linear as represented here, obviously, but the general shape holds good):

- the first noticing of signs or symptoms (of mental disorder, in this case)
- subsequent 'health seeking behaviour' (i.e. telling somebody about it; going to the doctor)
- referral to specialists
- investigations
- diagnosis
- treatment
- situating self-living with mental ill health beyond treatment

From repeated listening to the interviews, and the two-stage transcription of speech into text described above, I sensed that my data could be interrogated fruitfully using this device. Most of the participants told 'mental ill health stories' which could be seen to follow something like this trajectory (there was one notable exception). The 'mental stories' extracted from these interviews are responses to the basic request, phrased slightly differently among the interviews (Mishler,1986), 'Tell me what happened'. The responses to this request were not always straightforwardly sequential. Participants started at different places in their life, some with birth (Richard), some with more recent events (Mary began with the death of her husband), one with the mental disorder story itself (Judith). Two participants told stories structured by thought-association rather than by chronology (Rosemary and Sylvia).

Sometimes I uncovered more detail and more chronology at a later point in the interview. So, the ‘told mental ill health stories’ which are the basis of this analysis are in some ways constructed by me from the data. They are all the participants’ words, but they are not all whole sequences which were clearly embedded in the interview just waiting for me to lift them out.

The findings reported in chapters 6-8 are based on these told mental ill health stories, contextualised and interpreted in the light of relevant literature and theory. I really wanted to be able to reproduce the mental ill health stories at length (see Bourdieu et al, 1993) but, at more than 46 000 words, they are too lengthy. There are, though, two mental ill health stories which are short enough to be reproduced in full and one of them may be used as an example of how I used the concept of the illness trajectory as a structural device for analysing the interviews.

The story of Doris’s mental ill health is given a title using a phrase from her own speech (see McCormack 2004; Bourdieu et al 1993). The transcript is organised, here, to draw attention to its structure as it relates to the illness trajectory. Note that in the interview and in the worked transcript all this material is sequential.

Well, you could have knocked me for six

[First signs/doctor and referral/investigations]

Once again, I felt in my life, there was a brick wall in front of me that needed to be knocked down.
and I went to the doctor.
So, he sent me to hospital. This was too big for me I had to be hospitalised.
And, of course, they done the tests, and things.

Diagnosis and reaction]

And then they said it was severe depression.
Well, I was that…honestly, you could have knocked me for six.

[**Treatment]**

I was on medication, but I personally felt that I was not getting any better.
I'd had enough. So, my medical suggested that I think about ECT combined with medication. I was scared and apprehensive due to its bad press. My family were also totally against it. So, to finish up, then, the ultimate decision was my own and thank God I made the right choice and signed and agreed to ECT
I was in almost a year. I was in over Christmas and the New Year.
After I had a few ECT sessions, I felt light and my mood was changing. I did not want to sit in my room alone anymore. They gave me hope, I felt I was extremely lucky with the medical team who were so eager to help me get well. Slowly I felt I was pulling myself up the ladder from the darkness at the bottom…yeh
And the dirty window I was looking through was starting to become clean…

[Situating self in a life with mental ill health]

So, thank God, I've felt alright since. The only thing about… I've no balance for walking but that has nothing to do with that, you know.
The whole ECT team did a fantastic job at putting me at ease and supporting me through the experience.
The doctor did a good job, so he did, yeh, not so bad.

This narrator was brief and concise, but also comprehensive: all stages of the illness trajectory are reported, in outline. Other participants told longer, equally comprehensive but more detailed and expansive stories. In some it was less easy to trace the illness trajectory from the told-story.

5.3.3 Substantive analysis 2: Reading the mental ill health stories in the context of participants' life histories

The next chapters draw on the wider life stories participants told. The findings in these chapters are based on an exploration of the narrative interview data using the analytic questions, 'What other stories is the person caught up in?' and 'What differences depend on being caught up in these stories?' (Frank, 2013). The analytic strategy here began with a decision that the outcome I wanted to achieve was a piece of writing which wove together description of the data (what the participants said) with analysis and interpretation (what I did with the data and how I made particular meanings out of them), to provide both a discursive and explanatory account of what participants told me about their lives with mental ill health (Frank, 2013).

The method I chose to do this was initially to focus on the structure of the life story as told by the participant. There was great variation in the detail and length of the life stories, so for this analytic purpose I chose an exemplar interview: one with a clear chronological structure and rich in biographical detail (John Murray). The method was inspired by a combination of Labov & Waletzky's (1967) structural analysis and McCormack's (2004; 2000) approach to analysis of in-depth interview conversations. Essentially, this meant identifying relatively self-contained *episodic tales* (my coinage) within the story as a whole and labelling them with an *in vivo* title taken from the story (Bourdieu et al 1993; McCormack, 2004). This was a time-consuming process and unworkable as a method to be applied to all twenty narrative interviews. However, the process provided what might be called a 'sensitising mechanism' which fostered close attention to all the interview data on repeated re-reading and re-listening. Four additional interviews (one from each mental disorder group) were analysed using the *episodic-tales* approach with *in* vivo labelling, but without the micro-structural methods of Labov & Waletzky, in order to deepen familiarity with the interview content.

The overriding principle driving this method was an attempt to preserve a holistic rather than a categorical approach to the data (Riessman, 2008). This was a challenging and difficult process because, while I wanted to preserve a sense of the wholeness and uniqueness of each interview, at the same time, I wanted to make comparisons across interviews. For example, in relation to the analysis and interpretation of the life stories, told in the context of living with mental ill health, a dominant and cross-cutting theme of 'resilience' emerged, through a combination of familiarity with the data and a pre-existing orientation to the concept from the findings of my qualitative systemic review (Chapters 2 & 3).

In addition, I interrogated the life story data from a more etic perspective using analytic questions suggested by Frank (2013): ‘What other stories are people caught up in?’ and ‘What differences depend on being caught up in those stories?’. Exploring the data in the light of ‘grand narratives’ (Davey and Seale, 2002) and the ‘lens of culture’ (McCormack, 2004) further helped to situate and interpret the private experiences reported by these participants in a broader social context.

5.4 Summary

In this chapter I explained in detail the methods of data generation and analysis applied to this narrative research. I argued that qualitative data are inevitably co-constructed in the interaction between interviewer and interviewee and that life-story data generated in this way should always be considered as partial, selective accounts. I gave a detailed account of the specific interview method chosen for this study, indicating some of its strengths and weaknesses and showing where I modified it in use. I proposed a four-stage analytic method comprising a preliminary stage of transcription, followed by two substantive phases based on the concept of the ‘illness trajectory’ and on ways of reading the participants’ illness narratives in the light of their life histories. A final stage of analysis situated participants ‘personal stories in a broader social context. In the next chapters I present the findings derived from the data using these analytic methods, interwoven with interpretive commentary which is informed by selective reading from relevant bodies of literature.

CHAPTER 6

ANALYSIS AND INTERPRETATION OF FINDINGS (1) FIRST SIGNS OR SYMPTOMS OF MENTAL ILL HEALTH AND MEDICAL CONSULTATIONS

6.1 INTRODUCTION

In this chapter, and the two following chapters, I report and interpret findings from the narrative study which relate to the diagnostic and treatment periods of the participants' experiences of mental ill health. I attempt both a holistic and a categorical analysis (Riessman, 2008) by preserving as much intact narrative as possible, in the form of extensive quotations from interview transcripts, while at the same time presenting a thematic analysis in order to make some comparisons across cases. I present the findings with interpretive commentary in the light of relevant literature. I begin with analysis of the participants' stories of the first signs or symptoms of mental ill health and their help-seeking behaviour. I go on to report their experiences of receiving and reacting to the diagnosis of mental ill health (Chapter 7) and conclude by reporting their experiences of treatment (Chapter 8).

Public health information about mental ill health has long stressed the importance of early detection as one way of reducing the burden of mental ill health but also makes sound economic sense. The underlying assumption is that if mental disorders are identified at an early stage of their development then treatment is likely to be more effective. Intervening early to tackle mental ill health can prevent future public health problems. Most mental illnesses begin before adulthood and often continue through life. Half of all lifetime cases of diagnosable mental illness begin by age 14 and three-quarters by mid-20s. Tackling mental health problems early in life will improve educational attainment, employment opportunities and physical health, and reduce the levels of substance misuse, self-harm and suicide, as well as family conflict and social deprivation. Overall, it will increase life expectancy, economic productivity, social functioning and quality of life. It will also have benefits across the generations. Intervening early in the illnesses of older age, such as dementia, will lead to better health for people in later life and lessen their dependence on health and social care services (DoH, 2009b; Wilkins et al, 2008). Failure to detect mental disorders denies patients potentially effective treatment, and enduring psychological distress has profound effects on patients' capacity to work and enjoy a reasonable quality of life, in addition to the effect on their families. The problem is that there is no pre-symptomatic screening available for mental-disorders but much can be done to support and improve the lives of people with mental ill health and their caregivers and families, such as:

- early diagnosis, in order to promote early and optimal management;
- optimizing physical and psychological health and well-being;
- identifying and treating accompanying physical illness;
- detecting and managing challenging behavioural and psychological symptoms; and providing information and long-term support to caregivers (Jackson et al, 2016)

The assumption is that successful screening increases the likelihood that those in need of treatment will be identified and appropriately treated. Beyond clinical settings, the ease of administration of most self-report measures of psychiatric disturbance makes them attractive options for use in large research studies in which full assessment by means of structured clinical interviews may be logistically and financially prohibitive. Consequently, developing the science of pre-symptomatic screening, along with health policies designed to provide screening services and to encourage their uptake, has been a major feature of mental healthcare and treatment over the last decade. In the USA for example, Mental Health America (MHA) a community based non-profit has online screening tools for depression, anxiety, bipolar disorder, eating disorders, post-traumatic stress disorder (PTSD), alcohol and substance use, early psychosis, work health, as well as screenings that are youth-focused and parent-focused. Their goal is to get every American screened and aware of their mental health as a way to promote recovery and reduce the time of untreated mental health problems. Most mental disorders, however, are detected as a result of symptomatic presentation followed by medical investigations (Jackson et al, 2016). This was true for all but one of the participants in *Mental Ill Health Stories*.

The stories of mental ill health detection told by these participants may be grouped into four types of experience: i) those detected by screening; ii) mental disorders which had not produced symptoms (felt experiences) but which were detected by discovery of a ‘sign;’ that is, a physical change in the body; iii) mental disorders which showed themselves through the experience of symptoms, gradually worsening over time; and iv) mental disorders which suddenly and dramatically broke through into the person’s life.

Table 6.1 (p. 145) summarises participants’ signs or symptoms and first medical consultations. In sections 6.2-6.5 (below) I report these stories of the diagnostic pathway (Jackson et al 2016) in some detail. I consider the stories in the context of delayed presentation (both patient and physician delay) and go on to link this to what I call the ‘timeliness’ of diagnosis.

6.2 Mental disorders detected by screening

It should be noted that routine mental health screening is not offered to people in the UK who are aged 75 and older. Sam (age 82, persistent delusional disorder) was the sole participant whose mental ill health was detected by pre-symptomatic screening, which was provided, in his case, after recovering from a stroke and ‘became confused’. Sam enjoyed a successful career as a general manager in industry. He moved around the country as he gained promotions and took the optimistic view that exposing his young family to different experiences would be good for their education. His skills were so well regarded by his company that when nearing retirement, he was asked to take on a challenging assignment, managing two factories which were in difficulties, in a city he had worked in earlier in his career.

While still at work, around the age of 63, Sam suffered a stroke. He recovered from the stroke with only minimal left-sided weakness. Sam reports that he felt well at the time of discharge. During his convalescence he became very confused and began accusing his wife of being an impostor. He also thought that visiting relatives were being impersonated by strangers and that this was all part of a plot to deprive him of his money. He frequently threatened to strike others, although he did not actually commit violence. Sam's overall health, according to him, was good except that:

> The lady District Nurse, from …, can't remember her name now, very pleasant soul, said, 'your vital signs are fine but your blood pressure is a bit… is a bit high, erm, by that I'm talking about 140 over 90 so not excessive but it's worth you going back and talking to your GP and perhaps pursuing it.'

Sam took this advice, continuing his story with an account of his conversation aboutthis raised BP with his own GP.

> So, I went back and saw my GP, who was a gentleman probably in his 60s, and explained that, and showed him the report, who said, 140/90? Oh, I wouldn't worry about that,' he said. 'When it gets to 145 or higher, we'll start considering it.' So, I said, 'Oh well, fair dos, but, you know, this lady District Nurse had suggested I come and talk to you about it.' I said, 'I have also been very confused since, er, I was discharged. My wife is not happy with me' 'Well,' he said, 'if you want to do something about it and that, I'll send you for a health check; it's up to you.' So, I said, 'Well, ok then, pursue it.' [laughs].

Sam had a computerized tomography scan (**CT** or CAT **scan**) which revealed cerebral abnormalities, especially but not exclusively on the right side. In hospital, Sam was anxious, agitated and dejected. He was then admitted to a psychiatric unit and was diagnosed with persistent delusional disorder. He was treated with antipsychotic medication and individual psychotherapy.

Sam returned home functioning on a somewhat limited level but apparently 'free of delusions'. He has repeatedly relapse after discharge because he 'keep forgetting' his medications. Since Sam's mental ill health is lifelong, he remains under permanent psychiatric supervision. Sam affirms the value of the CT scan when he observes that 'I have a lot to say for that scan'.

6.3 Mental disorders detected through discovery of a physical ‘sign’

Rosemary (age 84, anxiety disorders & manic depression) was undergoing treatment for anxiety disorders at the time of our conversation. I didn’t know this when I arrived at her house, an old cottage on the grounds of the ancient church which she tends and felt some anxiety about the effectiveness of my recruitment strategy as I thought she only had manic depression. As she began to speak about her experiences it turned out that, a year before her mental ill health was diagnosed, she was involved in a car accident, she was active, babysitting for whole days her young grandson, and keen to get back to ‘work’ in her role as a volunteer in a local charity shop.

Rosemary’s mental ill health was detected in her early 60’s when her district nurse referred her to hospital after noticing signs of trembling, agitation and rapid heart rate. But in Rosemary’s mind she relates it to a serious car crash that she experienced a year earlier.

> I did have a car crash twenty-four or twenty-five years ago. I was coming…I was working in the charity shop and I was comin ‘ome and I had a car crash and me car was wrote off and I had to go in hospital cos I was black [i.e. badly bruised] and I went in hospital. And, then, after, I’d to go for an x-ray and scan. Now, with the car crash and the seat belt, the chest and forehead had gone in. I mean, I might be wrong here but it was always at the back of me mind, with the crash, I was dizzy, aches and pains everywhere, no energy an… eh blackout before the crash. I went for a scan and they said, ‘Oh, it’s just external bruising.’ And it’s always been at the back of my mind, did it affect my brain or did I have depression before? But then I did have x-rays and I suppose…but always at the back of me mind I thought, ‘Did it affect my brain?’ But then, since then, I must have had it. I must have had depression cos I…it’s just one year…later.

The relationship of the x-rays and scan to the car crash is not easy to establish in Rosemary’s reconstruction but it appears that her forehead and chest, unknown to her, was indented and that this was noticed by hospital staff when she was admitted for treatment following the car crash. Consequently, this was investigated while she was in hospital. In Rosemary's mind, though, the car crash was the result of being 'dizzy, no energy an… eh blackout' before the car crash. This lay belief is eventually superseded by her acknowledgement that she 'must have had depression' before the crash.

Doris (age 92), Christine (age 76) and Judith (age 75) all discovered that they had major depressive disorder by noticing physical changes. In medical terminology this would be described as a 'sign' of disease, rather than a 'symptom', which is a subjective experience of feeling unwell. In a research study of 850 women aged 67-73, Hansson et al. (2010) investigated patient's beliefs about the cause of their depression and major depressive symptoms. They found that 85% of the respondents were aware that weight loss and sleep difficulties could be symptoms of depression but that they were less knowledgeable about symptoms other than low mood or sadness, such as unexplained aches and pains (see Rosemary's story above). Their knowledge of risk was overly optimistic, with 50% believing the lifetime risk of mental ill health is one in hundred (actually it is 1 in 6). And 75% were not aware that risk increases with age. A third of the sample were not confident about detecting change in their bodies. Both knowledge of symptoms and risk were strongly related to educational qualifications, with greater knowledge associated with more education.

The women in *Mental Ill Health Stories* discussed becoming aware of symptoms approximately two weeks after onset. This included recognition that their mood, thoughts and behaviour had changed and were impacting on their functioning, however they did not necessarily label their symptoms as depression at that time. Participants recognised the onset of their symptoms by comparing their current state with their past self, and by making comparisons with those around them. These comparisons were important in symptom recognition, as they helped participants to decide whether the change they were experiencing was 'normal'. For Christine it was simply that, 'I felt really awful and I thought this can't be how people feel normally when they are a bit sad.' Rosemary began suffering from unexplained severe body aches and pains. She wondered what was wrong with her, assumed it was ominous and associated it with the stress caused by her caring involvement in her grandson's chaotic lifestyle: 'Gosh, I'm not surprised, I'm not surprised it's…I've got all worked up over him, you see.'

Both Christine and Rosemary followed their brief description of recognizing the onset of their symptoms by reporting their prompt consultation with a doctor. Doris (92) and Judith (75) both experienced some changes but delayed medical consultation (for six and eight years respectively). Neither of them reflected specifically on the potential impact on the development of their disease and the possible effects of the delay in presentation on the effectiveness of treatment (Jackson et al., 2008). Wilkins et al (2008) note that awareness of symptoms does not in itself lead to help-seeking behaviour but that a certain level of concern about the symptom needs to be reached before a medical consultation is sought. Symptoms which most concern women include continuous low mood and disturbed sleep (Elwy et al, 2011). Such concern may be a necessary but insufficient concern for help-seeking behaviour as both Doris and Judith expressed both awareness and concern about their symptoms (including pain in Christine's case) butwere prevented by fear from consulting their doctor. There is a wide evidence base that these psychological treatments can reduce the impact and chronicity of major depressive disorder (Barry et al.,2012; Williams et al., 2007), and can also reduce the riskfor relapse (Thomas, 2013; Barry et al., 2012). However, efforts to treat major depressive disorder are undermined by poor help-seeking rates. Studies indicate that between a third and one half of those with major depressive disorder do not seek treatment (Yoshimura et al., 2013; Bebbington et al., 2009). Furthermore, long delays prior to seeking help are common; the majority of depressed individuals wait 12-months before seeking help (Yoshimura et al., 2013; Brugha, et al., 2011).

Judith began her account in a non-specific, disembodied way, without referring to any signs or symptoms, or even to her disorder:

> Well, it started off, I knew what it was, really, but I didn't want to face it you know [pause]. If I knew what I know now, I would have done it. But you can't… can you? So, I waited quite a while and then, in the end, I had to go and see to it. But I knew what it was, you know, you Couldn't…I knew exactly what it was.

When asked, ‘***Could you tell me a little bit more about what was happening to you that made you suspect you had mental ill health?***’ Judith was a bit more specific:

> Oh, well, I got the symptoms. I had Bipolar and I got the symptoms. I got a bad bout of depression, you know, the hopeless, despairing sort And I thought, you know, ‘That’s odd. I shouldn’t be like that.’ And I watched it. I watched it grow, you know. Then it all got weird in a why-am-I seeing-things that-aren’t-there kind of way and BAM! Ever heard a carpet talking? You’re not missing much. And I thought, ‘There’s something not right, here. It’s not right,’ you know, ‘go tomorrer.’ And I didn’t [sheepishly], you know. And it got to the stage when I couldn’t put up wi’ it any longer and I went [to the doctor].

Later in the interview, after talking more about her life story, Judith comes back spontaneously to the beginning of the mental ill health story and her ignoring of the first signs, in the context of a general, evaluative comment about her life:

> No, all in all I’ve had a good life. I don’t regret anything whatsoever, nothing at all. Me only regret is I didn’t go to the doctor’s sooner. That’s me one big regret. And I think if I’d have had some guidance, I would have gone but…
>
> -***What might have been different if you’d gone sooner?***
>
> Do’t know. I wouldn’t have had that worry all that time would I? You know, I wouldn’t have worried about it all that time, you know.
>
> ***-How long was all that time?***
>
> Oh, about eight years. Something like that. Which was a long time, really. I think it was about that long. So, I wouldn’t have been sectioned, you know, you know. And when I look back. I think, ‘You idiot,’ you know, ‘you could have been like…’ now it’s like 25 years, I could have done that, say, years ago, like few months later, you know. But, er, anyway it hasn’t to be and I’m here and that’s it…

6.4 Mental disorders detected by the experience of symptoms, worsening over time

Norah (79) differed from all the other women in the study with mood disorders in that her depression developed over a period of time but was not aware of it as ‘she didn’t know what it was.’

> …it was not something that l knew much about at the time, so l didn't do anything about it, in fact it probably started long before then. When I began noticing that I lost interest in a lot of things, such as work or even life in general I knew it was really taking its hold. This feeling didn't just come about one day, it seemed to develop over a period of time, perhaps just a day here or there, then days, and then weeks. It is hard to think of just one main cause - it was probably a combination of things such as work and not being completely happy with what I was doing. I tried to battle it alone. ‘ohhhh!’ [imitates gesture of pain in her head and chest] the pain! And it lasted a while but ignored the pain for twelve months instead seeking medical advice. It became so bad that I went to see my own doctor.

The four men whose anxiety disorder was detected symptomatically (Clive 76, Mark 84, Richard 91 and John 83) all showed the classic symptoms of Post-traumatic stress disorder (PTSD), which is a type of anxiety disorder which you may develop after being involved in, or witnessing, traumatic events. The symptoms included: feeling numb or having trouble sleeping, vivid flashbacks, intrusive thoughts, nightmares, intense distress at real or symbolic reminders of the trauma, physical sensations such as pain, sweating, nausea or trembling, irritability or aggressive behaviour, disturbed sleep or a lack of sleep. The PTSD symptoms of all the men in the study, emerged more than six months after experiencing trauma (Delayed-onset PTSD).

John had difficulty remembering the start of his symptoms and asked his daughter to tell the story:

> Dad was in hospital and it was after he had his hip done and he had thrombosis with both his hips and he mentioned to the nurse about feeling

> sick and going to the toilet. He had to go quite often, in so much pain, sweating and nausea [….] and she said to him, ‘Have you been feeling like this all the time, or does it sometimes stop and start again?’ And she said, ‘Well, perhaps you should see the doctor when you get home Mr. Murray’. And then he went to the doctor and the doctor referred him then to go to hospital to see [name] because he was trem’lin’ achin’, stoppin’, and then star’ again, which is not, sort of, normal, you know. And he was havin’ a bit of difficulty goin’ to sleep. That was the start of it.

Richard, by contrast, remembers the experience of beginning symptoms more clearly. He reports the first symptoms briefly but as the interview proceeds, he goes into great detail, referring to written notes on his knee from time to time, especially when he wants to check a date.

> Well, things started to go wrong, first of all, about 16 or 17 years ago. I thought I was coping quite well to start with. Then I began experiencing unpleasant physical symptoms, similar to those of a heart attack: chest pain, tightness and dizzy spells so severe that I thought I would pass out [...] my heart was constantly racing and I felt permanently dizzy. I couldn’t leave the house and became afraid of going to sleep as I was convinced, I was going to die. And so, I did go and see a consultant on my own, er, in hospital.

Mark seems to attribute his persistent, unpleasant thoughts to his wife’s death in 1984 from cancer, though the way he tells the story leaves it unclear how long he has been having the symptoms:

> I were on a racing trip in XXXXX, some Labour club, and were drinking and I just said to this friend of mine, I said, ‘There’s summat wrong.’ He said ‘What?’ I said, ‘I can’t understand why I feel like my brain isn’t functioning. I can’t remember things; I can’t process things. These voices in my head… It is like my brain has just slowed down and ground to a halt,’ I said. And he said, kept on, he said, ‘I think you’d better see your doctor.’ So, I went. I made an appointment, then he went through, he said, ‘What do you think it is?’ I said, ‘I don’t know’, I said, ‘I feel very anxious and find it difficult to relax, the voices in my head’. So, he said, ‘I’ll make you an appointment with a psychiatrist.’

Richard, after telling a long story of his life as an engineer, and needing a prompt to tell his 'mental ill health story', reports his first symptoms in few words, and makes no mention of a visit to the GP, moving straight to the story of his admission to hospital and a vivid account of his first investigative procedure:

> And then, at the end of 1989, I was getting these terribly nightmares and the dizziness, panic attacks weren't too brilliant and, er, so I went into hospital and this Indian guy [....], poked his finger up [vigorous gesture] and things like that and said, 'Oh, umm, your symptoms are severe you'll need treatment.'

Three of the men and two of the women in this study had schizophrenia, a disorder that rarely occurs for the first time in older age. Only 10 % of people with schizophrenia experience the onset of the disorder after age 40. Consequently, older adults with schizophrenia often have a history of chronic psychotropic use and institutionalization. Older age appears to be related to reduction in frequency and severity of positive symptoms of the disorder, such as hallucinations and delusions. However, because of other aspects of schizophrenia, such as apathy and withdrawal, older people with schizophrenia are at high risk for social isolation and neglect by the mental health system (Harding, 1991). Cohen et al (2000) conducted an interesting study of 20 men and women with schizophrenia, designed to elicit information about the pathway to diagnosis. They sought to discover what symptoms people had (and when) which signalled, to them, a change in their health and what they did about it; that is, what was the 'trigger' event which took people to the GP and which led to investigations for and diagnosis of psychotic disorder?

Cohen et al used a 'directed interview' which began with a semi-structured series of questions based on a (retrospective) time-line starting with the question, 'What happened to me?' and tracking back over their memory of symptoms. A second part of the interview was structured and identical for all, asking more detailed questions about symptoms. An event line was constructed from these data and triangulated with GP and hospital records. Statistics were used to establish the measure of agreement between patients' memories and the written records. Interview data were also analysed thematically (Cohen et al, 2000) to gauge the patients' experience of symptoms. Thirty different symptoms were recorded and the most common (paranoia) correspond to the symptoms reported (that is, the trigger symptoms) in three of the five participants with psychotic disorders in *Mental Ill Health Stories* (Louis, Barbara, Trevor).

Paranoia is the most common form of psychosis in later years. Hearing loss may be one important risk factor for developing late-life paranoia (Thomas, 2013) . Other risk factors are social isolation, a long-standing personality disorder, dementia, and delirium. Paranoia in older adults tends to be characterized by beliefs that are less bizarre than those reported by younger adults (Thomas, 2013). People may be able to function adequately and demonstrate normal cognitive functioning. Unfortunately, because older adults with paranoia often have delusions related to relatives, friends, and caregivers, the disorder is especially likely to result in increased social isolation (Eisenhandler, 2008). In Cohen et al.' study there were patient delays in the sense that perceived changes in health status was tolerated for up to a median of seven months before a trigger event (e.g. couldn't cope with delusions any longer, or an episode of hallucinations) led to help-seeking behaviour. Physician delays, especially in the GP responses, do not seem to have been a feature of people's experience in Cohen's study, despite patients presenting with symptoms which differ from those listed in guidance for GPs on suspected psychotic disorders. This finding is repeated in *Mental Ill Health Stories* 'where patients reported what sounded like prompt referral: Trevor's GP wouldn't give a second course of medication when symptoms persisted but referred him to hospital; Henry seems to have been referred quickly; both Josephine and Barbara (and Louis, see below) commented on the speed of events.

Cohen et al. (2000) conclude that schizophrenia may not be, as it is commonly assumed, a 'silent' illness in which people do not experience any health changes until presenting with frank symptoms and advanced disease. The challenge, as indicated at the opening of this chapter, is to enable people to recognise early symptoms and to encourage them to act. It is a big challenge, given that no patients in Cohen et al study reported that their symptoms presaged schizophrenia, despite many being former military service men.

Barbara (84) doesn't specify any symptoms but the brief story that leads up to her referral to hospital suggests that she had been visiting her GP with symptoms of a chest infection:

> So, well… I, er, when I first went, I went to the doctors for some Sleeping tablets. It was insomnia, and then, after that, I went for some more sleeping tablets and he, er, he says, 'No, I'd better send you to the clinic.'

Trevor (81) had organised his life for the previous twenty years around having diabetes. He had created a disciplined, daily programme to ensure that his diet, medication and exercise were all in balance. This long experience, he said, helped him to cope with mental ill health. The first symptom of schizoaffective disorder was loss of appetite, but he attributed this to cholesterol-lowering medication (statins) prescribed by his GP. When the appetite loss persisted, despite halving the dose of statins, he returned to the clinic:

> I used to go and see the diabetic nurse about every three months for blood pressure checks, that sort of thing, and on that particular day I… she couldn't fathom it. And the GP whom I'm specified to be under, I don't think he was available on that particular day but there was another doctor upstairs, who I'd never met before. It was a lady doctor and… the level I used to go and see the nurse was on the bottom floor, I'd no stairs to climb. However, I went upstairs and I was out of breath *um* completely out of breath, perspiring profusely and my head was buzzing. So, when I went into her but couldn't speak, I was repeating words and statements; saying the same thing over and over. She, no further ado, got me on the couch and tested my chest, my head …and on the phone referred me to the psychiatric specialist.

Henry (83) had worked in plumbing and general maintenance since the age of 15, excluding his period of national military service. He had started to take amphetamines as a treatment for hyperactivity and narcolepsy when he was in the army, aged 17 or 18 and attributed his lifelong trouble with increased heart rate and hyperactivity, ('I bet I've had a session every year of a bad cough'), both to his prescription drugs and to an episode of glandular fever during his national service ('I were never t' same after that'). When asked specifically about the symptoms which took him to the doctor before the diagnosis of paranoid schizophrenia he said:

> Well, I wasn't…I'd given up taking tranquilizers then ***had you?*** Yeh, yeh, I hadn't, er, taken any, I hadn't taken any at all for 10 years now, or summat like that. I hadn't, I'd given up all that, then. But, what were I doin'? Were I 'avin a wash? And then I started, like, seeing the bugs all my body, like, you know, so, not a lot but, you know, how you like [mimes crawling] and I went to t'doctors. But, like, er, I saw, it was a doctor who were, like, what do they call it? I'd never seen her before, like. What do they call it ***a locum?*** a locum and, er, she were very nice and I said, 'Well, I've been, like, I've been, er, I've only come because I have bugs on my body, but I've been removing them, but, er, they keep crawling over me, like.' 'Oh,' she says, 'Well, in that case, we'll see if we can get you into t'hospital.'

Louis (88) despite having advanced psychotic symptoms (and still taking medication) was an active man, pursuing hobbies and interests which he said kept his mind from dwelling on mental ill health. In particular, he was regularly occupied in being attentive to the needs of others, his children, grandchildren and neighbours. He didn't regard himself as being in need of help and said he would rather give help to his children (aged in their 50s and 60s) than receive help from them. He had arranged to donate his body to medical science and organised all his finances so that there would be a minimum of trouble to his children in the event of his death. I interviewed him in August 2016 and he died in February 2017.

Louis's account of his first symptoms, reported in a matter of fact way, tends to disguise, and normalise, what might be thought of as unusual. Aged 61 (internal evidence later in the interview) and having recently completed treatment for his psychotic disorder, he flew to the USA to help his niece to move-house:

> Now after this [treatment for persistent delusional disorder] erm, after I'd had this, I was feeling a bit, er…this all came out, erm, my niece moved from Atlanta to Florida and she asked me could I go over and give her a lift. So, we hired a van and we went on route I-85, the full nearly 1300 miles in

> two and a half days. And whilst I'm unloading, you know, the, erm, the, erm, van with the…everything's packed up, I felt a bit funny in the back, something stabbing and digging my back, you know, and this was the first time I detected…

Josephine (87) told a life story of many hardships including domestic violence, the violent death of one of her daughters (which sounds like murder but is never explicitly described as such) and a catalogue of her own illnesses. These included a very rare, non-malignant tumour which made her, to her apparent delight, a focus of special interest to the medical profession, and schizophrenia.

Josephine's mode of storytelling, proceeding by thought-association rather than by chronological sequence, makes it difficult to detect a particular starting point for her paranoid schizophrenia. Even when she proclaims, 4500 words into the interview transcript, 'So, that brings me up to the big schizophrenia I had,' she does not go on to tell anything of the symptoms but moves straight to an apparently random series of recollections and anecdotes about the psychiatrist, her GP and a long story about a dramatic allergic reaction to Clozapine, or, what she called, 'Clozapine poisoning.' She never comes back to the starting point and I find during the course of the interview that, often, even when I ask what I think is a direct question, she gives me an answer that is oblique, or which even seems like an answer to a different question. So, I never really find out how Josephine's schizophrenia began.

For most of the participants with personality disorders, anxiety or mood disorders, nonspecific symptoms gradually became more troublesome and led to consultations with a GP. Sylvia (76, borderline personality disorder) experienced intermittent stomach pain, bloated and swelling, which she first attributed to overeating. Her symptoms worsened on a holiday in Canada but she resisted her son's attempts to have her check into hospital, determined instead to return home.

> ….and, er, then 19…no, 2001 we're into now aren't we, 2016, in February of 2000 after my husband's death, with my son, er we went off to Canada, just for a two week's holiday. And, er, but about a month

> prior to that I, er, I was feeling slight pain in my stomach and a little swelling, but I thought I was overreacting and it wasn't causing me any distress at all but, er, got to Canada and, er, had a nice trip. But, erm, the stomach was still swelling slightly, but nothing that bothered me. I was very angry though, er, I don't know why, explosive anger, my son said, So, came home off the holiday, was fine and then, erm, sorry, I've got that wrong, it was 2000, the first holiday there, but we'd enjoyed it that much in Canada that we decided we'd go again the following year, er, which we did. And, er, we went to Toronto and had five days in Toronto, thoroughly enjoyed… and during this time there was no pain, just anger and mood swings.
>
> And, er, then we flew down from Toronto to Calgary and whilst on the plane I felt pain and, er, our hotel was within three hundred yards of a hospital. My son wanted me to go into hospital because my stomach was beginning to swell then and I was very confused. Anyway, I decided not to. I didn't want to be hospitalised in Canada, erm, prefer to get home, which I did. And I went, er, we enjoyed the holiday of course, then came home and my stomach started to swell and that was in November of 2001.

Like Josephine, Norma (84, Hypochondriacal disorder) tells a meandering story unconstrained by chronological or thematic sequencing. Invited to tell something of her life before she got mental ill health, she links in her opening sentence a short reference to a lifetime of good health, 'Well, I never went to the doctor's a lot,' with her reaction to the diagnosis of a mental illness: 'So, it were a shock really.'

The next two paragraphs of the transcribed interview contain more reference to her lack of serious illness, comparing herself with her eldest sister, born with a 'bad leg' but still living, and another sister who died eighteen months previously from cancer and who had 'also been ill for years with blood troubles.' Norma reports a humorous exchange between herself and a psychiatrist performing the assessment which preceded the diagnosis and concludes, in reference to the news that her mental ill health will improve over time, and may recover completely, 'Well, you've just got to accept what they tell you.'

But to hear about the first symptoms I have to wait until sub-session 2 (see Chapter 5) of the interview and the opportunity to ask a direct question about what symptoms she was having which led to the physical examination performed by the doctor prior to being referred to a psychiatrist:

> Oh, I were ‘avin a lorra pains in me stomach, and I’d stuck it…well, I’d mentioned it to one doctor. He said me cholesterol were up and me blood pressure, t’nurse said, goes up. He said, ‘It’s up a bit, but it’s good, good cholesterol,’ he said, and took blood pressure. He said, ‘Could be you coming here, could get you…’ cos I only went once a year. So, they put me on a twenty-four hour one. That were fine.
>
> So, I did say to him, ‘I’ve started, like, an ache, a stitch, in me side.’ He said, ‘Are you worried about anything?’ Well, she [daughter] were wi’ me and she said, ‘Yes, she is,’ she said. Me sister’s just being diagnosed with bowel cancer. He said, ‘Do you think you’ve got it?’ I said, ‘No, oh no,’ I said. ‘She’s got other things wrong with her,’ so, just left it at that.
> I thought I must have strained it lifting, erm, that were 12-month after and she’s been dead two years now, er, and it kept going worse and I thought, ‘Oh, I’m gonna go and see him…’

The sequence of events is unclear, here, but it appears that Norma had an overwhelming fear that she had a serious disease, even though healthcare providers could find no evidence of illness. People with hypochondriasis misinterpret normal body sensations as signs of serious illness. Most people occasionally fear they have an illness, but people with hypochondriasis are consumed with fear. This fear is severe and persistent, and interferes with work, as well as relationships. An estimated 75 to 85% of people who have hypochondriasis also have anxiety, depression or another mental disorder (Fallon et al, 2012). Norma tolerated her symptoms of stomach pain and physical sensation in her right arm for some time (she’d ‘stuck it’), attributing the cause to a non-pathological source (‘I must have strained it lifting’). During this time, though, she did have consultations with doctors about the symptoms and even mentioned a family history of mental illness, though discounting its relevance to her. The transition from this state of continuous symptom monitoring (‘it kept going worse’) to more focused help-seeking (‘I’m gonna go and see him') reflects phases of what Wang et al (2004) call 'Symptom Appraisal', the time taken to consider the seriousness of the symptom, and 'Action Appraisal', the time taken from recognizing the potential seriousness (or inconvenience) of symptoms to doing something about it.

William's wife told me, in his presence, when we first met at the mental health clinic that he is 'not gifted with words.' She was keen to talk to me as well, to give the carer's perspective, and we agreed that after I had interviewed William, I would give her an opportunity to talk on the record, again, in his presence, about her experience. Consequently, I was not surprised that my interview with William (85, Post-traumatic stress disorder) produced the shortest sub-session 1 (see Chapter 5) of any of the interviews, at 3 minutes 5 seconds. In 262 words William gives a truncated account of his life story and the 'story' of his mental ill health.

> I was born in 1931 and I liv…went through the war years. Started work at fourteen. I had one or two jobs, finished up in the…I went in the army. Come out of…went a job as a postman and after that I finished up at Leyland Motors for thirty years. After that I got married, I have two children, two lads pause and we come to live here in 1960, 1966 sorry. I've been here ever since. But, coming to the mental illness thing, I never knew I'd got it because I'd no symptoms, anything like that. It was just a blow when they found out what it was. But can't do anything about it I don't suppose. So, just get on wi' it I think, that's all. Not much more I can say about that, really. But, t'only thing, I didn't want one of these bags. I don't like 'em. But what can you do? So, there you are. But otherwise you just get on wi life, that's all you can do really isn't it? You can't do nothing about it, unless you get a miracle or summat like that. So, I don't know but like [….] I've had very good treatment at th'ospital for it and can't grumble about that. So, just grin and bear it I suppose? Yeh [pause] I know it's a blow to anybody that's got PTSD but these things happen I suppose don't they? [pause] Well, that's about all I can say about I think, really.

One striking quality of this account is that it begins as a narrative which features temporal sequencing, geographical location, personal and social context (Clandinin and Connelly, 2004) but becomes, with the 'mental illness thing,' an evaluative commentary which only hints at a narrative structure. For a hearer or a reader there is a tantalizing narrative gap between the phrases, ‘I never knew I’d got it because I’d no symptoms,’ and ‘It was a blow when they found out what it was.’

Later in the interview, I try to fill this gap. Elizabeth referred in pre-interview conversation, with the recorder not yet switched on, to William’s visit to the GP with a chest infection. I try to find out how this turned into an investigation for Post-traumatic stress disorder, but I don’t succeed in discovering what it was that made the GP refer him to hospital.

> -***Just take me through what happened, then, from going to the GP and what happened after that.***
>
> Well, I went…I’d to go to [named] hospital for a…the camera, I don’t know what it’s called. And after that, what they found, they said, ‘We can’t do it here. You’ll have to go to [a different, named] hospital to have the operation done. ‘So, within about, I think, about a month, I were in [name] hospital having an operation [pause]. But, er, I wasn’t all that great when I’d had the operation. I were that weak, I don’t know what were happening *afterwards?* Yeh, I hadn’t strength to pick a paper up but, er, of course it takes time to recuperate.

In this exchange I think I am asking a ‘narrative pointed question’ (Wengraf 2008). I think I am asking William to tell me about what happened during his visit to the GP and then what happened after that. But, really, I conflate these two things and what William probably hears is, ‘Tell me about what happened after you went to the GP’ and goes on to tell me just that: ‘I’d to go to hospital for the camera’ i.e. endoscopy. I then go on to ask about the operation and I don’t make the opportunity to return to that narrative gap, which remains unfilled (Elizabeth begins her account with the diagnosis). So, this remains one of two interviews, with William and with Josephine, where the start of the mental ill health story remains unclear.

Elizabeth does, however, indicate a retrospective reappraisal of William’s symptom experience (loss of appetite, declining energy, nightmares and flashbacks) which, with hindsight, is seen to have indicated that something was wrong:

> One of the doctors at the surgeon's clinic said, after this operation, 'When you've recovered, you will feel better than you've felt for a long time.' And he (William) said, 'Well, I've not really felt ill.' But, when you look back, there were things not quite right. His appetite wasn't good. There were nightmares, screams at night. We kept saying, 'Well, when you're older you don't need as much food.' But his appetite had really gone right down. It was very difficult. Various little bits. And now that he feels so much better he realises, now, yeh, there were one or two little symptoms and […] But you don't put it down to PTSD do you, you know. It's the last thing you think of; appetite gone- something wrong with his stomach, an ulcer or…but you don't…you would never put your mind to PTSD.

Such normalising of symptoms experienced at an early stage of disease has also been noted in research with sufferers from Schizophrenia (Cohen et al. 2000) and major depressive disorder (Gulliver et al. 2012).

Finally, in this section, Mary (76, Agoraphobia/Neurotic depression) gives a concise but brief narrative account of her early symptoms which, like several of the participants, continues seamlessly into a story of referral, investigation and diagnosis. The part referring to first symptoms is highlighted in bold script:

> **And the start of the illness was, in a way, I suppose it was a good thing it manifested itself, er, by I wasn't able to breath properly, sleep or eat.**
> **In fact, I was like that for ten to twelve days,** before I'd eventually got into hospital. The GP had referred me after seven days and I was there in ward xx, the assessment ward, and I'd had an x-ray there which they didn't seem to pick up anything specific and I was sent home with some medication. That was over the weekend and, er, things were no better on the Monday, Tuesday and I went back to the GP who got me, er, sent back to the hospital immediately, then. And then I got… the treatment I'd had up to then tended to be by younger doctors and I hadn't…the consultant, N.…I forget his name, great gentleman there, he examined the x-ray and he could probably see a little bit more than they could and decided I had too much stress and sent me to a psychiatric hospital.

6.5 Mental disorders detected by sudden and dramatic onset of symptoms

Peter (75, Panic Disorder/Generalised Anxiety Disorder), alone among the participants in *Mental Ill health Stories,* experienced a sudden and dramatic start to the discovery of his mental ill health, though he had experienced earlier symptoms of panic attacks which he attributed to sleep problems or 'ongoing physical illness'. Misattribution of symptoms, along with the normalising we have already seen, has been noted in various studies of patient delay in presentation (Cohen et al 200o; Gulliver et al. 2012). Peter tells what Wengraf (2008) calls a 'rich in-PIN' (Particular Incident Narrative): a story full of detail, told as though the participant is reliving the experience:

> And, anyway, it came to a head that night, in December. I had a brandy at me friend's house; there were seven of us going to this social club and, er, we went in this club and, er, I got a pint of bitter. I can remember just having a few drinks and I thought, 'Oh, I don't feel right [sounds indistinguishable] me head,' which were unusual for me because everything used to work normal after a few drinks. I'd just lost my job again, twice now, you know. But I didn't want to feel like that again, you know.
>
> And then, er, then I went to the toilet at the club. I cried a lot, vomiting, I was cracking up and so confused. It took me ten minutes to clear everything up and washing everything down wi' a brush in this toilet. And I went back, and I said to me neighbour, "I'm goin 'ome, I don't feel so good, but don't say owt to the others, I'm goin 'ome." Well, I'd to walk about quarter of a mile from the club, you know. How I got home I'll never know, you know. I don't know.
>
> I got inside and straight on the toilet and it was just gushing out of me wi' vomit. The next day, I went to work, tried to hang me self… So, they rang for the ambulance…

6.6 Summary

The NHS policy context which forms the background to the experiences reported by this cohort of older people is one of great concern about the late presentation of mental ill health coupled with a continuing drive to educate the public about mental health prevention (Department of Health, 2016). The cultural context remains one in which mental ill health is feared (Curtin et al., 2018) but where fear may contribute either to help-seeking behaviour - Clive's fear that he might die from a mental disorder, - or to denial and the ignoring of symptoms (Judith and Doris).

Findings reported in sections 6.2-6.5 show that, like up to 90% of people with mental ill health, most of the participants in *Mental Ill health Stories* began their experience of mental illness with the symptoms or signs of disease (Nogueira et al., 2014). Only one mental disorder was detected by pre-symptomatic screening. There were lengthy delays to investigation and diagnosis beyond the first signs in some cases, as reported in other studies (Bebbington et al., 2009; Gulliver et al., 2012). This occurred most noticeably where participants ignored the signs and symptoms of disease (Doris, Judith) and where initial investigations failed to detect mental ill health (Clive).

Gulliver et al (2012), in a systematic review conducted to assess the quality and strength of evidence concerning risk factors for delays to diagnosis (both patients and providers), found strong evidence that older age is a risk factor for patient delay. Andrews et al (2001), in a population-based study of 287 women with newly diagnosed major depressive disorder, found that patient delay of longer than three months was reported three times more often in women older than 65 years. Christiana et al. (2000), found, by contrast, that delay was associated with psychiatric morbidity but not with age.

Barry et al. (2012) draw attention to this inconsistency in the literature of the association between patient delay and age. An important reason for patient delay in their study of patients with anxiety disorders was the tendency to minimise, or ‘normalise’ their symptoms. Cohen et al (2000) also found this in people with symptoms of schizophrenia and Christiana et al (2000) in women with major depressive disorder. Of the *Mental Ill- health Stories* participants with personality disorders, anxiety or mood disorders, this was true of Norma, Peter and, to some extent, William. Norah and Mark both presented promptly with unmistakable symptoms of pathology. Norah visited the GP after enduring a week of constipation and Mark experienced sudden panic attacks (though, as we have seen, he had misattributed earlier episodes of panic attacks and unpleasant thoughts to his beer drinking). Two of the participants with schizophrenia reported early symptoms but misattributed them to other causes: Trevor attributed his weight loss to statins and Barbara initially believed her constant headaches symptoms to be caused by infection.

Physician delay (sometimes called ‘provider’ or ‘system’ delay in the literature) seemed rarely to feature in the experience of these older people. For most participants who reported troublesome symptoms to their GP investigations were ordered promptly and diagnosis made in a timely manner (but there were notable exceptions to the timeliness and accuracy of initial diagnoses; see Chapter 8). Barbara’s doctor insisted on referring her to the mental health clinic on her second appearance at the surgery with symptoms; Trevor’s GP responded to his symptoms of breathlessness by referring him instantly to the hospital, with ‘no further ado.’ John’s doctor listened to his symptoms, asked him some questions and said, ‘I’ll make you an appointment.’ When Henry reports vomiting, the locum GP’s response is, in Henry’s words: ‘Oh, in that case we’ll see if we can get you into hospital.’ There was a delay in diagnosis for Norma, probably because of her non-specific symptoms (‘an ache, a stitch in me side’) and for Norah because she was at first attended to by junior medical staff who misinterpreted her x-ray. Peter delayed presentation because of his nonspecific symptoms, but delay was then compounded by initial misdiagnosis (see Chapter 8).

In the next chapter, I report in more detail the ‘mental ill health stories’ which tell of Participants’ experiences of, and reactions to, the diagnosis of mental ill health.

Table 6.1 First Symptoms and Medical Consultation				
Name	**Screening**	**Signs**	**Symptoms**	**1st medical consultation**
Anxiety Disorders				
Clive **(Adjustment disorder with major depressive disorder)**		Trembling and Twitching	Agitation, Trembling, Palpitations	Self-referral GP
Peter **(Generalised anxiety disorder (GAD)**			Attempted suicide, Grumpy, Aggressive, Bag of nerves.	Emergency hospital admission
John **(Post-traumatic stress disorder (PTSD)**		Attempted suicide, Trembling, Sweating, Nausea		Direct to hospital
Sam **(Post-traumatic stress disorder (PTSD)**	NHS (after stroke)			Self-referral GP (encouraged by District Nurse)
Mark **Obsessive compulsive disorder (OCD**)			Persistent unpleasant thoughts, Suicidal & Fear of deliberately harming my family.	Immediate self-referral GP
Mary **(Agoraphobia)**			Finding leaving the house stressful, Hyperventilating, Rapid heartbeat, ringing in the ears, Fear of losing control in public & losing her sanity.	Self-referral GP
Norma **(Hypochondriacal disorder)**			Panic attacks, Constant pain in her stomach, constantly feeling physically sick.	Immediate self-referral GP

Richard **(Complex Post-traumatic disorder**)		Dizziness, Chest pains, Stomach aches, Memory loss.	Emotional flashbacks, Nightmares, intense distress, Sadness.	Went into hospital (bypassed story of self-referral to GP)
William **(Post-traumatic stress disorder (PTSD)**			Vivid dreams, Fear, Sadness, Despair, Regular suicidal feelings	
Mood Disorders				
Norah **(Manic Depression)**			Lost interest in a lot of things including work, Feeling constantly tired and Suicide thoughts.	Self-referral GP
Christine **(Severe depression)**		Constantly fidgeting, sleeping badly, constantly feeling tired, No appetite, Various aches and pains.		Self-referral GP
Doris **(Depression)**		Fatigue and shaking.	Disinterested in life, no interest in anything, feeling worthless and guilty and suffering huge anxiety.	Delayed self-referral GP
Judith **(Bipolar disorder)**		Delusional, irritable and lack of energy.	Feeling sad, feeling very happy and elated and being disturbed.	Direct to hospital
Rosemary **(Bipolar disorder)**		Lethargic and overactive	Feeling very low, feeling very high, despairing, hopelessness, suicidal	Immediate self-referral GP
Personality Disorders				
Sylvia **(Borderline Personality Disorder**			Being emotional unstable, Impulses to self-harm, Impulsive behaviour, Eating problems.	Delayed self-referral GP
Psychotic Disorders				
Josephine **(Paranoid Schizophrenia)**			Unexplained anger, Severe anxiety and agitation, Argumentative behaviour, Unpleasant auditory hallucinations.	Self-referral GP

Barbara **(Paranoid Schizophrenia)**		Constant headaches, feeling shaky, Hearing things wrong, Nightmares, Attempted suicide.		Self-referral GP
Henry **(Schizophrenia)**		Racing heartbeat, Shortness of breath, Dizziness, Chocking sensation, Disorganised speech.		Immediate self-referral GP
Louis **(Persistent delusional disorder)**			Nightmares, Irritability, Intrusive thoughts, seeing things that are not really there and anger.	Delayed self-referral GP
Trevor **(Schizoaffective Disorder)**		Weight loss, lack of energy, Sleeping very little, Agitation, Poor motivation, Problems with speech and communication		Self-referral GP

CHAPTER 7

ANALYSIS AND INTERPRETATION OF FINDINGS (2) DIAGNOSIS AND REACTION

7.1 INTRODUCTION

For anyone facing mental ill health, either because they have suspicious symptoms or because they have received a positive screening result, it is important that diagnosis is timely and accurate, and that the information is conveyed sympathetically. In this chapter, I present and discuss findings relating to the accuracy of diagnosis, the disclosure of diagnostic information and participants' reactions to the diagnosis. As we have already seen (Chapter 6) for several participants, investigations and diagnosis followed swiftly on presentation of symptoms, the diagnosis was accurate, and treatment initiated quickly. For some, though, there were delays in the timeliness of diagnosis, affected by various forms of slowness to seek medical help (ignoring of signs and symptoms; 'normalising' or misattribution of symptoms). For some there was physician delay caused by initial inaccuracies in the diagnosis. Where participants report the manner of disclosure there is apparent deviation from concordance with standard practice. Reactions to the diagnosis range from shock to stoical acceptance.

7.2 Accuracy of diagnosis

For some participants, the timeliness of diagnosis was affected by initial inaccuracies in the results of their psychiatric investigations. There was a lengthy delay in the diagnosis of Clive's adjustment disorder as, in his report, the 'top man' whom he went to see ('well up in the anxiety disorder field') had to perform more than one assessment, with a gap of two years, before the diagnosis was confirmed:

> He went through it and in the end said, 'I think perhaps we'll do an assessment' but, er, not to worry; and they did but I was not diagnosed. But I was in his hands then and went back a couple of months later when he did give me the diagnosis. And I think, in fairness [Clive uses this phrase repeatedly during the interview] he said that the original one didn't know what it was. So, there was something there with a name...not just crazy. And he said…his view was that we wouldn't use ECT, but we could treat it with drugs.

Peter’s panic disorder was initially diagnosed as schizophrenia, and presented to him as a disease with a life sentence:

> But it was better, er, than what a doctor said to me on the 24th of December, sat in this very room. I sat in this seat here. She sat on the settee over there and told me she was sorry but I’d schizophrenia and it wasn’t possible to live long with it at my age. Er, to say I was shocked, erm, [with rising inflection]. I’ve since seen her, about six years ago, and she was in shock, then, because she never expected to see me again.

A large number of studies have been carried out over the years to try to find ways of predicting which types of patients with schizophrenia will do well and which will not. Some of the evidence has been conflicting, however a consensus now seems to have emerged which shows that the receipt of a diagnosis of schizophrenia is not a life sentence to an existence of low achievement ((Burton, 2012, Jones et al, 2004). However, there is extensive evidence that people living with schizophrenia have a shorter life expectancy by about 20 to 25 years than the rest of the population.(Brown et al, 2010; Parks et al, 2006).Compared with the general population, they have 2 times the risk of diabetes; 2-3 times the risk of hypertension; 3 times the risk of dying from coronary heart disease and 10-fold increase in deaths from respiratory disease for people with schizophrenia (Royal College of Psychiatrists, 2013). In addition, people with a serious mental illness are at much greater risk of obesity. This is because some of the medications they use are associated with weight gain (McElroy, 2009)

Other participants, too, were given provisional diagnoses, in these cases reassurance of non-mental disorder, which turned out on further investigation, or reinterpretation of original assessments, to be mistaken. Over a series of investigations Mark’s diagnosis moved from, ‘It’s depression,’ to ‘I’ve bad news for you, Mr. Davies, you’ve got obsessive compulsive disorder.’ Sylvia experienced a sequence of false reassurances: from a GP who examined her fatigue and concluded, ‘It’s not worth bothering about really, it’s in passing’; to a consultant report which ‘came back I had major depressive disorder’; to the assurance that the medication would be sufficient and, ‘You won’t need to be admitted to a psychiatric hospital or anything like that.’

> And I’m getting undressed to go to bed [….] and I thought, ‘Gosh, I can’t lift my arms, feel exhausted. What’s wrong with me? [….] So, I went to the

> doctor’s, I have a lady doctor, and she says, ‘Let me look love.’ So, she’s fiddling about. She said, ‘Do you know,’ she said, ‘It’s not worth bothering about, really,’ she said. ‘you probably have been overworking your body,’ she said. ‘But never mind, I’ll send you for assessments, be on the safe side.’ So, I go for this assessment. Now, it’s March, and it came back I was sane, nothing wrong with me. And I thought, ‘Thank God, ohh!’ And a couple of weeks after I get a phone call. ‘Er, this is the nurse from wherever,’ she said [….] ‘are you by yourself. ‘I said, ‘Yeh.’ She said, ‘Well, can you get somebody with you, cos we’re coming to see you,’ she said. Ohhh! Then, I’m sat where you are, and they tell like they’re saying you’ve got the flu; you know.
>
> So, she sits there, and she said, cos me cousin came, and she said, ‘Er, right love,’ she said, ‘er, you’ve got borderline personality disorder.’ [pause] And I looked at her and she said, ‘Yes,’ she said, ‘You see, we’ve done some assessments and you meet the criteria and we’d like you to come for more in-depth assessment.’ We need to rule out other common mental disorders, she said [….]. Now, I saw a lovely specialist before I went in, ooh he was nice, and he said, ‘Now, you’ve got a very complex mental health condition, our team only focus on people with psychotic disorders. It’s not really worth talking about,’-cos me sister kept saying, ‘I don’t think you should have gone at all. - ‘Very complex condition,’ he says. ‘But we’ll treat it,’ he said, ‘and you won’t need to be institutionalised, anything like that.’ ‘Oh, right,’ I said. Ohhh! [my marginal note in the transcript at this point reads: ‘sighs with raised eyes as if to say, ‘Oh yeh? Believe that!’]

In the event Sylvia was admitted into a psychiatric hospital where she remained for over a year. She was treated with medication for personality disorder, severe symptoms of depression and anxiety, followed by psychological therapy. At the time of the interview she was continuing to receive treatment. She expressed no real criticism of any of these health professionals though her facial expressions, nonverbal exclamations and some of the phrases she used (‘so, she’s fiddling about’; ‘they tell you like they’re saying you’ve got flu’) indicate that she doesn’t think very highly of their professional behaviour or their manner of communicating.

7.3 Disclosure of diagnosis

There is wide cultural variation in the practice of disclosing a diagnosis of mental disorders. In the UK and North America, the key concern tends to be the manner in which the diagnosis is disclosed (Bebbington et al 2009; Khan et al 2007; Thorne et al. 2009). There is rarely any question that the patient should not be told the diagnosis, though as recently as 1998, the authors of a mental disorder management textbook published in Britain could write, ‘Nowadays patients should **seldom** (emphasis added) be in total ignorance of what is wrong with them or what the treatment involves,’ (Kushner et al 1999). In cultures where the family is more dominant than the individual, or where there is strong religious belief, disclosure of a mental disorder diagnosis is often embargoed by relatives (Vogel et al 2007) despite evidence that patients themselves want information (Vanheusden et al 2009; Andresen et al 2003).

Diagnosis of mental illness is a significant part of the illness trajectory. It may be anticipated by the patient after a series of investigations which follow the first symptoms or signs. It may be feared, consciously or sub-consciously, in the delay which sometimes precedes help-seeking following the experience of first signs (Doris and Judith in Chapter 7). The diagnosis of mental disorder may come as a complete surprise (see Henry’s story in this chapter). Mental disorders are complex disease processes and are not always easily detected. The presence of mental disease may be missed or inaccurately perceived (see Clive, Norah, Mark, Sylvia and Peter’ stories in this chapter).

In contemporary clinical practice in the United Kingdom an ‘open awareness context’ (Glaser & Strauss, 1965; Seale et al. 1997), whereby the diagnosis of mental disorder is disclosed, and treatment options are discussed between clinicians, patient and family members, is now standard practice (Conner et al 2010). It was not so in a previous generation (Glaser & Strauss, 1965) and some evidence suggests it is still not universal (DOH, 2005a). As treatment for mental disorders has improved, bringing greater expectations of cure, the threat of mental ill health as an inevitably lifetime illness has receded, though among the general population the fear of mental ill health remains high. Since the diagnosis of mental ill health may not now be always seen as a ‘death sentence’ this may have influenced attitudes and behaviour in the direction of open disclosure.

In the setting for *Mental Ill health Stories* all participants had been informed of their diagnosis. It was less easy to determine the extent of prognostic information which had been disclosed or, indeed, desired (Happell, 2008a; Conner et al 2010).

The manner in which study participants had been told of the diagnosis, where it was reported, did not always conform with best practice. The reactions of participants to poorly conducted episodes of 'breaking bad news' (Department of Health, 2009b), as the disclosure of a mental disorder diagnosis is known among healthcare professionals, contrasts with findings from the literature which suggest that where 'bad news' is broken poorly (i.e. bluntly, insensitively, without warning or adequate follow up) there may be long-term psychological consequences for the patient along with damage to the clinician-patient relationship (Bebbington et al 2009). Participants in *Mental Ill health Stories* did not seem to be unduly perturbed by the experience of poor disclosure practices. They were not even particularly critical of practitioners whose practice may be deemed, according to some of the stories they told (Thorne et al 2009), less than satisfactory.

Henry told a story of diagnosis disclosure which suggests sub-optimal practice:

> It were a shock when he told me, t'doctor. He were very… not sayin' he were blunt, that's his job, innit? And I were glad it were…he told me that, like, right away. But it's still a….when you get to know. By gum, I nearly collapsed, like, *um,* when he told me *um*. Because, like I say, I wasn't expecting it. And he just, like, come out wi' it and said, 'You've got an anxiety disorder, schizophrenia.' And I thought, 'Whew, dearie me.' I were a bit upset. I didn't show anything there, at th'ospital [sic], but I were a bit upset when I come home, like, really, you know. But, er, that's what it is. They said they couldn't do anything to cure it, or, it just has to be. [I interviewed Henry in July 2016. He died in November 2016]

As reported by Henry, this doctor's manner of communicating a diagnosis suggests unfamiliarity with standard methods for 'breaking bad news' (Buckman, 1992, 1988; Kaye, 1996) in which, among other things, the extent of the patient's knowledge is gauged, signals are given that bad news is coming, sympathetic expressions are used and the patient is left with some grounds for hope (Crossley, 2001; Thorne et al. 2009). This is not straightforward. Crossley argue persuasively that hope is both 'vulnerable' and ‘enduring’. Its vulnerability implies a responsibility of the part of health professionals to preserve it. But its enduring quality makes it impervious to any attempts to alter or remove it, rendering any such attempt futile.

Despite the strength of Henry’s reaction (‘It were a shock…I nearly collapsed…I were upset when I came home’) he softens any criticism of the way he is given the news (‘Not sayin’ he were blunt,’ despite ‘I wasn’t expecting it. And he just, like, come out wi’ it and said,’ You’ve got a mental disorder, schizophrenia’) showing a forgiving and understanding attitude (it’s the doctor’s job to tell me and I’m glad he told me straightaway). This tolerance is in marked contrast to what might be expected from the literature on diagnosis disclosure (Bebbington et al 2009; Thorne et al. 2009).

In Richard’s story the disclosure of diagnosis is given as bluntly as his description of the digital examination which precedes the scan after experiencing ‘unpleasant physical symptoms, similar to those of a heart attack: chest pain, tightness and dizzy spells so severe that I thought I would pass out’, an investigation which presumably confirms the diagnosis and enables the doctor to proclaim: ‘You’ve got complex PTSD.’ Like Henry, Richard offered no direct criticism of this approach, but neither did he excuse it and his language, and his laugh give some hint of a critical attitude.

> I went into hospital and this Indian guy [….], poked his finger up [vigorous gesture] and things like that and said, ‘Oh, umm, you’ll have to have treatment.’ ‘You’ve got PTSD,’ you know. There was no…just bang, ‘You’ve got complex PTSD’ [chuckle], you know.

Trevor ‘had an idea that something was amiss’ and he was informed of the diagnosis on a ward round, in a paternalistic style which perhaps used to be typical and which still persists (DOH, 1999):

> I just had that feeling, as one does, I suppose, the psychiatrist, […] and his colleagues, students, quite a group of them grouped around every day, he came up there to the ward and grouped round and discussed various things, not in my earshot but I could tell he was discussing something of importance to somebody. And eventually, he arrived at my bed with the whole gang of them and duly informed me that they had found that I have a mental illness of this particular type, what’s it called now? Schizoaffective disorder (sic) something like that,

> which was an unusual type in the sense that people haven't recognized that they've got it. And I presume you don't recognize you've got it because, erm, apart from the fact that I had lost appetite, sleeping very little, agitated and such like I hadn't a clue. I had no pain with it.

Trevor did not comment directly on the manner of disclosure but his descriptive language ('not in my earshot'; 'something of importance to somebody'; 'eventually arrived at my bed'; 'whole gang of them'; 'duly informed me') may indicates a rather impersonal and over-formalised approach on the part of the doctors which may be thought less than fully respectful of the individual.

Participants in this study seemed to be tolerant and forgiving when they received a less than complete service (false reassurance, delayed or inaccurate diagnoses, unsympathetic disclosure) and one begins to get the impression of a cohort effect whereby older people, unused to the role of modern consumer with high expectations of choice and quality in all services, do not complain or voice dissatisfaction (Currin et al. 1998). Satisfaction with pre-diagnosis GP care, e.g., increased with age in the ONS Survey of Psychiatric Morbidity among Adults in Great Britain carried out in 2000 for the Department of Health, rated as very good by 71% of people aged 81 years or over compared with 50% in those aged 16-35.

Some participants expressed, on the contrary, a great deal of satisfaction. Doris expected to be 'told off' for not seeking help sooner. She finds, rather than the reprimand she expects, a positive affirmation of a caring attitude, particularly from a psychiatrist:

> He was extremely kind, you know, and he sat and talked to me [...] He was very good, you know, he put it to me he wasn't nasty or anything like that he put it to me [i.e. Told me I had severe depression and anxiety disorder) and I said, 'I'm sorry I've waited so long,' and he never said anything, you know. And when I went to see the psychiatrist after you know, I said, 'I've been very naughty. I should have come sooner.' She said, 'We're not here to, you know, reprimand people; were here to look after you,' you know. So, I thought, well, that was very good, you know. That puts your mind at rest a bit, you know. Cos you're a bit afraid of being told off you know. Well, I never got anything like that. As I say, I've been very well treated. And I have nothing [bad] to say about the

> National Health Service whatsoever, they've been very, very good to me.

In some participants' mental ill health stories, the disclosure of the diagnosis is absent (Josephine, John) or referred to fleetingly (Sam). The story of Sam's diagnosis, for example, was buried in his wife's report that, 'The doctor referred him to go to hospital to see [specialist] because he lost it after recovering from the stroke', and then it became worse…that was the start of it.' Sam himself began his story post treatment and I never found out how his mental disorder was diagnosed.

7.4 Reactions to diagnosis

Where they are reported, participants' initial reactions to the news that they had mental ill health range from the shocked (Christine, Henry, Peter) to the stoical (Louis, Trevor, Doris). The overall and longer-term reaction, for most, is one of fatalism. Christine was emotional as she recalled her feelings when she was told she had severe depression and, alone among these participants, linked her reaction to her religious faith:

> But the day the doctor told me I had manic depression, God I near died [holding back tears] *um um I bet, it's a shock to hear isn't it?* It is indeed. You never recover from depression… no one does isn't it? But I've put my trust in God [tears breaking into and through voice]. I don't know whether you believe in God or not but he just said he would look after me and so he did for so far.

We have already seen, in his story of the diagnosis disclosure (p.152), the strength of Henry's shocked reaction, such that he 'nearly collapsed' at the news. Peter, too, told of his strong feelings in reaction to his eventual diagnosis of a generalized anxiety disorder and panic disorder:

> It's, er, very, very disturbing when you get the news, er, that it's you're mental crazy when they've done an assessment and then relating it… the partners, Jackie and the family and you see the, the grandchildren S at 11, well he's eleven now, this year and R who's four this year of course that brings a lump to your throat when you've met them. But, of course, you don't tell them that you've got this. Anyway, I would have died… me killing myself? Their parents, my son, V. tries to explain that grandad's not too well.

On the other hand, Louis 'took it on the chin' when told sympathetically, of his psychotic disorder:

> They gave me an x-ray and a scan and everything. 'Well,' he says, 'I'm sorry to tell you this,' he said, 'but you know you don't have anything physically wrong with you… you have a mental illness, delusional disorder.' 'Oh,' I said, 'that's not good is it?' 'Cos I can take things, quite truthfully. I wouldn't drop through the floor because of that. So, I took it on the chin. And he says, 'I'll arrange for you to start treatment immediately.

Trevor, too, reveals a stoical attitude, which is of a piece with the fatalistic world view he shows at several points in the interview. And he maintains this outlook in spite of his family history of mental ill health, differentiating his own experience from his father's:

> After they told me, it didn't worry me. Alright, schizophrenia's a big word to some people, they're frightened to death of it. Now, my father died after living with schizophrenia, a few years ago now, and he had quite a lot of pain, hallucinations, banging headaches, you see. But I was fortunate, as I say, no pain.

Fatalism seems to run deep in this cohort of older people. Facing her own diagnosis of schizophrenia, and the recent death of her husband after severe depression, Barbara tries to 'be positive and get on with things.' William describes the news as 'a blow' but in the space of 182 words utters six sentences which are variants on the theme of 'grinning and bearingit.'

> But can't do anything about it I don't suppose.
> So, just get on wi' it I think, that's all
> You just get on wi life, that's all you can do really isn't it?
> You can't do nothing about it unless you get a miracle or summat like that
> So, just grin and bear it I suppose?
> These things happen I suppose, don't they?

William's wife, Elizabeth, encapsulated the tensions involved in receiving news of the diagnosis as a shock (William had no obvious symptoms and they had no family experience of mental illness) and in then trying to balance the attempt to be positive with the all-too-real feelings of despair and hopelessness:

> Well, it was a shock when he…when they said…first of all they said he's got

> a mental illness and still you think, ‘Well, yeh, fine but it’ll be alright, so he is depressed...’ But then when they say, yes, it is PTSD, it suddenly dawns on you that things are… your life’s gonna change, I suppose, which it did. They were very prompt with his treatment and everything, but I don’t think you envisage the impact it’s going to have. They sent him home from hospital extremely weak which I don’t complain about because I don’t think he would have got much stronger on the psychiatric ward. He improved quickly. But the difficulty for me, and probably for most partners, is trying to keep the morale of the patient up when your morale is down there and trying to talk positive and feel positive and say, ‘You’re alright, we’re alright, we can do this,’ about it and all the time you’re in despair yourself.

Doris is not shocked by news of the diagnosis because she ‘knew what it was, you know, you couldn’t…I knew exactly what it was.’ Her reaction, too, is one of fatalism. She repeatedly talks of just having to ‘get on with life.’

> You know, it wasn’t a shock when they told me, you know, and I thought, when they did, eventually, tell me, I thought, ‘Well, that’s it, there’s nowt you can do about it. Get on wi’ it, face it full on and do it. And that’s what I’ve done, you know. So…and up to now, touch wood, you know I’m alr…I feel alright. I don’t feel it’s a burden or I don’t, I don’t let it bother me in any way. I just get on, you know. I just get up in a morning and I think, ‘What have I to do today?’ and I get it done, you know. I do me garden, I do all sorts you know. I think ‘Well, it’s there, deal wi’ it, like I do all that wi’ problems, you know. I think, ‘It’s no good covering it up. But I did that with me mental illness and I wish now I hadn’t. I wish now I’d been a little bit stronger, you know, and gone earlier, cos I wouldn’t have had all that worry, all that time, you know. So I, now, I say to people, you know when we’re in conversation, I say, ‘If you’ve any problems or anything GO! Straight away, don’t delay, go!’ you know. So, I hope I’ve, you know passed it on to somebody. But I’m alright and, I mean, I’m 92 I shall be 93 in a couple of months. I haven’t done so bad have I?.

7.5 Summary

The ‘diagnostic pathway’ (Cohen et al 2000), represents a period of time which extends from the first awareness of symptoms through a decision to seek medical help and the undergoing of investigations, and concludes with the pronouncement of a diagnosis. This is a complex process. As we have seen, a number of variables affect the timeliness and accuracy of a diagnosis, including: the patient’s recognition of a suspicious symptom and their decision whether or not to act on it; the speed of referral from general to specialist practitioner; the accuracy of initial investigations. In addition, the presence of comorbid disease in older populations may complicate the assessment of multiple pathologies. There was no direct evidence of this in the stories told by participants in *Mental Ill health Stories,* but it may be thought unlikely that individuals would have sufficiently detailed knowledge of the disease processes competing in their bodies to be able to talk about this at length.

Mental Ill health remains a disease which, at least in the minds of the general public, represents a serious threat to health, or to life itself. Consequently, the appropriate disclosure of the diagnosis has been a matter of concern for clinicians and researchers alike. Recent studies reveal different foci in different countries and varied clinical settings. Some studies concentrate on measuring patients’ awareness of diagnosis or prognosis (Cavin et al 2007; Morris et al 2009). Others investigate patients’ preferences for knowing the diagnosis (Cavin et al 2007), or physician attitudes to disclosure (Morris et al 2009). Happel et al (2008) specifically investigated older patients (70+) preferences for prognostic information and involvement in treatment decisions. Rennie et al (2009) claim that there is a lack of specific studies on patterns of clinical communication in older patients. For some researchers the topic of interest is patients’ satisfaction with what is told and the manner in which it is told (Gabriel et al 2008). And, some UK and North American studies (Raymond & Wennie, 2005; Tolman & Bevin, 2008) have turned their attention from the *disclosure* (physician/provider focus) to the *receipt* (patient focus) of the diagnosis and emphasized the nature of receiving and understanding bad news as a process occurring over a period of time, rather than as an isolated incident.

In *Mental Ill health Stories*, participants were invited to talk openly about their experiences, without being specifically prompted to recall particular events. Some participants spoke about an occasion on which the diagnosis of mental ill health was disclosed though, for the most part, this represented one of several steps in a process of coming to know they had a mental disorder (Tolman & Bevin, 2008). And all the participants did know that they had mental disorder. In one study, by contrast, 72% of a small sample (n=47) of patients with advanced mental illness thought they had been informed of their diagnosis but not all of them stated the diagnosis in a manner which showed clearly that they were aware of the nature of their disease (Gabriel et al 2008). And, despite claims that patients want and need to be adequately informed, Brookfield et al (2005) found that nearly two-thirds of 203 patients surveyed claimed to have no knowledge of their diagnosis. The manner in which diagnosis was disclosed did not, in the reports of participants in *Mental Ill health Stories*, always conform with recommended practice and it will be one of the recommendations arising from this research that continuing effort be made to educate and support clinicians in the conduct of this important task.

The extent to which prognostic information had been disclosed, or received, among participants in *Mental Ill health Stories* was difficult to gauge. Four of the five participants with schizophrenia indicated that they knew ‘nothing could be done’, ‘it’s a lifetime illness’ and that any treatment they were receiving was for the relief of symptoms. Louis was the only one to refer, in a pragmatic way, to his likely to ‘live with schizophrenia till death but will give treatment a shot’. Richard had been made aware that his Post-traumatic stress disorder was long-term and he spoke of this in terms which suggested he now knew his lifespan was likely to be curtailed. As we will see (in Chapter 9) he was determined not to let this knowledge slow down his plans for a new business venture. William and Elizabeth had been made aware that William’s PTSD was serious, but what this meant for the future remained a source of uncertainty for them.

The diagnosis of mental ill health poses threats to physical and emotional well-being and is a significant stage of an illness trajectory. It forms the basis for decisions which are made about treatment of the disease. Participants’ experiences of treatment are reported in the next chapter.

CHAPTER 8

ANALYSIS AND INTERPRETATION OF FINDINGS (3)
TREATMENT

8.1 INTRODUCTION

Treatment is a significant milestone on the mental ill health trajectory. All the participants in this study received some form of treatment for their mental ill health; even if the disease was deemed to be advanced, they received psychiatric treatment. Many of the participants received multiple treatments including electro-convulsive therapy (ECT), psychotherapy, drug treatments and other psychiatric inpatient treatments. In this chapter, I report the subjective experiences of treatment told by participants under three headings: i) overall satisfaction with treatment; ii) the process of decision-making; iii) the effects of treatment. I illustrate these themes with detailed extracts from the narrative interviews.

It should be noted at the outset that the word ‘treatment’ connotes two meanings, both of which are relevant here. The first definition of ‘treatment’ which appears in the Shorter Oxford English Dictionary (OED) is the process or manner of behaving towards, or dealing with, a person or thing. Many participants spoke about their overall ‘treatment,’ in this sense, at the hands of the healthcare practitioners and systems they encountered during the course of their illness. They also spoke, in more or less detail, about treatment in a second sense, defined in the Shorter OED as, the application of medical care or attention to a patient, ailment etc. or subjection to the action of a chemical, physical or biological agent.

8.2 Overall satisfaction with treatment

Eight participants made evaluative comments, in the course of their narrative, about their treatment in the sense of the first definition quoted above: *the process or manner of behaving towards, or dealing with, a person or thing*. For the most part, they expressed satisfaction, sometimes in terms of glowing praise, with the way they had been treated. Trevor 'nothing but praise for the whole concept of the treatment I received, from start to finish.' Peter echoes this eulogy, saying, 'I just wish everybody that gets mental illness has the reassurance that I've had and the treatment that I've had. I definitely can't say enough about the treatment I've had; how good it's been.'

Three participants told brief stories to illustrate how good their care had been. Speaking about a consultant psychiatrist, Louis said:

> She's done a lot for me. Anything I ask for, medication for nightmares and that sort. I once asked her for urgent medication. And do you know when I got the medication? The doctor phoned me here, at night, could I go to hospital the same night? And they gave me the medication. My nightmares were traumatic.

Sam showed his appreciation of the treatment he received by making small, periodic donations to the Mental Health Centre:

> I've got to say that they've looked after me really well, there's no doubt about that. Sometimes I do, well, now and again I give 'em a few quid for appreciation for what they've done for me. And they appreciate that, because they always acknowledge with a letter, saying that they thank me. It's not a regular occurrence because, I mean, still, old age pension, you know [chuckles].
> I do it when I can.

There is mutual regard, too, in Doris's story of satisfaction, when a nurse tells her 'It's been a pleasure nursing you.' This raises an intriguing question about the dynamic nature of the relationship between individuals, and between individuals and a system. It may be not, simply, that individuals receive a service which they perceive to be 'good' and which, therefore, gives them satisfaction. It may also be that some individuals bring personal qualities to a relationship with healthcare providers which affects the quality of the service they receive. This has implications for the so-called 'unpopular patient' (Johnson & Webb, 1995).

> I can't complain about me 'ospital treatment or anything, no complaints at all […] I went in on the Thursday and I came home on the Tuesday and one of the nurses, she were lovely, she put her arms round me and she said,
> 'ta-ra Doris, it's been a pleasure nursing you.'

Doris took the opportunity to record her feelings of satisfaction formally when she received a patient satisfaction questionnaire:

> So, I filled it in, and, at the end it said, 'Any comment?' So, I thought, 'Right.' So, I put it all in: 'I was treated with the utmost respect'…and…two things…kindness and respect. And I was. So, I wouldn't be afraid [of having to go into hospital again]. And that's what I tell people, now, 'Don't be frightened,' you know, 'you'll be treated extremely well.'

In the reports of three participants, expressions of satisfaction, though made forcefully, were qualified. Mark's experience of nursing staff was positive, and, at first, expressed unequivocally. But it was marred slightly by the apparent indifference of some nurses:

> I was in hospital a month and day, and I couldn't have been looked after better. But there were different ones that were a bit, 'off,' you know, like, didn't have much time for you. But most of the time, I mean, the charge nurse on there, M. she were absolutely marvellous wi' me. And a lot of 'em were, you know. Most of 'em were. There was only odd ones as were, you know, like they couldn't be bothered if you shouted [for help] or rang your bell.

For Judith, 'They were lovely, the whole mental health nursing staff, and everything, was lovely.' But there were two sources of dissatisfaction. She felt 'a bit let down' because 'nobody's been in touch' since her discharge from hospital, and it falls to her relatives to activate some support from the Social Services department, with which she *is* satisfied:

> Me daughter-in-law was here and I was having a job showering because I was so weak when I came out […] and I said to her I was going to buy a stool. I said, 'They're selling them in Lidl's.' But me daughter had been telling me to get in touch with the [cough] social….you know, and I kept saying, 'No, they won't do nowt for you, they won't do nowt for me,' you know. Phone goes, and it's this person and she says, 'Your daughter-in-law's been in touch with us. I believe you had just come out of hospital and you're struggling to hold yourself up in the shower to shower yourself, can we come to see you?' 'Yeh, certainly.' That's where I've got the stool from. And they put me a grip in the shower and a handrail down the stairs. And I find that brilliant for coming down the stairs, 'cos I've a struggle getting up and down, you know. I don't suppose I look too bad, but I do struggle.

A second source of dissatisfaction for Judith arose from what she perceived as the abrupt manner of a doctor when Judith queried a prescription:

> [The] first time I saw her she was alright. But, the second time I saw her and she prescribed me Lithium. 'The only thing,' I said, 'I did read the list of what could…now, I've three sisters, fits,' I said, 'and it said on these lithium side effects could be fits.' Well, she wasn't very nice. I mean, you tell them these things don't you? 'Cos they asked me before the treatment had I had anything?
> I said, 'The only thing is, I've three sisters with fits.' Our M. was really bad, she nearly died with it. And they were very good in the hospital, 'cos they said, 'Well, now, we'll put it down here and we will keep an eye on things.' But she wasn't very nice when I told her […] 'Well, er, can't really give you anything else. Let me see can I give you something else.' She was very abrupt with me, as much as to say, 'You should take these and just be…', you know.

Henry's expressions of satisfaction with his treatment, in the sense of his positive interactions with individuals, come as a qualification to his *dissatisfaction* with what he perceives as everybody's (fellow patients and staff) avoidance of talking about his illness:

> It's funny, when you go for these [treatment] sessions, and you're meeting all kinds of people, aren't you, but nobody talks about it do they? You know, it's niceties, 'Oh, how are you? Are you alright? Nice to see you.' But, nobody ever mentions about being ill and what you have [paranoid schizophrenia]. They just steer away.

Henry speaks about this at length, repeating himself many times (exceeding even his characteristic manner of saying the same thing over and again) as though it is a matter of great significance to him. He describes just one incident when a fellow patient's husband spoke openly about her mental ill health and speculates on the reasons why people don't talk about serious mental illness, contradicting the male stereotype of strong silence in his preference for open discussion. (Interestingly, though, even he doesn't use the word 'schizophrenia' to describe his illness. He tells his friends he has a 'confused brain.')

> There were only one woman that ever talked about it, what we met, only one woman. It weren't her, it were her husband, they were open. And I said, [to his wife], 'Isn't that surprising, she's the only person out of all them people we met who's mentioned about being mentally ill.' It's funny isn't it, how people are?

> But, if people don't want to talk about it, well, fair enough isn't it, like, you can't alter that, can you? It 'appen upsets 'em. But, you'd think, like, if they did talk about it, it would 'appen help, like, wouldn't it? But, they don't seem to want to. I know it's a time when they can be worried, and things like that.

He elaborates on the hospital staff's avoidance of talking, while praising their skill in the delivery of his treatment. He tries to explain away their failure to talk about being mentally ill, but his repetition signifies his dissatisfaction:

> The nursing staff and all that were brilliant, you know what I mean. But even they didn't really mention it, you know. They were good on what they give you, the therapy they give you, but they didn't mention, like, about you being ill or nothing like that. Whether they were, I don't know, 'appen, told to be like that, I don't know, like, really, you know. But there were nothing ever mentioned. It were all about, like, what you were gonna have and how you …you know, what your treatment was and things like that. And they were really good, all of 'em, like, ECT and therapy, they were really, really good. But, again, there was nothing about being what you were and what were wrong wi' yer. That's what I found anyway.

Henry seems to be signalling here a form of ontological distress, captured in the Distinction he makes, and everybody's apparent failure to address it, between 'what you were' (severe mental illness) and 'what you were gonna have' (psychiatric treatment). The experience he describes is in marked contrast to the social support which Bebbington et al (2003) found to be the 'main activity' some years earlier at a similar treatment centre in a different large northern city. Later in the interview, Henry talks about this again, on this occasion revealing a difference between the staff at the treatment centre and those in the psychiatric department:

> The only thing is, like, it's more open when you go to see the consultant, you know, when you go to see Dr. V and her staff, things are more open then. They talk about it a bit then, I must admit. It is, well, it'll have to be hasn't it, but it is mentioned then. They try to cheer you up. And you could think, 'Well done,' you know, for doing that, really.

8.3 The process of decision-making

The findings from the *Qualitative Systematic Review* (chapter 2 and 3 of this thesis) show that the decision to treat older mental ill health patients is sometimes influenced by their age and that when patients perceive that they are being treated differently because of their age this has a negative impact on their psychological well-being and on their relationship with healthcare professionals. In *Mental Ill Health Stories (chapters 4 onwards)* no such influence was detected. Only one reference was made to ageist attitudes and that was to note their absence:

> As far as treatment for the mental illness is concerned, I've had the best of treatment one could get at [hospital]. I'm quite satisfied with it, and I've never felt that because of my age, that they're side-lining me [...] the treatment seems to be just the same as if I was 29 rather than 79, which is as it should be (Norah, manic depression).

Health professionals working with this patient group appeared to conform to Cummings et al.'s (2011) prescription that 'the management of mental ill health in older persons should be based on the individual needs of a patient and not on age alone'. The extent to which participants' individual wants, complementary to their needs as defined by healthcare practitioners, were assessed is not clear from the stories they told. In none of their accounts does it appear that 'two fundamental issues' identified by Adams et al (2007) were determined: i) participants' own preferences about the amount and type of information they need and ii) their actual, rather than perceived desire for decision-making.

As in *Experiencing Mental Ill Health* (chapter 2 and 3 of this thesis), the process of decision-making experienced by these participants can be represented as a continuum. At one end of the continuum there is little discussion, and treatment is decided unilaterally by the medical expert. Further along the continuum there are varying degrees of discussion, consultation and collaboration, with some evidence of dissatisfaction with, or resistance to, the expert's opinions. This continuum of decision-making experiences is explored in the accounts of the *Mental Ill Health Stories* participants below.

8.3.1 The expert decides

Norah's account of her treatment exemplifies the centrality of the consultant as decision-maker:

> He didn't really give me an option. He steered me into the way he thought I should go, in as much as he told me what options there were. But he thought that at my age and with severe physical illness, more medication wasn't really the way to go and, er, not one to be recommended by [sic] older people. So, he decided that ECT was the way to go, which he did. It solved the problem totally [….] (Norah, manic depression).

In many of the other stories told by these participants, too, decisions about which treatments to have are made by the consultant. For some the decision was, or seemed to be, taken away from them (Judith). ECT was given as a compulsory treatment under the Mental Health Act to some people, and others felt if they didn't agree, they would have been given it anyway (Norah). People who are detained under the Mental Health Act may nevertheless under some circumstances be able to refuse ECT (Coppock et al. 2010). Regardless of whether they were in hospital voluntarily or not, being able to make an informed decision about whether to have ECT was important to some participants.

According to Coppock and Dunn (2010) ECT often arouses strong ethical objections in part due to its symbolic association with acts of torture, control and electrocution. Critics suggest that there is little evidence that ECT is helpful and a good deal of evidence that it can be harmful with Breggin (2008) claiming it damages the brain because it produces the same acute confusion state that occurs after any trauma to the brain. ECT was often prescribed by professionals in cases of schizophrenia when anti-psychotic medication proved ineffective, but its principal modern use is for cases of depression when anti-depressant medication has had little or no effect. For most (with the exception of Mary) no dissatisfaction is expressed at this state of affairs; there is simply deference to the perceived authority of the doctor (DOH 2005b).

For example, Barbara (paranoid schizophrenia) reported her 'interview' with the doctor 'telling me what'd happen, how things'd be working, to see whether it'd be either four treatments or six treatments' of therapy with medication. Norma (anxiety disorders and hypochondriacal disorder) acknowledged her lack of medical knowledge as a reason for accepting what she is told: 'When they said, 'Yes, you are being admitted', I just thought, well, you've got to accept what they tell you. [….] I'm in your hands. You're doing what you…you know, what's right.'

William, too, acknowledged after the event that he had limited choice in his treatment for post-traumatic stress disorder: 'Can't do anything about it, I don't suppose. So just get on wi' it, I think, that's all. Not much more I can say about that really. But, t'only thing, I didn't want one of these bags. I don't like 'em. But what can you do?' Trevor's attitude to ECT treatment for his schizoaffective disorder is similarly accepting:

> It's just a procedure. You just accept it. I think the whole problem is, the whole business, if you accept what is to be done for your own benefit what more do you want? There's nothing you can do. So that's how I felt about the whole procedure. It's all about acceptance.

Richard regarded his complex PTSD as 'just an event' and 'just accepted it was happening' when he was taken into hospital. He referred to his ECT treatment as 'the forty-day trick' but said nothing about how the decision was made that he would need that treatment. Similarly, he said that, 'It came that you had to have these injections,' (paliperidone) without any discussions reported, other than whether he would continue to receive his injections at the hospital or the GP surgery.

When she finally went to see the doctor about her manic depression, Doris underwent investigations as an inpatient at a psychiatric hospital. Her treatment plan included ECT, medication and counselling. The language she uses reveals subjection to authority ('I had to go…She put me on medication…Right, it's ECT'*):*

> Then I had to go and see the psychiatrist and she put me on some medication […] She put me on these tablets, Clozapine, to try to decrease the symptoms, which sort of reduce suicide thoughts. And it did, you know, it sort of lessened 'em. And when it lessened 'em; I'm only talking to you like a layman, I don't know what I'm talking about [….] then they must have come to the stage, in July, where they said, 'Right, it's ECT.' Well, they told me right at the beginning that I might have to

> have ECT because medication alone might not stop the symptoms, you know, so I wasn't bothered about that because I'd got all these months to acclimatize meself. So I just accepted it, you know, and I thought, 'Well, it's there. Get on wi' it,' you know. And so I did.

Rosemary did not speak directly of decision making about treatment but alluded jokingly to her ECT treatment; 'There were six of us, we used to call it the looneys' club.' She spoke about all her other recent and current treatments, though, in a way which implied that it was not she who was the active decision maker, but an unnamed authority.

> And then, er, after that, [ECT] that year, I had to go in hospital again and I had to have a kidney removed. And then, the following year, I had to go in hospital again. My body aches and pains returned, I couldn't eat and was sleeping all the time.
> So, I had to go in again and have another dose of ECT. And I'm still going and taking more medication. And, as you see, they've just rung up and said I have to go back in again.

Decision making about Clive's treatment for adjustment disorders and depression was complicated by his planned removal to a distant city and by the different views of specialists. Among two psychiatrists at opposite ends of the country, one discouraged ECT at the age of 65 and the other recommended it. Taking into account the views of a consultant psychiatrist as well the decision for ECT was confirmed. The impression is given of a consultative process between patient and specialists but ultimately it was the expert's choice which prevailed.

> At the time, I was just coming up to retirement, just coming to 65, and his view was that we wouldn't use ECT, but we could treat it [adjustment disorder] with drugs. And I explained these complications that I'd put in front of my life, that I was going to retire to L. which was near S. and he said, 'Well, you won't want to come all the way up here. I'll put you in touch with one of my colleagues,' a chap called CS who's another psychiatrist, well up in the field.
> So, I went down and saw CS when we got there and he had a totally different view and he said, bear in mind he's a consultant psychiatrist this fella, [laughing] well, as the other chap was, to be honest, but he said, 'Well, I don't think RC's up to speed here,' he said. 'We would give you ECT here'.

> And so I said, 'Well, fair dos.' But he said, 'Bear in mind your age. That's fine but' he said, 'we wouldn't… if we didn't do anything now,' he said, 'when you get to 70, we wouldn't give you ECT then because you'd be getting a bit beyond the age where we would do it.'
>
> And he sent me to see a psychiatrist, as well, who was also in S. chap called B. And they were weighing the odds of ECT against drug therapy. And, in the end, they said, 'Well, there's not much to choose between them, but we think that perhaps the right way is to have ECT.' So, probably about four or five months after I'd been down there, I had ECT.

Seven years later, having returned to South East England and the care of psychiatrists, the decision to have ECT was made apparently without consultation:

> Now my mental state was deteriorating, the drugs were no longer working, if you like, it got a bit worse whilst up here until I became manic. I was admitted to the hospital and was given extremely high doses of all sorts of drugs; olanzapine, haloperidol and none of them worked. I'd been on olanzapine for 30 days it was having no effect. Dr S. took me aside and said, 'I think we do have to deal with this again, with ECT.' And I had 12 doses of ECT.

8.4 The effects of treatment

Mental Ill health is a complex disease and it is apparent from the experiences recounted by the participants in this study that a multi-level approach to treatment is often required (Vos et al, 2004). The range of treatments undergone by each individual can be seen in Table 8.1, p.180. Participants' spontaneous comments about the effectiveness of treatment (they were not asked about this directly) range from reports of partial success (Peter) through expressions of cautious hopes (Norah) to statements of satisfaction that the treatment seems to be stopping the mental disorder getting any worse (Henry and Trevor both know that 'nothing can be done'). Sometimes one treatment is seen to be successful while the outcome of another is awaited: for Norah, drug therapy completely solved the problem of nightmares but the effects of ECT on the manic depression remained to be seen. Rosemary had completed treatment for anxiety disorders but was still undergoing drug therapy for bipolar disorder. Most patients did not report symptom burden from the mental disorder itself.

The experiential world of the participants is revealed more extensively in their stories of the side-effects of treatment, rather than in their accounts of what they know about the impact of treatments on their mental disorders. Most of the treatment side-effects reported are transient. They may be difficult, even, in Richard's word, 'nasty', but mostly are portrayed as manageable. Ultimately, they wear off and the overall assessment is sometimes that it was worth it. For one participant (John) side-effects were persistent.

There was some indication that participants were informed about the nature of possible side-effects or the likelihood of their occurrence. Mark was told 'we're going to make you feel worse before you feel better'; Mary was advised against ECT because of possible side-effects; Clive reported that the possibility of lethargy and lack of sex drive were discussed with him and his wife. In the following sections,
I summarise participants' stories of treatment side-effects.

8.4.1 The side-effects of electro-convulsive therapy (ECT)

Five of the eighteen participants who received ECT
for their mental ill health experienced some side-effects of the treatment. Some side-effects of ECT were transient, and although predictable, could be surprising and uncomfortable (Mary's incontinence) or painful (Mark's sore locked jaw).
Mary described her experience with characteristic attention to narrative detail:

> I'd been hanging about waiting for this ECT treatment in six weeks and it didn't come. Finally, I had it on the 21st of April. How successful it's been, of course, I don't know. It was not an experience I wish to go through again. Apparently…when you sign the consent form, of course, they go through things and they point out various things that might happen and one of them was incontinence. They mentioned… I think it was about 3 %, certainly very low and…I was aware of that because of things I'd read before, that there was a very small possibility… BUT, I BECAME INCONTINENT…. devastating to me. That was the last thing I wanted. I'd absolutely nil control. Made a mess of things, really did, in the waterworks department. That's all it was, not bowel incontinence, but I'd definitely no

> control. And that to me was totally unexpected. Well, no I can't say totally, can I, in view of what I've just said, but I thought I was one of the unlucky ones you see, one of the 3%.
>
> And the nursing staff in the ward were, well, they weren't, it's not true to say they were almost blasé about it, but it was certainly treated as something by no means unusual. Now if somebody had said to me that that might happen, I would have been prepared for it and I wouldn't have been, well I can't say I was distressed because I wasn't tearful or anything like that, but I was very upset. I'm too fastidious really [chuckles] to be incontinent. But they were very good, and they said, 'Oh, well it would clear up in a few days in all probability.' But, of course, I was home before that cleared up and sure enough in two or three days, I virtually got full control back. But it was a bit of a shock, at 58 years old, to be put into nappies [chuckling] you know, not at all what I'd expected. People can cope with anything, almost, if they know what's likely to come and that was so with me.

Mark gave an apparently contradictory account of the pain he experienced from ECT, again, a predictable side-effect of the procedure. In this extract he reports intense pain, but at the same time indicates that he received intravenous injection of a short-acting anaesthetic which was effective. Really effective pain control, however, is achieved by calculating the dosage and frequency of administration of medication such that the intensity of pain described here does not arise.

> I mean, I were full of anaesthetic, a zombie, banging head and my jaw was sore, well my whole body really. I couldn't eat or do anything for myself, ohhh! it used to make me sick nearly, you know. And the pain. I couldn't describe it. I were taking pain killers, you know. I had pain killers, everything were alright as far as that goes, they wouldn't let you have pain, you know.

Other side-effects of ECT could also be predictable but have more serious long-term consequences. For one participant, Clive, the effects of a series of ECT treatments were permanent urinary incontinence and impotence. Initially, the incontinence which followed his treatment was manageable.

> I had a fair bit of trouble with the catheter. It kept choking up, and in

> consequence the district nurse came in and dealt with that, and I never went back because they'd taken the catheter out by then and said, 'Well, probably not worth coming back.' And I missed out, this is me, my version, on physio afterwards, which I think probably was a mistake, I think. Now, since then I've had a fair bit of incontinence. Perfectly liveable at that stage, it wasn't too dramatic. It's not so bad if you're lying down. But if you're upright, that is the time. And if I go out walking it does create a reasonable amount of leakage then. But I could live with that. I acquired a bicycle and I was fine on a bike. I could ride round on the bike and I did that and for those years down there [living elsewhere in the South of England] that was my mode of transport and that was fine.

When Clive returned to South East England some years later, he required more ECT to control his manic depression. Clive suffered the most prolonged effects from the second sets of ECT that worsened the urinary incontinence which had been the effect of the first doses of ECT.

> Now my mental state was deteriorating, the drugs were no longer working, … Dr S. took me aside and said, 'I think we do have to deal with this again, with ECT.' And I had 12 doses of ECT, which didn't help with the incontinence by any stretch of the imagination [kind of a chuckle that I Don't know how to describe] He did warn me, in fairness, there's no doubt about that. And it didn't help the depression, either, you know. I was still a bit of a mess, to be honest. And that really covers it. That's where I am now, with quite I suppose one could say, serious incontinence. Now, I've had support from the incontinence service. They do supply the kit. I'm working on them, but they still supply me female kit when I know you can get male kit. And we have tried various bits of kit where people are developing it, you know, fit over the penis and supposed to collect it from there. And, I'm afraid that when you've had ECT and the medication…, because ever since then I've never had an erection. And for all after the treatment [doctors] tried various medications and all these things none of it ever achieved that. So, in consequence you can't fit something on the penis because it won't stay there. So, that piece of kit which, in fairness, was under development, and I was prepared to put my few words into, didn't work. And I think they're struggling with that, still. But you can get male pads, which might be better. But they need to be very absorbent for my part [laugh]. I do leak a lot. If I measure it on an average day, I suppose I'm talking half

> to three quarters of a litre. So, you know, you're talking about 3 or 4 good pads a day which means you have to plan your days around certain stops you wish to make, especially if you're on your feet and up and moving [...] So, that's my main problem at the moment.

Sometimes there were unpredictable side-effects of ECT which also had potentially serious consequences. William experienced a heart attack after undergoing ECT which left him unfit for further treatments when his mental disorder got worse. In his wife Elizabeth's words:

> There was a possibility he needed more ECT treatments, Mr. S [Psychiatrist] went over to see him. He explained various aspects of it, and they sent him away to think about it. He said, 'I can give it to you. I will give you ECT, if you want me to,' he said. 'But bear in mind your age, the difficulties you had after your last treatment,' because he had a bit of a heart attack after the his first ECT treatment, got a few breathing difficulties. He said, 'Just bearing all that in mind,' he said, 'go away and think about it.' I think he was thinking, Mr. S, he's not really fit for another ECT treatment, you know, and I think W. agreed [...] So, he decided not to go ahead with it.

Of the 18 participants who underwent ECT treatment, nine reported side effects. There is variety in the intensity of expression used to describe side effects of ECT therapy and the detail in which participants reported them. There is an apparent gradient in the reporting moving from mild to severe. Sylvia, unusually, felt well during her 12 ECT sessions:

> I felt fantastic I must tell you, all the time I were 'avin me shock treatment I felt fantastic. And t'drivers, bringing me 'ome used to say, 'My dad had that love and he were always asleep, are you alright?' I said, 'I'm fine.' It's after, it's after [ie fatigue].

For Josephine, despite memory loss, 'It's nothing, isn't electrotherapy'. For Judith it was, simply, 'tiring'; for Louis, it was 'a bit of a rough job'; while for Richard it was 'nasty'.

Sam spoke of being confined to his upstairs bedroom with nausea for three monthswhile undergoing ECT:

> It was horrible, really, because if I ate anything, you see, if I ate perhaps a sandwich or a biscuit, even, it would…, I'd have to go after straightaway, through the ECT. And it was blinking awful, you know. And after a time, when I got a little better, I started to feel that I wasn't hungry. Elizabeth [wife] kind of give me stuff but I wasn't eating at all, then. I suppose it was because of the electric shock. But it was really terrible, it was. Because I thought, in fact…, I didn't realize…, I thought, when I had ECT you don't feel anything on that; it's not like medication, or, you know, not at all. I thought, 'Oh, this is pretty good. I don't mind going down to [hospital] and back and having it done. 'But after I come back, that's when it started, upstairs, you know, that was when the trouble started, and it was really bad.

Like Mark, Henry underwent both antipsychotic drug treatment and ECT, and found the side-effects of ECT to be the worse of the two, though the ill-effects were transient:

> I weren't too bad with clozapine. But that ECT…I started off, must have been like a few… a month or so after I'd had it and I went to t'doctors. Oooh, I'd pains in my stomach! And t'doctor says, 'What it'll be is,' he said, is that in extreme cases, ECT treatment can affect other muscles. 'And that's what's making you ill.' So, he gave me some medicine […] and it did cure…in the end it were about a few weeks of a job, but it did go. So, it must have been that, really. But, by gum, it were every night. It were like excruciating stomach- ache, you know. But it's been alright since.

8.4.2 The side-effects of Medication

All nineteen patients who had drug treatment for their mental disorder reported or alluded to side effects, including anorexia (Rosemary, Trevor), nausea (William, Mark- both still on treatment), weakness, lethargy, fatigue (Rosemary, Norma, Barbara) and mouth ulcers (Josephine). There was wide variation in their intensity and where the individual had received ECT as well, the side-effects of drug therapy were perceived to be less severe by comparison. Mark, for example, felt 'rotten', suffering from nausea and weakness from the combined effects of drug therapy and ECT. But he concludes that, 'ECT seemed to do me worse than ever':

> They told me at the hospital, when I were going to have this ECT and medication 'We're going to have to make you poorly to make you better'. Which they did. And I had antipsychotic drugs every day for five months and ECT 3 days a week for six weeks. Now they got on to it straight away. I was sent in more or less straight. The GP referred me to the Psychiatrist, and he found out what was wrong with me, and I was sent in and they started treating me. And I used to come up, they'd take me in a car and fetch me back from [hospital]. Absolutely marvellous, the way they looked after me. And I used to come home, and I felt that rotten I used to just kick me shoes off and go and lie on me bed for a couple of hours till I come around. Because I couldn't describe the feeling. It's like a sickly… you feel… it's like nausea, I couldn't describe it. And I felt that weak and with that…ECT seemed to do me worse than ever.

Rosemary received drug treatment for bipolar disorder which followed her manic depression (treated with ECT) and seemed untroubled by the attendant loss of appetite:

> I did have risperidone and olanzapine for six years to treat bipolar. It wasn't so bad, but I've never been able to eat a meal since. If you ask me what I'm having today for a meal, it's ham sandwich. And what am I having tonight? A ham sandwich. I did have a meal at Christmas, my daughter made me eat. But, never cooked a meal since. But I still don't lose any weight!

Trevor was phlegmatic about the loss of taste and his lack of desire for foods he would normally enjoy, approaching these effects of treatment with the same fatalism he brought to the whole experience of illness:

> Well, I must admit that from Mary's point of view [his wife] it's been a bit difficult in so far as my choice of food has been at great variance to what my normality has been. I've normally been able to eat anything, no problem. But since I've been on medication, I just couldn't face certain things, things I would **love** to eat before, but for some inexplicable reason …
>
> -***What sort of things?***
>
> Well, at the moment I'm off eggs. Initially I was off bread, and potatoes [wife chuckling]. Vegetables, I would normally eat a lot of. I haven't been doing, not

> lately. It'll come back [...] everything comes back bit by bit. It's just something one has to accept and does accept because you know what's going to happen, you're going to get normal.

Several participants had expected to have side-effects and were surprised at their relative lack of severity compared with their expectations. Norah, for example, reported that:

> I've just completed me last sessions of antipsychotics which, whilst it's not particularly pleasant, is not as bad as I expected it to be because you do hear people who've been through this before having numerous side effects and the only real side effect I've had, is feeling lethargic.

Norma's expectations of side-effects, too, were unrealised:

> When they told me about antipsychotic drugs, what could happen, I did panic a bit [...] but none of that's happened. So, if I'd have kept worrying, I'd have been worrying for nothing.

In keeping with her stream of consciousness storytelling style Josephine did not refer directly to her own antipsychotic drug treatment but, off the record, talked about blurred vision and tremors, from which it may be inferred that she experienced them as a result of drug therapy. Participants reported a range of side-effects from drug treatments for severe depression and anxiety (Christine) and adjustment disorderand depression (Clive), from benzodiazepines for panic disorder (Peter) and from antipsychotic drugs for paranoid schizophrenia (Josephine). In most cases the side-effects were temporary (Christine, Clive) and were sometimes tolerated in the light of other benefits brought by the drug (Peter) or of determination to continue with treatment (Josephine).

Peter reported experiencing some of the common side-effects of the benzodiazepines (mouth ulcers and sore feet) but, for him, they almost paled into insignificance in the light of his overall evaluation of the beneficial effects of the drug:

> The side effects are in my case mouth ulcers and, er, so that was back to children's food and very, very sore feet. But after two months of tablets and a month in between each course, or two weeks in between each course making a total of twelve weeks, erm, the panic disorders had reduced by, erm, almost disappeared completely [chuckle].

Finally, Josephine, with characteristic resilience, spoke of her tolerance of the side effects of antipsychotic medication and her determination to continue with the treatment:

> There's something wrong with it because of the side effects it produces. I mean once I were covered in boils. I were just covered all, from head to foot, in boils. And that were really painful. And I used to think, then, 'I'll give up to it, I'll stop taking it,' you know. And then I'd stamp me stick, like this, and I'd just think [spoken through gritted teeth] 'Put up wi' it, put up wi' it.' And, er, but I wouldn't give up to it. No, I've never given up to anything in me life, I'm not gonna start now.

8.5 Summary

In this chapter I have presented three themes from the stories of treatment told by participants in *Mental Ill Health Stories*, showing what they said about their satisfaction with their overall treatment, about their involvement in decision making about treatment and about the physical effects of various treatments. Just under half of the participants spontaneously expressed satisfaction, sometimes in strong terms, with their overall treatment. A few dissatisfactions were voiced, relating to patient-provider interactions (Henry, Mark, Judith) or to discharge follow-up (Judith).

With regard to involvement in decisions about treatment, findings presented here are broadly consistent with empirical evidence which suggests that older people with mental ill health may prefer to play a limited role in decision-making and to defer to their physician's expertise (Arora & McHorney, 2000; Llewellyn-Jones et al 2001; Say et al 2003). Happel et al (2008), for example, found that 52% of their study population of 73 individuals aged 70-89 with anxiety disorders preferred to delegate all treatment decisions to their physician. In younger age groups more active or collaborative roles may be preferred. Kaminskiy et al (2017) found that 67% of women with depression, with a mean age of 62 years, preferred shared decision making with regard to treatment choice.

Preference for involvement and control of decision-making does vary even within older age groups, however (Happel et al 2008). In a survey of 101 men with psychotic disorder, with a mean age of 70, mostly married and well-educated, Hamann et al (2006) found that more than 60% of the men wanted to share decision making about treatment with their physician. In addition, over 70% wanted detailed information at all stages of the illness. In *Mental Ill Health Stories* the better educated participants were more likely to question aspects of physician decision-making: Mary expressed her dissatisfaction with ‘watchful waiting’; Clive insisted on following up his adjustment disorder diagnoses result from his privately funded psychiatric assessment, against the indifference of his NHS practitioner; Richard insisted on drug treatment when he was in hospital and refused further ECT against the preferences of his consultant psychiatrist (‘she doesn't agree with me about one or two things’). In contrast, participants with a lower level of education and socio-economic status were more passive. Sam, for example, acknowledged that he ‘doesn't ask enough questions’ and was consequently in the dark about the extent of his disease and the nature of proposed treatment. John’s resistance to his psychiatrist’s recommendation for ECT took the form of a simple refusal.

Numerous studies draw attention to potential discrepancies between desired and actual roles in decision making about treatment and recommend that efforts are made by clinicians to minimise the disparity between the two (Kaminskiy 2015; Simon et al 2007; Happel et al 2008). As already noted, there is no evidence in the stories told by participants in this study that their preferences had been elicited. With few exceptions, participants accepted the treatments recommended by their healthcare providers, tolerating a range of unpleasant side-effects, in the interests of attaining a cure, or of slowing down the progress of their disease.

In the next chapter I move from analysis of the mental ill health stories to consider how Participants’ illness narratives may be interpreted in the light of what they told of their life stories.

Table 8.1 Treatments experienced by each participant

Mood Disorders	Personality Disorders/Anxiety Disorders	Psychotic Disorders	Anxiety Disorders
Christine Medication; electro-convulsive therapy (ECT); long-term psychotherapy; continuing medication **Doris** Psychiatric inpatient treatment; ECT; medication; counselling **Rosemary** Medication; shock therapy; counselling; continuing drug therapy **Norah** Medication; ECT **Judith** Detained under Section 3 of the Mental Health Act (1983 on 3 occasions); ECT, medication; continuing outpatient psychiatric treatment	**Sylvia** Psychiatric inpatient treatment; medication; psychological therapy **Mark** Psychotherapy; medication; ECT **Norma** Medication; psychotherapy **Peter** ECT; medication; counselling **William** Medication; ECT; psychotherapy	**Barbara** Psychiatric inpatient treatment; ECT; medication **Trevor** Antipsychotic drugs; counselling **Josephine** ECT; long-term psychotherapy; continuing medication **Henry** Psychiatric treatment; ECT; medication **Louis** Psychiatric inpatient treatment	**Sam** Anticonvulsant treatment; medication **Mary** Medication; psychotherapy; ECT **John** Medication; ECT **Richard** ECT; medication; psychotherapy **Clive** Medication; counselling; ECT **William** Medication; ECT; psychotherapy **Norma** Medication and psychotherapy **Mark** Psychotherapy; medication; ECT **Peter** ECT; medication; counselling

CHAPTER 9

ANALYSIS AND INTERPRETATION OF FINDINGS (4)
SITUATING SELF IN A LIFE WITH MENTAL ILL HEALTH

9.1 INTRODUCTION

The end point of the illness trajectory for people with mental ill health, in Corbin and Strauss's (1988) schema, is death. In the twenty-eight years or so since the publication of their book, treatment for mental disorders has become more effective. Hence, there is likely, for many people with mental ill health, to be a post-treatment phase of the illness trajectory, of varying length, which is characterised by a continuing life rather than by a rapid decline to death (Davidson et al, 2005; Deegan, 1988). This new reality has resulted in research studies and literature focused on what is called 'recovery' or 'survivorship' (Shalev et al., 2017; Jerwood at al., 2016; Sweers et al., 2013; NHS England, 2014; Foti et al., 2005; Spaniol, 2002).

Recovery has a range of meanings and does not always refer to the process of complete recovery from a mental illness in the same way as people may recover from a physical illness. According to the Mental Health Foundation (2017) for many older people, the concept of recovery is more about staying in control of their lives despite suffering from a mental illness. According to Deegan (2001) there is no agreed definition of, nor a single way to measure recovery. Nonetheless, the overarching message is that hope, and restoration of a meaningful life are possible despite serious mental illness. Instead of focusing primarily on symptom relief, as the medical model dictates, Deegan (2001) suggests recovery should cast a much wider spotlight on the restoration of self-esteem, identity and on attaining a meaningful role within society. In relation to the interview data generated for this study, I call this phase of the illness trajectory 'situating self in a life with mental ill health.

In this chapter, I draw on the wider life stories told by participants, going beyond the specific illness narratives of the 'mental ill health stories,' to interpret their experiences of mental ill health in the context of their overall biography. In addition, as explained in chapter 6, I interrogated the life story data from a more etic perspective using analytic questions suggested by Frank (2013): ‘What other stories are people caught up in?’ and ‘What differences depend on being caught up in those stories?’. Exploring the data in the light of ‘grand narratives’ (Davey and Seale 2002) and the ‘lens of culture’ (McCormack, 2004) further helped to situate and interpret the private experiences reported by these participants in a broader social context.

9.2 Characteristics of the ‘situated self’

The overriding features of situating self in life with mental ill health among the participants in this study are hope and hardiness, together forming a kind of resilience which appears to be psychologically protective and which fosters a determination to continue living positively. Hope is revealed both in specific and general terms (Hammer et al 2009): as a desire for successful curative treatment (Peter, Norah, Mark, Norma) and for the relief of symptoms (Mary, Clive) but also as an orientation to a positive outlook on life which is maintained even in the face of suffering. It is characteristic of this study population to make light of their suffering in comparison with that of others. This was also a common finding in the studies reviewed in chapters 2 and 3 of this study (Qualitative Systematic Review).The phenomenon is described in the psychological literature as ‘downward comparison’ (Wills,1981).

Hardiness is the ability to withstand adversity. It is closely linked to resilience, but in the view of some authors differs in that ‘resilience results in an improved or enhanced adaptive outcome,’ whereas, ‘hardiness allows individuals to endure significant adversity but there is not necessarily a positive change in outcome’ (Earvolino-Ramirez, 2007 p 80). Felten (2000) shares this view. Hardiness may, then, be considered a necessary but insufficient condition for resilience. Bonanno (2008) presents hardiness as one of four possible ‘pathways’ to resilience. Wallace et al (2001) suggest that hardiness offers an ‘internal personality reserve’ which produces resilience when combined with the ‘external reserve’ of social support, though the direction of influence between the two is open to different interpretations in their study.

In *Mental Ill Health Stories,* hardiness is seen in the robust characters of the participants, a robustness which underpins their adaptive responses to the adversities of living with mental ill health. In this narrative study, which did not seek to measure predetermined variables, hardiness is used as a term which is descriptive of the participants' characters, as perceived by the interviewer/analyst in response to their presentation of themselves in the telling of their life stories. It is thus an impressionistic use of the term which cannot easily be related to the theoretical constructs of hardiness (commitment, challenge, control) proposed by Antonovsky (1982) which underpin psychological research (Bonanno, 2008; Lambert et al 2003; Wallace et al 2001).

Resilience, 'the ability to bounce back or cope successfully despite substantial adversity' (Rutter, 1985), is distinguished from hardiness also by being redefined in contemporary literature as a dynamic, modifiable process (Luthar, Cicchetti & Becker 2000) rather than as a personality trait. In Earvolino-Ramirez' (2007) concept analysis, resilience is presented with six 'defining attributes' (See Box 9.1 below).

Box 9.1 Defining attributes of resilience (Earvolino-Ramirez, 2007)

- Rebounding/Reintegration
    - Bouncing back and moving on in life after adversity
    - Readiness to 'get back to normal'
- High Expectancy/Self-Determination
    - Sense of purpose and achievement in life
    - Not being overwhelmed by feelings of hopelessness or extreme challenge
- Positive Relationships/Social Support
    - Meaningful relations with at least one peer or family member
- Flexibility
    - The essence of adaptability
    - Being cooperative, amiable, tolerant.
- Sense of Humour
    - Able to make light of adversity, enhance coping mechanisms, moderate intensity of emotional reactions
- Self-Esteem/Self-Efficacy
    - Underpinning adaptive or maladaptive responses ('why some people snap and others snap back')
    - Present innately and from mastery of previous experiences.

Each of these defining attributes of resilience may be seen in the stories told of their life and mental ill health experience by participants in this study. Many examples of such responses will be reported in the rest of this chapter and will support Collins & Smyer's (2005) contention that 'despite the losses associated with ageing, older adults are surprisingly resilient to life stress' (p475).

The nature of hope, hardiness and resilience among the research participants is influenced by the type and stage of the mental ill health as well as by former and current life events. For Mary and Norah, hope resides principally in the desired curative outcome of their treatments for mental disorders (medication and psychotherapy for Mary; electro-convulsive therapy (ECT) and psychiatric treatment for Norah). For three participants with psychotic disorders who know that they have lifelong illness, with no cure but many treatment options (Barbara, Trevor, Henry), hopefulness is coloured by resignation, a realisation that the best that can be hoped for is that the psychosis treatments they have received will slow down the progress of their psychotic illness.

Louis, also with long-term psychotic disorder, expresses hope in his attitude of purposeful activity, both giving his time to help his family and neighbours in tasks of daily living and in pursuing creative hobbies 'to take his mind off the mental ill health.' Josephine's response to her psychotic illness is to persist with active treatment through participation in a clinical trial for Acute Psychosis, despite unwanted side effects, more in the hope that others will benefit than in the interests of her own recovery. John, Sam and Richard, all with chronic anxiety disorder, seem to express a kind of hopefulness in simply carrying on with their daily life, apparently unaffected by their progressive disease. Sam describes feeling concerned that the consultant has indicated he will need to have long acting injectable drugs, because he thinks, though hasn't been told, that means his acute anxiety disorder is advancing and now a 'psychotic disorder.' And he recognises that his habit of not asking questions has left him a bit in the dark about what is happening. He does not appear to be anxious, but he returns repeatedly in the interview to what he sees as his lack of understanding about his illness. But his daily life continues apparently unaffected. This is one of two occasions in the interviews where I felt compelled to step, temporarily, out of my role as researcher and enter my role of mental health practitioner. The other was in giving empathetic support to Clive in giving him 'permission' to feel that his incontinence was, indeed, severe and that he could legitimately regard it as a major problem deserving of health professionals' attention. At the end of the interview I made some suggestions about how Sam might question his consultant so as to get better understanding of his condition. John appears unconcerned that the recommendation from his consultant that he now needs ECT probably means that his mental disorder is advancing. He is more concerned with the inconvenience to him of daily attendance at hospital to undergo the treatment. Richard knows for sure that his disease is advancing but he is 'not losing any sleep over it' and is purposefully ploughing ahead with business plans.

Sometimes hopefulness is revealed more explicitly as a fatalistic resignation, typically a view that you simply have to accept what has happened (Trevor, William) and 'get on with it' (Doris). 'Life must go on' according to Rosemary (84) who is itching to 'get back to work.' Wagnild & Young (1990) found that such attitudes of 'equanimity' and 'perseverance' characterised older women who had experienced major loss in life. Christine, alone among the participants in this study, expresses religious faith as the underpinning of her hopeful attitude:

> I've put my trust in God [tears breaking into and through voice] I don't know whether you believe in God or not but he just said he would look after me and so he did, for so far, and, like I say, I can't complain because I've got a lot of years that I didn't think I would have.

It is faith in human relationships which nurtures a hopeful attitude in Mark. He singles out the psychological support of one of his friends as among the most helpful of his experience (Moloney,1995):

> She come down when she knew what were wrong wi' me, as I'd been diagnosed wi' acute anxiety disorder. She were upset, you know, she cried when she come in. And she said, 'I'm gonna write summat down and you'll be alright.' And that's what she wrote for me [shows me a list written as bullet points on the back of an envelope] and I look at it, you know. You know, it's grand. That did me more, good than owt, you know, looking at that thing every day [....] She said, 'Well, look at it this way.' And she wrote this down: 'They've named it. It's treatable. They're going to fix you. And then: treatment, quick appointments, short term inconvenience, isolated, nothing else'- 'Soon back to being as fit as a fiddle. Lots of family and friends support in the meantime.' Now, that's what she wrote for me and it and it did me good, too, when I read it. Now it does, you know.

9.3 Resilience

9.3.1 Influence of life-events on resilience

Each of the participants in this study expressed attitudes to their life with mental ill health which could be described as resilient (Earvolino-Ramirez, 2007; Felten, 2000; Moloney,1995; Nygren et al 2007; Wagnild & Young, 1990). One way to interpret this trait is to see their current character, personality, attitudes and behaviour as being forged by their life experiences, including episodes of hardship. In Felten (2000), all the women in the study described hardship earlier in their lives, including challenges associated with racism, religious or ethnic discrimination, divorce, the Great Depression, death of a husband, domestic violence, and the effects of war.' Seen in this light, both former and current life events can be seen to influence the response to living with mental ill health. A long life is rarely free of troubles (Frank's (2013) starting point for a 'story') and stories of divorce, illness, domestic violence, death and bereavement appear in the stories collected for this study. Josephine had been divorced, in traumatic circumstances. John, Richard, Christine, Sylvia, Doris, Rosemary, Peter and Mark had all been bereaved of their spouses (between 1-20 years ago). As already noted, one of Josephine's daughters died a violent death in her early twenties and she had suffered years of physical and emotional violence at the hands of her first husband. Sylvia's daughter had died at the age of 29 of a brain-tumour. John's adult son committed suicide following the death of his wife. Judith had lost two of her four sons, the eldest at age 16 from an accident and the second eldest at age 21 following a leg amputation for gangrene.

Resilience is formed also by more mundane experience, simply by experiencing the privations more typical of less affluent times (Mark), by the necessity for extremely hard work (Peter, Rosemary), by surviving multiple illnesses, including other mental disorders, (Louis, Christine, Josephine), or by the persistence of caring responsibilities into advanced age (Sylvia). Felten (2000) identified helping others as a characteristic of resilient older adults.

Mark was born in 1928, one of five children, and the beginning summary of his life into young adulthood is characterised by hints at relative poverty and lack of choice:

> Times were fairly hard. And I can remember like me mother say…I was in bed sixteen week with her cos she had a, you know, what they call a white leg, like a clot and when the doctor came, like, the bill was thirty odd pound, I couldn't remember, like, she said it was a lot of money, then, cos me dad he'd only be on about £8 a week or summat like that, I don't know. And, er, me childhood like it…we grew up and, er, I went to the school when I were five and, er, left school when I was fourteen and I started work on a farm, which there were nothing else, you didn't know owt else then, like, it were either farm work or goin wi me dad to Leyland to learn brick…and I didn't want to work with him, like, really, because [chuckling] you know, he were a bit of a gang master, like, you know, when we were at home, like, he were a bit strict. And, er, I worked for this farm for six years I worked there. And me first wage were twenty-eight shilling for the week. And, er, like it weren' a lot of money but, you know, I used to tip it up to me mum. She used to gi me two shillin', like, for spending money. This is going back to the old currency, now. And, er, after a while I left there and I went to another job which I were forced into, really, because you had to learn to do everything wi tractors and everything to plough to get on top money and the top wage were six pound a week.

Mark also exemplifies a physical resilience which comes from life of hard manual work:

> When you went for grain to these warehouses, if you hadn't a bulk wagon you used to carry it in two hundredweight sacks [...] and you had to carry them in your arm off a chute and load 'em into your wagon, 'cos they'd got it at bulk price, if you'd got it in two hundredweight bags, and, er, you know, like, you got a strong back. You used to wear some shoes out, and some shirts and jackets, you know, it were a rough job. But I stuck it because I had to do, you know.

Peter, born in 1941, also left school at 14 and apart from two seven-week periods when his life was aimless-one immediately following school 'dawdling', in his mother's view, on his grandparent's farm in South West England and one spell following the army doing bar work in Devon-his whole life was characterised by extremely hard work. He became an apprentice armature winder aged 14, 'winding big motors for diesel electric trains,' and worked for 40 years in the electrical engineering industry, sometimes for 12 hours a day, 7 days a week. Ten years later in his late 40's, the first symptoms of his mental disorder appeared.

Rosemary was born in 1928, one of seven children, and tells a story of her childhood, in tantalisingly little detail, which provokes a kind of internal horror in my mind as I compare her experience with what I see as the 'normality' and security of my own childhood. In particular, I am amazed that she seems so little affected by this experience and that the effects on her subsequent life are the reverse of what my attempts at psychological interpretation would lead me to expect:

> When I was younger, when I lived in a rural village, for some unknown reason my mother put me in an orphanage. It was a private orphanage [pause]. She was brought up there for quite a number of years and she put me in there. Still don't know why. And I was there about five and a half years. And you're brought up by nuns and your parents were not allowed to come and see you. And I believe I went home for a holiday and I wouldn't come back. So, that was part of my younger life, which was not a…me mother never explained why I was put in there.

Later in the interview, having heard stories of her involvement in church work, I return to this early experience and voice my curiosity that her early life should not have made her antagonistic towards the church. Rosemary's explanation suggests a normalisation of her experience in the light of her own family history, culture and personality:

> Well, you see, my mother, she was brought up in that convent for a number of years. So was her sister. Her dad…her own mother died when she were 28 so their dad was left with three children. One at two [years old]. I don't know how old Dorothy was…and there was Dorothy and me mother so he'd no choice but to put them in there. It was a private orphanage and she was in there for quite a long time. And then she came out and she had some relations in Hertfordshire, she lived wi them. Then, of course, she met me dad. But she was always one of these for church. You mustn't miss church and it's such a saint's day today, don't forget that. When you went to school it was that all the time and you must go to church and…I've come 'ome from dancing about four o'clock in the morning, she's got me up at six to go to eight o'clock mass, seven o'clock mass, and I've only been in bed a few hours [….] She was very, very strict on going to church and that. Same as Whitsuntide, the processions they had, the boys had to walk, not me, no, no didn't

> matter about me the boys had to walk in the processions. The boys had to go in the choir and they'd a marvellous choir in the village and the boys had to be in the choir and our life was all like that. It's a wonder it didn't put me off isn'tit?
>
> ***-But it didn't?***
>
> No, I'm just one of these, I'll help anybody. Doesn't matter what religion they are, who they are, what colour they are, doesn't matter, I'll help anybody. I've helped quite a few people. I've helped quite a few relations who've fallen out with their mother. I've said, 'Well, come and live wi me.' I've had a few. Yeh [pause] I'm just one of them, mine's an open door. If you can get in, come in, you know. It doesn't make any difference.

Rosemary's working life began, like Mark's and Peter', at age fourteen and has extended into the present time. She started work in a bank, then moved to a cotton mill, followed by a period working as a nanny, then a job in the shoe trade and, when married and raising her two children, owning and running a variety of shops before taking up the work of housekeeper and custodian of the nearby church. At the time of interview, she worked part-time in a charity shop.

Late in the interview, immediately following the extract above, Rosemary also discloses that she has fostered seven children. She is now, in the midst of treatment for anxiety disorder, active in providing domestic help for her adult children and in babysitting for her tiny grandchildren:

> Just done me son's washing. He likes it here because it comes out ironed, you see. That's his bag of stuff. He'll be [….] picking it up and bringing me some more. Then, me daughter's just gone back to work first time after havin't babies so her washin'll be comin [chuckle].

Although declaring herself to feel tired, Rosemary gives the impression of being a person of tremendous energy and optimistic outlook. She even looks much younger than her eighty-four years and she talks self-deprecatingly and humorously about the way people comment on her wrinkle-free appearance.

9.3.2 Resilience and comorbidity

Frank (2013) suggests that one of the analytic questions which may be posed when considering narrative interviews is: ‘What other stories is the person caught up in?’ I began this study with an interest in mental ill health and comorbidity in older people and planned an interview series which would carry this twin focus. Over a period of time mental ill health moved to the foreground of my thinking and comorbidity took on a background character. I expected to hear about comorbidity (Kleinman, 2017) in the open-style interviews that I would conduct, but I decided not, specifically, to seek information about concurrent illness. This expectation was realised and ‘comorbidity’ (a technical medical term which, it is a safe bet, would be unknown to the participants) can be seen as providing one set of stories in which the person is caught up, to a greater or lesser degree, alongside the mental ill health stories. For some participants, their experience of, and management of, concurrent illness provides evidence of the resilient attitudes and behaviour which, I argue, characterise their response to mental ill health. For others, concurrent illness seems to be something that is simply in the background of their lives.

Previous and concurrent illness (comorbidity) appeared in many participants’ lives. William ‘lost count’ of the number of operations he had undergone since retirement. Louis, a more precise counter, itemised eighteen operations over the course of his life and gave a detailed account of two of them (perforated duodenal ulcer and subarachnoid haemorrhage). He had also survived PTSD immediately prior to being diagnosed with persistent delusional disorder. Sylvia eventually retired from work owing to circulatory problems in her legs. Christine’s early life was severely affected by rheumatic fever, which limited her mobility and her ability to learn:

> When I was a teenager I couldn’t walk very far without getting out of breath and that, so I never had much of a life, you know, as a teenager, well, not till I had that operation *[….]* 1963 the operation was. So, what would that be, I’d be 24, 23 or 24 when I’d the operation and the doctor who’d been attending me, you know, he, [it was] mostly at night I got very out of breath, and he came out at night, the doctor. He was very good. […] He had been over in London at a big hospital, was it Guy’s Hospital, or something in London, and they were experimenting in heart operations

> then so he said I was a good one to send to them. And when I went that day [….] he told me he could do something for me. It was great, lovely. So, I'll never forget that, so [….] He took me in for tests and then, as I say, I went Royal and had the operation. And whenever I come home it was great. The first thing I done was went away across the fields for a walk, you know. It was great, so it was. Before that, like, I couldn't walk or anything, you know, so it was great, right enough […] I didn't go to high school. I only went to ordinary school and then I did join the tech, to learn book-keeping. But I couldn't keep it up so I just had to do what I had.

As if that wasn't enough to contend with Christine suffered a stroke while pregnant with her second child:

> It affected me all down my right side, so. I was always right handed and now I have to do everything with my left hand. That was in Royal in Buckinghamshire. So, anyway, the doctor then, consultant, told me I'd have to have another operation on my heart which I had because he said it was a clot or something […] my brain, you know. So, I'd another operation in Buckingham so that…I was fine then up till 2003. I had to go in for another heart operation and they put me in a mechanical valve, so that was in 2003.

Christine still lives with the effects of this stroke and my marginal note in the transcript of the interview reads: 'still has a dense rt. hemiplegia, which I assumed was from a recent stroke when I first met her. I was shocked to hear this.' The effects of the stroke did not impede her ability to bring up her children or to work for a living, though. She worked as a school secretary throughout her adult life. In a long catalogue of previous illness stories, including at least two different mental disorders, Josephine reveals an inner toughness in which she minimises all her troubles ('it's nothing isn't ECT'; 'I've had loads of electric shocks, they're not painful') and maximises her ability to endure ('you think you'll get me down, but you won't'; 'I felt I had to put up with it' (domestic violence). Her attitude to mental ill health is fearless and she encourages people she meets to be fearless too:

> I never, if I hear voices that make fun of me, insult me or anything like that, I never think 'Oh, I've got schizophrenia,' you know, I've got schizophrenia again. I never do. And people come in here, [husband] will bring them in, mainly men I must admit, they'll come in, and I know what they're coming for, and then

> they'll get around and they'll say, 'I've got PTSD, how do you cope?' I say, 'Well, you walk on here [coastal path at foot of garden] and you can't go round that bend till you get to it,' I says, 'so just meet it when you get to it, you know. It's there, and you just put yourself in the psychiatrist's hands or the doctor's hands or whatever they decide to give you. I know it's not a single person's decision. You have your psychiatrist, your psychologist and your nurse and there's a few and they make the decision which is best for you. And you won't regret going to [hospital]. There's nothing to be frightened of at all.'

Comorbidity loomed large in Josephine's illness stories. Her inclusion in the study was based on her having schizophrenia and at the time of the interview she was taking part in a clinical trial, a phase III study to evaluate weight gain of ALKS3831 compared to olanzapine in adults with schizophrenia. But her illness stories also include a recent stroke and the ongoing effects of a fractured hip for which she feels she did not receive appropriate discharge care and follow-up:

> I looked up and there were two ambulance men at bottom o't'bed and, er, I said 'What's to do?' They said, 'You're goin' home.' I said, 'Well, I'm not supposed to sit in a wheelchair.' They said, 'Charge nurse says you can sit in this wheelchair'. Well, apparently you're *not* supposed to sit in a wheel-chair. You're supposed to sit at 90 degrees angle or lay down and, er, well, I thought, 'Anything to get out of here.' So, they put me in a wheelchair and they wheeled me out to t'ambulance. But when they got me in t'ambulance they did put me on't stretcher and I came home on a stretcher and they left me there [indicates middle of sitting room floor] Saturday lunchtime, no care package, nothing. So, I'm two and a half years on and I still can't get any physiotherapy. I've rung all over and I've been all over and I still can't get any physiotherapy-cos I've no care package. [cough]. Me doctor's referred twice and he said 'I don't know what's going on. Ring x. Rung x. 'Ring y'.
>
> Well I've rung y. 'Ring erm z up'. Well I've rung z up.

This story is one of many in which Josephine portrays health professionals and health services, except doctors, in a poor light. She typically places herself at the controlling centre of her experience and when her management of other individuals and of systems does not bring the desired consequences she expresses dissatisfaction and criticism. Paradoxically, she also reveals a capacity for silent endurance, for putting up with things, which she attributes to her life experience of having worked long hours in a munitions factory during the war, combined with her childhood farm work and subsequent lack of choice about post-war transfer to work in the textile industry.

For Trevor, comorbidity was an asset. He modelled his reaction to mental disorder on his systematic self-management of his diabetes over the preceding twenty years:

> You conform to what is required of you in terms of being sensible and what you eat and whatever you do. And that has, to a certain extent, if not to a large extent, has given me an advantage in dealing with other things such as mental illness, in [that] you discipline yourself. You become used to this sort of procedure mainly because you have so many tablets to take. I'm on tablets for diabetes and you've to time that with food you eat etc. etc. And I've found, over the period of time, that if I have a regular programme, daily programme, sounds a bit boring but you repeat that day in day out [cough] and the more you stick to it the more successful you are. And I've found this out and it isn't easy always to adhere to because all sorts of events can crop up where it would tend to disrupt your timing, you know, and you've to try and work round it. But you have to be conscious of the fact that's what you're doing. But if you let things slip you suffer the consequences, so that's what I found out. I'm referring to diabetes because I've found that probably, as I've said, that's my best source of disciplining myself.

Overall, comorbidity stories were fewer in number and revealed effects less intrusive on daily life than I had anticipated in conducting interviews about illness with a study population of older people. Rosemary's concurrent bipolar disorder came as a surprise to her, and she was suffering side-effects of ECT (for manic depression), but her life seemed not to be unduly disrupted by it. Judith's asthma seemingly had the worst effects among those with concurrent illness. She had recently installed various aids to movement around the house and she terminated the interview because of breathlessness. Barbara claimed her knee (damaged from playing tennis when she was younger and awaiting surgery) gave her more trouble than her schizophrenia. Trevor's diabetes, as already seen, was under control and provided a model system for his management of mental ill health. Sylvia was taking medication for something which remained unspecified even on direct questioning. Norah was on tablets for high blood pressure. Richard suffered from heart disease and had recently developed diabetes, which, he said, he had ‘got well under control.’

9.3.3. Resilience in the context of relationships

Some participants were caught up in other stories too; notably, stories of family life. Frank (2013) supplements the analytic question: ‘What other stories are people caught up in?’ with the question, ‘What differences depend on being caught up in those stories?’ For Sylvia, being caught up in the story of her grandson’s chaotic life seems to have a paradoxical effect in the difference it makes to her own life. On the one hand she attributes the start of her mental ill health to her anxiety about him (‘Oh, gosh, I’m not surprised, I’ve got all worked up over him’, see Chapter 6). On the other hand, her active concern for his welfare (he was in prison at the time of the interview) despite his repeated challenges to her generosity (the rest of the family have disowned him) is of a piece with her lifelong other-centeredness and seems to displace, most of the time, any anxiety she feels about her own well-being. This concern for others rather than the self is another expression of hope, hardiness and resilience (Felten, 2000).

In less dramatic fashion than in Sylvia’s life other participants were also involved with, supported by, and still giving support to their families (see Koushan et al., 2019 on mutual spousal support). Trevor’s sons-in-law helped him with heavy gardening. Henry enjoyed his grandchildren visiting and lifting his spirits; and his two daughters helped with cleaning and shopping despite living in distant towns. Barbara’s three children, too, were active in helping with daily household tasks. Mary and her husband, with one daughter and grandchildren themselves, were also active honorary grandparents to their GPs children. John took an active interest in the lives of his grandchildren and Louis was more active than most in contributing to the welfare of younger generations in his family. Our initial arrangement for interview had to be postponed because he was ‘on standby’ to provide transport for other family members to visit his recently born great-grandson in hospital following urgent surgery. The interdependence at work in these relationships can be seen as another foundation on which resilience rested (Felten, 2000; Long, 2013).

9.4 Searching for contrary cases

I was sensitized to the concept of resilience as a fundamental feature in the lives of older people with mental ill health by the findings from my qualitative systematic review, chapters 2 and 3 of this study and I found abundant examples of resilience in the interview transcripts, as shown in this chapter. Reflection on my underlying attitudes to the study and to the life stories told by participants suggested the need to interrogate this interpretation, which privileges resilience as the dominant, characteristic response of these older people to living with long-term mental ill health (and in their life generally). The following extract from my research journal, September 21st 2017, illuminates this process of questioning and reveals an initial outcome which reinforces, rather than undermines, the dominance of resilience:

> ‘Maybe I want to find [that resilience in old age is common] because as I anticipate getting older (and as mental ill health stories make their way into my life) I want to know that there are hopeful stories of courage, of fortitude, of recovery-which can be my stories too. So, I need to look in the interview data for counter-stories, narratives which show or suggest the inability to bounce back from adversity. But I can’t think of any! How am I going to search? Or should I just listen again to all the interviews (as I began today) with this search in mind? Today, I noticed the reverse: a resilience story I had missed. Mary is telling me about a perforated peptic ulcer, the result of taking NSAIDs for rheumatoid arthritis, for which she was hospitalised, but which had begun to heal before finally diagnosed:
>
> ‘So, I was lucky, I escaped an operation. I nearly had an exploratory one but, fortunately, I didn’t.
>
> -***That must have been painful though***
>
> Well, it was. But, you know, these things happen in life. You’ve got to cope with them (rising intonation and emphasis). Life has got to go on.’

It appears that ‘Life has got to go on’ could almost be an epigraph for the whole study. A doctoral study of older adults with mental ill health in Scotland, confirms the dominance of resilience as a characteristic of older people’s response to living with mental ill health (Long, 2013). Long (2013) draws attention to the origins of resilience research in studies of childhood and adolescence and notes that some authors have argued that young people have the 'reserve capacity' necessary for resilience to a much greater degree than older people. Since reserve capacity is 'equated with the ability to grow beyond current or normal levels of functioning' (Long, 2013) it may be that 'resilience' is not quite the right word, or construct, to describe the quality of stoical endurance displayed by older people in this study. On the other hand, the strength of optimism and determination, accompanied by a present or future orientation, revealed in some of the narratives supports an interpretation of participants' attitudes as resilient.

9.5 Self and society: 'grand narratives' and the 'lens of culture'

A supplementary analytic question to Frank's (2013) 'What other stories are people caught up in?' which might help situate private individual experience in a broader social context, is to ask, "Are there points in all this storytelling where the personal life stories 'bump up against the century' (Crown, 2009), where the stories in which people are caught up may be part of a 'grand narrative'"? (Davey & Seale, 2002). Another way to think of this is to approach the interviews viewed analytically through a 'lens of culture' (McCormack, 2004). Rather oddly, it seems easier to show which grand narratives do NOT drive the life stories of these individuals, the cultural phenomena which do NOT seem to be features of their experience. There are at least three.

9.5.1 The self-help movement

First, in relation to the concept of 'survivorship' there has grown a self-help movement, supported in the UK by mental health charities. The first manifestations of this in the 1980s took the form of Mental Health Support Groups, typically organized and supported locally by small charities or parts of the health service. Groups were run by volunteers, typically comprising people who had experience of a particular type of mental ill health. This type of mutual support has extended to the Internet where there now can be found a host of websites representing a 'community of survivors,' (https://www.nsun.org.uk/ accessed July 16th 2017) who communicate and share their experience electronically with people they probably have not met. These are sites for the exchange of information, advice, mutual support and emotional release.

Participants in the present study ‘bump up against the century’ by NOT being involved in this culture of organized mutual support and self-disclosure. Their level of self-disclosure seems to be influenced by their personality and habits, rather than by the gendered expectations of male stoicism or female expressiveness (Hilton et al, 2009): William is ‘not gifted with words,’ in his wife’s report and, sure enough, he is a taciturn interviewee. Mark is loquacious, and the stories disclosed to a stranger (Kitwood, 1980) on a first meeting are full of rich detail. Clive affirms the opportunity to talk about his illness and the effects of treatment with fellow sufferers at the mental health centre; Henry, as we have seen in Chapter 9, bemoans his experience that (at the same centre) ‘nobody talks about your illness, do they?’ Josephine has a reputation at the mental health outpatient clinic for talking at length to anybody who will listen about her illness experience. Mark, as noted above, derives deep psychological comfort from what might be called the ‘enabling self-talk’ of his friend’s positive thinking (Bloch, 1993). Their support comes from family, friends, neighbours, rather than from self-help groups.

9.5.2 The turn to complementary therapy for mental ill health

A second grand narrative which participants in this study do not seem to be part of is the turn to complementary therapy for mental disorders. As shown in Chapter 9, ‘negotiating a plurality of therapeutic options’ (Coffey at al., 2019) is not a dominant feature of the treatment experience for most participants, even where the choice lies among conventional treatments. Complementary and alternative therapies are not referred to at all by participants in this study. This may be contrasted with findings of an American study a decade or so ago which reported that 81.7% of older adults with self-reported anxiety or depression, aged 65 and over (average age of 72), and with the same mental disorders as participants in *Mental Ill Health Stories,* used complementary therapies in the early stages of mental ill health treatment (Grzywacz et al 2006).

What reasons might be suggested to explain why participants in *mental Ill Health Stories* do not speak of using complementary therapy? I think it is because people in this cohort do not partake of the ‘increased individualization in contemporary cultural practices’ which Coffey at al. (2019) notes in relation to complementary and alternative medicine (CAM) but which is also a feature of wider society. Their cultural practices, including assumptions and behaviours clearly shown in the data collected for this study, are rooted in family and community, in work and obligation, rather than in individual experience, choice and aspiration.

9.5.3 End of life care

Mental ill health that is chronic or recurrent, requires ongoing intensive psychiatric treatment, and significantly impairs functioning (NICE, 2019; Foti, 2003). Serious mental ill health is associated with premature mortality across all age groups (Russ et al., 2012). In part, this is because the physical health needs of people with a mental health condition are often overlooked, and physical symptoms may be wrongly attributed to their mental health condition, as well as other factors related to having a severe and enduring mental health condition (Public Health England (2018); Jerwood et al., 2017). As a consequence, people may be identified as approaching the end of life late, which can affect the ability to plan care that meets people's individual needs (Shalev et al., 2017; Chochinov et al., 2012; Jerwood et al., 2017). Also, research shows that mental ill health patients often do not die in their place of choice (Waterman et al., 2016; Harrison, 2014; Foti et al, 2005) and it is still claimed (NHS England, 2014) that death is not spoken of in society, that it is taboo.

At a psychiatric hospital in England, Waterman et al.(2016) found that adult patients with severe mental illness and life-threatening, comorbid conditions and communication problems have particular difficulties in expressing their wishes and receiving optimal end-of-life care. Current health policy in England seeks to draw attention to the end of life in new ways (NHS England, 2014) and to ensure that as many citizens as possible have a dignified death over which they have some control. Death was hardly ever mentioned by participants in this study. It was felt in the background for Louis, Barbara and Trevor (all suffering from Schizophrenia) and Barbara had lost her husband to suicide after severe depression in the fairly recent past. Henry talked about death almost as something in the distant future, making sure he had all practical arrangements in place. In fact, as we have seen, he died within months of the interview. Josephine spoke about death at the end of the interview only to make a joke about self-termination should she develop Alzheimer's Disease. William hoped that treatment would 'buy him a few more years,' while Doris simply reflected phlegmatically that ‘everything comes to an end.’ None of the other participants referred to death or, importantly, gave any signals that they were concerned with thoughts of death. They seemed firmly to situate themselves in life.

9.6 Summary

In this chapter I have drawn on the wider life stories told by participants, going beyond the specific illness narratives of the ‘mental ill health stories,’ to interpret their experiences of mental ill health in the context of their overall biography. I have argued that their reaction to mental ill health is marked by resilience and that this resilience derives from their life experience. They situate themselves as people with a future orientation, firmly anchored to an existential and ontological position which insists on endurance and is encapsulated in the colloquialism ‘life must go on.’ Specifically, resilience is shown in relation to participants’ reactions to adverse life events (Bonanno, 2008; Bonanno et al 2002), to their experiences of comorbid illness and in the context of their family and other relationships (Polk,1997).

Analysing the narrative data through the ‘lens of culture’ (McCormack, 2004) and in the light of ‘grand narratives’ (Davey & Seale, 2002) reveals that contributors to this study typically do not participate in significant, health-related, contemporary cultural phenomena. Unlike younger people with mental ill health, they exclude themselves from formalised types of group and interpersonal support, whether face-to-face or internet- based, and they do not make use of complementary therapies.

Overall, the findings of this narrative study offer a positive picture of resilient older people, embedded in mutually supportive family and social networks, being offered a high quality of treatment and care in a well organised health system. Nevertheless, there is still excess mental ill health mortality in the over 75s in the UK, compared with the USA, for example, so broadening of Mental ill health awareness, early detection and appropriate treatment remain important targets, along with the creation of new models of support for adults living with mental ill health beyond treatment (NHS England, 2014; Russ et al., 2012). In addition, according to some of the stories told by these participants, there is still a need to educate and support clinicians to provide the highest standards of psycho-social care. In the next, and final, chapter, I conclude the thesis with a review of some methodological and theoretical considerations, and I suggest what significance may be drawn from the findings of this study.

CHAPTER 10

DISCUSSION

10.1 INTRODUCTION

The study of living with mental ill health in old age reported in this thesis is directed at answering the question, ‘What are older people’s subjective experiences of living with long-term mental ill health?’ The study is comprised of two different investigations: a literature-based section of the study taking the form of a qualitative systematic review (*Experiencing Mental Ill Health,* reported in Chapters 2 and 3), and an empirical section of the study using narrative methods of inquiry (*Mental Ill Health Stories,* reported in Chapters 4-9). In this concluding chapter I summarise the key findings across both the qualitative systematic review and empirical study and consider their significance for our understanding of older people’s experiences of living with mental ill health. I discuss the challenges of comparing findings from both the systematic review and empirical study which attempt to answer the same question, but which use different approaches.
I review and reflect on the identification of a research problem, the formulation of a research question and the principal approaches adopted by way of investigation.
I consider the strengths and limitations of the chosen research methods. I conclude the chapter, and the thesis, with some observations on the transferability of the findings to wider populations.

10.2 Summary and comparison of key findings from both the qualitative systematic review and empirical study

In this section, I summarise the findings from both the qualitative systematic review and empirical study and consider the ways in which findings from the narrative study (*Mental Ill Health Stories)* can be seen to confirm, extend or contradict findings from the qualitative systematic review (*Experiencing Mental Ill Health).* The findings from *Experiencing Mental Ill Health* suggested that, across a heterogeneous population of 414 older people, aged 51-92, with a wide range of mental disorders at different stages, and living in nine different countries, the experience of living with mental ill health was marked by ambiguity. Close analysis and interpretation of a secondary dataset derived from 19 reports of primary research revealed eight domains in which older people's experiences of mental ill health could be categorised: i) the experience of bodily suffering, ii) disability, iii) experiences related to treatment, iv) the condition of empowerment, v) states of mind and feeling, vi) impact of having mental ill health on a network of relationships, vii) stigma and viii) learning & management of illness.

The concept of ambiguity emerged in the analytic and interpretive process because in each domain a continuum of experiences was indicated such that for many experiences reported there was a counter-experience. For example, bodily suffering was extreme for some people, depending partly on the type and stage of their mental disorder, whereas for others it was less marked. But even where suffering was intense, older people found a variety of ways to mitigate their suffering and to endure their experience of pain. Where emotional pain arose in response to the fear of treatment or death, people were able to find consolations in religious belief or in their family and community relationships. Some people sought actively to empower themselves in exercising as much control as possible over their experience whereas others chose a more passive role; for example, in making decisions about treatment.

The central connecting motif of ambiguity was explored more intensively by investigating the data to discover 'dimensions of contrast' (Elofsson & Ohlèn, 2004) and by the application of Bury's (1982) concept of 'biographical disruption.' Interpretation of the systematic review data in the light of detailed analysis using these methods confirmed a conclusion that, for the cohort of older people represented in these studies, experience of mental ill health was marked by a condition of ambiguity.

Data generated by narrative interviewing in *Mental Ill Health Stories* revealed experiences of a more homogenous population of older people, ten men and ten women aged 75-92, with one or more of four most common groups of mental disorders, all resident in the same geographical region of a semi-rural county and all treated at different mental health institutions. I analysed these data narratively, using the concept of the 'illness trajectory' (Corbin & Strauss, 1988) as a structural framework, along with methods derived from other sociological and narrative concepts (the 'grand narrative' and the 'lens of culture') which were designed to interpret the participants' private experience in a social context.

The ‘illness trajectory’ represents a temporal arc structured by central events or processes including recognition of the first signs of illness, the decision to seek medical advice, having investigations and receiving a diagnosis, undergoing treatment and continuing to live with mental ill health beyond treatment. Participants reported experiences under each of these headings were described and interpreted in chapters 6-9.

The onset of mental ill health was experienced, perceived and acted on differently among the twenty men and women interviewed in *Mental Ill Health Stories*. Only one mental disorder was detected by pre-symptomatic screening. Sam’s persistent delusional disorder was detected by pre-symptomatic screening which was provided after recovering from a stroke and ‘became confused’. All the others presented with symptoms, some of which were ignored for months (depression) and some of which could not be ignored (schizophrenia). Delays to diagnosis arose from two sources: first, where participants held back from visiting the doctor because they were afraid to be told they might have a mental disorder and, secondly, as a result of the inherent complexities of diagnosing mental ill health accurately. Among those participants who told a story of receiving the diagnosis there were varied reactions, ranging from shock to stoicism, and varied experience of being told in a sensitive way that they had mental ill health. With a few relatively minor exceptions participants reported satisfaction, sometimes in glowing terms, with their treatment, both in terms of their overall experience of interactions with health service personnel and with the medical treatment employed in the attempt to cure their mental ill health or their symptoms. Even where there were permanent side-effects of treatment (for example, urinary incontinence following ECT which were experienced as burdensome, participants responded with tolerance and forbearance, rather than dissatisfaction and complaint.

Analysis of life-story data in the interviews suggested that participants’ stoical, sometimes fatalistic, attitudes to having mental ill health were consistent with life experiences in which many of them had endured a range of hardships or major responsibilities in their personal or working lives. It is this experience of endurance, evident in the findings of *Experiencing Mental Ill Health* and found as a dominant theme in *Mental Ill Health Stories* in the form of resilience, which most obviously connects the qualitative systematic review and empirical study reported in this thesis.
There are challenges in ascertaining ways in which the findings from *Mental Ill Health*

Stories can be said to confirm, extend or contradict the findings from *Experiencing Mental Ill Health.* Although focused on the same topic, the two parts of the study employed different methods in studying slightly different populations. Box 10.1 (p. 217) shows extracts from my field notes which indicate the continuing struggle I experienced in trying to make direct comparisons between the two.

I think there are some broad similarities and also some differences. Both the qualitative systematic review and empirical study reveal the importance of relationships in older people's lives. And they both show that older people with mental ill health are sometimes active in giving support to others as well as receiving it. Both parts of the study show that, in general, older people prefer to delegate decision-making regarding treatment for mental ill health to their doctors. There are differences of emphasis here across the two parts of the study: in *Experiencing Mental Ill Health* there is a strand of more definite partnership between patients and healthcare providers and in *Mental Ill Health Stories* there are examples of a more consultative or collaborative style of decision-making. In *Experiencing Mental Ill Health* there is some evidence of perceived age-related discrimination in access to treatment. This is completely absent in *Mental Ill Health Stories.*

There is more evidence of suffering, both physical and existential, in *Experiencing Mental Ill Health.* This is probably owing to the greater heterogeneity of the study population, which included more people who were frailer in both body and mind and some, death was imminent due to health problems. This is not to say that participants in *Mental Ill Health Stories* did not report experiences of suffering. For some, the shock of the mental disorder diagnosis caused intense suffering and some participants experienced great pain as a result of treatment. But reported or expressed suffering did not represent a dominant and overt theme of the narratives in the same way as it appeared in the secondary data set of the systematic review, despite the closeness to end of life of some of the participants due to old age or medical problems in *Mental Ill Health Stories* (two of the twenty participants died within months of interview).

There are differences of emphasis, too, in relation to the overarching themes in both the qualitative systematic review and empirical study. There is less evidence of ambiguity and of biographical disruption in *Mental Ill Health Stories,* where there appears to be a more uniform set of experiences across the cohort and where biographical continuity can be seen more clearly than biographical disruption. But the core finding from *Mental Ill Health Stories,* that older individuals with mental ill health are resilient, does confirm and extend a finding from *Experiencing Mental Ill Health.* This can be seen in the concluding observations from each part of the study:

> ***Experiencing Mental Ill Health***
> The findings from this review reveal the multidimensional nature of older people's experiences of living with mental illness, throwing into sharp relief both the sources of suffering endured and the resourcefulness and resilience (Nygren et al., 2007) older people bring to managing a changed life.
>
> ***Mental Ill Health Stories***
> I have argued that their reaction to mental ill health is marked by resilience and that this resilience derives from their life experience. They situate themselves as people with a future orientation, firmly anchored to an existential and ontological position which insists on endurance and is encapsulated in the colloquialism 'life must go on.' Specifically, resilience is shown in relation to participants' reactions to adverse life events (Bonanno, 2008; Bonanno et al 2002), to their experiences of comorbid illness and in the context of their family and other relationships (Polk,1997).

It is interesting to speculate about alternative methods of analysis which might reveal similarities and differences between the two studies in more detail. I think there are at least two ways in which they could be synthesised to achieve this. One way would be to incorporate the findings from *Mental Ill Health Stories* into the dataset for *Experiencing Mental Ill Health*, using Sandelowski & Barroso's (2007) definition of a finding (quoted in Chapter 2). This is an intriguing possibility, but it would be a large-scale undertaking, partly because of the volume of material (the findings chapters from *Mental Ill Health Stories* extend to 105 pages) and partly because the incorporation of additional data would be likely to change the nature of the dataset such that a different approach to analysis may become necessary.

Another way to link the qualitative systematic review and empirical study analytically would be to analyse the narrative data using the eight topics, or domains, identified in the systematic review data, along with the concepts of ambiguity and biographical disruption. This might also be interesting and, probably, would be more easily achievable than the first alternative approach. The reason I chose not to do this in my analysis was that it seemed too mechanistic to take a set of themes which grew from the analysis and interpretation of one dataset and simply apply them to a dataset generated by different methods. In both the qualitative systematic review and empirical study, the approach to analysis and interpretation emerged from close familiarity with, and hard thinking about, the particular data generated for each study. In both cases a genuinely organic, emergent process drove the analytic method. In the case of *Mental Ill Health Stories* this led to a narrative method of analysis which precluded using the themes from *Experiencing Mental Ill Health* as a coding frame.

In summary, then, resilience is the central concept which connects the two parts of the study. It is the interpretive core which defines the experience of living with mental ill health in old age among participants in studies across Australia, Canada, Hong Kong, New Zealand, Norway, Sweden, Taiwan, UK and USA. This finding is also consistent with conclusions drawn from a study conducted in Hong Kong, using in-depth interviews with thirty-three men and thirty-one women with mental ill health, aged 55 and older (Lai at al., 2019). Lai et al., observes that, 'older adults are often viewed as frail and not able to contribute to society or continue to grow as a person. In contrast, the older adults in this study were mostly resilient and full of life, despite the possible devastation of mental ill health'. This observation could hardly echo my own conclusions more closely.

10.3 Implications for practice

How does it help nurses working in a mental health ward, psychiatrists, psychologists, or social workers, community nurses, general medical practitioners (GPs) and others supporting people at home, to know that the people in their care, though very old and possibly with advanced mental ill health, are resilient? It should not mean that they can be left to look after themselves! But, knowing that many older people are resilient does mean that it is not to be assumed that they will simply succumb to mental ill health and die. It means that they should have access to the best possible treatment and services available, on an equal basis with other, younger, people with mental ill health. And it means that health and social care providers should be ready to help older people with mental ill health to expect and to plan for a life beyond treatment. Nurses, social integrated workers, and others should advocate for older people just as they would for people in other age groups. And, since the experience of having mental ill health is into a whole life, it is probably helpful if professional carers can get to know the person they are caring for as well as they can. Biographical approaches to care (Menn et al., 2019; Wilson, 2017; Zinn, 2005; Clarke et al., 2003., Clarke, 2000) can be helpful here.

Participants in this study reported a range of side-effects from drug treatments and ECT. Drug treatments appear to be of limited value in this context, and carry the danger of side-effects (Ouslander *et al.*, 2003). Decisions about treatment were, influenced by social context, that is, the general attitude to mental illness treatment in old age. Those in advanced old age felt that their age was a factor considered by health professionals in deciding treatment options, which in some cases meant limited access to various methods of therapy. Suspicions about being treated less carefully owing to old age exacerbated feelings of abandonment and uncertainty.

Although treatment, by and large, has similar efficacy in older and younger people, research has shown that GPs are much less likely to refer older people to Improving Access to Psychological Therapies (IAPT) services, which are based in primary care and offer psychological therapies (Pettit et al, 2017). Yet, when older people are referred to IAPT, they are more likely than younger patients to both attend therapy clinics and benefit from them (NHS Digital, 2017a). This pattern has been confirmed in a recent study that suggests old people who self-harm are less likely to be referred to specialist mental health services than younger adults, despite a higher risk of suicide in this group (Morgan et al, 2018). Age UK reports that, between 2008/2009 and 2015/2016, the total proportion of over 64-year-olds referred to IAPT increased only from 4% to 6.1%, well below the government's expectation of 12% (Age UK, 2016). They conclude that at this rate of increase, it would take until 2031 to meet the target.

Where are counselling psychologists in the provision of mental health services to older adults? What contribution can they make to improve the mental health of this growing sector of the population? Over the years, prominent psychologists have suggested that counselling psychology could play a greater role in the provision of services for older adults and lamented the apparent lack of enthusiasm on the part of counselling psychologists to work with this group (e.g. Karel *et al.*, 2012). A 2008 American Psychological Association Survey, of Counselling Psychology Health Service Providers, found that only 4.2% of counselling psychologists listed older adults as their main area of clinical service (APA Centre for Workforce Studies, 2008 reported in American Psychological Association, 2014). Similar figures were obtained from an Australian survey, in which 6% of counselling psychologists surveyed indicated that they were specialists in aged care, with 40% of the sample indicating they had no contact with older clients (Koder and Helmes, 2008a). UK figures are also comparable, with an international trend towards low resources for older people requiring psychological services. Investigations into reasons for this low level of psychologist interest have suggested the importance of a number of factors, starting with professional ageism.

From the time of Freud, there have been negative views regarding the potential of the older person to benefit from psychological therapies that are seen to require flexibility of thinking: ‘ . . . near or above the fifties the elasticity of mental processes on which the treatment depends, is as a rule lacking . . . old people are no longer educable’ (Freud, 1905, in Murphy, 2000, p.182). He was 49 years old at the time of writing this quote. As a consequence of lack of interest in working with older adults, therapeutic nihilism negatively impacts on older adults’ access to potentially efficacious psychological interventions (Hepple, 2004). A wide range of ageist views have been quoted in several studies, for example: ‘feeling that older people’s lives, filled with bereavement, failing faculties and limited opportunities, are inherently depressing-so what can one do?’ (Lee *et al.*, 2003, p. 5). An Israeli survey reported that 55% of their sample of clinical psychologists indicated they specifically did not want to work with older clients (Shmotkin *et al.*, 1992).

With longer life expectancy comes more years of living with chronic health conditions. Some of these are associated with chronic pain, which patients experience as frustrating and limiting, and clinicians can find challenging to treat. A randomized controlled trial (RCT) compared two psychological interventions (cognitive behaviour therapy (CBT) and acceptance and commitment therapy (ACT)) for chronic pain in a group of 114 participants, of whom 18% were over the age of 65 years (Wetherell *et al.*, 2011). Both treatments resulted in reductions in pain interference, depression, and pain-related anxiety, with no significant differences between the two interventions, but ACT was perceived to be a more acceptable therapy, resulting in fewer drop-outs. This highlights the role that psychological intervention can play in the management of chronic health conditions, in order to increase quality of life and functioning in older adults.

Counselling Psychologists are well-placed to conduct psychotherapy for the management of disorders such as depression and anxiety, with strong support from the research literature (for example, Andersson & Cuijpers, 2016; Cuijpers *et al.*, 2006; Frazer, *et al.*, 2005). The current cohort of older adults may be reluctant to seek psychological help, which can be seen as stigmatizing and a sign of weakness (Zarit and Zarit, 2011). However, as this study has shown, most older adults have grown up in an era of greater psychological awareness and are likely to make stronger demands for psychological intervention (Laidlaw, 2013). In light of the reluctance on the part of the therapists to work with older adults, it is possible that there will not be a workforce that is adequately trained to respond to their needs.

Also, as healthcare becomes more complex, the need for cross-disciplinary co-operation becomes increasingly important (Karel *et al.*, 2012). Patient centred care requires an integrated approach to meet the psychological and physical needs of the aging population, yet counselling psychologists remain underrepresented in the physical healthcare setting, and 'notably absent from policy analyses of geriatric workforce needs' (Karel *et al.*, 2012, p. 187). Counselling psychologists/therapists need to work closely with primary care providers in providing both education and early intervention regarding the ability of older adults to benefit from psychological techniques. In addition, counselling psychologists can be representatives on local health advisory boards, develop private practice partnerships within existing primary care physician or geriatrician clinical practices, and be part of regular multidisciplinary professional development networks to promote their role.

At the policy level, much could be done to increase access to psychological services. For example, currently in Australia, residents of residential care homes are not able to access rebated clinical psychology services but must either access already over-stretched public mental health teams or fund their treatment privately (Davison, 2016). More broadly, attitudes towards working with older adults are intrinsically connected to attitudes towards ageing itself. It is hard to see how a greater readiness amongst counselling psychologists to work with older adults can develop in the absence of a fundamental shift away from stereotyped images of ageing.

Counselling psychologists have much to offer, but have, as yet, not fulfilled that potential. Creating more opportunities to work with older adults, being more active in clinical and policy debates and working actively within the broader discourse about ageing to promote the psychological needs of older adults may help us to be prepared to meet the demand that future years will bring.

With the exception of some disclosure of mental disorder diagnosis which, in the report of participants, fell below their expectations, the treatment and care given to participants in *Mental Ill Health Stories* appear to have been satisfactory. However, there was an indication that some participants had been excluded from psychological treatment on the grounds of age, as in some reports in the findings from *Experiencing Mental Ill Health.* Continuing care seemed to be satisfactory for most participants, with the exception of one participant's dissatisfaction with arrangements at discharge from hospital.

10.4 Reflections on choosing a research question and designing a study

The research question underpinning both the qualitative systematic review and empirical study reported in this thesis is a simple one: 'What are the reported experiences of older people of living with long-term mental ill health?' Most standard research methods textbooks, in the world of health and social care at least, emphasise the importance of the research question in driving choices about the design and conduct of a study (Dickinson & O'Flynn, 2016; McLaughlin, 2012, Aveyard, 2010; Gerrish & Lacey, 2010; Parahoo, 2014). The research question itself should derive from a research problem. The research problem, in this case, is the perceived obscurity from the view of health professionals, researchers, policy makers and scientists, of older people's subjective experiences of having mental ill health. This is a problem because, in the contemporary world of healthcare, therapeutic benefit is seen to follow from the public disclosure of inner worlds of sickness. To remain hidden is to be disenfranchised in some way. This invisibility seems to increase with advancing age. Consequently, the research focus chosen for this project was on the experience of men and women aged 75 and older.

My approach to this particular research problem and research question was to ascertain the current state of knowledge by searching for existing research literature, before designing a qualitative study to address any demonstrable gap in knowledge. As explained in Chapter 2, most of the scientific literature relating to older people and mental ill health is concerned with matters of epidemiology and clinical treatment. Older people's subjectivity, their own accounts of their felt experience, is largely missing from the literature.

In the interpretive paradigm which influenced my approach to this research problem, research design is rarely fixed in advance but emerges over time and may undergo several iterations (Lincoln and Guba, 1985; Robson, 2002 and see Chapter 4). Consequently, my initial plan to conduct a conventional narrative or critical literature review was transformed into a decision to maximise the yield from the few studies retrieved which reported older people's experiences of mental ill health by subjecting them to qualitative systematic review (Chapters 2 & 3 and see section 10.4.1 below). Nineteen studies were reviewed, from nine countries (Australia, Canada, Hong Kong, New Zealand, Norway, Sweden, Taiwan, UK, USA) with 414 participants aged 51-92. Because only two studies concentrated on a population of people aged 75 and older, and because none of those two were from UK studies, I designed an empirical enquiry to investigate a more homogenous population, of people aged 75 and older, living in Semi-rural county in the UK (Chapters 4 & 5 and see section 10.4.2).

10.4.1 Qualitative systematic review: strengths and limitations

Qualitative systematic review is a relatively new approach to bringing together diverse studies to form a larger dataset which can be analysed and interpreted to produce new findings. It originates in the 'meta-ethnography' of Noblit and Hare (1988) which typically synthesised the findings of a small number of studies using similar methods. More later work (Britten et al, 2002) has shown the approach to be effective in producing new knowledge from studies using different methods, though all located within a qualitative paradigm, and with larger numbers of studies (Paterson, 2001; Sandelowski & Barroso, 2003a).

I think there are two particular strengths of the method used in *Experiencing Mental Ill*

Health in Old Age, influenced by the work of Sandelowski and colleagues (2012, 2007, 2003a, 2003b, 2002). First, the systematic and rigorous approach to defining what can be counted as the 'findings', which form the data for synthesis or, in Sandelowski's term, 'integration,' of the studies under review. This approach produces a larger and much more detailed dataset than might be anticipated from a reading of a qualitative research report which might, typically, display a set of findings as a small number of themes. Because Sandelowski's definition of a finding (see chapter 2) includes all the statements made by authors which derive from their data, close reading of a research report often reveals considerably more findings than the headline themes (414 findings from 19 studies in *Experiencing Mental Ill Health)* which expands the dataset for integrative analysis and, correspondingly, increases the scope for producing new interpretations.

Secondly, the method of introducing 'imported concepts (see chapter 3) as analytical tools enhances the possibilities for interrogating the secondary dataset and for producing interpretively rich conclusions. In *Experiencing Mental Ill Health,* the concept of 'biographical disruption' originally produced by Bury's (1982) work with younger people in the early stages of rheumatoid arthritis and applied since then in a number of health-related contexts, was usefully transferred to the context of older people living with mental ill health (chapter 3). The central finding of the systematic review, that mental ill health in old age is characterized by ambiguity, was confirmed by interpretation of the secondary dataset in the light of the six features of biographical disruption articulated by Bury (Chapter 2, pp. 68-72).

Some limitations have been identified in this approach. In qualitative research, credibility derives to some extent from researchers paying attention, in their analyses and interpretations, to the real-world contexts in which their research data are generated. The ability to do this is compromised to a degree in secondary data analysis, in which access to the original contexts of production is necessarily denied. Sandelowski & Barroso (2007) acknowledge that the findings produced in a meta-synthesis or research integration study are third order constructs, composed at two removes from the utterances of research informants. To some authors, this presents a formidable obstacle to the credibility and utility of qualitative systematic reviews (Campbell et al 2011).

Overall, I think the methods used in *Experiencing Mental Ill Health* enabled a synthesis to be made which was rooted in a careful and comprehensive identification of a body of research findings. These data were then analysed and interpreted systematically to produce new insights into the experiences of older people living with mental ill health.

10.4.2 Narrative methods: strengths and limitations

Narrative methods in social research seem to have arisen partly from a 'biographical turn' (Roberts, 2002) influenced by the Chicago school of sociology which produced rich accounts of individual lives (Webber, 2015), interpreted in the light of social and historical context (Liebow, 1967; Plummer, 1984). Narrative is now a rich and diverse collection of research practices employed across a wide range of disciplines, put at the service of understanding complex social interactions and the meanings that individuals ascribe to their experiences and relationships.

Narrative methods of data generation focus on the collection of individuals' accounts of experience, told as stories. Events which took place over a period of time are recounted with varying amounts of detail and commentary from the teller regarding geographical or spatial location, characters and relationships, and links between one event and another (plot). Narrators may or may not position themselves consciously in the role of storyteller but in every case what they say may be considered a performance of some kind, the construction of which is influenced by social interaction, by the presence of an audience, an individual or a group of listeners (Brody, 2003 p38), in what Gubrium & Holstein (2009, p10) call 'the environment of storytelling'.

A possible limitation of the approach taken in *Mental Ill Health* Stories may be that the generation of data based, more or less, exclusively on formal interviews does not adequately represent the complexity of 'narrative reality' (Gubrium & Holstein, 2009). Gubrium & Holstein argue that the incorporation of ethnographic fieldwork, and the use of narrative data arising in naturalistic settings, can do much to enhance the understanding of stories as lived in society. The point is well taken, but, in regard to the narrative study reported in this thesis, Gubrium & Holstein's approach to analysing narrative reality was encountered too late in the process to affect the research design or methods.

Narrative methods of analysis may focus on the features of storytelling outlined above (the content of the story); on the shape, structure and linguistic pattern of the narrative (the form of the story); or on a combination of the two (Elliott, 2005; Lieblich et al, 1998; Riessman, 2008). What Gubrium & Holstein (2009) call the 'situated shaping of the account' (p 17) or the 'storytelling process' (p21) can also form useful foci of analysis, going beyond the narrower confines of the internal organization of a story. Analysis in *Mental Ill Health Stories* concentrates predominantly on the content of the narratives (Chapters 5-7) though, periodically, the 'situated shaping of the account' and features of 'the storytelling process' are brought into view. In Chapter 9 the analytical range is extended to interrogate the data in the light of contemporary social contexts.

One of the strengths of narrative methods can be, at the same time, a limitation. The giving away of power and control in the interview which comes with the invitation to 'tell me what happened' means that interviewees may be more likely to follow their own course, to talk about what is meaningful to them, rather than feel constrained to answer researchers' questions. This is a strength when the hope is to generate a rich seam of storytelling. The limitation that comes along with this is the danger that the interviewee's discourse becomes dominated, or at least unbalanced, by stories and commentary which are not pertinent to the research questions. In the BNIM method (Wengraf, 2008) used in *Mental Ill Health Stories* this danger is avoided by careful construction of the interview setting, with a particular focus on the opening question (see Chapter 5) and then by trusting the process whereby meandering stories tend to come back on track, and along the way may present material which would never have been uncovered by more direct questioning.

Further limitations which pose potential threats, in particular to interpretive credibility, include some 'seductions' of narrative (Riessman, 2015; Bruner,2003). 'Narrative seduction' occurs when a story is so crafted as to seem capable of only one interpretation (Bruner, 2003). In the research context, one form of this seduction is the tacit assumption that a single narrative interview represents a whole life story. In truth, it is clear that a single interview can only represent a partial life story but, the longer you work with the transcript, because you don't have anything else, it begins to look and feel like the whole (of a person's life) story. The effect of this is to leave a question mark over any interpretation that is made which uses data that purport to be 'life story' because they are necessarily partial and selective. There may be contradictory stories which are not told.

There is also what might be called an ‘epistemological seduction’ of narrative. I mean by this the assumption that knowledge can be derived from stories. I think this is a genuine threat to credibility when stories which are generated to be representative of a predetermined class of narrative are offered as sources of knowledge; for example, stories produced by news media or charities which present mental health patients as heroic fighters to be celebrated as sources of inspiration. As I argued in Chapter 5, illness and life narratives generated for the purpose of research must be subjected to analysis and interpretation, not just celebration (Atkinson, 1997; Thorne, 2009). The threat is ever present, though. For example, in my representation of participants in *Mental Ill Health Stories* as resilient it may be that my interpretation was influenced by my inner celebration of what I heard and saw in their life stories, by what I saw as hope for my own future after breast cancer diagnosis and treatment. Reflexivity, and renewed attention to the evidence in the interview transcripts, were my principal guards against this tendency.

Another seduction in narrative research is the tacit belief that it is bad news which makes an interesting or important story. Researchers’ ears prick up during interviews, and their analytic eyes open wide reading transcripts, when people talk about the dramatic portions of their life story (child deaths, accident, murder, suicide; ‘domestic violence’). But, actually, these are not presented as defining moments; and, taken overall, the story told by respondents in *Mental Ill Health Stories* is a positive one, *contra* cultural representations of the miseries and vulnerability of old age.

Notwithstanding these potential limitations, I would argue that the particular strength of the narrative methods used in *Mental Ill Health Stories* lies in the open form of biographical data generation, which permitted an analytic view of participants’ mental ill health experiences in the context of their life experiences. This enabled both rich description of their encounters with symptoms, diagnosis, treatment and survivorship and the identification of resilience as a core interpretive concept.

10.5 Concluding Observations

It should be noted that in the interpretive paradigm on which these studies are based, all findings and conclusions must be seen as provisional. These qualitative data are susceptible of multiple interpretations which are influenced by analysts/interpreters' prior experiences and perceptions, research orientations and cultural antecedents. The findings and interpretations presented here were generated by me, in particular contexts. They are idiographic (pertaining to the unique individual) rather than 'nomothetic' (capable of expression as a universal law). These findings and interpretations, then, are not necessarily transferable to cohorts of older people other than those studied. Nevertheless, I would argue that they offer new and useful insights into older people's experiences of living with mental ill health. As a version of reality, they offer, in Bruner's term, 'verisimilitude,' rather than logical or scientific verifiability (Bruner, 2003).

The combined findings of *Experiencing Mental Ill Health* and *Mental Ill Health Stories* suggest that mental ill health presents, at the least, a disruptive potential in the life story of older adults, a disruption which is characterised by threats to bodily integrity, challenges to everyday living, spoiled hopes and fear of death. At the same time, partly because mental ill health is often only the latest in a series of adverse life events, inner resources of fortitude and hopefulness combine with family, professional and social support (Wallace, 2001) to produce a form of resilience which represents continuity in the life narrative and which mitigates the worst effects of disruption, even at an advanced stage of illness among older adults. The key contribution of both *Experiencing Mental Ill Health* and *Mental Ill Health Stories* reported in this thesis is to offer a counter-narrative to the societal expectation, or construction (Powell & Biggs, 2000), of vulnerability in old age; a counter-narrative in which the resources which older people themselves can bring to managing the life changes associated with advancing age and serious illness are brought into view and shown to be substantial.

Box 10.1 Extracts from Reflective Research Journal considering the challenge of linking two different Studies

January 14th 2018

Need to say something about links between systematic review and narrative study. I don't know yet what substantive links will be but already noting, during interviews and beginning analysis, comparisons with key findings from review. E.g. narrative study population presenting a picture of less suffering than review population, though similar resilience in response to hardships encountered in the past (including deaths of adult children by murder and by suicide, divorce, deaths of spouses) … Reasons for this may include factors that contribute to confident self-disclosure such as the age and gender of the interviewer; younger and female may engender greater self-disclosure than older and male; or it may be that participants in the narrative study are receiving effective treatment and therefore experience fewer troubling bodily symptoms which in turn relieves the mental distress of living with a serious mental disorder???.

February 11th 2018

How do emerging findings from the narrative study link to the findings from the systematic review? Tentatively, I can say in relation to this that in the narrative study: There is **less existential suffering.** For most, physical and emotional suffering is faced with fortitude and without anxiety. There is less bodily suffering too for most. Reactions to treatment have varied from terrible to minor. Persistent side-effects of treatment appear only in one person (Clive's urinary incontinence and impotence following ECT).

The importance of **relationships** is the same: with **health professionals** (almost universal approval: occasional disrespectful nurses cited (Henry, Mark) and one deviant case (Judith) disliked a consultant. Josephine is a special case in that her interview is peppered with accounts of relationships with healthcare professionals, most positive but many negative (especially with nurses) and all designed to show her in a position of power); with **family members**, many of whom are living close by and are actively involved in a caring and supportive role; **with friends**, e.g. Henry still socialising regularly with work mates after 10 yrs. retirement; Mark gained the greatest support from his friend's written note.

Resilience is the same, but **ambiguity** is less. They are fatalistic and tough.
‘It’s happened. Get on with it.’
For most, there is less focus on **the body** and its restrictions and more focus on what capability for independent action remains. Some deviant cases where restricted activity and changed roles loom larger e.g. Henry, Peter, Judith.
Treatment is accepted fatalistically i.e. ‘the doctor says I need this so I will have it’ and as though there is no other choice. There is no hint of any wish to decline treatment. Sometimes the offer of treatment is accepted enthusiastically (Mark) or gratefully. There is no indication at all in the narrative study, compared with the systematic review, of age discrimination in the availability of treatment.
Empowerment struggling to know how to compare with this one. I would say that none give a sense of having been disempowered either by their disease or its treatment or their relationships with healthcare professionals or indeed even by traumatic life events (1 lost a daughter to murder and suffered physical violence from husband; 1 lost a son to suicide; 1 lost 2 children, to cancer and to accident; at least 4 bereaved of spouses).
Mental and emotional effects. Most express gratitude for treatment combined with optimism, tinged with realism, for the future, or at least resignation to their situation. Though actually, for many, mental ill health now has a limited impact on their lives, even where it is advanced e.g. Richard who is actively pursuing a creative business interest at age 91 and knowing that there is no cure for his advance post traumatic disorder. There is variation here though. Clive, an otherwise healthy and active 76 yr. old, suffers severe incontinence as a side effect made worse by ECT. Only direct reference to sexuality is here. Peter suffers extreme fatigue from his ongoing ECT and the effects of. He was really the only participant to express any existential suffering in relation to his own disease, becoming emotional when talking about his grandchildren. Barbara was emotional too, but in relation to losing her husband to suicide after severe depression only a year before her own diagnosis. About her own illness experience, she was more resigned. In daily life her orthopaedic problems (knees) have more impact.

March 5th 2018
I have a nagging feeling of things not quite having the ‘fit’ that I want them to have. There are at least two reasons for that, I think. One is that I feel apprehensive about being led down a route of making overt comparisons between my literature study and my narrative

study, because they are different things. The literature study synthesizes and interprets findings from 19 studies covering a heterogeneous population of people aged 51-90+, representing a wide range of mental disorders at different stages of progress and treatment, across seven countries (Australia, Canada, Hong Kong, New Zealand, Norway, Sweden, Taiwan, UK, USA) and using a range of qualitative methods. The empirical inquiry studies a more homogenous population of older people aged 75-92, all resident in the same county, with one or more of the four most common mental disorders (admittedly at different stages of progress and treatment but treated at different mental health clinics) using narrative methods. I feel that I would have to think very carefully about what I mean by 'comparison' to embark on such a venture, which has implications of measurement that I do not intend, nor am in a position to make.

April 2nd 2018

I'm still resistant to trying to compare the systematic review and the narrative study but I do have to link them in some way. How am I going to do that? !.....they are linked by *resilience!*

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APPENDIX 1

Excluded Studies

Broussard, B. (2005) Women's experiences of bulimia nervosa. *Journal of Advanced Nursing* 49(1):43-50.
Exclusion grounds: Wrong study population

Chen, C.-M., Lee, I.-C., Su, Y.-Y., Mullan, J., and Chiu, H.-C. (2017) The longitudinal relationship between mental health disorders and chronic disease for older adults: a population-based study. *Int J Geriatr Psychiatry*, 32: 1017– 1026. doi: 10.1002/gps.4561.
Exclusion grounds: Wrong study design

Chernomas, W.M., Clarke, D.E. and Chisholm, F.A. (2000), "Perspectives of women living with schizophrenia", *Psychiatric Services*, Vol. 51 No. 12, pp. 1517-1721.
Exclusion grounds: Wrong study population group

Erdner, A., Magnusson, A., Nyström, M. and Lützén, K. (2005), "Social and existential alienation experienced by people with long-term mental illness", *Scandinavian Journal of Caring Sciences*, Vol. 19 No. 4, 373-380.
Exclusion grounds: Because of the age group.

Jacobs, L.M., Luci, K., Hagemann, L. (2018) Group-based Acceptance and Commitment Therapy (ACT) for Older Veterans: Findings from a Quality Improvement Project. *Clinical Gerontologist* 41:5, pages 458-467.
Exclusion grounds: Wrong study design and population

Jang, K., Lee, Y., & Lockhart, N. C. (2018). Does Confucianism still matter? A new insight from a study of the mental health of functionally dependent Korean older adults. *International Social Work*, *61*(6), 904-916. https://doi.org/10.1177/0020872816681656
Exclusion grounds: Wrong study design

Karp, D.A. (1994), "Living with depression: illness and identity turning points", *Qualitative Health Research*, Vol. 4 No. 1, pp. 6-30.

Exclusion grounds: Wrong population

Lester, H. and Tritter, J.Q. (2005), "'Listen to my madness': understanding the experience of people with serious mental illness", *Sociology of Health and Illness*, Vol. 27 No. 5, pp. 649-669.

Exclusion grounds: Wrong study population

Lewis, S.E. (1995), "A search for meaning: making sense of depression", *Journal of Mental Health*, Vol. 4 No. 4, pp. 369-382.

Exclusion grounds: Because of the age group.

Morrow-Howell, N.L., Proctor,E.K., Rubin, E.H., Li, H., Thompson, S. (2000) Service needs of depressed older adults following acute psychiatric care, Aging & Mental Health, 4:4, 330-338, DOI: 10.1080/713649968

Exclusion grounds: Wrong study design

Nehls, N., Sallmann, J. (2005), "Women living with a history of physical and/or sexual abuse substance use and mental health problems", *Qualitative Health Research*, Vol. 15, pp. 365-381.

Exclusion grounds: Wrong study population

Nyström, M., Dahlberg, K. and Segesten, K. (2002), "The enigma of severe mental illness: a Swedish perspective", *Issues in Mental Health Nursing*, Vol. 23 No. 2, pp. 121-134.

Exclusion grounds: Wrong population

O'Hare, T., Shen, C., & Sherrer, M. V. (2017). Subjective distress from trauma in older clients with severe mental illness. *Journal of Human Behavior in the Social Environment*, *27*(3), 180–186. https://doi.org/10.1080/10911359.2016.1270246.

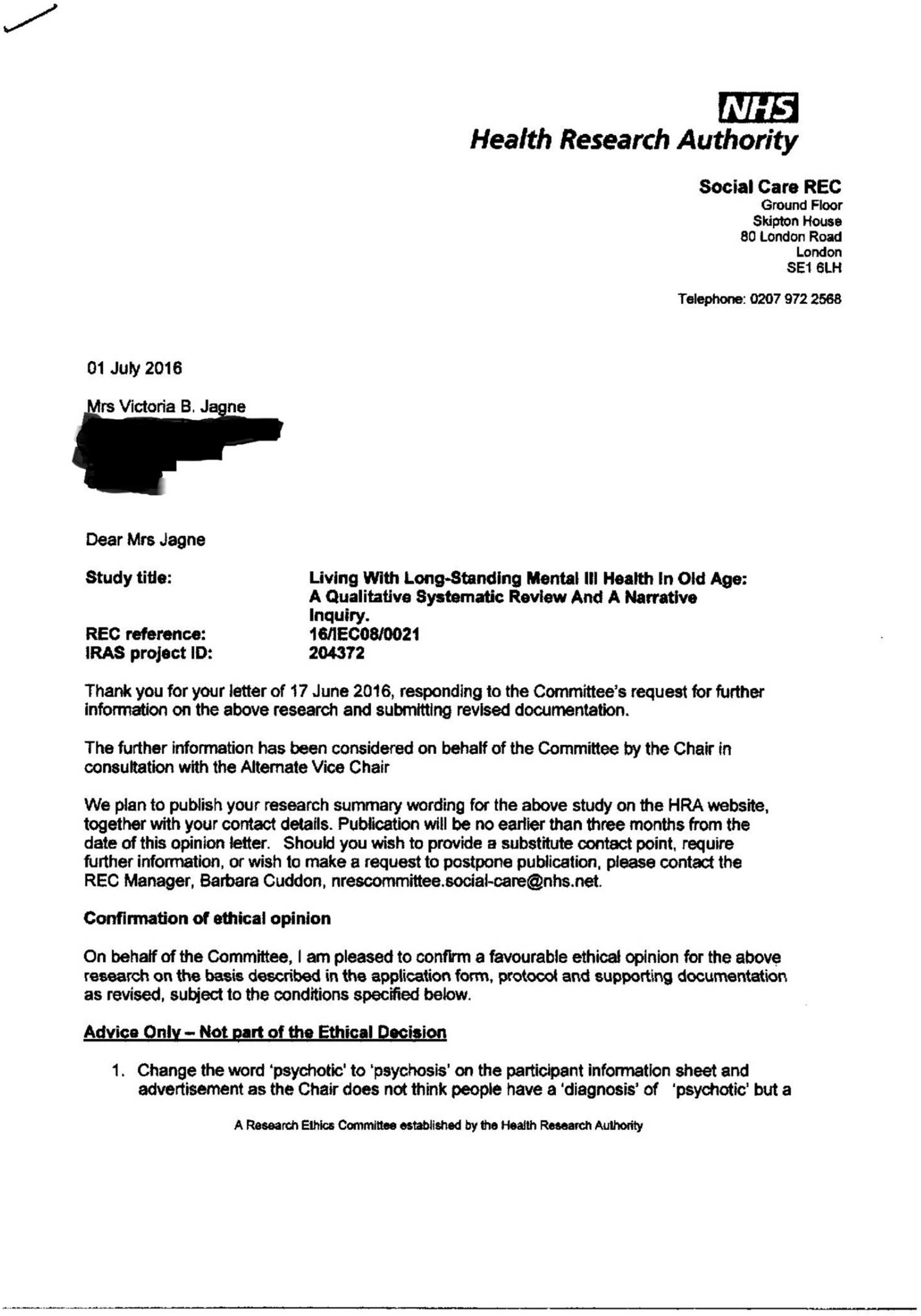
Exclusion grounds: Wrong study design

Roe, D. (2005) Recovering from severe mental illness. Mutual influences of self and illness. *Journal of Psychosocial Nursing* 43(12):35-40.

Exclusion grounds: Wrong Study Population

Salene M.W. Jones, Dagmar Amtmann & Nancy M. Gell (2016) A psychometric examination of multimorbidity and mental health in older adults, Aging & Mental Health, 20:3, 309-317, DOI: 10.1080/13607863.2015.1008988

Exclusion grounds: Wrong study design



NHS
Health Research Authority

Social Care REC
Ground Floor
Skipton House
80 London Road
London
SE1 6LH

Telephone: 0207 972 2568

01 July 2016

Mrs Victoria B. Jagne
[redacted]

Dear Mrs Jagne

Study title: **Living With Long-Standing Mental Ill Health In Old Age: A Qualitative Systematic Review And A Narrative Inquiry.**
REC reference: **16/IEC08/0021**
IRAS project ID: **204372**

Thank you for your letter of 17 June 2016, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chair in consultation with the Alternate Vice Chair

We plan to publish your research summary wording for the above study on the HRA website, together with your contact details. Publication will be no earlier than three months from the date of this opinion letter. Should you wish to provide a substitute contact point, require further information, or wish to make a request to postpone publication, please contact the REC Manager, Barbara Cuddon, nrescommittee.social-care@nhs.net.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

Advice Only – Not part of the Ethical Decision

1. Change the word 'psychotic' to 'psychosis' on the participant information sheet and advertisement as the Chair does not think people have a 'diagnosis' of 'psychotic' but a

diagnosis of 'psychosis'.

2. Add 'romantic' to 'significant relationships' to the question 'Are you married, widowed or divorced' in the Participant Interview Guide. This will focus the question in a better way.
3. Check the formatting on the consent form.

Conditions of the favourable opinion

The REC favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements. Each NHS organisation must confirm through the signing of agreements and/or other documents that it has given permission for the research to proceed (except where explicitly specified otherwise).

Guidance on applying for NHS permission for research is available in the Integrated Research Application System, www.hra.nhs.uk or at http://www.rdforum.nhs.uk.

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of management permissions from host organisations

Registration of Clinical Trials

All clinical trials (defined as the first four categories on the IRAS filter page) must be registered on a publically accessible database within 6 weeks of recruitment of the first participant (for medical device studies, within the timeline determined by the current registration and publication trees).

There is no requirement to separately notify the REC but you should do so at the earliest opportunity e.g. when submitting an amendment. We will audit the registration details as part of the annual progress reporting process.

To ensure transparency in research, we strongly recommend that all research is registered but for non-clinical trials this is not currently mandatory.

If a sponsor wishes to contest the need for registration they should contact Catherine Blewett (catherineblewett@nhs.net), the HRA does not, however, expect exceptions to be made. Guidance on where to register is provided within IRAS.

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

Ethical review of research sites

NHS sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Non-NHS sites

Guidance on Research Governance approval for social care organisations is available from the Research Governance Framework: Resource Pack for Social Care, 2nd Edition, April 2010 and can be found at:
http://www.hra.nhs.uk/resources/before-you-apply/non-nhs-recs/national-social-care-research-ethics-committee/

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

Document	*Version*	*Date*
Copies of advertisement materials for research participants [Recruitment Poster]	3	15 June 2016
Covering letter on headed paper [Covering Letter]	1	15 June 2016
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [Evidence of Sponsor insurance]		25 April 2016
Interview schedules or topic guides for participants [Participant Interview Guide]	2	15 June 2016
Other [Summary CV for Supervisor]		27 April 2016
Participant consent form [Participant Consent Form]	2	15 June 2016
Participant information sheet (PIS) [Participant Information Sheet Long Version]	3	15 June 2016
REC Application Form [SC_Form_27042016]		27 April 2016
Research protocol or project proposal [Research Protocol]	3	22 April 2016
Response to Request for Further Information		17 June 2016
Summary CV for Chief Investigator (CI) [CV]	2	22 April 2016

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Reporting requirements

The attached document *"After ethical review – guidance for researchers"* gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The HRA website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

User Feedback

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website:
http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance/

HRA Training

We are pleased to welcome researchers and R&D staff at our training days – see details at
http://www.hra.nhs.uk/hra-training/

16/IEC08/0021	**Please quote this number on all correspondence**

With the Committee's best wishes for the success of this project.

Yours sincerely

Barbara Cudden

pp Dr Martin Stevens
Chair

Email:nrescommittee.social-care@nhs.net

Enclosures: "After ethical review – guidance for researchers"

Appendix 3

Research Protocol Version3 January 2016

Victoria Jagne
Doctoral Researcher

Title

Mental health stories: the experiences of people aged 75 and older living in a semi-rural county.

Background

Old age is defined variously in western countries. People aged 50 and above are described as being in the ‘third age’ and are the recipients of special services (education, insurance, holidays) provided for ‘older people’. Withdrawal from mainstream working life at the official retiring ages of 60 for women and 65 for men is a further badge of old age. But increasing longevity, and better health, means that for many individuals the sixth decade of life is not seen as a time in which ‘traditional’ experiences of old age (restricted lifestyle and declining powers) are expected. Many individuals do not think of themselves as old at this time, except in terms strictly relative to chronology i.e. they are older than somebody who is 18 and older than the self they were at 18. In the seventh decade people may be more likely to think of themselves as old and by the eighth decade it is hard to avoid the full recognition of old age (Vincent 1999). The ‘oldest old’, individuals aged 80 and older, are increasing in number and are subject to periodic research investigations (Bury 1991) and press interest (The Guardian 2006; 2007).

Research Problem

Despite increasing longevity and generally improving health in the population the process of aging is associated with greater incidence of disease and illness, in particular of degenerative conditions such as musculo-skeletal disorders, ischaemic heart disease, neurological impairments and cancers and mental disorders. Co-morbidity is common in individuals aged 70 and older (Stevenson et al 2004; Extermann 2000). Mental ill health has its highest incidence in older populations. Conservative estimates of mental health problems in older adults suggest a prevalence of perhaps 40% of people attending their GP (Kendrick et al. 1991). Multiple social, psychological, and biological factors determine the level of mental health of a person at any point of time. As well as the typical life stressors common to all people, many older adults lose their ability to live independently because of limited mobility, chronic pain, frailty or other mental or physical problems, and require some form of long-term care. In addition, older people are more likely to experience events such as bereavement, a drop in socioeconomic status with retirement, or a disability. All of these factors can result in isolation, loss of independence, loneliness and psychological distress in older people.

Although there is an extensive literature reporting the incidence and prevalence of mental ill health in older age groups, little is known about the experience of having a mental disorder in older populations from the individual's point of view. There is continuing concern though, that older adults with evidence of mental disorder are less likely than younger and middle-aged adults to receive mental health services and that, when they do, they are less likely to receive care from a mental health specialist (Karel, Gatz & Smyer, 2012).

Aim of the research

The aim of this research study is to investigate the experiences of people aged 75 and older and living with a long-term mental illness. The research will reveal the views and opinions of older persons about the problems and challenges of living with mental ill health and, crucially, how health and social care professionals can best meet their specific needs.

In the framework outlined by Robson (2002)) the purpose of this research is predominantly *exploratory* rather than *descriptive* or *explanatory.* Important aspects of exploratory enquiry are that it seeks to find out what is happening, particularly in little understood situations; to seek new insights; to ask questions and to assess phenomena in a new light.

Overview of Research Design

This empirical study is one part of a doctoral study being undertaken by the researcher in the Department of Social Policy & Social Work at the University of York. It is complemented by a systematic review and meta-synthesis of qualitative literature which reports mental ill health experiences of older people. The whole programme of study has received funding from the U.S. Department of Education, William D. Ford Federal Direct Loan under the terms of its Doctoral Research Scheme, which provide tuition fees and a living expenses stipend for the doctoral researcher (for a period of 4 years) with some research expenses.

Since the principal focus of this enquiry is on participants' experiences a fieldwork design based on **biographical/narrative research** is appropriate, in which the research task is to collect, analyse and interpret individuals‟ accounts (stories) of their experiences (Roberts 2002; Cole & Knowles 2001).

Summary of Research Methods

- The primary method of generating data will be through in-depth interviews with a sample of men and women aged 75 and older. A research interview is a formal event which may not be every participant's preferred way of giving an account of their experience. Participants will be offered the opportunity to use other ways of telling their story if they so wish; for example, through a written account such as a journal or diary.
- The study will be conducted within an ethical framework which seeks to maximise the wellbeing of participants who choose to contribute to the study.
- Audio-taped interview data will be transcribed to text for systematic analysis following the framework used by Riley and Hawe (2005). Journals or diaries will be analysed using the same methods. Transcripts will be returned to participants for verification of accuracy and additional commentary. Participants will also be invited to comment on the researcher's interpretations of the data.
- Findings from the study will be made available in summary form through a project website and in documentary form. Consideration will be given to dissemination through local meetings.

Research Questions

The fundamental purpose of this research is to gain knowledge of, and to understand, the impact of long-term mental ill health on the lives of older people. What happens when an older person develops symptoms and signs of mental illness? What is it like to receive a diagnosis of mental illness and to go through what can be complicated treatments which older people often find it difficult to tolerate (Bartels 2004)? What is the experience of everyday life living with a mental health illness? What if treatment is not indicated? What is the effect of all this on living with other chronic diseases or long-term conditions concurrently with mental ill health? Answers to such questions have rarely been sought from older people themselves.

The provisional research questions in this study are:

- What is the impact of a mental health diagnosis on the person aged 75 and older?
- How does living with long-term mental ill health affect achievement?
- How are decisions about treatment made?
- What is the impact of mental health treatment on the life of the older person?
- What are older persons‟ reactions to being excluded from treatment?
- What is the impact of long-term mental ill health on the person's daily life?

Sources of data

The primary method of data collection will be a series of in-depth interviews with up to 40 people aged 75 and older who have been diagnosed with long-term mental illness. Interviews will have a dual focus: informants will be asked to describe their current experiences of mental illness in the context of their experiences of ageing. Since reflection on ageing often involves review of earlier stages of life, an approach to interviewing which allows reflection on the whole life course is appropriate (Bornat, 2002). Interviews will be tape-recorded, with permission, and transcribed. Participants who prefer to contribute a written account of their experience, such as a journal or diary, in place of an interview will be invited to do so in a style and format of their choice. Guidance will be available from the Researcher.

All participants will be assured of confidentiality and all reporting of interview or journal data will be anonymous. All interview material and personal data will be stored securely, in a locked filing cabinet. Electronic data will be password protected and stored on a portable hard-drive which can be detached from the computer for secure storage. Findings from this empirical enquiry will be informed by a parallel study based on a systematic review and meta-synthesis of qualitative literature which reports older persons' experiences of living with mental ill health. Data for this literature-based study have been collected and preliminary analysis has been completed (December 2015).

Study population and sample; study site and recruitment

Study population

The study population will comprise men and women aged 75 and older resident in a semi-rural county, who have been diagnosed with a mental health disorder. The recruitment process will focus on meeting people who could contribute to the aims of the research and answer the research questions. The age group 75 years and over has been chosen because, although the population defined as aged 65-100+ is heterogeneous, the incidence of age-related physiological changes is reported to increase sharply between the ages of 70 and 75 (Bartels 2004). This means that a cut off of 75 years is likely to reflect more fully the complex intersections of mental ill health, comorbidity and old age (Jorm, 2003) than a cut off of 65 years, the conventional beginning of 'old age' throughout most of the 20th century in western industrialised societies.

Study sample

Factors which influence decisions about sampling size in flexible designs/qualitative research include (Morse 2015; Robson 2002): *the nature of the topic* (fewer informants are needed if it is obvious and clear; conversely more informants are necessary if the topic is challenging and difficult to grasp); *the quality of the data (*fewer informants are needed if data are 'on target' and are 'rich and experiential'); *the study design and methods* (more data are acquired per participant with repeat interviews so fewer informants are needed; semi-structured interviews yield fewer data per person than in-depth interviews, so more informants are needed). Morse (1994) recommends approximately 30-50 *interviews* (note, not informants) for ethnographic and grounded theory studies.

Taking account of the above recommendations and placing them in the context of a biographical/narrative approach based on in-depth interviews which are likely to yield a lot of data, it is proposed to recruit up to 40 informants to the study. The inclusion criteria will comprise:

- Adults aged over 75 years of age
- On-going experience of mental ill health
- Experience of mental ill health from before the age of 55 and for at least 20 years
- Be well enough to take part in at least one interview, in English and lasting approximately 1-2 hours in length or otherwise provide relevant data (e.g. diary/journal).

The recruitment process will focus on meeting people who could contribute to the aims of the research and answer the research questions. People who lack mental capacity or who have moderate or severe dementing illness will be excluded.

Study site

It is proposed to base the study at the Mental Health Clinic and to seek assistance with recruitment through the mental health multi-disciplinary teams. The Lead Mental Health Nurse has also agreed to support the study and will facilitate the Researcher's attendance at clinics. The local Mental Research Network team is supportive of the study and has facilitated access to clinicians.

Recruitment procedure

In building on the advantages of recruitment outside mental health services (Allan & Dixon, 2009; Schrieber, 1996a & b; Thornhill et al., 2004; Wang, 2011; Mckay, 2010; LaFrance & Stoppard, 2006), the recruitment procedure aims 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 will be utilised. These will involve:

- A poster will be sent to all local libraries
- A poster will be displayed in local leisure centres
- A poster will be displayed in third sector (non-statutory) mental health support organisations
- A poster will be sent to local GP practices for display in their surgeries
- The research will be explained to;
    a. Adult Community mental health teams
    b. Local later life Community psychiatric nursing team
    c. Later life Psychiatrists, Clinical Psychologist and Counselling Psychologist
    It is hoped that staff will ask potential participants if they would be willing to be contacted by a researcher
- A request will be posted on the County's Mental Health Foundation, County's Mental health groups and Age UK websites asking for volunteers.

In addition, eligible participants will be informed about the project by clinical staff and invited to receive further information in person from the Researcher who will be in attendance at mental health clinics. Potential recruits will be provided with written and verbal information about the study and invited to discuss their participation. Participants will also be invited to discuss their participation with family and/or friends before making a decision. A decision to participate will not be sought at the time of first contact with the Researcher but participants will have at least 48 hours in which to make such a decision. Opportunity will be given for further questions by telephone or email if wanted before deciding to participate.

Detailed verbal and written information will be given to potential participants by the Researcher about the purpose and methods of the study and what will be involved for participants. They will be informed that the study is not intended to provide direct clinical benefit to participants but that it is hoped the findings will influence care for future patients. It is particularly important that it is made clear to participants that this study is not a clinical trial investigating the benefits of particular treatments.

Informed consent to participation in the study will be sought by the Researcher with the assurance given that participants may withdraw at any time without any impact on the healthcare they receive. Confidentiality will be assured, and participants will remain anonymous in all publications and disseminated material arising from the study. Participants will be assured that all personal and research data will be stored securely in locked filing cabinets and password protected electronic systems and that only *bona fide* personnel will have access to those data. *Bona fide* personnel include the Researcher and the Research Supervisors. Data will be recorded on a notebook computer that can be locked in a filing cabinet and will be backed up on a portable hard drive which can also be locked away.

Ethical considerations

Perceived benefits of the study

The primary ethical considerations in the proposed study concerns the perceived benefits of the study to be balanced against the risk of harm, conceived principally in terms of the potential for causing emotional distress by talking about mental ill health.

Mental ill health research has a high public profile in the United Kingdom, in particular through the activities of Mental Health Research UK (MHRU), a UK charity dedicated to raising funds for research into the causes of mental illnesses. Much of the research activity brought to the awareness of mental health patients and the public is concerned with development of more effective treatments with fewer side-effects. There is a powerful incentive for individuals experiencing mental ill health to take part in such studies. It is important that potential participants are helped to understand that taking part in the proposed study will not have a direct benefit on their health and will not affect any treatment for mental health disorder which they may undergo. This will be achieved by providing written information, supplemented by discussion, in which the purposes and methods of the proposed study are expressed as clearly as possible.

Ethical approval

Ethical approval and governance permission to undertake this study will be sought from Social Care Research Ethics Committee through the Integrated Research Application System (IRAS). Due to the interviews taking place in the participant's home, a lone worker policy will be implemented congruent with the social research association code of practice for the safety of social researchers (Social Research Association, 2001).

Privacy/confidentiality

It is important in any research interview in which participants reveal their personal thoughts, feelings, ideas or experiences that participants are able to be assured that their recorded statements are kept private and confidential. (Exceptions to this occur in oral history interviewing where it may be mutually agreed that interviews are made available to a wider audience). Participants in the proposed study will be assured of confidentiality by the researcher, who will conduct all interviews. This means that the researcher and clinicians who have access to data, will promise not to divulge participants' personal details, or the content of the interviews, to any third party not connected with the research study and will take steps to store securely all personal and interview data. Permission will be sought specifically from each participant to record the interview on digital audio recording media. Audio recordings will be transferred to computer at the earliest opportunity following the interview and will be password protected. They will be stored on a portable hard drive which will be kept in a locked filing cabinet, along with transcripts and other written data (journals, diaries or letters). Transcripts of interviews will be made anonymous, as will any statements, made by participants during interviews. Permission to quote from interviews, also made anonymous, will be sought specifically.

Anonymised written data (transcripts and copies of journals) will be retained for the maximum length of time permitted under the Data Protection Act. Audio recordings will be destroyed at the end of the study. Original written materials such as journals or diaries will be returned to participants.

Discomfort (physical) during interviews

Participants in this study will be older men and women who by virtue of their inclusion in the research have diseases, that is, the objective presence of pathology, of various kinds. The extent to which they will be suffering mental ill health, that is the subjective experience of symptoms, at the time of recruitment to the study and participation in interviews is unpredictable. Measures to minimise any physical discomfort to participants during the process of the interview will include:

- Reassurance that participation is entirely voluntary and that the participant may withdraw if feeling unwell enough to participate, either before or during an interview.
- Should the participant wish to negotiate participation at a subsequent date if feeling well enough this will be accommodated.
- Venues for the interview will be negotiated with each individual and it is anticipated will take

place either in the participant's home or in the hospital outpatient clinic. If the interview is to be conducted in the hospital a room will be sought which is comfortable, with ease of access and where refreshments can be provided. Rooms will be sought which have loop induction systems for the assistance of participants whose hearing is impaired and who use a hearing aid.

- Participants who wish to contribute but anticipate that they may become overtired in an interview which might last up to 2 hours will be advised to make arrangements to ease their withdrawal if necessary, e.g. bring a family member or friend who can take them home before the end of the interview.

Distress (emotional) during OR AFTER interviews

Talking about painful experiences can be therapeutic but it can also be distressing. It is important that people who are being asked to talk about their experiences are made aware that this reaction may occur. On the one hand, positive feelings may come from being listened to, and possibly seeing experience in a new light as a consequence; on the other hand, negative feelings of renewed pain may arise as distressing experiences are re-told and imaginatively re-lived. Participants in the proposed study will be informed about these important matters in the information leaflet they will receive before agreeing to take part in the research.

Should the recollection of painful experience during the interview become distressing the interviewer will honour the person's experience by pausing the interview and giving the participant time to express their feelings if they so wish. If the participant is too upset to continue the interview, then the interview will be terminated. Participants will be assisted to make the decision that best meets their own needs. Should this situation occur the researcher will use skills gained from many years of mental health counselling work in health to comfort the participant. If distress persists beyond termination of the interview participants will be referred to the mental healthcare team at the local NHS Foundation Trust for further support. At all times the participant's needs, will take priority over the demands of the research.

Safeguards

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

Data collection

Data will be collected through a series of individual, face-to-face in-depth interviews and/or through a diary or journal. Interviews will take place in the participant's home unless the participant objects, in which case a suitable venue will be sought. The reason for siting the interview at the participant's home is that in the type of narrative research proposed the dominant interest is in the life of the participant which is *other* than their life as a patient (Frank 2000). Hospital surroundings necessarily, if implicitly, focus all concerned on the life-as-patient. Participants may be accompanied at interviews if they wish.

A single interview lasting approximately 1-2 hrs will be the basis of an individual participant's contribution. The optimum length for a single interview in narrative research is around 90 minutes (Hermanowicz 2002; Seidmann 1995 cited in Elliott 2005). Participants will be informed in advance of the likely length of the interview. This is not only courteous but gives participants a sense of how much detail they might provide in the interview (Elliott 2005). If an interview needs to be curtailed owing to participants‟ tiredness a follow-up or continuation of the interview at another time may be negotiated.

Interview questions will be open, inviting participants to tell their story (Stanworth 2004). It is important in narrative research not to restrict or confine what people may say by asking too many questions (Elliott 2005). People who wish to take part in the study but who do not wish to be interviewed will be invited to submit a written journal of their experiences. Similarly, this will be an open request to write about their experiences in whatever style and form they choose. Guidance will be given to those who may want to write but who feel the need to have a more prescribed structure. The Researcher's' experience in teaching reflective writing to health professionals and students will be of assistance here. Any data collected in this way will be stored securely, as described for interview data.

Data Analysis

Interview data will be audio-taped with participants 'consent and transcribed to text for analysis using a published interpretive framework (Riley & Hawe 2005). Computer software (AtlasTi) will be used to manage the data and assist with analysis. Data from initial interviews will be subjected to a first-level analysis to inform subsequent data collection and to evaluate interview technique. Data from journals or diaries will be analysed in the same ways as interview transcripts.

Narrative research is an interdisciplinary venture and analytical frameworks can be found in a range of domains e.g. discourse analysis, socio-linguistics, literary criticism and poetics. The following features of a 'story', a participant's account of their experience, are among those which can be subject to analysis and interpretation:

- purpose/s of the storytelling: overt and hidden
- structure/s of story: overt and hidden
- 'outcome/s' of the story
- language: literal and symbolic
- social relations and power structures between key actors (implicit or explicit)
- 'positioning of the narrator in the story
- narrator's positioning of others in the story
- narrator's sequencing of events
- positioning of the recorder (i.e. the interviewer)
- recorder's impressions, perceptions, judgements, interpretations
- placing of the whole story in a social and political context
- links to other research (including results of qualitative meta-synthesis conducted in parallel with this empirical inquiry)

Riley & Hawe (2005: 230) provide a useful interpretive framework which can provide a starting point for analysis. In Riley & Hawe's scheme analysis focuses on:

- Language: *are the sentences descriptive, consecutive, consequential, evaluative, and transformative?*
- People: *who is mentioned in the telling of events, and who is absent, and what are their roles?*
- Context: *what is the nature of the storytelling occasion?*
- Content: *what is the 'plot' i.e. what the stories are about?*
- Form: *the flow of the narrative over time ('stable' 'regressive' 'progressive')*

Reporting and dissemination of findings

I think it is important that the findings from the study are disseminated as widely as possible. I propose an ambitious and extensive dissemination strategy. In addition to writing a PhD thesis, I will produce a number of interim reports for the local Mental Research Network*,* together with a final Report. I also expect to publish a number of papers in peer-reviewed journals and to disseminate findings at relevant professional and academic conferences. I will seek the collaboration of the local Mental Research Network in organising meetings to report the findings to people affected by mental ill health, including those who contributed to and participated in the research. A booklet, written in non-professional, non-technical language, which summarises the methods and findings of the project will be made available for those who cannot attend meetings. A project website will also display the findings and implications of the study. Finally, I plan to write a book based on this research.

Summary timetable

- Preparation (obtain ethical approval, arranging NHS R & D approval, collaboration at research site): December 2015- April 2016
- Sampling, recruitment, data collection: May 2016- October 2016
- Analysis and interpretation and writing report: November 2016 – April 2017
- Writing Report: May 2017 – October 2017
- Submit complete first draft of thesis to supervisors – November 2017
- Revision of thesis – November 2017 – December 2017
- Submission of thesis for examination – December 2017
- Feedback meetings – Early 2018

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Appendix 4

Mental Ill Health Stories: experiences of people aged 75 and older living in A South East England County

Participant Information Sheet (Long Version)

My name is Victoria Jagne. I am a postgraduate research student at the University of York. I am inviting you to take part in a research study. Before you decide whether to take part, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with friends and family if you wish. Please ask if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

What is the purpose of the study?

Mental illness is more common in older people, who also are more likely to have a range of other long-term diseases. But there is not much research which tells us what it is like for older people when they get a mental illness. This study looks at what older people experience when they get a mental illness. Participants will be asked to talk about their experiences, to tell their 'stories', of living with long-standing mental ill health in one-to-one interviews with me or by writing down some of what happens to them and what they feel about it. A collection of these stories can then be used to help doctors, nurses and other carers to understand more fully what mental ill health is like for older people and to base the treatment and care they provide on the knowledge of what older people think, feel and say about their experiences.

The study is part of my PhD research work at the University of York.

Why have I been chosen?

I am asking people over 75 who have a diagnosis of one of the four most common mental disorders; psychotic, anxiety, mood, personality or dissociative disorders; to take part in the study.

Do I have to take part?

No - taking part is voluntary. It is up to you to decide whether or not to take part. If you decide not to take part you do not have to give a reason, nobody will be upset and the standard of care you receive will not be affected in anyway. If you do decide to take part, I will ask you to sign a consent form and give you a copy to keep. If you decide to take part, and then change your mind you are still free to withdraw at any time even after you have signed the consent form. You can contact me on the number below if you change your mind.

What will I be asked to do if I take part?

If you agree to take part, I will arrange an appointment with you for a discussion or "interview" about your experiences of having mental ill health. The interview is likely to last between 1-2 hours. If our discussion seems that it will last longer than 2 hours, I may ask you if we could meet for a second interview. So at the least I will ask you to talk to me on one occasion for about 1 hour, at the most we might meet on 2 occasions but for a maximum of 2 hours each time. This will depend on how much you feel you have to talk about and is likely to be different for different people. You can agree to only one meeting if that is as much as you want to do. The interviews can be arranged to take place wherever is most convenient for you. I can visit you at home if you wish, or we can arrange to meet in the hospital or clinic if that suits you better. If you need to make a special journey for the research, we can refund your travel expenses. With your permission these interviews will be audio-recorded, but you can request that the recording be stopped, replayed or edited at any time.

If you want to take part in the study but you are not keen on the idea of meeting a researcher to talk about your experiences, you could tell your 'story' in writing. You could either keep a diary of what happens to you over a couple of months or just write a story of what you experience. If you think you might like to do this, I will be able to talk to you about it in a bit more detail before you decide.

What are the possible disadvantages or risks of taking part?

This study involves talking to me in an interview or writing down some of your experiences. There should be no risk to your physical health in taking part, but some people may find it upsetting talking or writing about their feelings and about coping with difficult circumstances. If you do begin to find talking about your experience upsetting, we will stop the interview until you feel better, or stop it altogether if that is what you would prefer. If you find that talking about these things has upset, you deeply I will offer to talk with you about what might help you to feel better.

What are the possible benefits in taking part?

The information you give will help us find out how doctors, nurses and other carers can best meet the needs of older people with mental ill health. In addition, some people say they have found it helpful to have the opportunity to talk about their experiences and feelings in studies similar to this. The study is not designed to provide any direct benefit to your condition or general health.

Will my taking part in this study be kept confidential?

Recordings of interviews will only be listened to by the principal researcher, Victoria Jagne. They will be stored securely in a locked filing cabinet. You will be able to have a copy of the recording to keep if you would like one. All written information (for example, transcripts of interviews and other written material such as diaries which you provide for the study) will be made anonymous by removing material which might identify you. You will be able to read the transcript of your interview and make comments on it if you want to. Transcripts and other written materials will also be stored securely in a locked filing cabinet and will be destroyed or returned to you (for example, diaries or journals) at the end of the study.

I may use quotations from interviews in documents and publications about the study and these also will be made anonymous so that you cannot be identified.
None of the information that you give in either interviews or written materials will be fed back to your doctor, nurses or anyone else, unless you make criminal disclosures or suggest that you may harm yourself or others.

What if there is a problem?

If you have any questions or concerns about the research you can contact me, Victoria Jagne, on xxxxxx. If you have a complaint about the conduct of the research, you can contact Professor Martin Webber, PhD Supervisor at the University of York, on xxxxxx.

What will happen to the results of the research study?

The final results of this study will be known by May 2017 when all interviews and documents have been obtained and analysed. I will let you know the results when they are available. I may ask you to check some of the early findings for me before then. Results will be reported in articles, books or meetings so that the best possible use can be made from the research, but you will not be identifiable in any way.

Who is funding the research?

The whole programme of study has received funding from the U.S. Department of Education, William D. Ford Federal Direct Loan under the terms of its Doctoral Research Scheme.

Who has reviewed the study?

Ethical approval and governance permission to undertake this study is being sought from Social Care Research Ethics Committee through the Integrated Research Application System (IRAS).

What happens now?

Thank you for considering taking part in this research. I will contact you in a few days when you can ask any questions you have and discuss whether you would like to take part. Or you can contact me by phone or email.

Victoria Jagne

Postgraduate Research Student, University of York

Mobile: xxxxxx ***Tel: xxxxxx***

Email:xxxxxx

Appendix 5

Participant Information Sheet (Brief Version)

The 'Mental Ill Health Stories' Research Study

What? A research study exploring the experiences of people aged 75 and older who are living with long-standing mental ill health

Why? To gain deeper insight into the needs of older people with long-standing mental ill health

Who? People aged 75 and older who have a primary diagnosis of **psychotic, anxiety, mood, personality or dissociative disorders.**

How? Talking to a researcher (Victoria Jagne) from University of York about your experiences of living with mental ill health

Where? Wherever is most convenient for you. The most obvious choices are at your home or at the hospital/clinic in a quiet and private room

When? At a time, convenient to you.

Contact? Victoria Jagne

Telephone: xxxxxx
Email: xxxxxx

Department of Social Policy and Social Work

Appendix 6

Consent Form

Mental Stories: Experiences of People Aged 75 and Older

Name of Researcher: Victoria Jagne

Please initial box:

1. I confirm that I have read and understand the information sheet dated January 2016 for the above study. ☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time without my medical care or legal rights being affected. ☐
3. I understand that my responses will remain confidential unless I make criminal disclosures or indicate that I may harm myself or others. ☐
4. I understand that comments I make may be reproduced in publications, But that my comments will be anonymous. ☐
5. I give permission for the interview to be recorded. ☐
6. I am willing to allow access to my health records by the researcher. ☐
7. I agree to take part in the above study. ☐

______________________________ ____________________
Name of participant Date Signature

______________________________ ____________________
Name of researcher Date Signature

1 copy for participant, 1 for researcher

Recruitment Poster Appendix 7

ARE YOU OVER THE AGE OF 75?

Have you lived with emotional (‘nerves’) or mental health problems (e.g. anxiety, depression, hearing voices), for over 20 years?

I am a research student at the University of York 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:

Victoria Jagne
University of York
Department of Social Policy and Social Work
Heslington, York, YO10 5DD
Telephone: xxxxxx Mobile: xxxxxx
Email: xxxxxx

Appendix 8

Mental Ill Health Stories: Experiences of People Aged 75 and Older

Participant Interview Guide

Have you ever participated in a research study before? If yes, how did you find it?

At what age did you leave school? Can you tell me about that? Was that usual? What were the circumstances? Did you want to stay on? Did you take exams at school?

At what age did you finish work? Can you tell me why you finished work then?

What would you say are your best achievements in life so far? Can you tell me moreabout this being 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?

What were your particular challenges? What effect did your mental health problems have on this?

Are you married, divorced or widowed? Can you tell me about your experience of this? How were your mental health problems affected by this or how did it affect your mental health problems?

(If a parent), would you say that you have been your best as a parent. Can you tell me what this means to you?

How do you feel 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 mental health problems helped? Can you identify any positive aspects to your experience of mental health problems? 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? (Researcher to clarify) if it comes up; the effect of the illness or the diagnosis?

Did you ever feel disabled by your mental health problems? Can you identify what you thought of the future when you were ill in the past? Has it been the case?

What is your experience of mental ill health now? Is it better, worse, same? Why do you think that is?

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, service users or professionals?

Does mental ill health 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 stilllike 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? 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?

(Researcher to clarify questions from the interview) Can you tell me more about what you mean…; You also said…; Can you tell me more about what you meant…; You said that…; You also refer to… Can you tell me why you feel like this?

How do you feel after doing the interview?