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Making the Best of it

An emerging grounded theory of
caring for an older person with
mental health problems

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ABSTRACT

Making the Best of it: An emerging grounded theory of caring for an older person with mental health problems

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Aim

This study aims to develop a substantive grounded theory of the informal care of older people with acute functional mental health problems in the community, using data from qualitative interviews with informal carers and classic grounded theory methodology.

Results

The theory presented is based on field notes and memos from in depth interviews conducted with 11 informal carers of people aged 65 and over with a functional mental illness. The participants include carers of people with depression and anxiety (n=8), bipolar disorder (n=2) and schizophrenia (n=1). Many of the people cared for also had physical co-morbidities. Most patients had longstanding mental illnesses with equally longstanding caring arrangements. The age range of carers was 40 to 93 years, and of patients was 65 to 88 years. Five of the carers were female, and six male. Eight patients were female, and three male. Carers were related to patients as husband (n=5), wife (n=3), daughter (n=2) or son (n=1). Most carers lived with the person they cared for (n=9).

The theory explains, predicts and interprets how carers of older people with longstanding functional mental health problems who have received mental health service input attempt to resolve the tensions that they face as part of caring through *making the best of it*. *Making the best of it* consists of three inter-related dimensions: *aspirational optimization, adjustment and keeping going*.

Aspirational optimization is the carer's desire for the best for the person they care for, and their desire to do their best for them. The six aspects of *adjustment* are *dependency adjustment, identity adjustment, expectation adjustment, illness adjustment, adjustment resourcing* and *balancing priorities*. *Making the best of it* explains how many carers of older people with longstanding functional mental health problems who have received mental health service input continue to live with unresolved tensions, *keeping going* despite the fluctuating demands placed upon them, while carrying out corresponding adjustments, which are resourced internally and externally.

Making the best of it is discussed in relation to the concepts of family burden, coping, obligation, adaptation and identity. The theory shows how carers of older people with longstanding functional mental health problems who have received mental health service input manage the challenges and the rewards that accompany caring on a daily basis in the decisions, sacrifices and prioritizations they make. It is useful for health and social care practitioners and researchers, as well as contributing to the body of extant classic grounded theories.

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CHAPTER 1

Background and Justification for Research

1.1 Introduction

Each year in the UK, six million people provide care for a relative or friend (ONS 2001). This study aims to develop a grounded theory of the behaviour of carers of older people with acute functional mental health problems in the community, using data from qualitative interviews with carers.

There has been considerable interest in carers in academic literature and in policy since the 1980s. This literature has been reviewed extensively elsewhere (for example, Carretero *et al* 2009). A selective review is provided here of the aspects relevant to the study in question.

A carer can be defined as a person who:

“...spends a significant proportion of their life providing unpaid support to family or potentially friends. This could be caring for a relative, partner or friend who is ill, frail, disabled or has mental health or substance misuse problems.” (Department of Health 2008, p.11)

A carer is usually a spouse, relative or friend who provides help on an unpaid basis, and normally does not have previous training in caring (Meltzer *et al* 2002, Carretero *et al* 2009). The term ‘informal carer’ is often used in academic literature, but has been criticized by some carers for not fully expressing the challenges of the role. Many prefer the term ‘carer’ (Clements 2009). Additionally, many people in caring roles do not consider themselves to be carers (Department of Health 2008). Twigg and Atkin (1994) point out the difficulty of distinguishing care from normal family ‘tending’, especially in the case of women, as many women carry out tasks which would be considered ‘caring’ if done by men. They provide a definition that takes into account this difficulty, defining caring as:

“...the performance of tasks of a supportive character where these go beyond the normal reciprocities common between adults.” (Twigg & Atkin 1994, pp.7-8)

Caring often involves physical tasks, including providing personal care, but it also involves providing emotional support, encouragement and attention, and feeling a sense of personal responsibility for the person being cared for (Twigg & Atkin 1994, Clements 2009).

People with mental health problems struggle more with the activities of daily living, such as personal care and household activities, than those without mental health problems, even after accounting for physical ill-health (Meltzer *et al* 2002, Evans *et al* 2003). For older people, there is considerable interaction between physical, social and mental health problems, with social isolation and chronic physical ailments compounding psychological difficulties (Evans *et al* 2003, Godfrey *et al* 2005). In addition to this, many carers themselves are older and have their own physical and psychological health needs (Maher & Green 2002).

1.2 Mental Illness and Older People

Three million older people in the UK suffer with mental health problems, within which depression is the most common. People may either develop mental health problems in older age, or 'grow old with them'. Mental health problems may be accompanied by suicide attempts, self-harm and self-neglect (Lee 2007).

The term 'older people' refers to those aged 65 and above, a distinction used in service allocation and research. A distinction is also made between 'organic' and 'functional' mental illnesses, with organic problems referring mainly to dementia in the older age group. Functional mental health problems include depression, anxiety, schizophrenia and bipolar affective disorder. This study focuses on those with functional mental health problems, a group that has received less attention than those with dementia in research on mental health, older people and caring (Godfrey *et al* 2005). It is important to note that there is an overlap between functional and organic mental illness, with depressive symptoms often accompanying the first signs of dementia and some physical illnesses contributing to depression aetiology (Evans & Mottram 2000, Alexopoulos 2005).

The symptoms of depression affect 25% of older people in the community, with 10-15% meeting clinical diagnostic criteria (Lee 2007). The prevalence of the symptoms of depression increases with age (Godfrey *et al* 2005), though many older people do not seek medical intervention or are not diagnosed (Alexopoulos *et*

al 2002). Rates of depression are significantly higher in acute hospital and care home populations (Lee 2007).

The symptoms of depression include low mood; loss of energy; reduction in activity; loss of enjoyment, interest and concentration; sleep and appetite disturbance; and feelings of worthlessness and guilt. Depression may also be associated with physical symptoms such as early morning waking, psychomotor retardation, agitation and loss of libido. Delusions and hallucinations may also be experienced (World Health Organization 2007). Physical and cognitive symptoms are often more marked than affective symptoms in older people with depression (Alexopoulos *et al* 2002). Additionally, depression is associated with increased mortality in older people, including an increased risk of suicide, and an increased risk from physical illnesses including cardiovascular disease (Alexopoulos 2005).

2-4% of older people in the community meet the diagnostic criteria for anxiety, with 10-24% having 'sub-threshold' anxiety (Lee 2007). The spectrum of anxiety-related conditions includes phobias, panic disorder, generalized anxiety disorder, obsessive-compulsive disorder and post-traumatic stress disorder. Symptoms include nervousness, lightheadedness, palpitations, chest pain and fear of dying (World Health Organization 2007). Anxiety accompanies depression in 80% of older people with depression (Evans & Mottram 2000).

Bipolar affective disorder is defined as two or more episodes of significantly disturbed mood and activity levels, sometimes reduced in depression, and other times increased in hypomania or mania (World Health Organization 2007). The needs of older people with bipolar disorder are often complex (Lee 2007), with over a quarter having other mental health problems including anxiety, substance misuse and dementia (Sajatovic *et al* 2006).

Schizophrenia is diagnosed in 0.5% of older people in the community. Most older people with schizophrenia are women, as men with early onset schizophrenia have a reduced life expectancy and may not reach later life (Lee 2007). People with schizophrenia may experience 'positive' symptoms, such as hallucinations or delusions; 'negative' symptoms such as apathy and social withdrawal; and 'affective' symptoms such as depression. Schizophrenia is often characterized by acute relapses interspersed with periods when symptoms are controlled. The

particular challenges of schizophrenia in later life are poorly understood (Godfrey *et al* 2005).

Recent developments in mental health care have meant an increased emphasis on community care, including the management of acute psychiatric crises in the patient's home with the intervention of a crisis intervention team (Joy *et al* 2006).

It has been reported that the needs of older people with mental health problems and their carers have not received the services they require, 'falling through the gap' between the National Service Frameworks for Older People and Mental Health (Department of Health 1999b, Department of Health 2001, Philp & Appleby 2005, Lee 2007). This has led some authors to refer to the 'invisibility' of older people with severe and enduring mental health problems in policy, practice and research (Godfrey *et al* 2005, Lee 2007). Thompson and Doll (1982) also warn about the invisibility of people with mental health problems cared for in the community. This study aims to make these carers more visible and their voices audible.

1.3 Carers and Caring

The distinction is often made between 'formal' and 'informal' care, where formal care consists of the statutory, voluntary and commercial sectors, and informal carer is carried out by family, friends and neighbours (Wenger 1984, Qureshi & Walker 1989). It has been argued that the two sectors are interdependent rather than distinct, needing and relying on each other. But it is recognized as a valuable distinction as it helps in understanding the relationship between formal and informal care (Qureshi & Walker 1989).

Most care is informal care (Wenger 1984), and more specifically, most care is between kin (Twigg & Atkin 1994), with formal services 'filling in the gaps' when needed (Qureshi & Walker 1989). This poses difficulties for our aging population due to the shrinking of family sizes, increasing geographical separation between kin and increasing numbers of women in work outside the home. These difficulties have been referred to as creating a 'care gap', whereby fewer people are available to care for the increasing number of older people requiring care (Wenger 1984, Finch 1989, Qureshi & Walker 1989, Wanless *et al* 2006).

Research on caring generally classifies carers according to either features of themselves, features of the person they care for, or in terms of their relationship with the person they care for. Authors have suggested that there are benefits to viewing carers as a whole, as many of the challenges they face are similar (Twigg & Atkin 1994).

Services may view carers as resources, co-workers, co-clients or superseded carers. When carers are viewed as resources, the focus is on the well-being of the person they care for and carers are seen as useful only inasmuch as they are able to care. As co-workers, carers are seen as working in collaboration with 'formal' services. The assumption is made that carers want to continue caring, and any help given is aimed at encouraging this. Where services view carers as co-clients, the emphasis is on the well-being of the carer over and above the needs of the person they care for. In such services, only the most involved carers are included, so as to restrict resources to the most needy cases. In the superseded carer model, services either emphasize the independence of the person receiving care and try to help them function without dependence upon a carer, or see cessation of caring as beneficial for the carer, and support the carer in the decision to stop caring. Such services tend not to use word 'carer' as it has associated ideas of obligation, instead using the terms 'family' or 'relatives'. Their aim is the independence of both the carer and the person they care for (Twigg & Atkin 1994).

In the large body of literature on caring, various theoretical approaches have been used. Twigg and Atkin (1994) point out six theoretical discourses apparent in the debate surrounding caring: (1) kinship obligation; (2) feminism, where caring is seen largely as a female enterprise and is linked with definitions of role and position; (3) the burden of caring and the rights of carers; (4) the New Right, where criticism is made of the welfare state and its expense; (5) the rationalization of community care, where informal care is seen as a cost effective way of providing care; and (6) the social construction of disability, and, therefore, of caring, where emphasis is on the empowerment of the person receiving care, rather than focusing on the carer.

1.4 Policy and Caring

The distinctive property of caring is that it takes place within a relationship. This affects policy considerations and service provision, as both the needs of the carer and those of the person being cared for must be taken into account (Twigg & Atkin 1994). In the past, policy on care has been criticized for “exploit[ing] the duty felt by families and female kin in particular to provide care for elderly relatives” (Qureshi & Walker 1989, p.16).

The most recent policy concerning carers is the revised Strategy for Carers, *Carers at the Heart of 21st Century Families and Communities* (Department of Health 2008), which followed the first Strategy for Carers, *Caring about Carers* (Department of Health 1999a). The new Strategy aims to prioritize the needs of carers in the health and social care agenda, recognizing their needs and value to society in their own right. The Strategy states that:

“Our vision is that by 2018, carers will be universally recognised and valued as being fundamental to strong families and stable communities. Support will be tailored to meet individuals’ needs, enabling carers to maintain a balance between their caring responsibilities and a life outside caring, whilst enabling the person they support to be a full and equal citizen.” (Department of Health 2008, p.7)

The fulfilment of this vision is seen as a shared task for government, the NHS, the voluntary sector, and families and communities. It recognizes the unique insight that carers have into their own needs and challenges, as well as their ability to evaluate the effectiveness of new measures (Department of Health 2008).

Part of the Strategy is the aim of providing personalized services to support carers in their role. This is done through a carer’s assessment, which was first introduced in the Carers (Recognition & Services) Act 1995 and extended in the Carers & Disabled Children Act 2000 and the Carers (Equal Opportunities) Act 2004. It is a requirement that every carer providing or intending to provide substantial care on a regular basis is assessed as to their willingness and ability to continue caring and their desire to work, undertake training or take part in leisure activities (Clements 2009).

Clements (2009) has commented on the shift in emphasis on carers in social care legislation, from legislation supporting carers so that they can continue to provide

care in the 1980s, to an emphasis on looking after carers in their own right, respecting their needs and wishes and providing support for them.

1.5 The Contribution of this Study

Carers of older people with mental health problems face challenges common to all carers, as well as those specific to their individual situations. In particular, services for older people with mental health problems and their carers have often not been of the same standard as those for younger people (Philp & Appleby 2005, Beecham *et al* 2008), older people often face physical and social difficulties in addition to their mental health problems, carers may be older and in poor health themselves, and they may also be subject to “layers of invisibility” in clinical services and society (Godfrey *et al* 2005).

The increased focus on community care in acute situations, along with an aging population and a policy focus on carer well-being makes research about carers of older people with functional mental health problems a priority. There is, at present, no grounded theory of ‘informal’ caring, particularly in mental health and older people. Using interviews with carers, this study aims to develop a grounded theory of the way carers deal with caring.

CHAPTER 2

Methodology

2.1 Grounded Theory

2.1.1 History of grounded theory

Classic grounded theory originated in Barney Glaser's (1965) article, *The Constant Comparative Method of Qualitative Analysis*. Glaser had, until then, been a quantitative sociologist at Columbia University, taught by Paul Lazarsfeld. The same year, Glaser collaborated with Anselm Strauss, a qualitative researcher from the Chicago School, which was associated with Herbert Blumer and symbolic interactionism. They worked together on a book entitled *Awareness of Dying* (Glaser & Strauss 1965) in which they sought to develop an abstract theory of the interactions between patients and staff in hospitals at the end of life, rather than to provide a descriptive analysis of events or attitudes. They described this as an 'explanatory theoretical scheme' (p.ix) and an 'integrated substantive theory' (p.275). They implied that such a 'substantive' theory may, in the future, be extended to a 'formal' theory (Glaser & Strauss 1965).

Two years later, Glaser and Strauss published the methodology they had developed during the Awareness of Dying study in the book, *The Discovery of Grounded Theory* (Glaser & Strauss 1967). Chapter five of the book was reprinted from Glaser's 1965 article, *The Constant Comparative Method of Qualitative Analysis* (Hernandez 2008). In the preface, Glaser and Strauss (1967) presented grounded theory as an attempt to close "the embarrassing gap between theory and empirical research" in sociology (p.vii). They wrote that neither academic tradition from which they had originated had succeeded in this task. In this statement, they detached themselves from the approaches of their training, and situated grounded theory in a category of its own (Glaser & Strauss 1967).

Glaser continued to clarify the theory in his book, *Theoretical Sensitivity* (1978), in which he provided step by step guidance for doing grounded theory, and explained many of the stages. In 1990, however, Strauss and Glaser parted ways when

Strauss published *Basics of Qualitative Research: Grounded Theory Procedures and Techniques* with Juliet Corbin (Strauss & Corbin 1990). Glaser disagreed with many of the stances taken by the book, criticizing Strauss and Corbin's method for producing description rather than theory and forcing preconceived codes on data. Glaser responded with the book *Basics of Grounded Theory: Emergence vs. Forcing* (Glaser 1992).

Since 1992, Glaser has written many books and articles explaining the methodology of classic grounded theory, which is also known as Glaserian, orthodox or authentic grounded theory. The Grounded Theory Institute and its journal, the *Grounded Theory Review*, were founded to promote the understanding and use of the methodology. Subsequently, many other versions of grounded theory have been developed (Glaser 1999), for example, by Kathy Charmaz (2006), contributing to confusion surrounding the definitions of terms used in grounded theory, its purposes and methods (Hernandez 2008). The work of Corbin (Strauss & Corbin 1998) has become more closely associated with symbolic interactionism, a link which Glaser does not make (Hernandez 2008). Classic grounded theory remains, however, an inductive, general research method, applicable to quantitative and qualitative data. Classic grounded theory is used in this study, and its methodology is explained here.

2.1.2 Classic grounded theory method

“The goal of grounded theory is to generate a conceptual theory that accounts for a pattern of behavior [sic] which is relevant and problematic for those involved. The goal is not voluminous description, nor clever verification.”

(Glaser 1978, p.93)

The purpose of classic grounded theory is to generate conceptual theory from data. A good grounded theory should be understandable by all, it should fit the data, be relevant to the behaviour being studied, work by explaining, predicting and interpreting what is happening, and it must be modifiable by subsequently collected data. It should also be abstract of time, place and people (Glaser & Strauss 1967, Glaser 1978). Glaser and Strauss (1967) define theory as,

“...a strategy for handling data in research, providing modes of conceptualization for describing and explaining.” (p.3)

Glaser differentiates between substantive and formal theory, which are both types of 'middle-range' theory. Substantive theory is a theory of a substantive or empirical area, such as patient care, whereas formal theories concern formal or conceptual areas, for example, stigma or socialization (Glaser 1978). The current study aims to develop a substantive theory of the informal care of older people with mental health problems.

Fit, workability, relevance and modifiability

The four criteria of fit, workability, relevance and modifiability are the criteria by which all grounded theory are judged. If a theory 'fits' the data, it means that the categories that make up the theory, as well as the structure of the theory, are not forced upon the data, but are allowed to emerge from the data itself. The nature of emergence means that the categories will fit the data easily and well. Grounded theorists should remain open to the data, and not preconceive what they think will emerge, but simply allow it to emerge from the data through constant comparison. For this reason a thorough literature review of the specific area under study is not advised prior to the study (Glaser & Strauss 1967, Glaser 1978, Glaser & Holton 2004).

Glaser (1978) explains the criterion of 'work' as that:

“...a theory should be able to explain what happened, predict what will happen and interpret what is happening in an area of substantive or formal inquiry.” (Glaser 1978, p.4)

Closely linked to this criterion is that a theory must be 'relevant' to the area under study. This means relevance to the people or situation under study, not relevance to the preconceived ideas or academic interests of the researcher (Glaser 1978). Glaser (1978) explains that one way to know if a grounded theory fits these criteria is if it “rings true” with the “person in the know,” that is, a person who is in the situation being studied and is an expert by experience.

The final criterion is that a theory must be 'readily modifiable' as and when new and varying data arise. Theories and categories must remain modifiable, and theorists need to maintain a 'nothing is sacred' attitude. This applies during theory discovery and after, when integrating extant grounded theories (Glaser 1978).

A complete methodology

Grounded theory has been called a “highly structured but eminently flexible methodology” (Glaser & Holton 2004, p.2). It consists of a number of “double-back steps” including data collection, coding, theoretical sampling, memoing, sorting and writing up. Most stages continue throughout the research process, but some will be more apparent at different points. This means that data analysis occurs concurrently with data collection. It is necessary to follow the steps as described, in order to produce a theory that is conceptually rich and integrated (Glaser 1978).

In order to build theory, classic grounded theory treats ‘all as data’, including the preconceptions of the researcher, the context, observations, and interviews. Grounded theory may be conducted with qualitative or quantitative data, though most research to date has used qualitative interview and observational data (Glaser & Holton 2004, Glaser 2008). When collecting data using interviews, field notes are preferred to transcripts as they help delimit the data for coding (Glaser & Holton 2004). An interview guide is not used, but the concerns of the participant are allowed to emerge and then explored.

Coding and the constant comparative method

Classic grounded theory maintains emergent fit as key to the generation of theory, and data must not be forced to fit preconceived categories or pre-existing theories. Data is coded initially using open line-by-line coding. In order to find a place in the theory, each code must ‘earn’ its way there. The process of coding involves “raising the conceptual level” of the data; conceptualizing, or abstracting, rather than describing what is happening. It involves asking questions of the data systematically. These questions are:

- *What is this data a study of?*
- *What category does this incident indicate?*
- *What is actually happening in the data?* (Glaser 1978, p.57)

The method of constant comparison is used, whereby three levels of comparison are used. This starts by comparing incident to incident in the data in order to elicit conceptual codes or categories. Secondly, incidents are compared to the codes already elicited to see if they fit and add new dimensions or properties to them.

This allows the properties and boundaries of each code to be established. These codes are called substantive codes and they conceptualize what is found in the data. The third type of comparison is between substantive codes. This results in theoretical codes, which conceptualize how the substantive codes relate to each other. They are the 'building blocks' of grounded theory. Substantive codes fracture the data and theoretical codes rebuild it into theory (Glaser 1978).

One theoretical code will emerge as the core variable, which explains how participants continually resolve or process their main concern. In order to be classed as the core variable, the code must relate to most of the other theoretical codes, and account for much of their variability. When the core category has emerged through open coding, then coding and sampling become selective to the properties of the core category and its related categories (Holton 2008).

Theoretical sampling and theoretical saturation

The concept of theoretical sampling is fundamental to classic grounded theory. Theoretical sampling is where the direction of further data collection is directed by the emerging theory. It is enabled by the joint collection, coding and analysis of data (Glaser & Strauss 1967). Because sampling is guided by the aim of saturating concepts as they emerge, the direction of further sampling cannot be predicted in advance (Glaser 1978). Similarly the number of interviews needed cannot be known prior to the study commencing.

The aim of theoretical sampling is theoretical saturation of the concepts in the emerging theory.

“Theoretical saturation of a category occurs when in coding and analyzing both no new properties emerge and the same properties continually emerge as one goes through the full extent of the data...Drawing out the theoretical properties of the code, eventually saturates the code by helping define *boundaries* of it, the empirical *criteria* on which the code rests, the *conditions* under which it emerges or is evident, and its theoretically coded *connections* and significance to both the data and the major theoretical themes in the data.” (Glaser 1978, pp.53 & 85, emphases in original)

Once each concept is theoretically saturated and is integrated into the grounded theory, sampling on that concept stops. This process continues until the theory is fully integrated (Glaser 1978).

Grounded theory is inductive, using data to develop theory; but deductive methods are used in theoretical sampling, where the developing theory is used to direct sampling (Glaser 1978).

Memoing

Memoing is the process by which theory is developed in grounded theory. Memos are written by the researcher throughout the research process to capture theoretical ideas about categories and their inter-relationships. Memos vary in length, but they aim to capture the conceptual ideas of the researcher at a point in time. Glaser explains that the four goals of memoing are:

“...to theoretically develop *ideas* (codes), with complete *freedom* into a memo *fund*, that is highly *sortable*.” (Glaser 1978, p.83, emphases in original)

Sorting and writing up

Sorting of memos on theoretically saturated codes allows the conceptual framework of the theory to be established. Memos are sorted by the “similarities, connections and conceptual orderings” between the categories and properties about which they have been written. The process of sorting memos stimulates the writing of more memos, which will also be integrated into the theory. In the final theory, the categories are delimited to the smallest number necessary to fully conceptualize the situation being studied (Holton 2008). Glaser points out that the aim of grounded theory is “theoretical coverage”, not “descriptive completeness” (Glaser 1978, p.114).

The key aim of grounded theory is to develop a theory that explains how participants continually resolve their main concern. The focus is not on the ideas that the researcher brings to the study, but on the participant’s own perspective and behaviour. Each substantive grounded theory has a place in relation to other grounded theories. Grounded theories do not prove or disprove each other, but are “placed, extended and broadened” in relation to extant theories (Glaser 1978).

2.2 Study Design and Ethics

2.2.1 Study design

Background to the study

The study was designed in response to the need to explore the experiences of informal carers of people aged 65 and over with functional mental health problems. A study by Richman *et al* (2003), based at Cheshire and Wirral Partnership NHS Foundation Trust, found that an older people's outreach support team, which ran concomitantly with day hospital facilities, succeeded in keeping three out of four patients in crisis out of hospital. However, the extra pressure placed upon carers as a result of this was highlighted as an avenue for further research, in order to expand the limited literature on crisis teams in general, and older people's crisis teams in particular (Richman *et al* 2003).

The older people's crisis home treatment team began in July 2008, replacing the day hospital and outreach support team, which had been the provision for older people's mental health as well as inpatient services. The crisis team accepts referrals from people aged 65 and over with functional mental health problems, receiving referrals from community mental health teams. The aim of the crisis team is to prevent hospital admission in times of crisis by supporting patients and their carers in their homes. It is not necessary to give full details of the service here, as this study concerns wider, general experiences of carers, and includes carers of patients who were seen by community mental health teams (CMHTs) as well as by the crisis team.

In this study, the terms "client" and "patient" are used interchangeably to refer to the person being cared for. It is recognized that a carer may also be a client of either carer-specific or other services, and that carers may also be patients within health services for physical or psychological health needs. Additionally, there is debate surrounding the use and definition of the term carer. For the purpose of this study, however, these delineations of "client/patient" and "carer" will be used to avoid confusion.

Aims

This study aims to develop a grounded theory which explains how informal carers of older people with functional mental health problems deal with caring. The purpose of any grounded theory is,

“...to explain conceptually how the studied participants, by their behaviour, recurrently resolve a main concern.” (Christiansen 2008, p.22)

It was designed to be completed in one year by an intercalating medical student with a background in mental health nursing.

Setting

This study was based at the older people’s crisis home treatment team at St Catherine’s Hospital, Cheshire and Wirral Partnership NHS Foundation Trust, and at the four older people’s community mental health teams (CMHTs) serving the people of Wirral.

Interviews were conducted in the community, in participant’s homes.

Choice of methodology

Grounded theory was selected as the methodology for the study, using qualitative data from interviews. Grounded theory is widely and increasingly used in health and social science research (Glaser 1999, Pope & Mays 2000), and is suited to use in situations where a result needs to be seen in a set amount of time. It provides a structured framework within which to carry out research on a substantive area, producing a theory that is relevant and publishable (Glaser 1999).

When deciding upon the method to be used in conducting this study, three forms of grounded theory were considered: classic – or Glaserian – grounded theory (Glaser 1978), Straussian grounded theory (Strauss & Corbin 1990) and Charmaz’s constructivist grounded theory (Charmaz 2006). Reading was carried out on the three types of grounded theory, and a three-day seminar and workshop from the Grounded Theory Institute – advocates of classic grounded theory – was attended. The workshop provided opportunity to learn about and practise techniques used in classic grounded theory first-hand, with world-class experts in the field. Subsequent email contact has been maintained with the editor-in-chief of the

Grounded Theory Review, Dr Judith Holton, since the workshop, and she has provided advice and guidance throughout the research process.

Classic grounded theory was decided upon due to its adherence to the origins of grounded theory and the constant comparative method, as devised by Glaser (Glaser 1965). It was felt that classic grounded theory was most suitable as it leads the novice researcher step-by-step through the process of discovery of a multivariate, conceptual theory of the substantive area under study, rather than focusing on description as in other forms of qualitative data analysis. Classic grounded theory requires that the methodology be followed in full, without 'cherry picking' elements of different methods (Glaser 2008). Central to classic grounded theory is the concept of *emergent fit*, whereby codes and theory emerge from data and are not preconceived or forced onto the data (Glaser & Holton 2004).

Accordingly, a full literature review was not conducted before the commencement of data collection and analysis, in order to maintain openness to the concepts emerging from the data itself. A brief scan of relevant literature was performed, in order to write the research proposal and to complete the requisite Local Research Ethics Committee approval process. Please see Appendix One for the letters of approval.

Throughout this thesis, the term 'grounded theory' is used to mean classic grounded theory, as opposed to other forms of grounded theory.

Participants

The participants in the study are 'informal' or unpaid carers, caring for people aged 65 and over in the community with functional mental health problems. The issues concerning defining caring have been covered in the first chapter. For the purpose of this study, a carer was defined as such if they identified themselves as a carer, and/or the staff at the crisis team or community mental health team recognized them as a main carer for their patient. This definition was made intentionally broad, in order to be inclusive of all types of carer and in order to recognize the debate around the definition and labelling of carers. Therefore, no stipulation was made that the carer must live with the patient or perform a minimum number of hours of caring per week. It was acknowledged that carers would probably be

spouses or children, but could also be friends, neighbours or other family members (Meltzer *et al* 2002).

Inclusion criteria were outlined as:

- Someone providing *unpaid care* within the *home*, for an adult aged *65 or over* with a *functional mental illness* (depression, anxiety, schizophrenia or bipolar affective disorder).

Exclusion criteria:

- Carers who lack capacity to consent;
- Carers of patients who lack capacity, or who refuse, to give consent to their carer taking part;
- Carers under the age of 16.

These exclusion criteria were created as a carer who lacks capacity to consent is unlikely to be able to complete a one- to one-and-a-half hour interview. It would have been unethical to have interviewed the carer of a person who refused to give consent. It was considered unlikely that we would encounter a carer aged under 16, as the patients concerned were aged 65 and over, but it was decided that the particular concerns of young carers were outside the remit of this study.

Recruitment

Recruitment began with the crisis home treatment team. However, due to the number of referrals received and the acute nature of the problems faced by carers of patients referred to the crisis team, recruitment from the team was slower than anticipated. Therefore, as time was limited, recruitment was extended to the four community mental health teams (CMHTs) from whom referrals to the crisis team are received. This improved the rate of uptake for the study.

Consent was gained from the four consultant Psychiatrists who lead the CMHTs, and from the staff of the crisis team, for the study to go ahead. Members of the health care teams (doctors, nurses, psychologists, occupational therapists, support workers and social workers) were told about the project and given a staff information sheet and copies of the participant information sheets for carer and client (see Appendices Two A and Two B). They were asked to approach the main

carer of their patients and to tell them briefly about the study, giving them an information sheet which had an opt-in form attached.

Carers who wished to find out more about the study, or who were happy to be contacted, either called the researcher on the telephone number provided, or filled in the opt-in sheet with their name, address and telephone number. The opt-in sheet was returned to the researcher by post or by giving it to a member of staff from the team, who then gave it to the researcher. The researcher then telephoned the carer to answer any questions they had about the study, before arranging a time to visit them in their home, if they were happy for this to happen.

During the visit, the researcher outlined the information in the participant information sheet and answered any questions. Informed consent was sought from the carer as well as the person they cared for (see Appendices Three A and Three B for consent forms). If appropriate, the interview was conducted, or a time arranged for it to take place on another date.

The consent procedure is detailed in the Ethics section below, in addition to the precautions taken to ensure the safety of the carer, patient and researcher.

Data collection: Interviewing

Grounded theory is a general methodology, and can be used with qualitative or quantitative data (Glaser 2008, Holton 2008). In this case, qualitative interview data were chosen due to their richness and the ability for them to be collected by one researcher in the time period allocated (Glaser 1999). Qualitative data were considered ideal in this case, as it is a study of human behaviour, the outcome of which cannot be predicted (Christiansen 2008).

Interviews were selected as the mode of data collection as they provide a confidential and safe setting in which respondents can discuss personal and potentially emotive subjects (Yates 2004). This was especially important as many of the participants in this study were involved in deeply personal and challenging care due to their spouse's or parent's mental illness. Interviewing allows access to understanding of the participant's perspective (Yates 2004) and exploring how they deal with their situation and continually resolve their main concern (Christiansen 2008).

For the in-depth interviews a topic guide was prepared as part of the research proposal, as requested within the ethical approval process, to give an idea of the scope of the interview. In practice, however, in depth interviewing began by asking “Tell me what it’s like to care for ___”. Subsequent questions were guided by the answer provided to this question, without limiting the potential topics of conversation, in accordance with grounded theory, the aim of which is to allow the participant to talk freely (Christiansen 2008). As the study progressed, questions were asked in relation to the emerging concepts from previous interviews – more “empirically grounded” questions (Christiansen 2008). Notes were taken during the interviews, with effort made not to write excessively during the interview, in order not to disrupt the interview.

Interviews were conversational in style, following guidance in Chapter 12 of *The Grounded Theory Perspective* (Glaser 2001). Early interviews began with a question such as, “Tell me what it is like caring for ___”. It became apparent after the first few interviews that many ‘carers’ did not relate to the term ‘carer’ and therefore the question was changed to, “Tell me what it is like living with ___”. Carers usually spoke freely on this topic. If they needed more prompting, the researcher would ask if, and if so, how, life was different before and after their spouse/parent became ill and then follow the direction of their response. The interview then explored issues that the carer raised, to clarify the researcher’s understanding.

As the theory emerged, questions specifically aimed towards eliciting properties and dimensions of emerging categories and relationships between categories were asked. For example, “Some people have described their lives as plodding along day to day. Is that something you relate to?” or, “Do you feel looking after __ has affected having time to yourself?” These questions changed from interview to interview as the emerging theory directed theoretical sampling in interviews.

Specific questions and the way in which they were asked varied from interview to interview, guided by theoretical need and by the participant’s approach. Some participants spoke voluminously with very little questioning; others needed more prompting. In this case, questions relating to previous interviewer’s responses were sometimes used to initiate “the spill” (Glaser 2001), for example, “Some people feel like all they are is a carer. What do you think about that?”

Usually a rapport was established through careful and thoughtful listening, empathising, reflection and clarification of the participant's statements. Some interviews lasted just 20 minutes, others for 90 minutes.

Tape recording of interviews is not encouraged by Glaser (Glaser & Holton 2004) as it affects the data collected. However, in this study, due to ethical requirements and the desire to remain accountable, as well as the fact that this was the researcher's first time conducting research interviews, a digital audio recorder was used to record the interviews, with assurance to the participants that the recordings would be confidential.

Reliance on transcription of interviews is not advised within grounded theory, with preference placed on the use of field notes (Glaser & Holton 2004). This is due, in part, to the fact that field noting saves time and energy by starting the process of conceptualization by delimiting the data for coding. In this study, the first interview was field noted and also subsequently transcribed from the recording made. A comparison of the two versions of the interview was conducted by the researcher and supervisor (EP). It was found that the field notes brought out the main emphases from the interview, but missed some of the subtlety and nuance of the responses given by the participant. Dr Judith Holton was contacted in reference to this, and her response is provided here:

“...it is important to remember that you are doing a GT not a qualitative study so you are not trying to capture everything that is going on but rather, you are looking for a pattern to emerge from your data. Thus, it is not about capturing subtleties and nuances but patterned occurrence of concepts. You want to see the “forest” rather than every tree individually and completely – so to speak. You are seeking conceptual abstraction rather than rich detail as in qualitative research...It is about letting go of the detail in order to see the abstracted conceptual pattern of behaviour.” (Dr Judith Holton, personal correspondence)

Please see Appendix Seven for the interview guide submitted to the Research Ethics Committee. It was made clear in the Research Ethics Committee meeting that the interview topic guide was indicative of the general scope and style of the interview, and that, in accordance with grounded theory methodology, questions would change over time in response to the emerging theory and the need to sample theoretically. All interviews did include some of the broad-based questions

outlined in the interview topic guide, but more specific questions relating to the emerging theory were also included in later interviews, in order to test the emerging theory as part of theoretical sampling with the aim of theoretical saturation. As Glaser (2001) writes regarding the research proposal and grounded theory,

“..the GT researcher can only give, if he has to, general questions to cover about his area of interest, with explanation on the emergence of interview style and specific questions.” (p.141)

The initial research proposal was written before the author had attended a Grounded Theory Institute seminar about the classic grounded theory process, and the proposal stated that transcripts would be made of every interview. At the seminar, Glaser made it clear that, although the current emphasis in grounded theory has been on the use of transcripts, he prefers field notes as they allow the researcher to record the most salient points of each interview, and begin the analysis immediately. This was tested by the researcher and supervisor (EP) after the first interview in the study, which was field noted immediately following the interview, before the recording was transcribed by the researcher. The two accounts were compared for similarities and differences and this exercise confirmed that field notes could provide an accurate account of an interview. Although approval had been given for the analysis of transcribed interviews, it was not felt that not transcribing had ethical implications for the participants that could not be overcome by saving recordings of each interview to be used if needed to check the reliability of field notes and to allow transcription to take place if necessary later in the research process if cross-referencing was required.

The degree of congruence between the transcript and the field note of the first interview convinced the researcher and supervisor of the strong degree of congruence between the two. When combined with the strength of recommendation from Glaser towards the use of field notes, and the time-saving benefits provided by not transcribing, a joint decision by the author and supervisor (EP) was made to proceed with only field notes, while still continuing to record and save the recordings of each interview.

In subsequent interviews, field notes alone were used for coding and analysis. Although tape recordings of interviews were kept, they were not transcribed or

listened to. Field notes were written as soon after the interview as possible (Glaser 1978). In most cases, this was immediately after the interview; in a few cases there was a delay of up to several days. Field notes were based on the notes made during the interview and the memory of the researcher. They were generally written in order of significance (for example, the most striking or memorable points first) and emerging concepts (for example, grouping incidents that related to each other conceptually), rather than giving a chronological, or interview-ordered, account of the conversation. See Appendix Four for an example of a field note.

Glaser is clear about the effects of recording and transcribing of interviews on theory development, as demonstrated in the following extract from his book, *The Grounded Theory Perspective* (Glaser 2001):

“GT requires constant data collection, coding and analyzing to delimit data collection, to respond in a timely way to theory driven saturation of categories by successive questioning of participants during site spreading. Taping and typing, even only listening to tapes, brings effective theoretical sampling to a halt. It prevents daily or routine memo making which is the conceptual writing up of constant comparisons which direct theoretical sampling. Taping and typing takes too much time, and is unnecessary and unwise.” (p.166)

Glaser advises the use of field notes and provides guidance on how to write them:

“It is hard enough to keep the theoretical ideas in one’s head much less the data, when it is not possible to record in the field, as one is actually interviewing and/or observing. The general approach, of course, is to dictate or write the details of the interview as soon as possible after leaving the field. We have found, that a good strategy to recapture most of the details later, is to jot down after leaving the field, the ideas (and perhaps an illustration) the analyst was collecting data on, even if he was only implicitly sampling on the idea...A few days later the analyst can refer to his “jots” which lead to a recall of the interview. His recall gets better and better as the generated theory develops and he gets more “into” the analyst. By this strategy the analyst records details from which he will generate properties of his categories and they inevitably spill over into details that will yield related categories.” (Glaser 1978, pp.52-53)

An example of a paper that exclusively uses field notes from interviews as data is Alborzi *et al* (2008).

Due to the constraints of time and the acute nature of the illnesses faced by many of the people carers were caring for, it was decided to conduct one interview with each participant, lasting one to one-and-a-half hours, in their home, at a time to suit them. It was not possible to stipulate whether the person being cared for would be present or not, due to the diverse nature of the caring situations. In most cases, the person being cared for was in the room when the interview took place. Recruitment and consent procedures were followed, as well as ensuring researcher safety.

For the purpose of gaining ethical approval a figure of 15 interviews was quoted as an estimate of the number of interviews to be carried out. According to grounded theory, it is not feasible to determine before a study starts exactly how many interviews will be needed, as sampling and data collection should continue until each category is theoretically saturated and integrated into the emerging theory (Glaser 1978).

Analysis

Analysis was conducted in accordance with classic grounded theory methodology (Glaser & Strauss 1967, Glaser 1978, Glaser 1998). Please see the preceding section on grounded theory method for an outline of the interrelated stages, including coding, memoing, theoretical sampling, sorting and writing up. Please see Appendices Four and Five for examples of a field note, coding and memos.

Grounded theory is not a linear process, and each of the interrelated stages of the methodology were carried out to a greater or lesser degree throughout the entire research process.

Field notes, coding and memos. Field notes were written by hand as soon after each interview as possible, as outlined above. They were then typed up the same or the following day. Field notes were based on notes taken by the researcher during each interview. Any verbatim quotes noted down during the interview were copied into the field note, to ensure accuracy in case the quotes would later be cited in the thesis. Each field note was labelled with the date, the participant identifier letter, the ages of the carer and patient, the diagnosis of the patient and the relationship of the carer to the patient. Field notes were typed up in a table format with the field note on the left and a column for coding on the right.

As soon as possible, and usually concurrently with typing up the field note, the researcher began line by line coding of the field note and memoing on the codes emerging. Sometimes this was done on the computer, other times the field note was printed out and line by line coding was performed by hand. As coding was being done, memos were written on the codes. These were typed out in a similar format to the field notes, and labelled with the date, a title which detailed the main category the memo concerned, and an identifying letter and number. The letter referred to the participant identifier of the corresponding field note, and the number referred to the number of the memo concerning that field note.

Every memo was printed out and line-by-line coded. As the method of constant comparison was followed, incidents were compared with incidents, incidents were compared with codes and codes were compared with codes (Glaser 1978). This resulted in many memos on memos. Each was labelled to allow identification of the title of the category to which it referred and the identifiers of any memos or field notes to which it referred.

Sorting. As categories began to emerge, the memos were sorted into those categories. This stimulated the writing of more memos about the properties, dimensions and boundaries of categories, with the memos gradually becoming more theoretical in nature, exploring relationships between codes, and beginning to form theory. Again, each new memo was labelled, printed out and coded.

As sorting allowed the theory to begin to take shape, diagramming was experimented with, in order to provide an outline of the 'shape' of the theory. It was found that this had benefits in clarifying the nature of the relationships between categories, but did not adequately represent the final theory; one of dimensions. The emerging theory was discussed regularly with the researcher's supervisor (EP) in order to check that the naming of categories had 'grab' and to give opportunity for explanation and clarification of ideas.

Sorting continued, along with more theoretical memoing about relationships between categories and the structure of the emerging theory. Memos and 'memos on memos' were coded and sorted to be integrated into the theory. Theoretically sampled data collection continued during the first stages of the sorting process.

During the sorting process, the core variable was identified as 'Making the best of it'. After the core variable had been identified, sampling and coding were selective to the core variable, its core categories and their properties. The number of categories was reduced to the smallest number possible, while maintaining full theoretical coverage, by integrating categories together theoretically.

Process of writing up. When the structure of the theory began to take shape following extensive sorting, theoretical memos were grouped and ordered to allow them to be written up and linked together with illustrations and linking passages. A draft sketch of the theory was written, and submitted to Dr Judith Holton, who confirmed that the theory was a dimensional analysis. The process of memoing and sorting continued while the theory was redrafted, and new memos incorporated.

Theoretical sampling. Throughout the research process, data collection was aimed towards development of the emerging theory through theoretical sampling.

Glaser (1978) explains the inductive-deductive nature of grounded theory as follows:

"Grounded theory is, of course, inductive; a theory is induced or emerged after data collection starts. *Deductive work in grounded theory is used to derive from induced codes conceptual guides* as to where to go next for which comparative group or subgroup, in order to sample for more data to generate theory." (pp.37-38, emphasis in original)

Initial data collection was based in the selected substantive area (carers of older people with mental health problems) at the concentration site (the Crisis Intervention Team). Sampling was extended to a further site (site spreading) when it spread to the carers of users of Community Mental Health Teams. Further site spreading, for example to other hospitals, voluntary organisations or support groups, was not possible due to ethical requirements and the lack of time.

As the theory emerged, interview participants were asked questions about emerging categories in order to improve saturation of each category. Theoretical sampling also included going over previous field notes for extra dimensions of emerging categories. Coding became selective for the categories of the emerging

theory. Theoretically driven sampling included speaking to carers of people with varying relationships to the person they cared for, for example, husband, wife, daughter and son; carers of different ages and carers of people with different functional mental health problems, for example, depression, anxiety, schizophrenia and bipolar disorder.

“Theoretical sampling is, then, used as a way of checking on the emerging conceptual framework rather than being used for the verification of preconceived hypotheses. Comparisons are made continually between kinds of information to generate qualifying conditions, not disprove hypotheses. While in the field, the researcher continually asks questions as to fit, relevance and workability about the emerging categories and relationships between them. By raising questions at this point in time the researcher checks those issues while he still has access to the data. As a result, he continually fits his analysis to the data by checking as he proceeds.”
(Glaser 1978, p.39)

The use of theoretical sampling in theory development in this study is outlined above; the use of it in order to check the emerging theory late on in the research process was limited by time. As Glaser (2001) states, potential avenues for theoretical sampling are endless but it must always end somewhere, and the limiting factors are often human or resource-based:

“However theoretical sampling must come to an end, usually based on human limits, with the appeal to future research to give directions for a subsequent GT researcher...Modifying is endless but enough is enough. Stop when sufficiently, theoretically complete, and take the energy to the next GT project.” (pp.183-184)

Site spreading, whether to other hospital services, voluntary sector services or private individuals would have enhanced the theoretical sampling of the study. As outlined in the Discussion section, further avenues for theoretical sampling in this study include whether *making the best of it* is a process, whether there is a typology of caring, the nature of the differences between caring for a spouse and a parent, the theory behind caring breakdown, the process of adjustment and resourcing of adjustment, carers of older people with other health problems such as dementia or physical health problems, carers of younger people, formal carers such as nursing staff, families dealing with other stressful situations, and how people deal with ageing. It would also have been helpful to have combined interview data with data collected from observation of the caring situation, literature on caring, personal

accounts of caring and attendance at support groups, and to have interviewed carers on more than one occasion.

Theoretical saturation. Theoretical saturation, signalled by the emergence of no new properties of categories and the same properties emerging repeatedly, was sought through theoretical sampling (Glaser 1978). Time prohibited complete saturation of the theory during sampling, but saturation was aided by the sorting and memoing processes.

“There are several reasons to stop sorting. Running out of memos is of course a prime one. Another is the theoretical saturation of the core variable, and most sub-core variables. Personal saturation is another. Time, money, and energy are always limited and so are the social structural possibilities of the research situation itself. Nevertheless, there is also a firm rule to follow; theoretical completeness...Though the analyst perhaps could do more if he had more resources, his theory does explain sufficiently with concepts that fit, work, have relevance and are saturated. Once integration starts, sorting forces theoretical completeness. This is all that the grounded theory analyst can claim; he can get no more from “his” conceptual work.” (Glaser 1978, pp.124-125)

All grounded theories are judged by their fit, work, relevance and modifiability. A grounded theory is not right or wrong; it simply has more or less fit, work, relevance and modifiability (Glaser 1978). When commenting on a grounded theory that had been criticized for its small sample size of 10 interviews and its lack of site spreading, Glaser (2001) maintained that the theory was good, “yet ready for more extension by theoretical sampling” (p.170). This quote aids the understanding that grounded theory is flexible to the resources and time available, and that a theory still stands even if further theoretical sampling would extend it. Glaser (2001) continues,

“I say that a GT is good as far as it goes irrespective of the sample size. More data will simply modify it while verifying fit of categories, if not enough data was available.” (p.170)

In terms of saturation, Glaser (1978) writes about the analyst who, “reached true saturation and closure in his analysis, given his capabilities and the data.” (p.25)

This acknowledges that theoretical saturation in grounded theory is dependent upon the capabilities of the researcher and the nature of the data available. Glaser

(1978) also writes that it is normal to feel that the discovered theory could go further:

“Needless to say, the transcending nature of grounded theory makes the analyst quite sensitive to his data, where to take it conceptually and where to collect more data. It makes him humble to the fact that no matter how far he goes in generating theory, it appears as merely “openers” to what he sees that could lay beyond.” (p.6)

Although grounded theory requires time, deadlines and time constraints are compatible with grounded theory. When talking about the appropriateness of grounded theory for use in masters and doctorate studies, Glaser (1999) writes that,

“...grounded theory is a methodology that provides a total package, which takes one from data collection through several stages to a theory and in a scheduled amount of time. This ensures a finished product that can comply with a deadline.” (p.836)

The current study can be seen within the spectrum of grounded theory quality as the best that could be done within the constraints of researcher experience and available time. It could be improved, better integrated and more conceptually rich with the investment of more theoretical sampling and analysis. However, it remains a theory that is readily modifiable by any further emerging data.

Theoretical sensitivity. Theoretical sensitivity is both a personal characteristic and a skill that can be developed (Glaser and Holton 2004). The theoretical sensitivity of the researcher in this study was aided by attendance at a Grounded Theory Institute seminar, during which the opportunity was given to practise coding and memoing, under the supervision of grounded theory experts. It also provided the chance to witness how experienced grounded theorists code and develop theory, including extending the researcher’s vocabulary for codes and types of codes. These skills were further developed by extensive reading of grounded theory texts, especially Glaser’s (1978) book *Theoretical Sensitivity*. Additionally, reflective work with the researcher’s supervisor allowed honing of coding and conceptualizing skills.

The process of constant comparison and the discipline of memoing allowed the further development of theoretical sensitivity, through remaining open to the data.

“The first step in gaining theoretical sensitivity is to enter the research setting with as few predetermined ideas as possible.” (Glaser & Holton 2004, p.11)

2.2.2 Ethical Issues

The study was approved by Sefton Research Ethics Committee. Several ethical issues will be dealt with here, including access to participants, informed consent, confidentiality and safety (Yates 2004).

Access to participants

Access to participants was gained through the staff of the crisis team and the community mental health teams. This ensured that participants did not feel pressurized into taking part by the researcher, and that they were given adequate time to consider the participant information sheet before being contacted.

Informed consent

Written informed consent was sought from all participants, and the person they cared for. Participant information sheets – one for carers and one for patients – were given to carers and patients by their keyworkers prior to the visit by the researcher. The participant information sheets make clear that the study is about the views and experiences of the carer, and does not directly concern the person being cared for. However, it was felt that it was necessary to obtain consent from the person being cared for in addition to the carer.

Opportunity was given for questions to be asked prior to obtaining consent. It was also emphasized that refusal to take part or withdrawal from the study at any time would not in any way affect the care that the carer or the person they cared for received.

The researcher spoke to the patient’s keyworker prior to visiting, in order to establish whether there were any concerns regarding capacity to consent. If a carer or patient lacked capacity to consent, the carer was not included in the study.

If a carer or patient subsequently withdrew from the study, all data held about them were destroyed. If a carer or patient subsequently lost capacity to consent, their data were held and analysed as usual. Carers and patients were given copies of the consent forms to keep, along with the participant information sheets.

Confidentiality

The nature and limits of confidentiality were outlined to all participants in the participant information sheet and explained in person prior to gaining consent, in accordance with *NHS Code of Practice: Confidentiality* (Department of Health 2003). It was made clear that all information collected was confidential, that only the researcher would listen to the tape recording of the interview and that, if any information was to be shown to anyone else or included in a written report, it would be anonymized and would not include any identifiable details.

It was also explained that, if something was disclosed that needed to be told to another member of staff for reasons of safety of the person concerned or someone else that, as far as possible, the researcher would inform the carer or patient of this before confidentiality was breached. The minimum amount of information necessary would be disclosed, and only those who needed to know would be informed.

Storage of data

Electronic data were stored on the University server, and paper records in a secure locked filing cabinet at the University department. Data from the study will be kept for 15 years in accordance with Cheshire and Wirral Partnership NHS Foundation Trust practice. Consent for this was gained in the consent process, as well as explicit permission to tape record the interview. To reduce the chance of any data going missing or getting into the wrong hands, all personally identifiable data was kept separately from transcripts, field notes and audio recordings of interviews, all of which were securely stored at all times.

Safety of the carer

The nature of in-depth interviews includes the discussion of potentially upsetting issues. This is due to the emotional and personal nature of the topic being studied. The researcher remained sensitive to the emotional state of the participant, and considered the phrasing of questions carefully. It was made clear that participants did not have to answer any questions they wished not to. If, at any time, a participant became distressed during an interview, the researcher offered to turn

off the tape and stop the interview. According to the participant's wishes, the interview was restarted when appropriate, or resumed at a further date.

Safety of the researcher

The researcher carried out interviews in carers' homes. This involved a potential risk to safety. Journeys to participants' homes were made by car, and telephone contact maintained with staff at the University department before and after each visit. The researcher spoke with staff at the relevant team before visiting any home, to find out whether there were any safety issues on the part of the researcher, the carer or the patient themselves that they should be aware of. This included any acute mental distress or symptoms that could be worsened by the visit taking place. The decision whether to visit or not was based upon this advice. On two occasions the researcher was accompanied on the preliminary visit by a member of the relevant team in order to be introduced to the patient and carer by someone known to them.

Potential benefit and follow-up

There was not expected to be any direct benefit for participants, but the process of talking about their experiences and views may have been found helpful. Participation in the study enabled carers to have their opinions listened to, and they may have benefited from having time to discuss the issues they face with a person removed from their situation.

The results of the study will inform development of services at Cheshire and Wirral Partnership NHS Foundation Trust. Participants may benefit from these improvements in service in the future.

Many carers expressed a desire to be informed about the results of the study. A letter will be sent to participants offering them the chance to contact the research team for further information. They will then be sent details of publications or reports available. This may include a presentation evening.

The results will also be presented to the five health teams involved (one crisis team and four CMHTs) to enable them to see the product of the research process and to thank them for their involvement.

CHAPTER 3

Making the Best of It: An Emerging Theory

3.1 Theory Overview

The theory presented is based on field notes and memos from in depth interviews conducted with 11 informal carers of people aged 65 and over with a functional mental illness. The participants include carers of people with depression and anxiety (n=8), bipolar disorder (n=2) and schizophrenia (n=1). Many of the people cared for also had physical co-morbidities. Most patients had longstanding mental illnesses with equally longstanding caring arrangements. The age range of carers was 40 to 93 years, and of patients was 65 to 88 years. Five of the carers were female, and six male. Eight patients were female, and three male. Carers were related to patients as husband (n=5), wife (n=3), daughter (n=2) or son (n=1). Most carers lived with the person they cared for (n=9). Please see Appendix Eight for details of the demographics of the sample.

In the following account, specific carers are referred to by letters of the alphabet in order to protect their anonymity. When illustrations from the data are given, field notes are indicated by the letters 'FN.' followed by the relevant letter of the alphabet. Memos are referenced by the letter 'M.' followed by the reference number of the memo. Illustrations are footnoted for ease of reference. Some patient and carer details have been altered to protect anonymity.

Everything written in the Results section is based upon the memos and field notes created as a result of interviews carried out in this study. Where a point relates directly to one field note, for example a descriptive example from one carer's interview, this is referenced at the bottom of the page. Similarly, memos that are directly quoted are referenced at the bottom of the page with the memo reference number. All other writing in the Results section relates to the findings of this study and is based on theoretical memos written and sorted during the grounded theory process, with some linking passages. There is no inclusion of data, ideas or concepts from other literature. These are integrated in the Discussion section.

The presentation of the theory in the Results section is modelled on the theory writing style of the originator of grounded theory, Barney Glaser. Please see page 98 of Glaser and Strauss' 1965 book *Awareness of Dying* for an example of the format of theory presentation and the use of illustrations. Classic grounded theory does not require researchers to stipulate where in the data every statement originates. It is implicit in the methodology that concepts are grounded in data, and Glaser (1978) explains his approach to presentation of theory in the following excerpt:

"The *credibility* of the theory should be won by its integration, relevance and workability, not by illustration used as if it were proof. The assumption of the reader, he should be advised, is that all concepts are grounded and that this massive grounding effort could not be shown in writing. *Also that as grounded they are not proven; they are only suggested.* The theory is an integrated set of hypotheses, not of findings. Proofs are not the point. Illustrations are only to establish imagery and understanding as vividly as possible when needed. It is not incumbent upon the analyst to provide the reader with description or information as to how each hypothesis was reached." (p.134, emphases in original)

Making the best of it

Carers of older people with mental health problems face many tensions in their complex relationships with the people they care for. These are family relationships between husbands and wives, and children and parents. These tensions fluctuate in time and intensity. They are inter-personal and intra-personal, often concurrently. Tensions are competing demands, perspectives, or thoughts.

One tension encountered is between the needs and desires of the carers of older people with longstanding functional mental health problems who have received mental health service input, and the needs and desires of the person they care for. This also encompasses the issue of identity of the carer in relation to the person they care for. Connected with this tension is the tension between being together and being apart, missing the person as they used to be but still needing their companionship and closeness, and wanting time together but also recognizing the need for time apart.

Another tension faced is that between increasing demands on the time, ability and energies of carers of older people with longstanding functional mental health problems who have received mental health service input, and the simultaneously increasing limits faced in meeting these demands in the form of physical or psychological ill health, time, increasing age and financial worries. This may result in the ability to meet increasing demands being restricted.

Many carers of older people with longstanding functional mental health problems who have received mental health service input also face the tension between choosing to care and feeling they have limited choice in the matter. For many spouses the caring commitment is incorporated in the marital commitment, but especially for carer sons and daughters, the tension between choosing a life defined by the caring role and feeling little choice in carrying out this role is evident.

These tensions are present in carers of older people with longstanding functional mental health problems who have received mental health service input in varying degrees. It is usual for the two sides of the tension to co-exist in one carer.

The main concern as expressed by participants is the resolution of these tensions, and it is explained by the core category *making the best of it*. This concept acknowledges the tensions faced by carers of older people with longstanding functional mental health problems who have received mental health service input, in their lives and in the caring relationship, and the fluctuating nature of these tensions, as well as the fact that many of these tensions are not easily resolved. *Making the best of it* explains how carers of older people with longstanding functional mental health problems who have received mental health service input continually attempt to resolve these tensions.

From this point on, the term 'carer' is used to refer specifically to the subset of carers included in this study, that is, carers of older people with longstanding functional mental health problems who have received mental health service input.

Making the best of it has three inter-related dimensions: *aspirational optimization*, *adjustment* and *keeping going*. See Appendix Six for a table of dimensions and categories.

3.2 Aspirational Optimization

Aspirational optimization is the desire for the best. It includes *wanting the best for the person cared for* and the carer *wanting to do their best* as the person caring for them.

Aspirational optimization is always present in decisions and adjustments made, even at the expense of the choice, freedom or even health of the carer. It also provides motivation for *keeping going*. The hopes held on to, whether realistic or not, provide a reason and an incentive to keep going, to keep pushing against difficulties as they come, and to make *adjustments* as needed.

3.2.1 Wanting the best for the person cared for

Wanting the best for the person cared for involves hoping that things will get better. This includes hopes for the future: hoping the patient will make a full or partial recovery or that certain activities will one day be enjoyed again. It hopes that the person cared for will be happy and enjoy life. Even if active hoping seems too farfetched, the desire for this to happen often remains; that is, the carer would like to see them feeling better or doing more, even if they know this is very unlikely to happen.

Two interconnected aspects of this concept are: *desiring happiness for the person cared for*, and *hoping for improvement in health and function*.

Desiring happiness for person cared for

Carers have a strong desire for happiness, enjoyment and fulfilment for the person they care for. As patients, and many carers, are older and approaching the later years of their lives, there is a desire for them to make the most of the time they have and to do things they enjoy. This also extends to desires for their future to be, as far as possible, illness- and conflict-free. In some cases there is an interconnectedness between the happiness of the carer and that of the patient, with many carers saying, "If he/she is happy, I'm happy," but there may also be a tension, when carers' needs conflict with those of the patient. This is explored further in the concept of *adjustment*.

The desire for happiness and the best may be associated with a sense of confoundedness, when the carer wants to see the patient enjoying life, but this is not being realised, sometimes over a protracted length of time. It can be very frustrating for carers to come to terms with the fact that they long to see their loved one better, but it is not happening. A sense of futility may ensue, with carers not knowing what to do next in their attempts to foster happiness and healing (see *keeping going*).

Hoping for improvement in health and function

This concept explains carers' hopes to see improvement, and to avoid further deterioration, in the health and function of the person they care for. Some carers describe this as wanting to get the "real" person back, feeling that the illness has somehow taken away the person they knew (see *identity adjustment*). It is associated with a realization that further deterioration in health and function could lead to negative consequences, such as the patient having to go into a residential or nursing home, and the desire to prevent this as far as possible. There is also a desire to guard what they have, such as a couple's independence, or the carer's own independence in the context of their caring responsibilities.

The desire to see improvement leads to attempts to help the person they care for, including finding the right resources and care, as well as individual attempts to improve symptoms and functionality. This may include ensuring medications are taken, taking the person they care for out for a walk or doing other things that they know are helpful (*illness adjustment* and *adjustment resourcing*).

It extends to hopes that are held on to, although they may never occur. This includes such things as a wife wishing her chronically depressed husband would make conversation with her, as she misses talking with him, or a husband wishing he and his wife could go on holiday again despite her advanced cancer and depression. There is often a sense that carers cannot see an end to their caring; it seems interminable and sometimes endlessly repetitive. Desires for things to be different remain, and are held onto as well as the knowledge that they are unlikely.

Dreams of what could be done if their loved one was better are held alongside the reality that many carers live day to day and find it difficult to plan for the future, due to the unpredictable nature of hospital appointments, illness and other issues,

some of which are part of ageing. These sometimes unachievable hopes are held none the same.

3.2.2 Wanting to do their best.

The carer's desire to do their best is seen in the desire to do as much as possible for the person they care for at home. This sometimes means refusing help, because of a sense of personal responsibility for the person's well-being, and a desire not to let the person down, or for them to feel that the carer has given up on them. It includes the carer wanting to stay well so that they can adequately meet the needs of the person they care for and do the best they can at the time.

Four aspects of carers *wanting to do their best* for the person they care for are: *feeling personal responsibility for their well-being, wanting to do as much as they can, wanting to stay well to care for them, and not wanting to let them down.*

Feeling personal responsibility for their well-being

Carers feel a sense of personal responsibility for the person they care for. It motivates care and *keeping going* despite difficulties. Personal responsibility is linked with issues of family responsibility and loyalty ("She's my mum", or "He's my husband"). In this context, caring is often unquestioned and accepted as part of the family or marriage relationship. There may, however, be a tension between choosing to care and feeling there is no alternative but to provide care, especially in parent-child caring dyads, where it can lead to a sense of missed opportunities or unfulfilled expectations (see *expectation adjustment*). The nature of the tension, however, means that the sense of responsibility, as well as attempts to balance carer and patient needs, are felt at the same time.

The sense of personal responsibility has an ever-present, inescapable, all-consuming nature, whereby carers express the feeling that they are constantly thinking about how the person they care for is, even when they are away from them or even if they themselves are ill in hospital. These thoughts affect the decisions they make about what they do. When they are away from the person they care for, they cannot stop thinking about and worrying about how they are coping and whether something has happened to them. Some carers feel constantly present with the person they care for, in their mind if not physically.

There is a sense that the caring responsibility lies solely, or predominantly, with them, and that only they can do the best job of caring for the person – no one else can do it as well as they can. Such comments as, “How would she cope without me?”¹ and, “I need to stay well for him,”² illustrate this point.

Wanting to do as much as they can

Carers often express the desire to do as much as their health, time and abilities will allow. This is strongly related to the sense of personal responsibility for caring. In some this is seen as an extension of working life: transferring skills used in a job to the caring role, and the desire to “do a good job.” This was especially seen in retired men.

For some carers the need to do a good job is applied to the caring role as it was in the work situation before retirement and, when the ability to do a good job is made more difficult by circumstances, including the mental illness of the person they care for, it can lead carers to complain of frustration, depression, irritability and sometimes anger. The carer cannot do what they want to do, or as much as they want or used to do. This may be because of ill health, limitations associated with ageing, an illness that is continuing despite their best attempts to help, or a health service that is not listening and responding to their loved one’s distress or needs (see *living with unresolved tensions*).

Sometimes the desire to do as much as possible risks the health of the carer. For example, a retired man caring for his wife felt a deep sense of responsibility and determination to take care of all the housework himself. He had previously had several heart attacks and worried that certain tasks around the home may cause another (see fieldnote excerpt below). However, he said that as long as he was able, he wanted to do these things himself, and was strongly against the idea of having any help around the house.³

Fieldnote excerpt: Wanting to do their best

He wants to do his best for his wife while he is able, and does not allow anyone to help with the jobs around the house. He feels that as it is his home, it doesn’t seem

¹ FN. Y

² FN. A

³ FN. Y

right for someone else to help while he is able. He also prevents his wife from helping with jobs for fear she might hurt herself as she is not steady on her feet. He is frustrated that he can't do as much as he would like around the house, as a result of his age and his own health problems. He feels caring is getting harder...However, always at the back of his mind is the thought that he might have another heart attack while changing the beds or pushing her wheelchair. "And how would she cope if anything happens to me?" When he was in the hospital after his stroke, all he was thinking about was how she was back home and how he needed to get back to her. He also said he is always thinking/worrying about her when he's out of the house.⁴

Carers may experience frustration as they realise their own limits. In the example above, the carer expressed that he often experienced bouts of frustration, anger and depression because he could not do as much as he would like, to the standard he set, around the house. Many carers struggle with their own health difficulties and limitations associated with ageing. Carers of working age struggle with balancing wanting to do as much as possible for the person they care for with the demands of their jobs and their commitment to other family members. These demands and limitations threaten the standard of care carers provide, as well as their own independence and sense of control.

For some, wanting to do as much as they can means seeking out and drawing on the resources available, such as good health care (see *adjustment resourcing*), or trying strategies to help (see *illness adjustment*). On the whole, carers are happy to accept help if it means the person is looked after well.

Wanting to stay well to care for them

Being present and able to care is important to carers. This category is concerned with carers wanting to maintain their own mental and physical health for the sake of the person they care for, in order to give them the best care they can. Caring may take a toll both mentally and physically on the health of the carer, but the desire to be well remains.

Carers may try to avoid causing the person they care for to worry about them, sometimes saying that they have enough to worry about already. This can lead to carers de-prioritizing their own health needs, for example, putting off having

⁴ FN. Y

operations for fear of what would happen if they left the person they care for. It may also mean finding a balance between the need to spend time on themselves in order to stay well, while also finding it difficult to leave the person they care for. Even if the caring situation is difficult, most carers want to stay with the person they care for and express views such as, “I don’t know how I’d survive without them.”⁵ This demonstrates an element of mutual needing or interdependency between the carer and their spouse or parent.

Not wanting to let them down

Another aspect of carers wanting to do their best is not wanting to let the person they care for down, or to give up on them. This extends to not wanting the health services from whom the patient receives care to give up on the patient. There is a sense of wanting to avoid guilt, as well as a sense of ‘owing’ the person they care for their best.

3.3 Adjustment

Adjustments are made in response to changes in circumstance. These ‘change triggers’ may be in the form of reduced capability or illness in either party – particularly changes in psychological symptoms or illness of the person being cared for, but also including mental or physical illness of the carer. Other change triggers include age, time and finance. In the face of change, new ways need to be found of making things work and doing the things that are wanted or need to be done. Adjustments take place with every assault on the taken way of existing, and they are dealt with as they come. They may be adjustments of behaviour or cognition.

Change triggers are often “more”, “extra” or “increasing” demands, limits, morbidity, complexity, needs, responsibilities or magnitude, but they may also be “less”, such as in the case of recovery from a relapse. In this case adjustments are just for a time and can then be adjusted back. In other cases, adjustments, once made, remain, and may be followed by more adjustments in the same direction. For example, when the carer takes over the shopping, then the cleaning, then the cooking.

⁵ FN. G

Changes can be dramatic or subtle; they can happen suddenly or gradually. They can move back and forth rapidly or stay one way for a long time. As changes may be gradual or sudden, compensatory adjustments may also be gradual or sudden. There is a sense of a constant state of flux of changes and adjustments, which at times is more or less noticeable, but is always present.

There is sometimes a mutuality of caring and adjusting between carers and patients. This continuum may be inhabited anywhere along its length, with some carer-patient couples acting in a mutually compensatory and inter-dependent way (*mutual resourcing*), and others where the carer is totally depended upon and the patient totally dependent.

The adjustments made may be *dependency adjustments*, *identity adjustments*, *expectation adjustments*, or *illness adjustments*. The type of adjustment depends upon the change trigger.

3.3.1 Dependency adjustments

Dependency adjustments involve the performance of tasks around the home, such as cooking, cleaning, paying bills and remembering hospital appointments. They also involve psychological support and stability, memory-related issues, organization and emotional (inter-)dependency. There is a continuum along which there are different gradations of dependency. In some cases this dependency adjustment is so stark that carers report a feeling of role reversal, where a daughter feels like the 'mother' or a husband feels like the 'wife' in the relationship. These adjustments can lead to challenges to notions of identity.

The concept of *dependency adjustment* contains the categories of *compensating for the other* and *delegating tasks*.

Compensating for the other

Compensation in roles occurs over time as mental or physical illness takes its toll on the capability of the person cared for. Taken-for-granted divisions of labour or role definitions may be affected. There may be an additional element of declining ability in the carer (see *mutual resourcing*).

Some carers struggle with these adjustments in role and responsibility. Frustration may be experienced as a consequence of having to do tasks that they find difficult and may have avoided in the past due to the ability of the patient. The difficulties carers experience may be due to the limits of their physical or psychological abilities, or stereotypical ideas of role and division of labour. For example, a retired man who cared for his wife who had longstanding physical and psychological difficulties, struggled to come to terms with what he called being the “wife”, which he defined as doing the cleaning, cooking and shopping, a role which he said was “alien” to him.⁶ Other carers took on responsibility for the personal hygiene of the person they cared for which, they felt, changed the marriage relationship (see *identity adjustment*). Some carers struggled with feeling that the person they cared for could do more than they did. This sometimes led to resentment.

The adjustments in role may be permanent or temporary, depending upon the circumstances and change triggers. Where compensatory changes are insufficient, delegation may be employed in order for the carer-patient couple to keep going and make the best of the situation.

Delegating tasks

When a carer finds that they are unable to carry out tasks that need to be done, they may delegate them to others, including friends, family or employed contractors. Delegation is performed willingly by some, reluctantly by others and, in some cases, is positively avoided. Delegation is dependent upon access to willing and able helpers, as well as the money to employ contractors. Carers may experience a sense of disenfranchisement as they are reluctantly relieved of a job they have done diligently, and are now unable to do.

Delegating tasks relates strongly to the category of *adjustment resourcing*.

3.3.2 Identity adjustments

Identity adjustments concern the repositioning of self in a changing environment or relationship – the carer’s husband, wife, father or mother may not seem like the person they used to be, whether transiently or permanently, and the nature of the marriage or parent-child relationship may have changed. This triggers an

⁶ FN. Y

adjustment in self-identity in relation to the changing identity of the person cared for. Coming to terms with the carer's own ageing may also trigger *identity adjustment*. The adjustments in identity are linked to whether the change has taken place gradually or suddenly. For example, a daughter or son who has grown up with a chronically depressed and anxious parent may have developed into the caring role, and may never have known any different.

The four aspects of *identity adjustment* which will be examined here are: *repositioning self in the face of change, redefining identity, comparing own situation with others' situations, and maintaining contact with the outside world.*

Repositioning self in the face of change

Change presents itself in many ways to carers: changing relationships, a changing partner or parent, changing roles, changing illness and changing demands.

The caring role is usually instigated in response to a reduction in ability of the patient. This may be difficult for a carer to accept: a husband who was once capable and in charge now seems vulnerable, a wife who was once independent is now dependent. Sometimes, carers feel that the person they care for is no longer the person they knew. But often there is a longing to hold onto what they have in the person they care for: a deep appreciation of the person, more than the illness and its effects on personality, behaviour and relationship dynamic. And there is a dependence upon and deep appreciation of the relationship, even in its changing or changed form. This prompts the mental repositioning of the carer themselves within the relationship, as well as the repositioning of the relationship in the wider world. Social roles are different, needs and dependencies are different, outlooks are different.

Ageing and retirement bring changes, as do unpredictable illness and symptoms. Carers reposition themselves over and over as things change. *Repositioning self in the face of change* and *redefining identity* form a two-stage process of *identity adjustment*.

Redefining identity

There is a link between the changes that occur and the identity of those involved. Many, however, want to hold on to who they are, and not lose their identity to the

changing circumstances of the relationship. The concept of caring provokes mixed responses: some people accept the term 'carer' to define their role; others do not accept that the term is necessary or appropriate. They unquestioningly accept caring responsibilities as part of their family or marital relationship. Some carers define themselves apart from caring; for others caring is their life. The relationship between the identity of the carer and the identity of the person they care for is complex. Additionally, when the changing nature of this relationship is considered, it creates an extremely complex and varying picture.

Carers define themselves in relation to the person they care for, as well as individually. Their identities are bound in each other, but also bound in themselves. There is a mingling of carer and patient. They both have, or had, lives of their own, but still their definition revolves around each other: wife as well as mother, husband as well as employee. The amount that couples have in common varies. As life changes, things of the past are relied upon as the basis from which to define and redefine identity. As the goal posts change, carers consider where they fit. Who are they? Who is the person they care for? Do they know each other? When things that previously bound a couple together are gone or changed, what is left? These are core questions about identity.

Carers cannot escape the changes that happen around and to them. They therefore redefine themselves in the face of them. This applies to the relationship as much as it applies to the individuals within the relationship.

Comparing own situation with others' situations

In defining and redefining themselves, and in coming to terms with their situation, carers often compare themselves with others. This may include comparing with others in a caring role, especially with those worse off, often concluding that their own situation is not as bad as that of someone else. This enables *keeping going*, as it is seen that others, despite their difficulties, still manage to get by.

Maintaining contact with the outside world

Maintenance of contact with the outside world – for example, getting out to do the shopping – is important to many carers, along with maintenance of contact with people, especially family. It allows carers to relate their situation to the situations

of those around them: to identify where they are in relation to others, to find their place, and to work out their coordinates in relation to the people around them. It often provides a point of stability and support.

3.3.3 Expectation adjustments

Expectation adjustments surround the experience that expectations of life are not, or have not, been met, and are linked to *prioritizing* decisions that are made as part of *adjusting*. *Prioritizing* of needs and desires takes place to guide decisions about behaviour, short- or long-term, but may lead to unfulfilled expectations on the part of the carer. For example, a daughter did not go to university so that she could care for her mother⁷; or a hoped-for retirement of leisure and holidays has not materialized and a couple are now spending their retirement doing the opposite of what was anticipated.⁸ When expectations are not met, they may be adjusted in response. Despite this, the hope that things will or could be different (*aspirational optimizing*) may remain.

Two aspects of *expectation adjustment* are *adjusting expectations of the relationship* and the carer *adjusting expectations of their own life*.

Adjusting expectations of the relationship

A relationship that once was based on mutual trust and dependency may now seem more one-sided, or a daughter who thought she would be spending her adult life concentrating on her own children is instead deeply involved in caring for her mother. Carers may miss the old person, the old personality and the role they used to play. They may miss the old way of life, the old relationship, the way things used to be. They may mourn for the things they long to be able to do again. This concept may also include adjusting expectations of the person cared for. In times of acute, as well as chronic, illness changes in expectation of the relationship enable carers to keep going and *make the best of it*.

Adjusting expectations of own life

Carers may feel that their lives have not worked out the way they had expected or hoped they would. Their own illness may have prevented them from working, their

⁷ FN. C

⁸ FN. Y

parent's illness may affect the work-life balance they expected to have, their spouse's illness and their own ageing may have affected the nature of the retirement they hoped for, or anticipated retirement may bring unanticipated feelings of loss about work. There may be grief for what is lost – independence, ability to do things, the life they once lived, the things they once enjoyed doing. Some carers accept these changes as a normal part of getting older, with one carer saying that “You don't expect to have the flush of youth for ever,”⁹ and another saying that, even if he had the chance, he would not want to be young again because he could not take with him the wisdom brought by age.¹⁰

There may be a transient aspect to *expectation adjustments*. For example, a son caring for his mother felt he was putting his social life on hold to look after her, but he anticipated that, once his mother was better, he would resume contact with his friends. How realistic this proposition was is unknown, but it enabled the carer to adjust his expectations of his own life in order to provide care for his mother. He did acknowledge, however, that he felt some opportunities had been missed for ever.¹¹

One carer also admitted that the avoidance of certain behaviours or opportunities in order to be available for her mother has led to a certain regret.¹² Carers who care for their parents often feel that their life has been shaped by their caring, and that who they are is dictated by their parent's illness. Other carers are eager not to miss opportunities and try to find ways to do the things they want to do despite their caring responsibilities.

3.3.4 Illness adjustments

Illness adjustments are made in the face of the patient's illness, in order to prevent relapse or to lessen symptoms. Carers often try several strategies to help the person they care for, such as ensuring medication is taken, encouraging their loved one to do 'normal' things such as going for a walk, or waiting for time to pass and symptoms to get better. These strategies are justified by what has worked successfully in the past. Other times, different strategies are tried sequentially in

⁹ FN. D

¹⁰ FN. F

¹¹ FN. W

¹² FN. G

the hope of finding an effective one, or the same approaches are repeated for lack of knowledge of what else to do. Strategies are informed by the carer's knowledge and enabled by their skills and resources.

Illness adjustment includes the categories of *attempting several strategies, repeating strategies, waiting for time to bring healing, tailoring behaviour, moderating disclosure, and acting to avoid negative consequences.*

Attempting several strategies

Carers employ several strategies to help the person they care for day to day. These include encouraging the person to take part in everyday life, arranging special outings or experiences, working in partnership with mental health services, involving friends and family in care and speaking in encouraging ways.

Repeating strategies

Many carers report an experience of repetition, especially when looking after someone with depression or anxiety. Carers find themselves using the same reassurances time and again, with varying success. They may have the same conversations repeatedly with the person they care for, or have to use the same strategies over and over to cope with behaviour. This may be due to the temporary success of the strategy, or because the carer does not know what else to try. Carers often express a desire for new strategies or techniques because of a feeling that nothing has worked so far. This may bring frustration for carers and it may contribute to a feeling of the endlessness of caring.

Waiting for time to bring healing

One strategy that is used is *waiting*. Many carers reported that, when their loved one is ill, they wait for time to pass, knowing that they will get better in time. One carer said that he knows his mother's depression must "take its course".¹³

For some, this is linked with a resignation of control and sense that they can do nothing more to help: that "What will be, will be." For others this is used as a method of coping, alongside encouraging the person they care for to take their medication and trying other strategies to help. The hope of future recovery is often

¹³ FN. W

held onto and facilitates *keeping going* despite what may seem a “lengthy process”.¹⁴

Tailoring behaviour

Carers adjust or tailor their behaviour to what they know or believe to work best in caring for their loved one. This may extend to the wider family or friendship circle, as well as the primary carer. Two key examples of this type of tailoring behaviour are *moderating disclosure* and *acting to avoid negative consequences*.

Moderating disclosure

Moderating disclosure is where a family or carer does not tell the person they care for about certain things – such as a grandchild being in trouble with the police or a son taking sick leave to care for his mother – for fear that it will cause a relapse or worsening of their symptoms. Alternatively, carers may phrase things in a way that subdues their meaning, or they may avoid expressing anger or frustration towards the person being cared for. *Moderating disclosure* means adjusting what is told to the patient according to how the carer perceives it will affect their mood or feelings: disclosure of the carer’s feelings is mediated by the carer’s prediction of the patient’s resultant feelings, as illustrated in the following memo excerpts:

He tells her positive things in order to lift her mood and ‘create a positive atmosphere’, but he does not share his frustrations or struggles with his own mental health for fear that she will feel a burden to him, and may take another overdose.¹⁵

One carer explained this as the whole family “treading on eggshells” around the patient. A memo about this reads:

This seems to be a family enterprise – avoiding things that will make her worse, not telling her things that might upset her or make her ill, not shouting or expressing frustration with her but walking away.¹⁶

¹⁴ FN. W

¹⁵ M. W2

¹⁶ M. C1

Acting to avoid negative consequences

Fear of anticipated consequences affects behaviour and decisions made, including the avoidance of possible triggers for deterioration, or, for example, deciding to stay at home in case the patient tries to commit suicide. Decisions may also stem from prioritization of the cared-for's needs above those of the carer's, for example, one carer did not want to have a needed hip replacement for fear that leaving her husband would lead to deterioration of his mental state.¹⁷ Wanting to avoid negative consequences also influences decisions made for the protection of other family members. For example, one carer did not allow her grandson to be alone with the carer's mother when she was ill, for fear that he would grow up witnessing her depression as she did as a child.¹⁸ This concept also includes the tendency for carers not to talk to others about their situation for fear of "burdening them".¹⁹

Adjustments are resourced through internal and external *adjustment resourcing*.

3.3.5 Adjustment resourcing

Adjustment resourcing involves marshalling internal and external resources in order to make adjustments. It includes making the most of those resources already possessed and availing oneself of resources that are needed, in order to adjust, deal with changing demands and do what needs to be done (*keeping going*).

One aspect of *adjustment resourcing* is utilizing the strengths and abilities of the carer and other people in response to increasing demands and limits, which may mean the carer delegating tasks to friends, family, or an employee; or finding the internal resources to adjust by taking on the extra responsibilities and demands themselves. The carer takes up as much as their health, time and abilities allow, and the rest is delegated out.

Within the caring relationship *adjustment resourcing* can mean compensating for, and complementing, each other in day to day things: one does what one can and the other what they can. This *mutual resourcing* is more evident in some carer-patient couples than others.

¹⁷ FN. Z

¹⁸ FN. C

¹⁹ FN. G & FN. W

This concept involves drawing on those resources already possessed, as well as acquiring or increasing those that are lacking. Resources may include the carer's physical and mental strength, abilities, money and people to provide help.

Adjustment resourcing varies according to carer characteristics and carer-patient relationship dynamics as well as depending upon money, an able and willing network of friends and family, appropriate and accessible health services, and the willingness of the carer to accept and draw on the resources available.

Adjustment resourcing includes the concepts of *drawing on internal resources*, *drawing on external resources*, *increasing resources*, and *mutual resourcing*.

Drawing on internal resources

Adjustment resourcing includes *drawing on internal resources*, such as physical and emotional strength, energy, personal faith, memory, abilities and knowledge. Carers draw on the internal resources they have to cope with changing circumstances, and they develop the resources to cope with those things that challenge them. Carers may find their own internal resources limited by changes in their own health or circumstances. In these situations, they find different ways to get the job done, including asking for help from others.

Limits may cause reliance on others and changes to the way things used to be. They prevent and affect things, they make things more complicated, things take more effort, or a different type of effort. Carers may sometimes feel that their energy is waning. Sometimes it needs to be mustered even when it is difficult. Carers need to find the ability to do things they would not naturally do, things their spouse once did. Other things need to be handed over to others, such as children, healthcare workers or employees.

Drawing on external resources

Drawing on external resources includes delegating tasks to others, such as family and friends. It also refers to using money to enable tasks to be done; for instance, employing someone to do the gardening, decorating or cleaning. It may mean making use of health services or day hospitals. *Drawing on external resources* is done easily by some carers; others may be more reluctant to change the way things

have been done in the past. However, age and illness, as well as lack of time, may necessitate such adjustments.

Increasing resources

Resourcing involves maximizing the resources that carers have, such as making the most of the time that their loved one is at a day hospital to get things done around the house. It also means *increasing resources* when needed. This may mean learning a new skill, or drawing on extra resources at times of acute crisis. For example, one carer needed transport to and from the hospital when her husband was admitted. She found that her church friends were happy to draw up a rota of people to take her each day. This was a great support to her at a time when increased resources were needed.²⁰

Mutual resourcing

In some, but not all, patient-carer pairs, resourcing is carried out by the patient as well as the carer. When both patient and carer contribute their abilities and resources, this is called *mutual resourcing*. In case A, the wife of a man who had suffered memory loss in addition to having bipolar affective disorder found that she had assumed the role of the “strong one” in the relationship, a role which her husband had historically held. She had to remember things for him, and come to terms with his decline in ability. Previously he had been very capable and practical. Now he has forgotten how to do the things he used to do. She has taken over what she can, but she also suffers from joint pain. Therefore, her husband carries out some tasks that she now cannot do, including the vacuuming and other cleaning tasks, as well as anything else that requires physical strength. This is an example of *mutual resourcing*. They also receive help from friends, family and contractors to do the things neither can do (see *delegating tasks* and *drawing on external resources*).²¹ Although they have extensive help from friends and family, the need of each other is apparent.

3.3.6 Balancing priorities

Caring involves *balancing priorities* at many levels. Many carers find themselves juggling other family, work or household commitments with caring for their parent

²⁰ FN. A

²¹ FN. A

or spouse. There are competing demands on finite amounts of time, physical and emotional energy, and other resources. Carers prioritize what needs to be done – what is most important at a certain point in time – but prioritizing necessarily leads to limiting of other non-prioritized things, which means sacrifices may be made in other areas.

The concept of *balancing priorities* includes *prioritizing*, *sacrificing* and the concept of the *guilt paradox*.

Prioritizing

Prioritizing means making something a priority either cognitively or as demonstrated through behaviour. It may mean deciding where time, money and effort is spent, or on whom. Or it may be seen as who occupies the majority of the carer's thoughts or attention. Often the person being cared for takes the position of priority, especially during an acute crisis in their mental health. However, many carers have other things that vie for priority, such as other members of their family.

Caring becomes increasingly complicated if a carer looks after more than one person. For example, a lady who cared for her husband also had an adult child with a disability. Before her husband became ill, she devoted a lot of time to caring for her disabled child. When her husband became acutely mentally ill, her priorities changed and someone else visited her child for her, as she made the daily trip to see her husband in hospital. Now that her husband has made a partial recovery, she shares her time more evenly between the two.²² As in this example, decisions of priority may be temporary. In other cases they may be more permanent.

Sacrificing

The prioritization of the person cared for may mean that carers think less about their own needs and spend less time on them. For some carers, the distinction between the needs of themselves and the person they care for may be very definite. They may see a definite boundary between time for them and time for their loved one, to the extent that one or the other factor is entirely ignored in favour of the other, either temporarily or permanently. Other carers maintain a more integrated approach to their interlinked needs. *Prioritizing* and *sacrificing* are especially

²² FN. A

instrumental when caring during the acute phase of illness, when demands are greatest. At other times, the needs, views or desires of the carer or a friend or another family member may be prioritized for a period of time.

Guilt paradox

In their efforts to balance priorities, some carers experience a *guilt paradox*, whereby they feel guilty if they do something, as well as if they do not do it. For example, a woman caring for her depressed mother felt guilty when she spent time with her mother, feeling that she was neglecting her husband, children and grandchildren. However, when she spent time with the rest of her family, she felt guilty for not being with her mother and anticipated feeling guilty if anything happened to her mother when she was not with her. She seemed unable to escape the feeling of guilt, whatever she did. At the same time, she longed for time to herself, and she had booked a holiday with some friends. She said she was looking forward to the holiday, but knew that she would feel guilty for not being with her mother when she was away. She had previously cancelled several holidays for this reason.²³

The *guilt paradox* describes the way that, although carers avoid doing things so that they can be with the person they care for, when they are with them, they feel guilty that they are not with someone else or doing something else. If they do something else, they then feel guilty that they are not with the person they care for. It relates to a constant tension between the needs of the person they care for and those of other family members and the carer themselves. Many carers struggle to juggle these competing needs.

3.4 Keeping Going

Tension resolution is often transient and fluctuating, in tandem with changing triggers and the resultant *adjustments*. There is a sense that carers must come to terms with tensions in their unresolved or resolving state. Not all is resolved, and often accompanying frustrations, and feelings of guilt, anger and resentment may remain; again, often in a fluctuating state. The concept of *keeping going* applies in the face of difficulties, adjustments, repetitions and unresolved tensions.

²³ FN. C

It has the property of resilience, linking with the concepts of wanting to stay healthy and able for the sake of the person cared for (*aspirational optimization*), as well as using resources available to do the best day to day (*adjustment resourcing*). *Keeping going* is facilitated by *adjustment* and motivated by *aspirational optimization*.

Keeping going consists of the categories of *keeping going despite difficulties* and *living with unresolved tensions*.

3.4.1 Keeping going despite difficulties

Keeping going includes living with frustrations and *accepting caring responsibilities* – even if reluctantly – and *keeping going* despite them. It means *living day to day*, even if unable to look to the future or see the end. It is “in the meantime,” before hopes are realized or tensions resolved.

Keeping going involves being a maintaining force in the carer-patient relationship, acting to maintain and maximize health, and to maintain the home. *Keeping going* occurs in the face of difficulties, mustering energy day to day, fighting against challenges, straining forward and *struggling on*.

The dimensions of *keeping going despite difficulties* are: *accepting caring responsibilities*, *doing what needs to be done*, *living day to day*, and *struggling on*.

Accepting caring responsibilities

Regarding this category, there may be different perspectives: some spouses did not find the word ‘carer’ easy to relate to. They considered their caring responsibilities to be an integral part of being married. As one spouse said, “You take the good times and the bad times.”²⁴ This sense of familial or marital responsibility was common to all carers, although for some the tension between their needs and the needs of the person they cared for was more obvious. Some said that they cared because they did not have a choice: their relative was in need so they cared for them; but they simultaneously maintained that it was their choice to care.

Accepting caring responsibilities also means accepting responsibility for some of the negative things associated with caring. For example, one daughter carer felt that she was partly to blame for feeling “caged in” by the caring situation with her

²⁴ FN. D

mother; a feeling that she had allowed herself to take up the role of carer, along with the sense of isolation she felt with it.

Doing what needs to be done

Carers keep going by *doing what needs to be done* on a daily basis. This includes making *adjustments* as they are needed, and drawing on resources in order to facilitate such adjustments (*adjustment resourcing*).

Living day to day

Many carers find that they are unable to look to the future. They may have hopes of what may happen, but their day to day life feels more like a plodding or coping situation, rather than planning and working towards something. They often have a sense of not being able to see the end of their caring, but they just keep going day to day.

Struggling on

Struggling on explains the concept of pushing forward despite difficulties and resistance. Carers may fight against challenges as they come, and continue to care. Many carers maintain resilience even in the face of their own illness and feelings of loneliness or depression. *Struggling on* may mean keeping trying even when nothing seems to have worked, or keeping repeating the same cycles of behaviour and response that may be seen in caring for someone with a mental illness. It is not always easy, however, and resources may be stretched in order to facilitate *struggling on*. Carers may have a sense that they cannot carry on like this for ever; that something may give if things continue as they are.

3.4.2 Living with unresolved tensions

Adjustment does not always lead to the resolution of the tensions that may be present in the patient-carer relationship. Carers live with many tensions unresolved, though they may attempt to resolve them through *adjustment*. *Living with unresolved tensions* may bring psychological difficulties, including *experiencing frustration, guilt and anger*.

Experiencing frustration, guilt and anger

Frustration may stem from feelings of not being able to do as much or what one would like to, not being able to make the patient better, dealing with difficult symptoms of illness, not being able to get the help the carer or patient needs, unresolved tensions, experiencing a lack of resources, or dealing with changes of identity, personality, resources or ability. For instance, a carer experienced frustration because he could not get adequate psychiatric treatment for his acutely depressed wife. Despite his best attempts, she was not referred to a consultant psychiatrist until she had attempted suicide. He felt that she had experienced unnecessary anguish and suffering because of a failure of the health care system.²⁵

Many carers find the psychiatric symptoms of their loved ones frustrating. They may feel angry at the situation they are in, both for themselves and for their spouse or parent. They may feel guilt that things have not worked out the way they wanted to. The experience of grief is also very real for many carers, who may grieve the loss of independence, the marital relationship, and opportunities.

²⁵ FN. E

CHAPTER 4

Discussion

4.1 Introduction

The theory outlined in the previous chapter is a dimensional analysis of how carers of older people with longstanding functional mental health problems who have received mental health service input 'make the best of' their situations. The three dimensions: *aspirational optimization*, *adjustment* and *keeping going* are facets or aspects of *making the best of it*. By understanding them, the shape of the core category, *making the best of it*, becomes clearer. For this reason there is some overlap between the concepts: they are looking at the same thing from different angles. As when looking at a transparent object, there is some 'show-through' between facets.

Making the best of it explains how, at the heart of the caring arrangement is the carer's desire to see the person they care for enjoying life and feeling fulfilled, and this inspires their attempts to do their best to make this happen. Carers of older people with longstanding functional mental health problems who have received mental health service input feel a strong sense of responsibility towards the person they care for, and they commit time, effort and skills to their care, often taking pride in the way that they care, and feeling that their knowledge of the person equips them to provide care that is optimal.

The caring situation, however, is a changing one, with constant fluctuations in demands and limits; demands which often compete for time and energy. Carers of older people with longstanding functional mental health problems who have received mental health service input cope with the changes they encounter by adjusting to them as they happen. The way in which carers adjust depends upon the nature of the change encountered, and adjustments are facilitated by internal and external resources, including the support of friends, family and formal services. Adjustments may concern the dependency status of the person they care for, the carer's identity in the context of the caring relationship, the carer's expectations of their life and their relationship with the person they care for, or the demands

caused by the illness of their loved one. Where there are competing demands or tensions, the strategy of prioritization is often employed.

The final aspect of *making the best of it* is *keeping going* despite difficulties.

Although the caring situation is often difficult, requiring regular adjustments and readjustments, as well as the balancing of competing demands and acceptance of continuing cognitive tensions, carers keep going. Many find that they cannot look too far into the future, but find the only way to cope is to keep a short-term perspective, living day to day and doing the things that need to be done. Carers of older people with longstanding functional mental health problems who have received mental health service input often display remarkable resilience and determination in the face of these challenging circumstances.

It should be noted that the 11 patient-carer pairs, at the time they were interviewed, were living 'successfully' with the patient-carer dynamic. That is, they were existing in a caring relationship that, to whatever extent, was 'working', in that they were still in it. It is well known that breakdown of the caring situation occurs (Aneshensel *et al* 1993), and it could be argued that each of the dyads involved in this study were somewhere along a continuum between carer-patient 'success' and carer-patient breakdown, if indeed it is a continuum. Whether caring breakdown is a process or not is a topic for another study.

Nonetheless, at the time these 11 carers were interviewed, they were in a caring role. It could then be argued that *making the best of it* is a theory of what happens in those successful or pre-breakdown relationships. It may help to explain why these carer-patient pairs have stayed as they are: as patient and carer, and have not become patient and visiting family member, as they would if the patient were admitted to hospital or a nursing home. This is the aim of community care: to keep people at home, with those they love, for as long as is reasonably possible. This theory could be seen as an insight into how 'successful' caring relationships function; how they deal with the changes and tensions that are part of life and that are amplified in the mental illness and caring situations. Despite this, it should be remembered that, just because a caring arrangement is continuing, does not mean that it always will, and just because a carer is continuing to care does not mean that they are happy or that the situation is a 'good' one. Each situation must be considered on its own merits.

This discussion will cover several points raised by the study in the context of literature about caring and coping. The concept of carer burden will be examined in the light of the findings of this study, followed by the contribution that coping models make to understanding *making the best of it*, and vice versa. This is followed by exploration of *making the best of it* in relation to literature about identity, mastery and self-concept. The way in which care is related to the concept of obligation is assessed, as well as further examination of the concepts of adjustment and adaptation. Finally, relevant extant grounded theories will be discussed with reference to the present study.

4.2 Gender and Caring

To begin with, it is necessary to mention the issue of gender and caring. Much of the literature about informal caring emphasizes its gendered nature, focusing on the disproportionate representation of women in caring roles. This has been highlighted as a major factor in research on carers of older people, mainly due to the preponderance of daughters and daughters-in-law (Finch 1989, Duijnste 1992).

The current study, however, includes an almost equal number of male and female carers, with men just outnumbering women. Six carers were men, and five were women. Of the six men, five were husbands caring for their wives, and of the five women, three were wives caring for their husbands. The remaining carers were adult children of the people they cared for. Although these numbers do not have any statistical significance, a similar finding was reported in a study of informal carers of older people performed by Qureshi and Walker (1989). They found in their sample that the number of husband carers was twice the number of wives who provided care for their husbands. Their study only included spousal carers whose responsibility for household tasks had increased substantially as a direct result of the disability of the person they cared for. Qureshi and Walker (1989) admit that this may have led to the exclusion of a number of wives whose husbands were dependent upon them, and who may have been providing equivalent care to those who were classed as carers, but whose role had not changed substantially since their husband's disability. Nevertheless, the differential between the numbers of men and women was marked, and certainly did not reveal the excess of women that may have been expected in the light of literature on the subject.

There may be several reasons for this. Qureshi and Walker (1989) explain that husbands are more likely to provide care than wives, as women are more likely to be disabled in later life, and older men are more likely to be married. Many studies of informal caring do not include spouses, even though the spouse, if capable, is usually the first person to be called on if care is needed (Qureshi & Walker 1989). Some studies only include informal carers who do not live with the person they care for (Finch 1989), which may also affect statistics on the numbers of men and women who care if, as Qureshi and Walker (1989) point out, spousal carers are more likely to be male.

The analysis of the collected data in the present study, did not lead to the emergence of gender-specific categories. For this reason, the issue of gender, although significant in the wider study of caring, its social construction and implications, will not be dealt with in depth in the following discussion.

4.3 Making the Best of it and Carer Burden

“A “burden” taken on in loving care or from a sense of social obligation may not be regarded as such and in any case may be preferred to what others, anxious to help, may visualise as “relief”.”

(Hoenig & Hamilton 1966, p.167)

As a theory of caregiving, *making the best of it* brings into question elements of the widely used concept of carer burden. The concept of carer or family burden has featured strongly in carer literature since the 1960s (Mills 1962, Grad & Sainsbury 1963, Hoenig & Hamilton 1966). Maurin and Boyd (1990) state that the term ‘burden’ was adopted to describe the experience of carers,

“Because the impact observed was often viewed by respondents and researchers as requiring family members to place their needs and wishes after those of the patient.” (p.99)

Hoenig and Hamilton (1966) made a distinction between ‘objective’ and ‘subjective’ aspects of burden. In their study of families of people with schizophrenia, objective burden included such factors as the ‘adverse effects’ upon the household, finances, health and daily life of the family, as well as the behavioural disturbance of the patient due to their mental illness. Subjective burden was defined as the carer’s

views about caring for the patient and whether they felt they experienced burden. Their study found that levels of objective burden were substantially higher than levels of subjective burden (81% and 60%, respectively), and that objective burden had no effect on the level of subjective burden. For instance, a carer with a very high level of objective burden may report little or no subjective burden, and vice versa. They attributed this discrepancy to “tolerance accorded to the schizophrenic patient” (p.175).

Thompson and Doll, in their 1982 study, also found little correspondence between measures of objective and subjective burden. Their criteria were different to Hoenig and Hamilton’s (1966), in that behavioural and symptomatological factors were excluded from measures of objective burden, instead being treated as an independent variable. They also further defined subjective burden as, “the emotional costs the patient’s presence and behavior [*sic*] had on his or her family,” (p.381) and within this included feelings of embarrassment, overload, entrapment, resentment and exclusion. They found that twice as many relatives were classed as having severe objective burden (27%) than severe subjective burden (15%) and, strikingly, of the relatives assessed as having *no* objective burden, 70% reported some degree of subjective burden. The explanation given was that, “This discrepancy likely signals families’ adaptive tolerance” (p.384).

Several authors have commented on the problems associated with the concept of burden, both operationally and conceptually. Problems include variations in the definition of burden, including its objective and subjective elements, which “obscure the conceptual basis of burden” (Maurin & Boyd 1990, p.103). It has been referred to as an “umbrella term” (Duijnste 1992). In addition to discrepancies in the definition, there are differences in the unit of analysis, methodology and outcome measures employed between studies. Often one family member is asked for their experiences, and the results presented as representing ‘family’ burden. Additionally, different instruments of measurement are employed, leading to difficulties in comparing and collating results. Operational difficulties arise when, as in many of the studies on carer burden, the carer is asked to rate the patient on levels of objective burden, for example behavioural aspects. This can lead to confounding as the carer will be influenced in their responses by their own perceptions and subjective burden (Maurin & Boyd 1990). Several studies have

found that carer perception of patient health and behaviour is a strong predictor of level of subjective burden (Thomson & Doll 1982, Haley *et al* 1987).

On a conceptual level, burden can be seen as only presenting one aspect of a complex picture:

“As real as the burden of mental illness is for families, consideration should be given to the fuller experience of what it means to have a mentally ill family member. Mental illness is accompanied not only by burden for family members, but ambivalence, uncertainty, successes, and love as well...To focus only on the burden simplifies a very complex experience and holds the danger of victim-blaming.”
(Maurin & Boyd 1990, p.105)

The studies outlined above (Hoenig & Hamilton 1966, Thompson & Doll 1982) demonstrate the dangers of ‘objectively’ judging what a carer is experiencing: only carers themselves know the particular challenges they face, and their struggles in facing them. Their voice is essential in any research into caring and its effects. The current study would support the idea of an ‘adaptive tolerance’: carers are not the victims of unmitigated burden, but, despite difficulties, find a way to get through, a way of *making the best of it*. For many carers of older people with longstanding functional mental health problems who have received mental health service input, caring is not a wholly negative experience, but is associated with positive elements, including a sense of doing their best for the person they care for, and with whom they have often had a previous relationship.

Some more recent research has focused on the positive elements of caregiving (Lopez *et al* 2005), and on the dyadic nature of the caregiving relationship, as opposed to focusing exclusively on the perspective of the carer (Spruytte *et al* 2002).

Lopez *et al* (2005) found that most relationships between carers and patients aged over 60 with psychiatric or physical illnesses had positive aspects for the carer. Despite the stressors associated with caring, many carers reported a high level of carer satisfaction, defined as,

“...the perceived subjective gains and rewards, and the experience of personal growth that occurs as a result of providing care.” (Lopez *et al* 2005, p.82)

This is shown in the theory of *making the best of it*, where carers of older people with longstanding functional mental health problems who have received mental health service input often take pride in caring and being there for their loved one.

Making the best of it explains how, in some caring relationships, there is a mutual resourcing and compensating, an interconnectedness of well-being. It stresses the significance of the relational aspects of caring. Another study that supports the idea of the caring relationship being one of mutuality is by Spruytte *et al* (2002), who highlight the importance of studying the two-way relationship between carer and patient. They used the concept of Expressed Emotion (Leff & Vaughn 1985) to explore the nature of relationships between carers and patients with functional and organic mental illnesses, and found that most relationships were characterized as, “warm, affectionate and relatively free of conflict and criticism” (Spruytte *et al* 2002, p.306). They proposed a circular process of mutual influence between carer and patient within the relationship.

Making the best of it, as a theory, incorporates the complexity of the caring experience, which is contextualized in the familial caring relationship. Carers of older people with longstanding functional mental health problems who have received mental health service input experience many and varying competing and conflicting demands, socially and psychologically, which are explained by the concept of tension. On its own, the concept of burden does not sufficiently explain the day to day caring situation, which has been described as characterized by “complex, ambivalent, often inconsistent reactions” (Thompson & Doll 1982, p.382).

4.4 Coping and Making the Best of it

“Coping refers to efforts, both cognitive and behavioral [sic], to manage environmental and internal demands and conflicts affecting an individual that tax or exceed that person’s resources.”

(Coyne *et al* 1981, p.440)

Attempts to deal with the complexity of the caring experience have included the application of stress and coping models to caregiving (Lazarus & Folkman 1984, Pearlin *et al* 1990).

Making the best of it can be viewed as a way of coping with the challenges associated with caring. The transactional and multi-dimensional aspects of caring must not be forgotten: many carers of older people with longstanding functional mental health problems who have received mental health service input view caring not as a role inflicted upon them, but as a normal part of life, and their coping responses may be seen as 'normal' responses as well. In their theory of stress and coping, Pearlin *et al* (1981), emphasized the need for coping models to be applicable to normative, as well as to extraordinary, circumstances. Carers of older people with longstanding functional mental health problems who have received mental health service input vary in whether they view caring as an ordinary or an extraordinary situation, but *making the best of it* applies in both circumstances.

Pearlin's Stress Process (Pearlin *et al* 1981) conceptualizes stress as a process consisting of a source, mediator and outcome. Sources of stress can be life events, role strains and the diminishment of the self-concept, which consists of the dimensions of mastery and self-esteem. In this context, mastery is "the extent to which people see themselves as being in control of the forces that importantly affect their lives" (p.340), and self-esteem "involves the judgments one makes about one's own self-worth" (p.340). Attacks on these elements of self-concept, as well as life events and role strains, are seen as making one susceptible to stress outcomes. The particular stress sources, or stressors, seen in the caring situation include the primary stressors of daily care activities, and secondary stressors of psychological or social difficulties associated with the caring role (Aneshensel *et al* 1993). Examples of stress outcomes include carer depression (Pearlin *et al* 1981) or institutionalization of the person being cared for (Aneshensel *et al* 1993).

Pearlin *et al* (1981) argue that stressors and outcomes are not related in an unmediated way: mediating factors affect the impact that stressors have on a person, and the degree to which they experience stress. In the Pearlin Stress Process, these mediating factors are social support and coping. Coping is defined as, "any response to external life-strains that serves to prevent, avoid, or control emotional distress," where life-strains are "conflicts, frustrations, and threats" (Pearlin & Schooler 1978, p.3). Coping responses perform several functions, outlined as:

“...the modification of the situations giving rise to stressful problems; the modification of the meaning of problems in a manner that reduces their threat; and the management of stress symptoms.” (Pearlin *et al* 1981, p.341)

In the light of this, *making the best of it* can be seen as a way of coping with life-strains, or stressors, presenting in the form of change triggers and tensions. Pearlin *et al* (1981) found that, although the two mediating factors of social support and coping are defined separately, they perform the same function, and are both used together. *Making the best of it* supports this idea, in that carers of older people with longstanding functional mental health problems who have received mental health service input draw on external resources, including formal and informal social support, as well as implementing coping responses such as *adjusting* and *keeping going*.

In another conceptual theory of stress, Lazarus' cognitive-phenomenological Theory of Psychological Stress, mediating factors are appraisal and coping (Folkman & Lazarus 1980). Appraisal is the cognitive process of evaluation of what is at stake (primary appraisal) and what resources and options are available for coping (secondary appraisal). Coping is defined as,

“...the cognitive and behavioral [*sic*] efforts made to master, tolerate, or reduce external and internal demands and conflicts among them” (p.223).

In Lazarus' theory, coping can be problem-focused (“the management or alteration of the person-environment relationship”) or emotion-focused (“the regulation of stressful emotions”). Folkman and Lazarus (1980) found that, in everyday life, people use both problem-focused and emotion-focused coping, and that both forms of coping are used in dealing with each stressful episode. In their study of 100 people, in less than 2% of the 1,332 incidents analysed only one type of coping was used.

The choice of coping response depended on the person's appraisal of the situation. If a situation was appraised to be changeable, problem-focused coping was used; if the situation was not seen as changeable, emotion-focused coping was used. Emotion-focused coping was found to be more common in health situations, and less common in work situations (Folkman & Lazarus 1980). Pearlin *et al* (1981) also reported that the type of coping response varied according to the particular

challenge faced. This links with the findings of the current study, where particular adjustments were made in response to particular change triggers.

The concept of appraisal is connected with resourcing. Resourcing is a concept that features strongly in *making the best of it*, in terms of internal and external resources, which are drawn upon in order to adjust to varying situations. In *making the best of it*, *adjustment resourcing* encompasses drawing on internal and external resources, as well as increasing those resources where necessary and possible. Coyne *et al* (1981) explain their concept of appraisal as the evaluative element conducted before the responsive element of coping. Although *making the best of it* does not emphasize the cognitive nature of resourcing, similarities can be seen with the concept of appraisal, especially in its “continually re-evaluated judgements about demands and constraints in ongoing transactions with the environment and options and resources for managing them” (Coyne *et al* 1981, p.440). Carers of older people with longstanding functional mental health problems who have received mental health service input, as they face changing demands as well as limitations, use resourcing in order to meet those demands by adjusting.

Folkman and Lazarus (1980) conceive that the coping process leads to an ‘adaptational outcome’. Although not conceptualized in terms of a process, *making the best of it* involves *keeping going* despite challenges and corresponding *adjustments*, and in this sense could be seen as an example of an ‘adaptational outcome’.

Folkman and Lazarus (1980) emphasize the dynamic nature of coping, both between situations and within situations: coping is not static, but as the situation changes, different forms of coping are used. *Making the best of it* shows that carers of older people with longstanding functional mental health problems who have received mental health service input may use a series of coping methods, particularly in *illness adjustment*.

Although Pearlin *et al* (1981) acknowledge the complexity of the stress process, Folkman and Lazarus (1980) focus on its transactional elements, which they see as a constant reciprocal relationship between the individual and their environment.

Making the best of it supports the view of living with caring as a series of fluctuating tensions and changes, which are met with corresponding adjustments.

4.5 Identity and Mastery

“...life events can lead to negative changes in peoples’ roles, changes whose persistence wears away desired elements of self-concept, and that through this set of linkages stress is aroused.”

(Pearlin *et al* 1981, p.342)

Making the best of it highlights connections between identity, the caring relationship, and the degree to which carers feel they have control over, or choice about, caring. Two aspects will be examined here: identity and mastery.

Pearlin’s Stress Process lists diminishment of self-concept as a contributor to stress, with the core elements of self-concept being mastery and self-esteem (Pearlin *et al* 1981). Caring may present a threat to self-concept through its challenges to role and identity, as well as to the sense of control or mastery a carer has over their circumstances. *Making the best of it* includes the categories of *repositioning self in the face of change*, *redefining identity*, and *expectation adjustments* of the caring relationship and the carer’s own life, all of which are closely related to self-concept and mastery. This is particularly relevant as it refers to the tension between making the choice to care, or not. For many carers of older people with longstanding functional mental health problems who have received mental health service input this is an unresolved tension which they continue to wrestle with throughout their experience of caring.

To begin with the issue of identity, caring involves many changes in circumstances and in relationships, which can challenge identity and self-concept.

Strauss (1977) writes of “turning points in self-conception,” which occur throughout adulthood as well as childhood. He talks of the development of self throughout life, “adjudicating between the demands of stable kinds of status, but also in juggling differential temporal placement” (p.129), characterized by a temporal and constantly changing identity. The constant changing of status means that resolution is never fully or finally, but only partially and temporarily, achieved (Strauss 1977).

The 'turning points' or 'critical incidents' which prompt changes in self-concept are signalled by "misalignment – surprise, shock, chagrin, anxiety, tension, bafflement, self-questioning" (p.93). Strauss (1977) points out that challenges to self-concept and the responses they provoke are not always predictable. Therefore, any theory of caring should take into account,

“...the open-ended, tentative, exploratory, hypothetical, problematical, devious, changeable, and only partly-unified character of human courses of action.” (Strauss 1977, p.91)

Strauss (1977) also notes that challenges to self-concept may not be immediately obvious, or occur suddenly. They are often subtle in onset, a point that is made in *making the best of it*. Changes may be sudden or gradual, and only at a tension or turning point, the carer realises the changes that have taken place, the opportunities that may have been missed, and the realignment necessitated (Strauss 1977).

In their study of the caring role of relatives of people with Alzheimer's disease (AD), Aneshensel *et al* (1993) provide a conceptual account of self-concept and the role of caring that echoes the findings of *making the best of it*:

“...the gradual absorption of a person into a caregiving role. Long before family members became caregivers, they were wives and husbands, daughters and sons – relationships characterized by mutual caring and reciprocal exchanges of affection and assistance. As AD progresses, these qualities, central elements of primary relationships, become less mutual and more unilateral. Thus, caregiver and patient remain husband and wife or parent and child, as they were before, but the core elements of these relationships undergo a metamorphosis of role-related expectations, obligations, and norms as adult autonomy is replaced by patient dependency. Complex family relationships are reorganized, in essence, into a single dominant component, the unilateral provision of care. The sheer restructuring of an important and established relationship is by itself difficult and stressful, independently of the level of daily care needed by the relative. This restructuring, consequently, may leave one harboring [*sic*] feelings of being held captive by a relationship which resembles only superficially the relationship that once existed.” (Aneshensel *et al* 1993, p.55)

Some of the challenges faced by carers of older people with dementia are specific to the disease, but many overlap with caring for a relative with a functional mental illness, as can be seen in the similarities between the above account and the findings of the current study. Spruytte *et al* (2002) found that the relationships between informal carers and patients with dementia are more similar than they are different to those between informal carers and patients with functional mental health problems. Irrespective of the particular illness, these are family relationships facing changes and challenges.

Several carers in the current study expressed the feeling that caring defined their life. This represents an aspect of the challenges to identity faced by carers. Skaff and Pearlin (1992) named this concept 'role engulfment' and found that, as the carer felt their life was being taken over by caring, there was a converse effect upon the carer's identity, whereby they experienced a loss of self.

Another related aspect of identity challenge is the issue of choice in the caring situation. For many carers this was a point of tension. Aneshensel *et al* (1993) have written about the concept of 'role captivity,' whereby carers feel trapped in the caring role against their own will:

"With regard to caregiving, the demanding responsibilities associated with care matter, but less than the fact that these responsibilities are experienced as *obligatory* and *inescapable*, not as voluntary or optional." (Aneshensel *et al* 1993, p.56, emphases added)

According to Aneshensel *et al* (1993), role captivity can contribute to the loss of mastery – a sense of powerlessness and the unchangeability of the situation – thereby increasing stress and the likelihood of cessation of caring and patient institutionalization. Aneshensel *et al* (1993) found that the sense of role captivity was strongest in adult children caring for their parents, rather than spouses, as they were likely to have their own children and jobs in addition to caring.

The present study found that, rather than carers feeling completely captive to the role of caring, there is tension between choosing to care and not choosing to care. On the one hand, carers of older people with longstanding functional mental health problems who have received mental health service input want to be there for their

parent or spouse, but on the other hand they want to meet their own individual needs and those of their families.

Tensions are demonstrated in the competing demands that vie for priority. These tensions are widely found in caring relationships, and any attempt to explain the way carers deal with caring must take these tensions into account. *Making the best of it* explains that, although carers of older people with longstanding functional mental health problems who have received mental health service input continue by *keeping going*, many tensions remain unresolved.

The difficulty these tensions present to coping models concerns the way that coping models tend to emphasize the purpose of coping as the psychological well-being or equilibrium of the person in question. This, however, is an incomplete view. As demonstrated in *making the best of it*, people take into account not only their own psychological integrity, but also a myriad other considerations, including the well-being, happiness and safety of others: in this case, the patient, as well as other members of the carer's family and friends. Carers of older people with longstanding functional mental health problems who have received mental health service input deal with these competing demands constantly, and do not always choose the response that leads to their own happiness or well-being. In many cases, carers choose to prioritize others' needs above their own.

Aneshensel *et al* (1993) found that the decision for a patient to go into a nursing home resulted in benefits for the ex-carer, but deleterious effects for the patient, including shortened life expectancy. The tension created by the knowledge that what is good for one may not be good for the other, also adds to the challenges faced by carers in the day to day caring situation.

4.6 Obligation and Caring

"...behaviour that is in accordance with established norms needs no explaining."

(Qureshi and Walker 1989, p.132)

Carers' struggles with the choice to care, as discovered in the current study, can be understood with reference to the concept of obligation. Several authors have drawn attention to this issue, including Aneshensel *et al* (1993), who wrote that there is a "tension between what one *must* be and do and what one *wants* to be and

do” (p.56). Finch (1989), who pioneered work in family obligation, points out that obligation is to do with the distinction between what people ‘ought’ to do and what they actually do.

In the theory of *making the best of it*, family obligation can be related to the concepts of *accepting caring responsibilities* and *feeling personal responsibility for the well-being of the person they care for*. It also contributes to *identity adjustments* and *expectation adjustments*, as well as *keeping going*. Carers of older people with longstanding functional mental health problems who have received mental health service input often explain that they feel a sense of duty or obligation towards the person they care for. This may be expressed by a comment such as, “Of course I will look after her: she’s my wife.” In several interviews, carers struggled to relate to the word “carer” as they associated their contribution so strongly with their role as wife or husband. Where the most marked tensions were seen in this area were in adult children caring for their parents.

Children often feel a strong sense of obligation towards their parents, but they also have to balance this with competing demands. Skaff and Pearlin (1992) explain this as,

“...a conflict between what they should/would like to be doing with their life at this stage and the usurpation of those goals by caregiving responsibilities.” (p.662)

As a result of the fact that most people now have a family by procreation (spouse and children), as well as by orientation (parents and siblings), many carers encounter this conflict at some point (Finch 1989). An additional factor is the way that caring responsibilities often begin and develop gradually, with the realization of what caring really entails occurring some time later (Wenger 1984).

It is clear that many carers in the current study felt a strong sense of responsibility, and even duty, towards the person they cared for, whether they were their parent or spouse. Finch (1989) warns, however, that a person’s caring behaviour should not be assumed to originate from a sense of obligation, even if the carer themselves says that it does.

The concept of obligation is complicated, including legal and moral aspects. In 1948, the Poor Law was amended to relieve children of the legal obligation to provide for their parents, although a legal obligation remains between spouses.

Although children are no longer 'liable relatives' there remains a strong assumption that children will provide care for their parents. There is a popular belief that the parent-child relationship is the strongest kin relationship and there is an associated expectation that reciprocal care will be given if and when needed, within certain guidelines (Finch 1989).

Finch (1989) uses the concepts of 'normative guidelines' and 'negotiated commitments' to develop a theory of family obligation. Normative guidelines, or moral norms, are guidelines which indicate factors to be considered in the decision of whether to provide care; in working out 'the proper thing to do'. The five factors are, (1) how the person is related to the potential carer, where there is a tendency to favour the spouse and children, but there are no "clear-cut rules"; (2) how the potential carer gets on with the person; (3) the previous history of reciprocity, exchange and mutual aid in the relationship; (4) the effect providing care would have on the dependence and independence of the person receiving care; and (5) how caring would fit in with the "expectation of patterned change" in the relationship and life stages of the potential carer and receiver of care. Finch (1989) maintains that, additionally, the particular circumstances of each situation must be taken into account. In her model, normative guidelines are complemented by the concept of negotiated commitments and do not stand alone as the way in which obligation is defined.

Obligation is related to independence and interdependence. Wenger (1984) has defined interdependence as "a chain of dependence and reciprocities".

Independence is valued by many older people, and receiving care can upset the balance of reciprocity that is characteristic of family relationships. Finch (1989) has suggested that mutual interdependence and reciprocity act to preserve independence for both parties. Part of negotiating obligation involves consideration of the impact of caring on independence and reciprocity (Finch 1989). The concept of *mutual resourcing* in the theory of *making the best of it* is a form of mutual reciprocity, seen in many caring relationships, whereby each party offers their abilities to the relationship, in order to protect individual independence.

Qureshi and Walker's (1989) hierarchical decision model for predicting the level of obligation of a potential carer takes into account the relationship, type of

household, geographical proximity of the potential carer and the health of household members in forming a hierarchy of potential carers (p.126):

1. spouse;
2. relative in lifelong joint household;
3. daughter;
4. daughter-in-law;
5. son;
6. other relative;
7. non-relative.

A notable exception to the above model is that a spouse with ill-health may still be expected to care, as far as they are able (Qureshi & Walker 1989). Qureshi and Walker (1989) also propose that the “order of priority among normative obligation” in contemporary Western society is (p.137):

1. family of procreation (spouse, children);
2. family of orientation (parents, siblings);
3. affinal family (spouse’s family of orientation).

They maintain that, in order to provide care, ‘prior obligations’ in the order of priority must have been discharged (Qureshi & Walker 1989).

Finch’s (1989) concept of ‘negotiated commitments’ has two aspects: negotiation and public morality. Public morality, which is influenced by social policies, dictates acceptable behaviour. It leads families to behave accordingly, not wanting to be out of sync with normality and what they see others doing (Finch 1989). Qureshi and Walker (1989) write that “behaviour that is in accordance with established norms needs no explaining” (p.132). Therefore, when a carer says, “Of course I will look after her: she’s my wife,” they assume that the guiding principles that have led them to the conclusion that caring is the appropriate thing to do, are also shared and understood by the listener. The concept of obligation also helps understanding of the *guilt paradox in making the best of it*. Qureshi and Walker (1989) note that the internalization of normative beliefs regarding obligation may lead to feelings of guilt.

The negotiation element of the concept of 'negotiated commitments' refutes the notion that decisions of family obligation are made consciously and rationally through weighing up pros and cons, but instead uses the concepts of bargaining and negotiation. Bargaining results in a compromise or the subordination of one person's interests in favour of another's, as seen in the concepts of *prioritizing* and *sacrificing*. Negotiation is an implicit or explicit agreement that is reached over time about what one person will do for another (Finch 1989). Strauss describes negotiation as a way of 'getting things done' (Strauss 1978). Negotiation does not always lead to full resolution, or to all parties feeling comfortable with the result. Negotiations are affected by external influences and taken for granted beliefs, but may not be consciously processed (Finch 1989).

The concepts of obligation and negotiation fit well with the way that carers in the current study found it difficult to explain how they came to care, and whether it had been a choice or not. Most said that they had chosen to care, but had simultaneously not chosen to care. The way that carers end up in the caring situation may not be the result of a deliberate or conscious choice. For many it is a combination of a sense of obligation and circumstances. At a later stage in the caring relationship, carers realise where they are, and this could be seen as a 'turning point' (Strauss 1977), triggering an adjustment of self-concept, identity or expectations of their life.

4.7 Adjusting and Adapting

"...the developmental life cycle consists of a series of adjustments and adaptations."

(Wenger 1984, p.184)

The second dimension in the theory of *making the best of it* is the concept of *adjustment*. Adjustment has been examined in the context of coping models. It will now be discussed in light of the wider body of literature on adaptation and ageing.

Adjustment is associated with the concept of adaptation which is found in literature on caring as well as on ageing in general. Other authors have found that adaptation is central to the way people deal with getting older as well as with caring. For example, Qureshi and Walker (1989) write about "a process of mutual adaptation by carers and cared for to changes in the elderly person's circumstances and capabilities" (p.184). Wenger (1984) writes extensively in her book, *The Supportive*

Network, about the way that older people adapt creatively to the challenges and limitations they face. She argues that, far from the stereotype of older people being averse to change and unable to cope with it, they “make appropriate adaptations to deal with the problems of ageing flexibly and competently” (p.22).

Lascelles’ (1991) Dimensions of Adjustment model provides an outline of aspects to be considered when counselling a person dealing with loss. It provides a helpful outline of the types of loss that may be encountered and the ways that people can be encouraged to adjust in order to deal effectively with loss. Carers may experience loss on many levels, including loss of ability, changes in the person they care for, loss of intimacy, loss of identity, and loss of role. According to Lascelles’ (1991) model, adjustment is a necessary and healthy part of dealing with the losses that are encountered; losses that may be part of the natural progression of life, or may be due to an illness process or bereavement.

Lascelles (1991) outlines several dimensions of adjustment. These are intellectual, psychological, spiritual, physical, emotional, behavioural, social and practical. According to the Dimensions of Adjustment model, as adjustments are made in each area, people are facilitated in their discovery of a new role and a new purpose in life (Lascelles 1991). The dimensions of adjustment given in Lascelles’ model overlap with those outlined in the theory of *making the best of it*, where adjustments are conceptualized as relating to dependency, identity, expectation and illness. *Making the best of it* contributes a way of looking at the particular challenges faced by carers of older people with longstanding functional mental health problems who have received mental health service input, and the way in which they adjust to them.

Many carers are themselves elderly, and the challenges of caring can be seen in the wider context of their lives and experience of growing older. As Wenger (1984) argues, and as *making the best of it* demonstrates, many carers are able to, and do, adapt and adjust to the changes that occur in life in general, and as part of caring in particular.

4.8 Making the Best of it and Related Grounded Theories

Three extant grounded theories which can be related to *making the best of it* are Stabilising of Life (Jussila 2008), Doing Good Care (Sandgren *et al* 2008) and Helping Behaviour (Moran 2006). *Making the best of it* supports the theories of Stabilising of Life (Jussila 2008) and Doing Good Care (Sandgren *et al* 2008), and it challenges the theory of Helping Behaviour (Moran 2006).

In Stabilising of Life, Jussila (2008) provides a typology of the ways in which families deal with a diagnosis of cancer. She found that the core concept, 'stabilising of life', had the properties of 'facing of hardships' and 'assuming an attitude towards the future'. Four typologies were presented, depending upon,

“...whether facing of hardships and the associated feelings and actions are life-embracing, persistent and active or powerless, dejected and passive, and whether assuming an attitude towards the future and the feelings and actions related to it are positive, hopeful, meaningful, balanced and trusting or negative, hopeless, anxious, fearful and doubtful.” (Jussila 2008, pp. 30-31)

The four typologies are: 'detaching from the disease', 'fighting against the disease', 'adjusting to life with the disease' and 'submitting to the disease'.

Making the best of it does not provide a typology of ways in which carers deal with caring, but many of the properties of these typologies are similar to categories in *making the best of it*. For example, 'detaching from the disease' includes the categories of 'maintaining hope' and 'changes in self concept'. 'Fighting against the disease' involves 'overcoming adversities'; 'adjusting to life with the disease' involves 'resorting to help' from friends, family or professionals; and 'submitting to the disease' includes the concept of 'life turning more difficult'. Each of these can be seen in the theory of *making the best of it*, which provides a dimensional analysis of the way carers of older people with longstanding functional mental health problems who have received mental health service input deal with caring. It is significant, therefore, that many of the issues and behaviours seen in family carers of older people with mental health problems can also be seen in the families of people facing a diagnosis of cancer. Although the diseases are different, some of their effects on the family overlap and may be dealt with in similar ways.

Jussila (2008) highlights connections between her theory and McCubbin and McCubbin's (1993) Resiliency Model of Family Stress, Adjustment and Adaptation. This model also bears similarities to *making the best of it*, particularly in relation to stress and coping models. In their work, McCubbin and McCubbin (1993) reported the discrepancy between the severity of stressors and the level of stress experienced by families in stressful or crisis situations. The Resiliency Model proposes that families differ in their ability to adapt to stressors or crises. Their capability to adapt is determined by their resources which include social support, and their cognitive and behavioural coping responses. Changes or adaptations are made in order to balance resources and the demands placed upon them by stress or crisis. This is in agreement with *making the best of it*, in which carers use the internal and external resources of psychological strength and abilities, as well as money and formal and informal sources of support, in order to make the adjustments needed to *make the best of* their changing circumstances. *Making the best of it* extends the Resiliency Model by emphasizing the motivating force of *aspirational optimization*, or wanting the best for the person cared for.

A grounded theory which also recognizes the significance of the desire to do the best is Doing Good Care (Sandgren *et al* 2008). This theory explores how nurses caring for patients with cancer in the community continually resolved their main concern of 'doing good care'. The most common typology, or way of dealing with the main concern, was 'momentary caring'. The optimal typology was 'anticipatory caring', and in some cases 'stagnated caring' was used. The three ways of providing care may be used at different times by the same person, but all are motivated by the desire to 'do good care'. In 'anticipatory caring', this is a nurse's desire to do their best and even better. In 'momentary caring', it is a desire to do their best at that particular moment, and in 'stagnated caring', nurses do what is expected.

Although the theory of Doing Good Care is based on the study of nurses, rather than family carers who may have a more intimate relationship with the person they care for, *making the best of it* shows that nurses and family carers face many of the same challenges and deal with them in similar ways. Some authors have noted an overlap between formal and informal care, and the way in which formal care can become more like informal care over time, as relationship develops between the people involved (Qureshi & Walker 1989). The attitude of nurses towards their

patients bears similarities to the way carers feel towards the people they care for, including a sense of obligation. Carers and nurses face many of the same tensions and challenges:

“The nurses thus feel a responsibility towards the patients and their relatives. When nurses sense that they fail in doing good, they also feel that they are letting the patient down, which may lead to frustration and powerlessness. A failure in doing good can come from not having the right resources, either internal or external...When nurses cannot do what is best for the patient, this may also lead to ethical stress, for example knowing what to do, but not being able to do it is distressing and leads to feelings of guilt.” (Sandgren *et al* 2008, p.22)

‘Anticipatory caring’ is characterized by ‘forseeing trajectories’, ‘building trust’, ‘collaborating’ with others and ‘prioritizing’ time and resources. In ‘momentary caring’, limited resources and time mean that nurses cannot provide anticipatory care, although they may want to. Instead, they deal with challenges as they come. If there is a lack of recognition or resources in ‘momentary caring’, nurses may stagnate or burnout, and begin to provide ‘stagnated caring’, where they ‘avoid changes’ and ‘resign’ themselves or give up (Sandgren *et al* 2008).

Making the best of it echoes aspects of ‘momentary caring’, whereby carers of older people with longstanding functional mental health problems who have received mental health service input live day to day, dealing with changes as they come. However, many carers do incorporate elements of ‘anticipatory caring’, such as ‘prioritizing’ and ‘collaborating’ or drawing on external sources of support. It is important, therefore, that carers are provided with adequate resources and recognition in order to promote ‘anticipatory caring’ and prevent ‘stagnated caring’.

Moran’s (2006) grounded theory of Helping Behaviour conceptualizes helping behaviour as preceded by a decision making process consisting of three stages: ‘rational-emotive beliefs’, ‘relational-emotive ties’ and ‘rational-pragmatic deliberations’. In the theory, which examines the helping behaviour of a religious order and other members of the community towards marginalized young people at risk in the Philippines,

“Helping was perceived as a means to...free them from debilitating circumstances, to improve their coping skills in handling debilitating situations, and to improve the quality of life of the one who needs help.” (Moran 2006, p.106)

'Rational-emotive beliefs' are philosophical, moral, political or religious beliefs about what one should do in a given situation, combined with knowledge of the specific situation of the person needing help. The potential helper's knowledge of the person's problem, "energizes, gives focus and sustains a desire to help the target" (Moran 2006, p.107). This bears similarities to the concepts of *aspirational optimization* and *accepting caring responsibilities*.

'Relational-emotive ties' refers to the nature of the relationship between the potential helper and the person needing help. In the theory of Helping Behaviour, closeness of relationship is associated with a heightened sensitivity to the person's needs. In the theory, 'rational-emotive beliefs' and 'relational-emotive ties' are evaluated in relation to several 'rational-pragmatic deliberations' in order to inform the decision to provide help or not. These deliberations include the 'appropriateness' of helping the person in need, the cost-benefit ratio of helping, the capability to provide help and the logistics of helping. The decision reached may be re-evaluated in the future (Moran 2006).

Moran's (2006) theory conceptualizes the decision to provide help as conscious, rational and deliberate. In this respect, *making the best of it* challenges Helping Behaviour. *Making the best of it* acknowledges that carers of older people with longstanding functional mental health problems who have received mental health service input often feel a sense of responsibility towards their relatives and want the best for them. However, it does not present a process by which a decision to care is reached, recognizing that such a decision, if indeed it is a decision, is complex and not always reached entirely by rational deliberation. Circumstances and expectations, as well as thought processes, contribute to the eventual caring situation. It is unclear whether, or to what degree, differences in cultural values contribute to the variations between the theories.

Making the best of it emphasizes a constant state of *adjustment*, made within a relationship, with the aim of *keeping going*, rather than an isolated logical decision which governs behaviour with the potential for periodic re-evaluation.

4.9 Summary

Making the best of it refutes the notion of carer burden as a sufficient explanation of caring. Carers of older people with longstanding functional mental health problems who have received mental health service input face many challenges in their roles, but these are by no means unmitigated or simply accepted as they come. Carers adjust and face changes through *making the best of it*, often gaining pride and satisfaction from the caring experience. The need to examine each situation individually is emphasized, rather than applying general formulae to the caring condition in an attempt to predict carer experience or perception.

The literature on coping and stress helps in understanding *making the best of it* as a series of responses to the changing situations and tensions associated with caring. *Adjustments* are tailored to the particular changes faced, and are facilitated by drawing on internal and external resources. *Keeping going* is another type of coping response.

The concepts of adjustment and adaptation have been proposed as central to coping with growing older. *Making the best of it* demonstrates how the concept of *adjustment* can be applied to the particular situation of caring for an older person with mental health problems.

Caring can pose challenges to identity in many ways, through changing roles and changing relationships. It also affects the sense of control carers of older people with longstanding functional mental health problems who have received mental health service input have over their own lives. Although carers make *identity adjustments*, tensions often remain between the desire to provide care and the feeling that caring is defining their lives. *Making the best of it* challenges the principle that coping responses aim to maintain the psychological integrity of the carer above all else. In fact, carers often act in ways that favour the person they care for. This can be explained in part by the concept of obligation.

Obligation encompasses many of the factors that carers of older people with longstanding functional mental health problems who have received mental health service input face in contemplating the decisions to commence and continue caring. These include societal expectations and kin relationships, as well as personal feelings towards the patient. The complexity of influencing factors means that the

decision to care is not always a decision that is fully rationalized or weighed up, if indeed it is a decision. As Finch (1989) writes, questions of obligation,

“...go to the heart of certain central questions which social theorists have tried to resolve, about how far human beings can be seen as taking autonomous, independent actions and how far we are constrained by social forces.” (p.144)

4.10 Weaknesses and Limitations

Classic grounded theory is designed to be used as a complete methodological package of data collection, analysis and theoretical writing (Glaser & Holton 2004). Many of the limitations in the use of the methodology were due to the constraints of time, which, in this study, was less than seven months between the commencement of data collection and thesis submission. The limitations concern theoretical sampling, theoretical saturation, pacing, and the tape recording of interviews.

The pacing of the study (Glaser 1978) was affected as there was a pressure of time to finish and write up the theory. Therefore, the analysis was more selective than would have been preferred; some categories were not able to be fully saturated, and the available time for preconscious processing was limited. There was, therefore, limited opportunity to continue theoretical sampling, which led to some codes not being fully saturated. Potential avenues for theoretical sampling are outlined in the section on implications for further research.

Restrictions of time also meant that the analysis relied entirely on interview data. It would have been preferable to combine this with observational data, as well as a thorough integrative analysis of extant theories related to the theory, which would have served to enhance theoretical saturation. If more time was available, it is anticipated that the theory would be richer and more integrated.

Tape recording is not recommended in classic grounded theory studies, as Glaser and Holton (2004) write that it affects the data collected. In this study, a tape recorder was used, as at the time of the initial ethics application the author was unaware of the strength of the disinclination towards tape recorder use in classic grounded theory. The effect of tape recording was highlighted in one particular interview, where a carer was extremely guarded in answering questions when the tape recorder was turned on. After several attempts to elicit a response, the researcher decided to abort the interview and turned the tape recorder off, at

which point the carer spontaneously spoke freely and candidly about his experiences of caring. Although this was an extreme example, and other carers did not have such a marked response to the tape recording of their interviews, it is likely that tape recording affected some or all of the interviews in some way. However, as 'all is data' in grounded theory (Glaser 1978), it is held that the analysis and emergent theory represents the main concern and its processing for the participants interviewed.

Another limitation is the cross-sectional nature of the data. It would have been useful to have interviewed carers on more than one occasion in order to build a fuller picture of their experiences over time. However, the participants interviewed did represent carers at various stages, including those who had been caring for many years and those for whom caring began very recently.

4.11 Implications for Future Research

At present, the emerging theory of *making the best of it* applies to carers of older people with functional mental health problems. The extent to which it can be applied to other caring situations is not known. It would be necessary to use theoretical sampling to see how the theory applies to other carers and other challenging situations. Glaser (1998) calls the areas for theoretical sampling that are beyond the scope of the resources of a grounded theory study, the 'come backs' and the 'left outs' and they, along with the implications of the theory, indicate the direction for future work.

Further theoretical sampling could be used to explore whether *making the best of it* is a process. The emergent data suggests that it may be, but without further theoretical sampling, it is not possible to know this. Another potential avenue is whether there is a typology of caring, explaining how different carers deal with the caring situation. This is something that began to emerge, but it was not possible to sample for fully, or therefore integrate into the theory. Theoretical sampling would also facilitate exploration of the differences between carers who look after their spouses and those who look after their parents. Differences did emerge, but again, they were not able to be fully investigated due to the constraints of time. It would be interesting to speak to former carers of people who have entered care homes or alternative accommodation, to find out how the caring situation came to change.

This would better inform research on how caring can break down, and how this can be avoided.

Making the best of it is a dimensional theory that includes the concept of *adjustment*. However, it does not detail exactly how adjustments take place. Is there a process, and does that process differ according to the type of adjustment? Are there other factors that affect adjustment and how adjustment can be maximized? Are there types of adjustment that are good and those that are bad? Further research is also needed into exactly what internal and external resources are most useful in facilitating adjustment, and how they can best be provided or enhanced.

The theory could also be broadened through further research to incorporate carers of older people with dementia or physical health problems, carers of younger people, formal carers such as nursing staff, families dealing with difficult situations and people facing getting older. This could contribute to the development of formal theories of Caring and Ageing.

4.12 Implications for Clinical Practice

It has been shown that objective external assessment of caring bears limited resemblance to carer perception (Hoenig & Hamilton 1966, Thompson & Doll 1982, McCubbin & McCubbin 1993). *Making the best of it* looks at the carer's perspective, in order to help in gauging need and designing services.

Carers are integral members of the health care team. Their contribution, though invaluable, is often neglected or taken for granted. *Making the best of it* demonstrates the need in clinical practice to treat carers of older people with longstanding functional mental health problems who have received mental health service input as partners in care, and not to ignore them or overload them with responsibility. Carers need to be included in designing care packages for the person they care for, as well as to be asked how they are managing and what assistance they feel they need. This could be done through regular home visits, with a focus not just on the symptomatology of the patient, but also on the wider circumstances at home, including the well-being of the carer and the carer-patient relationship. Qureshi and Walker (1989) promote the concept of shared care, in

order to reduce dependency on residential care and to share responsibility for care between the family and wider society.

Making the best of it emphasizes the need for resources in order for carers to make the adjustments that are necessary in caring. The resources needed include knowledge about the condition that the person they care for has. In order to be fully valued and effective as a member of the caring team, knowledge about symptoms, illness trajectory, treatment and possible difficulties is necessary. Along with this, carers need to be informed of good techniques to use in dealing with their loved one's symptoms and behaviour, as well as to be given advice about what other carers experience in similar situations. Hand-in-hand with this is the need for sources of support to be available for timely and accurate advice, emotional support or practical help, as and when needed. It should be remembered that carers usually turn to family and friends first in times of difficulty. Such services would, therefore, complement the help that carers receive from their own informal support systems, and would ensure assistance for those who do not have any family or friends nearby.

Other forms of support or external resources include help for carers with carrying out activities of daily living for the person they care for. Carers often have responsibility for personal care, as well as a large proportion of other jobs around the house, including cleaning, gardening and decorating. Support in the performance of these tasks would help to alleviate some of the stresses that carers face in trying to balance spending time with the person they care for, getting things done around the house, and having time for themselves. It should not be forgotten that older people with mental health problems, and their often elderly carers, frequently have physical health problems which add to the challenges and limitations they face.

Support provided by health and social care teams should be delivered with the assumption that teams will try to support caring within the home as long as the carer wants to continue caring, and undue pressure should not be applied to encourage institutionalization if the carer could continue caring with additional support and would like to do so. Many carers of older people with longstanding functional mental health problems who have received mental health service input wish to continue caring, and they are capable and adaptable in the face of change.

They often want to maintain independence, but may need help in the areas where they lack resources, knowledge or ability. Such assistance must be provided sensitively in order to promote independence. Such help should be flexible, timely, affordable and tailored to the particular needs of the carer.

Caring and mental illness can produce complex situations in which difficult decisions have to be made. Such situations and decisions, although having common elements, are unique to each family. Health and social care services should provide families with what they need in order to make the right decisions for themselves, including prompt access to support and resources as they are needed, to allow caring to continue at home if it is possible and it is what the carer and patient want.

It is recognized that such recommendations require extra funding as well as development of services already in place. It is hoped that the recently proposed changes to the funding of care in later life will enable some of these recommendations to be met.

4.13 Strengths and Contribution to Knowledge

Making the best of it is a theory that is grounded in data and is therefore relevant, works, fits and is modifiable. The theory provides understanding of the situation from the participants' perspective, and the resulting theory serves to explain, predict and interpret what is happening in the lives of the carers interviewed (Glaser 1978).

“The interrelated jobs of theory in sociology are:

- (1) to enable prediction and explanation of behavior [*sic*];
- (2) to be useful in theoretical advance in sociology;
- (3) to be usable in practical applications – prediction and explanation should be able to give the practitioner understanding and some control of situations;
- (4) to provide a perspective on behavior [*sic*] – a stance to be taken toward data; and
- (5) to guide and provide a style for research on particular areas of behavior [*sic*].”

(Glaser & Strauss 1967, p.3)

In this respect, *making the best of it* is a relevant, useful theory that can be used to inform future research on caring, mental health problems and families, as well as to

inform future policy and service development in health care and its interaction with informal caring.

Its usefulness is also found in the way that it fits well with previous research on the topic of caring, both in the grounded theory literature and elsewhere. It helps to complement the body of literature on the way that carers deal with caring, and in that sense strengthens the case for carer-focused research and intervention, as well as supplementing the findings of previous work.

The study began with the aim of talking to carers of older people who were acutely mentally ill. Due to recruitment difficulties, including the challenges posed by attempting to interview carers experiencing acute crises, participants included those caring for people who were chronically, as well as those who were acutely, unwell. This could be seen as a limitation as the emphasis was shifted from acute care to more general issues around care. However, this allowed a broader picture of the issues faced by carers of older people with functional mental health problems, within which acute phase caring is one element. It is important not to assume that coping with psychiatric symptoms is the most significant challenge for carers. In fact, this emerged as just one of a number of concerns and tensions faced by carers in the wider context of their lives together with the person they care for.

This study's unique contribution to knowledge is a theory that explains, predicts and interprets how carers of older people with longstanding functional mental health problems who have received mental health service input attempt to resolve the tensions that they face as part of caring, through *making the best of it*. Carers deal with these tensions through *aspirational optimization, adjustments* and *keeping going*. Many carers continue to live with unresolved tensions, and may not be completely satisfied with their situation. However, they keep going despite the fluctuating demands placed upon them, while carrying out corresponding adjustments, which are resourced internally and externally.

Making the best of it provides a 'bigger picture' of the way carers of older people with longstanding functional mental health problems who have received mental health service input live, not just looking at coping responses, but also at motivations and challenges. Issues of family obligation and responsibility are woven into the theory along with tensions around identity, roles, expectations, and

day to day behaviour. Much of caring takes place on a day to day basis, plodding along, struggling on, without attention grabbing crises. This theory shows how carers manage the difficulties and the rewards that come along with caring on a daily basis in the decisions, sacrifices and prioritizations that are necessary.

The theory of *making the best of it* allows a glimpse into the world of carers of older people with longstanding functional mental health problems who have received mental health service input, deeper than the view that many health professionals see in their brief encounters. In this way it is useful for those who work in health care, to foster understanding of the challenges this subset of carers face, how they face them, and how they can be helped in facing them.

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APPENDICES

Appendix One:

Letters of Ethical and Research & Development Approval



National Research Ethics Service

Sefton Research Ethics Committee

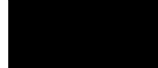
Victoria Building
Bishops Goss Complex
Rose Place
Liverpool
L3 3AN

Telephone: 0151 330 2051

Facsimile: 0151 330 2075

30 January 2009

Lydia Dodd



Dear Lydia Dodd

Full title of study: Who Cares? The experiences of carers of older people with mental health difficulties; a qualitative study.
REC reference number: 08/H1001/174

Thank you for your letter of 16 January 2009, 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 Vice-Chair.

Confirmation of ethical opinion

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

Ethical review of research sites

The Committee has designated this study as exempt from site-specific assessment (SSA). The favourable opinion for the study applies to all sites involved in the research. There is no requirement for other Local Research Ethics Committees to be informed or SSA to be carried out at each site.

Conditions of the favourable opinion

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

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

Management permission at NHS sites ("R&D approval") should be obtained from the relevant care organisation(s) in accordance with NHS research governance arrangements. Guidance on applying for NHS permission is available in the Integrated Research Application System or at <http://www.rforum.nhs.uk>.

This Research Ethics Committee is an advisory committee to North West Strategic Health Authority

The National Research Ethics Service (NRES) represents the NRES Directorate within the National Patient Safety Agency and Research Ethics Committees in England

Approved documents

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

<i>Document</i>	<i>Version</i>	<i>Date</i>
CV - Miss Dodd		
Peer Review		
Letter from Sponsor		15 October 2008
Covering Letter		31 October 2008
Investigator CV		
Application		
Home Visit Protocol	1.5	10 December 2008
Response to Request for Further Information		16 January 2009
Participant Consent Form: person being cared for.	1.5	10 December 2008
Participant Consent Form: Carer	1.5	10 December 2008
Participant Information Sheet: Person being cared for.	1.5	10 December 2008
Participant Information Sheet: Carer	1.5	10 December 2008
Interview Schedules/Topic Guides	1.5	10 December 2008
Letter from Sponsor		16 January 2009
Protocol	1.5	10 December 2008

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Now that you have completed the application process please visit the National Research Ethics Website > After Review

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.

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
- Progress and safety reports
- Notifying the end of the study

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

We would also like to inform you that we consult regularly with stakeholders to improve our service. If you would like to join our Reference Group please email referencegroup@nres.npsa.nhs.uk.

08/H1001/174

Please quote this number on all correspondence

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

Yours sincerely



PP
Mr Mike Williamson
Sefton REC Vice Chair

Email: kayleigh.roberts@liverpoolpct.nhs.uk

Enclosures: "After ethical review – guidance for researchers"

Copy to: *University of Liverpool*
Professor K M Wilson, University of Liverpool; Cheshire and Wirral
Partnership NHS Trust
[R&D office for NHS care organisation at lead site]



**Submission Point for Electronic
Approval of Research**

Academic Unit
St Catherine's Hospital
Church Road
Birkenhead
Wirral
CH42 0LQ
Tel: 0151 604 7333
Fax: 0151 653 3441

3rd February 2009

Lydia Dodd
Academic Unit/University of Liverpool
St Catherine's Hospital
Church Road
Birkenhead
Wirral
CH42 0LQ

Dear Lydia,

Re: Research Governance Decision Letter

Unique SPEAR Identifier: 0802

Project Title: Who Cares? The experiences of carers of older people with mental health difficulties; a qualitative study

Further to your request for research governance approval, we are pleased to inform you that this Trust has approved the study.

Trust R&D approval covers all locations within the Trust; however, you should ensure you have liaised with and obtained the agreement of individual service/ward managers before commencing your research.

Please take the time to read the attached 'Information for Researchers – Conditions of Research Governance Approval' leaflet, which give the conditions that apply when research governance approval has been granted. Please contact the R&D Office should you require any further information. You may need this letter as proof of your approval.

May I wish you every success with your research.

Yours sincerely

Helen Newell
Research and Effectiveness Officer

cc : Research Governance Sponsor
Employing Organisation

Enc: Approval Conditions Leaflet
Induction & ID Badge Information, TrustTECH Leaflet

Appendix Two A: Participant Information Sheet for Carers

(To be on headed paper)

Information about the research (Carer)

The experiences of carers of older people with mental health difficulties

We would like to invite you to take part in our research study. Before you decide you need to understand why the research is being done and what it would involve for you so please take time to read the following information. Talk to others about the study if you wish.

Part 1 tells you the purpose of this study and what would be involved with taking part. Part 2 gives you more detailed information about the study. Ask us if there is anything that is not clear. Take time to decide whether or not you wish to take part.

Part 1

What is the purpose of the study?

We want to find out about the experiences of carers of older people with mental health difficulties. This is to help the staff at the Crisis Home Treatment Team to design their services in a way that best helps carers and service users.

Why have I been invited?

You have been invited to take part because a person you care for has been referred to the Community Mental Health Team. The staff of the Community Mental Health Team have been asked to let you know about this study so that you can decide whether you would like to take part.

Do I have to take part?

It is up to you to decide whether you would like to take part in the study. If you would like to find out more about the study, please fill in the form at the end of this information sheet. We will then contact you on the number you provide in order to answer any questions you may have and to see if you are interested in taking part. If you would like to take part, we will then arrange

a convenient time for our researcher to visit you in your home. When we visit, we will describe the study and go through this information sheet. This should take about 10 minutes. If you decide you would like to take part, we will then ask you to sign a consent form. You are free to withdraw at any time, without giving a reason. This will not affect the standard of care you or the person you care for receive.

You will be given a copy of this information sheet and a signed consent form to keep.

What will happen to me if I take part?

If you decide to take part, our researcher will visit you to ask you some questions about your experiences of caring, and give you time to speak freely. The interview will last about one hour, but not more than ninety minutes. The conversation will be recorded on an audiotape. The tapes from the conversation will only be listened to by the researcher and no one else. Everything you say will be treated confidentially. If you want to stop the interview at any point, you may do so.

What are the possible disadvantages and risks of taking part?

The interview will take up to one-and-a-half hours of your time. If during the course of the interview you become upset or would like to take a break from the interview, we will stop the interview. Should you wish to continue either later or on another occasion this will be discussed and arranged.

What are the possible benefits of taking part?

We cannot promise the study will help you but the information you provide will be used to improve health care services for carers in the future. Many people find that it is helpful to talk about their experiences.

What if there is a problem?

Any complaint about the way you have been dealt with during the study will be addressed. The detailed information on this is given in Part 2.

Will my taking part in the study be kept confidential?

Yes. We will follow ethical and legal practice and all information about you will be handled in confidence. The details are included in Part 2.

If the information in Part 1 has interested you and you are considering participation, please read the additional information in Part 2 before making any decision.

Part 2

What will happen if I don't want to carry on with the study?

You can withdraw from the study at any time. Any information we have collected from you will be destroyed.

What if there is a problem?

If you have a concern about any aspect of this study, you should ask to speak to the researcher, Lydia Dodd, who will do her best to answer your questions, on (0151) 604 7333. If you remain unhappy and wish to complain formally, you can contact the Chief Investigator, Professor Ken Wilson on (0151) 604 7333.

In the event that something does go wrong and you are harmed during the research and this is due to someone's negligence then you may have grounds for a legal action for compensation against the University of Liverpool but you may have to pay your legal costs. The normal National Health Service complaints mechanisms will still be available to you.

Will my taking part in this study be kept confidential?

The audiotapes will be kept securely stored at all times and all the information collected during this study will be kept strictly confidential. This means that only the researcher will listen to the tapes. After the tapes have been listened to, they will be stored securely on University of Liverpool premises. You will not be named or identified in any reports of the study. We may include brief written quotations from interviews in future publications but we will always change details so that nobody can be identified. The information will be kept securely for 15 years in accordance with University of Liverpool guidelines.

If you say something that the researcher believes they need to pass on to someone else, for the sake of your safety or that of anyone else, the researcher will always tell you before they speak to anyone else.

What will happen to the results of the research study?

The information from the interviews will be used to write a report to the Cheshire and Wirral Partnership NHS Foundation Trust about the experiences of carers. It may also be used for publication in an academic journal. We will always change details so that you cannot be identified.

Who is organising and funding the research?

The sponsor of this study is the University of Liverpool. The research is being carried out by the researcher as work towards the qualification of MPhil.

Who has reviewed the study?

All research in the NHS is looked at by an independent group of people, called a Research Ethics Committee to protect your safety, rights, wellbeing and dignity. This study has been reviewed and given favourable opinion by Sefton Research Ethics Committee.

Further information and contact details:

For further information please contact the researcher, Lydia Dodd:
Tel: (0151) 604 7333 Email: L.M.Dodd@liv.ac.uk

If you are happy for the researcher to contact you by telephone to answer any questions you may have and/or to arrange a convenient time to visit you in your home, please fill in your details below, cut off the slip and post to the address below or give to the staff at the Community Mental Health Team. Please be assured that your details will be treated in the strictest confidence.

Thank you for your time.

Name _____

Address _____

Postcode _____

Telephone number (including area code) _____

I agree to be contacted by the researcher (Lydia Dodd) at the telephone number above:

Signed _____

Date _____

Please post to: Lydia Dodd, Academic Unit, St Catherine’s Hospital,
Derby Road, Birkenhead, Wirral, CH42 0LQ.

Appendix Two B: Participant Information Sheet for Clients

(To be on headed paper)

Information about the research (Client)

The experiences of carers of older people with mental health difficulties

We would like to invite your carer to take part in our research study. Before you decide you need to understand why the research is being done and what it would involve for you so please take time to read the following information. Talk to others about the study if you wish.

Part 1 tells you the purpose of this study and what would be involved with taking part. Part 2 gives you more detailed information about the study. Ask us if there is anything that is not clear. Take time to decide whether or not you are happy for your carer to take part.

Part 1

What is the purpose of the study?

We want to find out about the experiences of carers of older people with mental health difficulties. This is to help the staff at the Crisis Home Treatment Team to design their services in a way that best helps carers and service users.

Why have I been invited?

The person who cares for you has been invited to take part because you have been referred to the Crisis Home Treatment Team. The staff at the Crisis Home Treatment Team have been asked to let you know about this study so that you can decide whether you would be happy for your carer to take part.

Do I have to take part?

It is up to your carer to decide whether they would like to take part in the study, but we also want to know that you are happy for them to take part. Your carer has been given a sheet like this one. If they would like to find out more about the study, they can fill in the form at the end of their information sheet. We will then contact them on the number they provide in order to

answer any questions you or they may have and to see if they are interested in taking part. If your carer would like to take part, and you are happy with this, we will then arrange a convenient time for our researcher to visit you in your home. When we visit, we will describe the study and go through this information sheet. This should take about 10 minutes. If you decide you would be happy for your carer to take part, we will then ask you to sign a consent form. You are free to withdraw at any time, without giving a reason. This will not affect the standard of care you or your carer receive. You will be given a copy of this information sheet and a signed consent form to keep.

What will happen to me if I take part?

If your carer decides to take part and you agree to this, our researcher will visit your carer to ask them some questions about their experiences of caring, and give them time to speak freely. We will not be talking directly about you, but about your carer's experience of caring. It is not necessary for you to be present when the interview takes place, but you are welcome to be there if you wish. The interview will last about one hour, but not more than ninety minutes. The conversation will be recorded on an audiotape. The tapes from the conversation will only be listened to by the researcher and no one else. Everything they say will be treated confidentially. If they want to stop the interview at any point, they may do so.

What are the possible disadvantages and risks of taking part?

The interview will take up to one-and-a-half hours of your carer's time. If during the course of the interview your carer would like to take a break from the interview, we will stop the interview. Should they wish to continue either later or on another occasion this will be discussed and arranged.

What are the possible benefits of taking part?

We cannot promise the study will help you but the information your carer provides will be used to improve health care services for patients and carers in the future. Many people find that it is helpful to talk about their experiences.

What if there is a problem?

Any complaint about the way you have been dealt with during the study will be addressed. The detailed information on this is given in Part 2.

Will my taking part in the study be kept confidential?

Yes. We will follow ethical and legal practice and all information about you will be handled in confidence. The details are included in Part 2.

If the information in Part 1 has interested you and you are considering participation, please read the additional information in Part 2 before making any decision.

Part 2

What will happen if I don't want to carry on with the study?

You can withdraw from the study at any time. Any information we have collected from you will be destroyed.

What if there is a problem?

If you have a concern about any aspect of this study, you should ask to speak to the researcher, Lydia Dodd, who will do her best to answer your questions, on (0151) 604 7333. If you remain unhappy and wish to complain formally, you can contact the Chief Investigator, Professor Ken Wilson on (0151) 604 7333.

In the event that something does go wrong and you are harmed during the research and this is due to someone's negligence then you may have grounds for a legal action for compensation against the University of Liverpool but you may have to pay your legal costs. The normal National Health Service complaints mechanisms will still be available to you.

Will my taking part in this study be kept confidential?

The audiotapes will be kept securely stored at all times and all the information collected during this study will be kept strictly confidential. This means that only the researcher will listen to the tapes. After the tapes have been listened to, they will be stored securely on University of Liverpool premises. You will not be named or identified in any reports of the study. We may include brief written quotations from interviews in future publications but we will always change details so that nobody can be identified. The information will be kept securely for 15 years in accordance with University of Liverpool guidelines.

If your carer says something that the researcher believes they need to pass on to someone else, for the sake of your carer's safety or that of anyone else, the researcher will always tell your carer before they speak to anyone else.

What will happen to the results of the research study?

The information from the interviews will be used to write a report to the Cheshire and Wirral Partnership NHS Foundation Trust about the experiences of carers. It may also be used for publication in an academic journal. We will always change details so that you and your carer cannot be identified.

Who is organising and funding the research?

The sponsor of this study is the University of Liverpool. The research is being carried out by the researcher as work towards the qualification of MPhil.

Who has reviewed the study?

All research in the NHS is looked at by an independent group of people, called a Research Ethics Committee to protect your safety, rights, wellbeing and dignity. This study has been reviewed and given favourable opinion by Sefton Research Ethics Committee.

Further information and contact details:

For further information please contact the researcher, Lydia Dodd:

Tel: (0151) 604 7333

Email: L.M.Dodd@liv.ac.uk

Thank you for your time.

Appendix Three A: Consent Form for Carers

(To be on headed paper)

CONSENT FORM (Carer)

Title of Project: The experiences of carers of older people with mental health difficulties

Name of Researcher: Lydia Dodd

Please initial box

1. I confirm that I have read and understand the information sheet dated 10 December 2008 (Version 1.5) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.
2. I consent to the audio-taping of my interview and the possible use of quotations from my interview.
3. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected.
4. I understand that, under the Data Protection Act, I can at any time ask for access to the information I provide and I can also request the destruction of that information if I wish.
5. I agree to take part in the above study.

Name of Participant

Date

Signature

Name of Researcher

Date

Signature

When completed, 1 for patient; 1 for researcher site file

Appendix Three B: Consent Form for Clients

(To be on headed paper)

CONSENT FORM (Client)

Title of Project: The experiences of carers of older people with mental health difficulties

Name of Researcher: Lydia Dodd

Please initial box

1. I confirm that I have read and understand the information sheet dated 10 December 2008 (Version 1.5) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.
2. I consent to the audio-taping of the interview with my carer and the possible use of quotations from my interview.
3. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected.
4. I understand that, under the Data Protection Act, I can at any time ask for access to the information I provide and I can also request the destruction of that information if I wish.
5. I agree to my carer taking part in the above study.

Name of Participant

Date

Signature

Name of Researcher

Date

Signature

When completed, 1 for patient; 1 for researcher site file

Appendix Four: Example of a Field Note and Coding

FIELD NOTE A

Patient ■ yrs, male, diagnosis Bipolar

Carer ■ yrs, female, wife

	<i>Date: 22/04/09</i>
<p>I visited Mr and Mrs A in their home.</p> <p>Mrs A cares for her husband who has bipolar disorder, as well as him caring for her as she has physical ailments, especially with her knees and shoulders.</p> <p>Mrs A has also cared for her own daughter who has learning difficulties. She cared for her mother as well when she was alive.</p> <p>She said it is difficult caring for her husband as he is an adult and used to be so capable. She reported a reversal of roles and stated that, since his hospitalization 3 years ago, she has had to become the 'strong one'. Even though she is weaker physically and her husband has taken on more physical jobs in the house due to problems with her knees and shoulder, e.g. hoovering and cleaning. She maintains the cooking and they shop together. Mrs A said that they need each other and she wants to stay well for him. She feels frustrated that she cannot do more around the house.</p> <p>Financial/paperwork is done with the help of their children. Their daughter with learning difficulties lived with them until a few years ago when she moved into a residential home (before Mr A was diagnosed with bipolar).</p> <p>When Mrs A was in hospital for an operation, their son came to stay with Mr A.</p> <p>Mr and Mrs A found it difficult when their daughter was living with them, as she demanded all of Mrs A's attention. Mr A, particularly, found this a strain, and has a difficult relationship with his daughter still. Mrs A takes responsibility for looking after her when she visits and visiting her in the home.</p> <p>Mrs A reported that she often feels depressed herself and has taken medication for this, since her husband has been ill. She particularly found the time when he was in hospital difficult, as she was visiting him every day, as well as needing to take care of</p>	<p>EXAMPLE CODING</p> <p>Caring reciprocation</p> <p>Caring recurrence</p> <p>Reversing roles</p> <p>Becoming the 'strong one' (what does this involve?) Weaker physically</p>

things at home and see her disabled daughter. She stated the support she received from friends at church as very helpful, giving her lifts if needed, taking her out and making them both feel wanted. They are both heavily involved in the local Catholic church, and attend daily mass every morning. They also carry out prayers together at home, and report that this is a great help to them spiritually.

She reported that his memory problems are the most difficult to deal with. This means that he is unable to take care of the financial aspects of home life without help, but she has always left him to do this in the past.

Mrs A said that she finds it impossible to plan ahead, mainly due to the number of medical appointments they both have, and the short notice given for them. She would like to plan a holiday for this year but has found this difficult to do in the past. She stated that it would be nice to be waited on. Finds it hard to look forward – lives day to day.

Appendix Five: Examples of Memos

EXAMPLE: SUBSTANTIVE MEMO

MEMO A2

<i>Title: Caring reciprocity/Mutual needing</i>	<i>Date: 05/05/09</i>
<p>In this couple there is a reciprocity of caring, a mutual need of each other. Mr A does the physically demanding jobs around the house, and Mrs A does the jobs she can physically, as well as cooking and ensuring her husband takes his medication, and being an emotional support for him. This mutuality of need is also seen in her statement that they need each other and she needs to stay well for him. Although they have extensive help from friends and family, this need of each other is apparent.</p>	

EXAMPLE: THEORETICAL MEMO

MEMO Z4-1

<i>Title: Utilizing/compensating for lost capability</i>	<i>Date: 22/05/09</i>
<p>Capability-</p> <p>Several aspects:</p> <ul style="list-style-type: none"> - The loss of capability by the patient - The resulting increase in capability by the carer - The loss of capability by the carer - The reluctance of the carer to increase capability - The inability of the carer to increase capability - The use of others with capability to compensate for the loss of capability in carer and patient/their relationship (family, friends, employees) - Using capability to the max – either their own or their capacity to include or employ others (family, neighbours, friends). They have to ask people to help with things they used to do themselves. <p>Other aspects:</p> <ul style="list-style-type: none"> - The response of the carer to loss of capability in the patient (frustration, anger, sympathy, love, 	

<p>wanting to get away, matter of fact acceptance)</p> <ul style="list-style-type: none"> - The response of the carer to the need to increase their own capability (frustration if can't, resentment, shaping of life choices, that's just life) <p>What is this capability leading to? Why is it so important? Something about maintaining the status quo, keeping things going (X8), surviving (being his memory – A13)</p> <p>There is sometimes a reciprocity in this, of differing levels – some patients do more due to carer physical problems (A), some carers do everything due to patient physical/psychological difficulties. Some manage to maintain a life away from the carer, for others caring is their life. Some have to manage juggling their own family (children, etc) with caring for their parent/spouse. This involves competing demands on time and emotional energy.</p> <p>Can lead to a change of the 'normal order of things' e.g. mother becoming like daughter, wife becoming like husband, husband becoming like wife – Accommodating? Adjusting? Responding? Surviving together – finding a way through?</p> <p>Others can only see surviving themselves as important – a need to hold on to who they are – not wanting to lose it to the changing circumstances of the relationship. Some feel they have already lost this (daughter, son) – who they are is dictated and historically shaped by their parents'/spouse's illness – missed opportunities. Others are in this time – not wanting to miss opportunities (B9) – finding ways to do things without him – desperate to hold on to identity as they know it – not being able to see a changed identity as themselves. There's also something about identity of the patient as well – they are changing/have changed. Are they still the same person? They have lost memory and the capability to do things they used to do (A). This could be said for the couple – they are both growing older together, finding things harder, getting frustrated, not being able to do the things they want to do. Keeping independence (X1)</p> <p>The response to this is different in different couples (X10)</p>	
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Appendix Six:

Making the Best of it: Table of Dimensions and Categories

Dimension	Contributory categories	Properties of categories
Aspirational optimization	Wanting the best for the person cared for	Desiring happiness for person cared for Hoping for improvement in health and function
	Wanting to do their best	Feeling personal responsibility for their well-being Wanting to do as much as they can Wanting to stay well to care for them Not wanting to let them down
Adjustment	Dependency adjustments	Compensating for the other Delegating tasks
	Identity adjustments	Repositioning self in the face of change Redefining identity Comparing own situation with others' situations Maintaining contact with the outside world
	Expectation adjustments	Adjusting expectations of relationship Adjusting expectations of own life
	Illness adjustments	Attempting several strategies Repeating strategies Waiting for time to bring healing Tailoring behaviour Moderating disclosure Acting to avoid negative consequences
	Adjustment resourcing	Drawing on internal resources Drawing on external resources Increasing resources Mutual resourcing
	Balancing priorities	Prioritizing Sacrificing Guilt paradox
Keeping going	Keeping going despite difficulties	Accepting caring responsibilities Doing what needs to be done Living day to day Struggling on
	Living with unresolved tensions	Experiencing frustration, guilt and anger

Appendix Seven: Topic Guide for In-Depth Interviews

Introduction

Thank you for agreeing to talk to me today. I received your name and address because you returned the form given to you by the Crisis Home Treatment Team at the Rycroft Unit. But other than that, I don't know anything about you. During this time, I'd like it if you could tell me your story.

The carer

- Who they are (age, occupation, who lives in the house with them, their own health)
- Tell me a bit about yourself

The caring relationship

- Who do you care for?
- How long have you been caring for ___?
- How did you start caring for ___?

The impact of caring (physical, psychological, social, financial, family)

- Has caring for -- had an impact on your life?

A typical day

- Tell me about a typical day for you.

Strategies for coping (psychological, physical, social, financial)

- What helps you to manage?
- Who has been the most helpful to you during this time?
- Has any organisation been helpful? What did they help you with? How has it been helpful?
- What has your experience of the Crisis Home Treatment Team been?

Lessons/advice

- Have there been any lessons you have learned through caring for --?
- What advice would you give to someone who has just found out that ___ has ___?

Anything else?

- Is there anything else you think I should know to understand your experiences better?
- Is there anything you would like to ask me?

Appendix Eight: Participant Demographic Details

Participant identifier	Age carer	Age patient	Sex carer	Sex patient	Relationship of carer to patient	Diagnosis of patient
W	40	66	M	F	Son	Depression/ Anxiety
X	93	88	M	F	Husband	Depression/ Anxiety
Y	69	65	M	F	Husband	Bipolar
Z	75	78	F	M	Wife	Depression/ Anxiety
A	78	79	F	M	Wife	Bipolar
B	75	77	F	M	Wife	Depression/ Anxiety
C	43	75	F	F	Daughter	Depression/ Anxiety
D	77	77	M	F	Husband	Schizophrenia
E	63	70	M	F	Husband	Depression/ Anxiety
F	72	75	M	F	Husband	Depression
G	50	68	F	F	Daughter	Depression/ Anxiety