

**The Contemporary Dynamics of Caring – A qualitative study of the
relationship between mental health professionals and carers of
people with long term mental health conditions**

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Abstract

At the heart of this study is the experience of caring for someone with a long term mental health condition and the relationship between mental health professionals and carers, who are largely family, partners or friends. The study has been conducted at a time when there is increasing awareness of carers but at the same time limited understanding of the day-to-day lives of people caring for someone with a mental health condition.

Using a psychoanalytically informed psychosocial approach seven carers and eight mental health professionals were interviewed using a free association narrative interviewing approach, which provided a framework for participants to share their experiences.

In the next phase a combined focus group of 16 participants was held, comprising nine carers and seven mental health professionals and vignettes were utilised to facilitate discussion. Data from both methods was analysed using a reflexive and psychoanalytical approach which encouraged the emotional response of the researcher to be taken into account. Alongside, a thematic analysis was undertaken to enable cross-referencing.

The study found that the disturbing nature of mental health conditions directly affects carers and mental health professionals, and within this environment carers place high value on support that is built on a meaningful relationship with a mental health professional. However this is not always available as professionals seek to defend themselves from the distress that is bound up in the caring experience, and therefore they idealise carers and maintain professional distance, with the result that carers' anxiety is not dealt with effectively.

Three implications are drawn from the research: firstly, that relational based support is developed based on the principles of 'being alongside' which includes: discerning those issues that need immediate response, and those that need time for a period of reflection, honesty about the nature of mental illness and what is realistic, agreeing respective expectations at the beginning of the work, and valuing seemingly mundane and everyday achievements that are often overlooked. Secondly, that there is no such thing as a service user, only a service user in relation to their carer, and the two are a unit that must be worked with together by the professional. Finally, that the framework of care in the community should adopt a different model in which the structures of an institution are utilised. Therefore each service user, carer and mental health professional form a mini community institution in which they all become members of the institution, and have a role in developing it.

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Jeremy Walsh, December 2015

Glossary and Reference Key

Glossary

The following glossary of terms incorporates all those that are used in the dissertation.

Acute Services: In respect to mental health services, acute services include all those who support people when their mental health necessitates the most intense form of support. They include an inpatient psychiatric unit, home treatment team, or psychiatric liaison service linked to an Accident and Emergency Department.

Capacity: This is legally defined and can be demonstrated through a person possessing the ability to understand and retain information given to them, and are able to believe in its truth, and possess the ability to make a choice.

Care Act: This refers specifically to the Care Act (2014) which came into law on 1st April 2015.

Care in the Community: The name of the national policy to move care for people with mental illness out of large hospital institutions into a range of settings in the community, including residing at home with family.

Carer: A carer is anyone involved in caring activity for another person who is vulnerable owing to their physical or psychological health. The term is often used with a further prefix such as paid, unpaid, informal, formal and these are defined below.

Care Programme Approach: A system of care required by government since 1991. It involves assessment, a care programme or care plan, a key worker (referred to as 'care coordinator'), regular reviews of care, and elements of risk assessment where concerns exist.

Community Services: In community mental health services this includes community mental health teams, improving access to psychological therapies (IAPT), complex needs services for people with personality issues, and teams that specifically deal with age specific conditions such as early intervention teams and older adult services.

FANI: Free Association Narrative Interview (FANI) is a methodology to support interviewing subjects that has emerged from a psychosocial tradition, and has been used in this research project.

Formal Carer: The title of formal carer is often used and associated with being recognised as the carer by services, although it has no connection to legal powers.

Incapacity: This is a legally defined disability in which a person is considered unable to make certain decisions for themselves.

Informal Carer: The title is associated with family, friends, neighbours, work colleagues who provide care on an ad hoc basis to the cared for person who is vulnerable due to their physical or emotional health.

Mental Health Professional: Refers to those who work with people with mental health issues. A variety of occupational groups specialise in the field, notably: psychiatrists, clinical psychologists, mental health nurses, occupational therapists, and social workers. Other groups include counselling psychologists, forensic psychologists, counsellors, arts therapists, psychotherapists and pharmacists who specialise in mental health work. Although not recognised by a professional body there are also groups of staff employed to be support workers, employment and welfare rights advisors. The term mental health professional is used throughout this research project.

Mental Health Condition: This refers to the range of conditions or illnesses that affect the mental health and psychological well-being of someone. They can include the following illnesses: schizophrenia, depression, manic depression, bi-polar disorder, personality disorder, dementia and delirium. With all of these illnesses there are a wide range of symptoms and different levels of severity.

Nearest Relative: Under the Mental Health Act a specific framework is set out for deciding the 'nearest relative'. This is a specific role under the Act that has specific powers in respect to the treatment of the individual service user.

Long Term Mental Health Condition: In mental health there are a number of enduring conditions (see above) where a complete recovery or cure is unlikely. The approach taken by services has to be providing support to the service user and carers to maintain hope about the idea of recovery, although this may be some way

off in the future. In mental health services the diagnoses that are likely to require long term support include schizophrenia, severe depression and forms of mania, and forms of personality disorder.

Schizophrenia: Schizophrenia is a long-term mental health condition that causes a range of different psychological symptoms, including: hallucinations (hearing or seeing things that do not exist), delusions (unusual beliefs not based on reality that often contradict the evidence), muddled thoughts (based on hallucinations or delusions), and changes in behaviour. Schizophrenia is also referred to as a psychotic illness which means sometimes a person may not be able to distinguish their own thoughts and ideas from reality.

Service User: This is the title of the cared for person generally favoured by social care organisations and used throughout this research (as opposed to the term 'patient' which is generally used when a service user is in a psychiatric hospital receiving care).

Triangle of Care: The Triangle of Care is an alliance of service users, carers and mental health professionals that has established best practice elements for improving relationships between all these parties. The triangle symbol is used to denote the importance of keeping all three parties working together.

Unpaid Carer: This refers to all carers, be they family, friends, neighbours or work colleagues, who are not paid formerly for providing support. This is in contrast to mental health professionals who are paid. Some carers receive state benefits such as Carers Allowance for providing regular and substantial care, or receive a direct payment as part of a package of care. Receipt of these allowances does not alter the status of an unpaid carer to paid carer.

Reference Key

The research data is identified by: source, document, carer/professional (C/P), individual identity, and then page number i.e.

- *(Interview, transcript C4:13)*
and
- *(Focus group P50)*

Sources are:

- Interview transcript

- Focus group transcript
- Reflective log notes
- Supervision notes
- Research Support Group notes

'P' denotes professional

'C' denotes carer

First numeral denotes the actual carer or mental health professional (a list of participants by number and name is at Appendices A, B and C).

The second numeral denotes the page number of the document.

(The participants who attended the focus group are introduced but are generally identified as either professional or carer in referencing their contribution).

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Chapter One

Introduction

1. Background

This research came about through my experiences as a social worker practising in different mental health settings, later moving into senior management roles in the NHS. I found that my professional life continued to be entwined with the lives of carers, and their experiences of caring for someone with a mental health condition who may be a parent, sibling, adult son or daughter, husband, wife or partner, friend or close neighbour. One of my keenest feelings in meeting with and working with carers was: 'how do you do it?' As a professional I was able to draw on the support of colleagues, supervision and leaving work behind at the end of the day and at weekends, but carers seemed to have none of these advantages and I became increasingly aware that this difference added a degree of tension to the task of caring. As I noticed this sense of friction I became more interested in both the significance and complexity of the relationship that exists between carers and mental health professionals, be they a social worker, nurse, occupational therapist, consultant psychiatrist, or psychologist. I observed these relationships sometimes appeared to work well, but at other times were marked by a sense of conflict. I questioned whether this tension in the relationships was directly related to caring for someone with a mental health condition, inherently involving distress and disturbance, and impacting those close by.

In my growing curiosity I was keen to understand how the relationship between the carer and professional became filled with so much anxiety and tension. At the same time, I was keen to explore whether in being a carer there was some part of the experience that could possibly have elements of satisfaction and reward, in addition to those recognised feelings of burden and sacrifice. I also had a growing sense of the disconnect: while there is greater prominence for carers than ever, their lives are largely hidden away within the domestic sphere and are not valued in terms of any financial or social status return, and in fact there can be a deep sense of sacrifice and of opportunities having been given up. In a meeting with the family of a mental health service user who had spent some time as an inpatient owing to severe

depression and attempts to take his own life, the family, as carers, came prepared with a dossier of problems they had encountered including the attitude of the ward staff and cleanliness of the environment. Although some of the issues were easy enough to address I was left feeling that part of the anxiety from the family had been pushed onto me, and I was left wondering whether there was anything I could do to make the situation better. Had the meeting really been about the state of the ward, or, had the meeting, which left me feeling wounded and angry at the family's complaints actually been about the pain of having a senior father figure in the family who wished to end his own life? As a manager I was also increasingly held to account for a range of targets for aspects of work with carers, such as the number of carers' assessments that are completed. Despite encouragement and support, all the teams I managed, at some stage or other found the work that sat under the headline targets more difficult and challenging than I had envisaged. I was struck by our professional hesitancy in forming relationships with carers, and whether the familiar and folksy 'triangle' used to symbolise the user, carer and professional was entirely satisfactory.

In parallel to my professional life my personal life also led me to be becoming a carer for a close family member who developed a mental health condition. This has meant having to take off my professional hat and relate to mental health professionals from the perspective of being a carer. It also led me to realise more fully how a mental health condition can remove the essence of the cared for person, and how painful it is as a carer to endure this form of loss, whilst the caring work continues.

During my social work and mental health management career I am keenly aware that I have managed my position on the 'boundary' between health and social care, which is an uneasy and highly anxious environment, in which a multitude of organisational structures attempt to straddle their differences. In a reorganisation that took place during the time of the research, an attempt was made to identify and separate out individual cases based on either health or social care being the most significant factor in each service user's life. The enterprise of allocating people to one category or the other underlined the complex nature of mental health conditions, and how the effects of mental illness permeate and disturb every aspect of someone's daily functioning, and their ability to maintain meaningful relationships. This highlighted for me the essence of caring in this environment and the essential

skills that are needed by a mental health professional to develop a meaningful relationship with the service user and their carer.

2. The structure of the dissertation

Chapter 2 provides a literature review of those areas that link most closely to the dynamics of caring within the context of mental illness. The development of mental health services is examined, along with different models for understanding mental health, and key aspects of legislation that have been most influential. This is followed by a review of caring, how it has surfaced into public awareness and what we really mean by caring. In the third section the psychosocial approach is examined in terms of its contribution to understanding health and social care work.

This is followed by a chapter examining the methodology. In order to get below the surface and closer to the essence of caring within mental health, the free association narrative interviewing approach was used. This emerges from a psychoanalytically informed psychosocial approach, and provides a framework that engages with the inner world of the participants, their emotional experiences both conscious and unconscious, as well as the wider social policy environment. This enabled my professional and personal experiences to be valued as part of taking on the role of researcher, and in interviewing participants enabled me to draw data from the content of the interviews captured in the transcripts, but also consider my emotional response to the interviews and focus group.

During the course of my advertising the research a carer also volunteered to become a research assistant, and their input proved hugely valuable in discussing how the work was developing as well as supporting the practical arrangements around the focus group. The experience of working with a carer in the research also provided me with an opportunity to consider in more depth the nature of boundaries between professional and carer: in this case who is in the research team and who is a participant? This reflects the traditional view in mental health where you are either part of the 'sane' workforce, or the 'insane' service user group. When the world is divided in this manner carers challenge the boundary and this is an area that is explored in this thesis.

Chapters 4, 5 and 6 contain the research findings and these are examined from the perspective of the three key questions set out in the research proposal:

- a. How do mental health professionals and carers for people with mental health conditions experience each other?
- b. What is the nature of the lived experience of caring for someone who has a mental health condition, and how do mental health professionals affect this?
- c. How do elements of sacrifice and burden, as well as satisfaction and reward manifest themselves in caring for someone with a long term mental health condition?

3. Implications of findings

Chapter 7 discusses the implications that emerge from the findings and the consequences of mental health professionals employing a range of defences, as a way of avoiding being overwhelmed by the anxiety that emerges from the disturbance caused by mental illness. Professionals know that distress lies within the service user and a range of defences are in place to support this. However, another source of anxiety is within the carers of people with mental health conditions, and professionals also try to reduce their exposure to this anxiety through a range of defences. While some of the defensive approaches deployed by professionals had the potential to be containing, such as a degree of professional distance, others served to increase anxiety and frustration, and resulted in an enhanced sense of 'them and us'.

Implications that are identified from the context of caring amidst anxiety start with the high value that carers place on having a meaningful relationship with a mental health professional. 'Being alongside' is a proposed framework for developing relationships between professionals and carers and consists of: honesty about what can realistically be achieved for someone with a long term mental health condition, clarifying expectations and re-visiting them regularly, discerning different sorts of demands and how to respond, and valuing the everyday and seemingly mundane elements of caring.

A second implication is the importance of the professional engaging with the service user *and* carer, as two parts of a single network. The proposal is drawn from the ideas described by Winnicott (1960) that there is no such thing as an infant, only an infant and its care giver. Developing practice in this way also ensures the vulnerable

person with the mental health condition is not isolated from their network, through being the 'service user' and sole recipient of services.

A third implication relates to the 'contested space' in which caring is undertaken within the community. Within this often lonesome space, caring from family and friends is undertaken alongside professional caring, although the absence of structure leads to people losing touch and not knowing where they stand. This can result in further isolation and heightened anxiety, and is a driver for reconceptualising the space by establishing an institution-like approach. Within the proposed 'mini community institution' the professional engages with the service user and carer as one unit, forming an institution where everyone is a member, and expectations of each member are clearly set out as part of agreeing the 'constitution'. Through becoming a member, respective roles are defined, and like any other institution, not every member has the same role, and members have specific rights and responsibilities as part of agreeing the constitution. From the structure of a mini community institution the development of meaningful relationships between professional, service user and carer are supported, and the institution forms a strong container to manage respective anxieties.

Chapter Two

Literature Review - The Dynamics of Caring for Someone with a Mental Health Condition

1. Introduction

Set within contemporary mental health services this research is driven by curiosity to learn more about the relationship between two groups: mental health professionals who are generally health or social care workers, and carers who are most often family members, partners, or friends of people with long term mental health conditions. The research aims to understand more about the relationships between these two groups, their respective experiences of caring for someone with a mental illness, and how they experience each other.

The research has been conducted at a pivotal point with the introduction of The Care Act (2014) in April 2015 which promises strengthened rights and recognition for carers. Using the broad concept of 'wellbeing', which includes a range of areas including personal dignity, physical and mental health, protection from abuse and neglect, and participation in everyday activities such as work and education, The Care Act Statutory Guidance (2014, p.2) makes clear that access to wellbeing applies equally to adults with care and support needs *and* their carers:

“There is no hierarchy, and all should be considered of equal importance when considering “wellbeing” in the round”.

There is undoubtedly greater awareness of the role of carers across society as evidenced in The Care Act (2014), and in narratives that underline the importance of supporting carers in their caring activities. A campaign by a local carers support organisation in London featured two goals: 'give carers a break' and 'help carers to continue to care'. On one hand these straplines give greater prominence to carers, but on the other hand they place us at a distance from the day-to-day experiences of carers, leaving them more prominent than ever but also ignored. Within the area of mental health the hidden experiences of caring are particularly relevant as the relationships between mental health professionals and carers are played out amidst the disturbance of mental illness.

In terms of a review of the literature informing the relationship between mental health professionals and carers, three key areas are explored which form the main theoretical basis of the research:

- Development of mental health services, the contrasting models underpinning these services, and how the philosophy of care in the community continues to be shaped by new approaches;
- The emergence of care, caring, and the role of carers with a focus on mental health and the contribution from 'ethics of care';
- Psychosocial contribution to our knowledge of human relations and how this illuminates the functioning of individuals, organisations, and whole systems involved in mental health care.

I have approached this literature review as a practitioner researcher, being a senior NHS manager and qualified social worker with a range of experiences in different mental health settings, as well as a doctoral researcher undertaking qualitative psychosocial research. Through openly acknowledging the influences on me as a practitioner researcher I have been able to be more reflective and this has been supported by regular individual supervision and participation in a research support group. This has led me to focus on the range of mental health provision by health and social care organisations and their role in undertaking 'care in the community'. In reflecting on the experiences of carers I have also been interested in the greater recognition of carers and whether the passing of legislation has led to some tangible benefits for them, as well as my own uncertainty about the degree to which significant improvements have actually taken place in the everyday lives of carers involved in caring for someone with a mental health condition. I have also been keen to explore the extent of shared understandings regarding both professional and unpaid caring within the context of mental illness, and how these are experientially different from physical health related conditions.

2. Development of mental health services

a. Approaches to mental illness

A number of traditions have sought to impose a framework of understanding on mental health conditions with a distinct vocabulary and prescribed means of bringing resolution to the disturbance that is created by the phenomena. In the summary of

these approaches set out at Figure 2.1 below it is important to note that present day mental health services generally operate within a multi-disciplinary environment involving staff from numerous professional training backgrounds including: psychiatry, social work, occupational therapy, community psychiatric nursing and clinical psychology. Within the context of this research into the contemporary dynamics of caring, multi-disciplinary arrangements indicate the possibility both of benefits and added complexity in examining the relationship between mental health professionals and carers.

Figure 2.1 Perspectives on mental distress

Perspective on Mental Distress	Suggested treatment	Critique
<p>Medical Model - Mental illnesses such as schizophrenia, depression and bi polar affective disorders have been described and defined in international psychiatric journals to ensure accurate diagnoses (ICD and DSM). The model proposes that a chemical imbalance in the brain or a malfunctioning receptor have led to the condition emerging.</p>	<p>Treatments for psychiatric illnesses lie within the realms of pharmacology which is able to ‘treat’ the chemical imbalance in the brain, or resolve receptors malfunctioning, which have led to the condition emerging. The discovery of psychotropic medications in the 1950s opened up the possibility of treatment to reduce symptoms of psychotic illnesses such as schizophrenia.</p>	<p>A key driver for de-institutionalisation, it has not been able to resolve the criticisms of being coercive and euro-centric. While the symptoms of psychotic forms of illness can be reduced there is still no cure for psychotic illnesses through pharmacological approaches.</p>
<p>Psychological Model – Mental distress is due to maladaptive thought processes and ways of experiencing the world, or patterns of thinking that inhibit functioning.</p>	<p>Treatments include cognitive behavioural therapy, or other forms of talking therapy and counselling, either one-to-one or in groups. Psychological approaches to mild to moderate mental illnesses</p>	<p>Generally aimed at people with less complex and less serious mental health conditions who are willing to engage with the structure of the therapy. It is unable to engage with the wider impacts of having a</p>

	have become more valued as seen in the development of the national programme of 'Improving Access to Psychological Therapies' (IAPT).	severe and enduring mental health condition.
Psychotherapy Model – Mental distress is owing to early childhood trauma such as an unsatisfactory attachment, or premature/delayed separation from a parental figure.	Advocates the value of one to one psychotherapy over a prolonged period of time to support an individual to come to terms with previous experiences, especially those occurring in childhood.	Has been seen as the preserve of largely middle class and white recipients and does not effectively engage with the social disadvantages that can emerge from mental illness such as unemployment and poor housing.
Social Model – Mental distress is relevant to groups of people who have been disadvantaged owing to their class, race/ethnicity, disability status, sexuality, and their consequent ability to secure housing, employment and appropriate educational opportunities.	Responses include supporting the individual to access resources and adopting an empowering approach to establish a stronger community network that ensure their needs are met.	Is reactive and without major changes to society will not be able to provide a curative framework. Underplays the impairments that arise from disability: "The problems associated with disability cannot be entirely eliminated by any imaginable form of social arrangements, people are disabled by society and by their bodies". (Shakespeare, 2014: p.75)

(Barnes (1997), Pilgrim (2010), Shakespeare (2014), Wilson et al (2011))

Voicing caution on the efficacy of the entirety of all current interventions for long term mental health conditions, Cooper and Lousada (2005, p.111) assert:

“there is considerable contest about the nature and meaning of mental distress and what can reasonably be expected from a successful intervention”.

While the eminence of psychiatry and the medical model endures, the roll out of the national NHS programme of Improving Access to Psychological Therapies (IAPT) is a recognition of the relevance and acceptance of ‘talking therapies’ based on psychological and psychoanalytical approaches to mental health problems. Criss-crossing with this movement has been the emergence of user empowerment, ‘recovery’ and ‘personalisation’ which all seek to alter the dynamics between services, service users and carers and to alter the way that mental health conditions are viewed. While an examination of changing structures and emerging and declining philosophies is important, the one variable that has persevered throughout, is the disturbance that emerges from severe and enduring mental health conditions, such as are the focus of this research. In an observational study undertaken in a large mental hospital, prior to its closure, the nature of mental illness is described:

“Mental illness has an intrusive, damaging effect on those in close contact with it”

(Rees, 2002: p.52).

However, the key reflection from this previous era, on the cusp of moving to care in the community, and with great hope invested in the new arrangements, is that:

“A new style of service, based on the same foundation as before, will suffer the same limitations. Or to put it differently, if within a new structure there is no greater possibility of containing the anxieties of working with mentally ill people, then the resulting system will be equally defensive”

(Rees, 2002: p. 53).

In the historic overview that follows, the idea that the same limitations that were identified in the old mental hospital canteen may have endured in the new arrangements will be held in mind.

b. How history informs the present

Busfield (1996) sets out three historical phases in the response of society to mental health conditions: healing, segregation and community care. During the ‘healing’ phase, which endured till the eighteenth century, people with mental health conditions largely lived in the same community settings as everyone else. Mental

health problems could be addressed through various combinations of 'healing remedies' such as sedative drugs e.g. laudanum, and baths in various forms as a method of calming agitated patients (Lawton-Smith & McCulloch, 2012). This societal 'attitude' came to an end with the arrival of the Age of Enlightenment period in the eighteenth century which led to the emergence of a new set of views known as 'segregation'.

c. Segregation (Eighteenth century – 1950s)

During the 'segregation' period those deemed to be insane were actively separated from those deemed normal through the establishment of charitable voluntary asylums which later came under the responsibility of the state and were publicly funded. Previously, places of confinement had been generic in terms of their access criteria and had provided for those with physical and mental illnesses, as well as poverty and destitution. Marking the move to separation Jones (1996, p.128) states:

“In 1807 a government Select Committee recommended that each county should provide an asylum financed out of local rates. Eighteen counties established asylums and in 1845 the rest were compelled by legislation to follow”.

The legislation had success, if this can be measured, in terms of the inpatient population growing, and Jones (1996) reports that in 1800 there were 1000 inmates within psychiatric asylums but by 1900 this had risen to 100,000.

Figure 2.2: View of a former County Pauper Lunatic Asylum in Greater London: 1841, 1905, today and plans for the future



Turning to the involvement of family members, whom we now refer to as carers, Busfield (1996) highlights the close involvement of relatives in the development of the first asylums. This provides an early indicator of the complex position that carers occupy in relation to a family member or friend who may be experiencing a mental health condition, and their unwillingness or inability to accommodate mental distress within the family home. A wider function of segregation in the midst of industrialisation in the UK during this period is described below:

“public asylums were developed as a solution to the problems of social and economic order created by economic, social and personal dependency and had a clear motive of collective social control”

(Busfield, 1996: p.136).

Jones (2002, p.13) also highlights how family members were not passive through this period of changing societal responses to mental illness, but were key stakeholders in the process:

“historical evidence suggests that they did this in a very tangible way by deciding to use the asylums to place their relatives who they deemed to be insane ... it alerts us to be aware that the actions of families may well be a factor that shapes alternatives to those asylums”.

Whilst to a great extent asylums were the last resort for an insane relative, many of the founding principles of these institutions were benevolent:

“The essential humanity of the mad was emphasised; they might be irrational and childlike but they were still human beings capable of rational thought”

(Jones, 1996: p.128).

This resonates with the root of ‘asylum’ as ‘protection from danger’ and links with the idea of ‘refuge’ as ‘a place of safety from danger’ (Oxford English Dictionary, 2014). One of the long stay psychiatric asylums developed by the Quakers in 1796 underlines this vision in setting out an approach which advocated taking a daily regime of healthy exercise, walks, rest, reading and conversations (Jones, 1996). The concentration on physical exercise and occupation is not so different from today’s emphasis on wellbeing which features in The Care Act (2014) and includes: personal dignity, physical and mental health, and participation in everyday activities such as work and education.

d. De-institutionalisation

To effect the change from segregation to care in the community a period of de-institutionalisation was required to physically move mental health patients from the large psychiatric asylums into a range of different care settings in the community. While the physical movement is relatively easy to undertake and can be monitored through reducing bed numbers and increasing numbers of outpatient appointments, changing and monitoring the attitudes of patients, carers, mental health professionals and wider public is more challenging.

A number of drivers for the policy shift from segregation to care in the community can be identified and these are examined through the decades in which they emerged. Before doing so it is important to flag why the historical context is important in researching the contemporary dynamics of caring. From a psychoanalytically informed perspective some of the drivers for change that prompted de-institutionalisation of mental health care are germane to the present arrangements of mental health care in the community. Beginning with the premise that by moving mental health patients into the community the experience of segregation would end. This overlooks a claim that isolation for mental health service users actually emerges due to the long term impact of mental illness, and not as an outcome of the setting in which the care is undertaken:

“psychiatric patients can become isolated and can deteriorate while in the community, in ways that resemble the processes in the old institution. Those that shuffled round our mental hospitals now shuffle along our streets”

(Hinshelwood, 2004: p.110).

Although not arguing for a return to institutionalised forms of mental health care, the idea of institutions being the sole source of the problems for mental health patients is important to critique. It also overlaps with current critiques of the social model of disability which do not sufficiently take account of the impairing nature of disability (Shakespeare, 2014). The three phases of de-institutionalisation are now examined.

(i) 1950s: Asylum system under threat

Muijen (1996) reports that in 1955 there were 155,000 patients inside the large psychiatric asylums; the highest recorded number of people who were incarcerated within institutions in the UK at any one time. As well as a growing anxiety about the sheer numbers of inpatient beds that were increasing year on year, the spiralling costs of such provision was also an increasing concern (Means & Smith, 1998). 1955 was also the year that ‘Chlorpromazine’ appeared as the first of a family of antipsychotic medication, thus opening up the possibility of treating many forms of severe and enduring mental illnesses, such as schizophrenia, in different care settings including at home. In 1959 the then Health Minister, Enoch Powell, made his landmark ‘Water Tower’ speech, a reference to the characteristic architecture of

the large psychiatric institutions, in which he called for a new direction and the necessity of a struggle with those who wished the system of segregation to remain:

“the asylums which our forefathers built with such solidarity. Do not for a moment underestimate their power of resistance to our assault”

(Powell cited by Leff, 1996: p.157).

A need to wage war is evoked to indicate the battle required to overcome the institutionalised arrangements for the care of people with mental health issues. There are a number of sources of possible resistance including the workforce of the large asylums, which were a source of stable employment. Entire communities were dependent on them for their livelihoods, housing, children’s schooling, and social lives. However, resistance may also refer to those families who decided to incarcerate a ‘mentally infirm’ relative within these long stay hospitals, those who in the future would become known as carers.

(ii) 1960s and 1970s: No turning back

In the 1960s and 1970s a further driver for policy change emerged in a series of government reports highly critical of the standards of care in long stay hospitals. These were in part prompted by information about the standards of care within psychiatric institutions which leaked out into greater public awareness. Robb (1967) also published a series of accounts (‘Sans Everything’) and launched a campaign to improve or close long stay psychiatric hospitals. Following this a series of leaks to the national media about conditions at Ely long stay psychiatric hospital in Cardiff highlighted brutality and neglect. An official enquiry was undertaken, and its findings confirmed the allegations of poor care, as well as being highly critical of conditions, staff morale and management. The report was subsequently leaked to the press by Richard Crossman, the then Secretary of State for Health, who hoped to obtain increased resources for the health service. Public awareness of the regimes within these total institutions also increased as a result of popular fiction and film including: ‘One Flew over the Cuckoo’s Nest’ (Kesey, 1972) and ‘Woman on the Edge of Time’ (Piercy, 1979).

The underlying themes included in these critiques are caught by Goffman (1961, p.139) in his seminal work 'Asylums' which highlights the pernicious impact of psychiatric institutions on both patients and staff:

“The more ‘medical’ and the more progressive a mental hospital is – the more it attempts to be therapeutic and not merely custodial – the more he (*the patient*) may be confronted by high ranking staff arguing that his past has been a failure, that the cause of this has been within himself, that his attitude to life is wrong, and that if he wants to be a person he will have to change his way of dealing with people and his conceptions of himself”.

During the same period the anti-psychiatry movement was also gathering momentum, led by a disparate group of psychiatrists including Thomas Szasz (USA), Ronald Laing (Scotland), Frantz Fanon (Algeria) and David Cooper (England). Although ‘anti-psychiatry’ is not an entirely appropriate description of the group as many of the key contributors were not actually rejecting psychiatry, the movement encouraged the knowledge base of psychiatry and its role within society to be opened up to criticism. New ways of understanding mental distress were heralded, including psychoanalysis, existentialism and phenomenology:

“Laing and Cooper were keen to explore the ways in which unintelligible conduct might make sense within a person’s social situation (particularly in the family)”

(Pilgrim, 2010: p.151).

Although the drivers for change appeared to be aligning during the 1960s and 1970s, the necessary shift from large long stay hospitals to care in the community appeared to lack dynamism, and the need to fight referenced by Powell in 1959 resonates through the extent of vested interests continuing to resist change. The period from 1962 onward is referred to as the ‘disaster years’ for people with mental health problems because of the unsatisfactory process for transitioning ‘inpatients’ from institutionalised care to care in the community:

“there were 60,000 fewer residents in large mental hospitals than there had been in 1954, but very few services at all existed in the community”

(Murphy (1991) cited by Means and Smith, 1998: p.32).

The legacy of this lost period has continued to resonate in present day services, in the renewed drive to achieve 'parity of esteem' for mental health services:

“Achieving 'parity of esteem' will require a fundamental change in the way services are commissioned. Consideration will need to be given to equitable distribution of resources and supporting the commissioning of services which tackle the association between physical and mental disorders. Mental health receives less than half the level of funding that might be expected, given the relative morbidity of mental illness, so it is unsurprising that parity is still some way off”

(NHS England, Parity of Esteem, 2015).

Set against the parity of esteem argument and the lost years of mental health resourcing, is the continued reduction in the numbers of psychiatric inpatient beds from a peak of roughly 150,000 in 1955 to approximately 22,300 in 2012. This has led to both mental health professionals and carers having very different experiences of mental illness than previously, in their endeavours to contain the disturbance that emerges from mental illness within the home environment.

(iii) 1980s: Care in the community arrives

In the early 1980s the ideas underpinning normalisation theory arrived. Although predominantly focused on attitudes and the provision of services for people with learning disabilities (then termed mentally handicapped), a report by the Kings Fund; 'An Ordinary Life' (1982) highlighted three fundamental principles that were also influential in driving change in the care of people with mental health conditions:

1. People with disabilities have the same human value as anyone else and so the same human rights;
2. Living like others within the community is both a right and a need;
3. Services must recognise the individuality of disabled people.

These principles were supported under later national legislation 'Valuing People' (DH, 2001) which set out choice and inclusion as key principles at the heart of government policy toward vulnerable people. Closely linked is the disabled people's

movement which had been developing since the 1960s and sought to reject the paternalism of state welfare policies, and develop a new social model of disability:

“that distinguished between people’s perceived physical, sensory and intellectual impairments and the negative social reaction to them, which they described as disability”

(Beresford, 2014: p.17).

While important to the development of mental health services in their post segregation phase, the social model was later critiqued for not attending sufficiently to the impairments that can arise from the actual disability. For example, the struggle to order thoughts in the experience of schizophrenia, or the lack of motivation brought about by a long standing depressive illness. In response to the social model, Shakespeare (2006, p.75) argues that people are disabled by society *and* by their bodies, or minds in the case of mental illness, and that:

“the problems associated with disability cannot be entirely eliminated by any imaginable form of social arrangements ... the priority for a progressive disability politics is to engage with impairment, not to ignore it”.

The emphasis on community based care also filtered into the updated Mental Health Act (1983) which provided a new legal framework for mental health care based predominantly in the community, with provision for compulsorily admitting someone to hospital if they became a risk to themselves, a risk to others, or a risk of harm from others. The Act also provided key roles for family members with the introduction of the concept of ‘nearest relative’ based on a description and hierarchy of relationships with the service user. The Act included expectations that mental health professionals consult with the nearest relative regarding some forms of compulsory treatment, and seek their agreement in others, such as arrangements for aftercare following an admission to hospital.

The late 1980s also saw significant legislative change under the Conservative Government. Sir Roy Griffiths emerged as a key player across health and social care after being asked by the Secretary of State for Social Services to review the way in which public funds were used to support community care policy, and recommend options for improving the use of resources. This was another significant milestone in

the journey of mental health services moving out of the institution and towards an increasing role for family and friends:

“For the most part, people with mental health problems as well as physical or learning disabled people should receive support and therapeutic services in ‘ordinary environments’ rather than in hospitals or long stay residential institutions”

(Barnes and Bowl, 2001: p.56).

Many of the themes identified in the subsequent Griffiths Report, ‘Community Care: An Agenda for Action’ (1988), were included in the subsequent White Paper ‘Caring For People’ (1989, p.4) and underline the ethos in relation to caring: “the great bulk of community care is provided by friends, family and neighbours”.

Further measures included: an emphasis on community based services such as the development of the independent sector, clearly defined agency responsibilities, development of needs assessment and care management, promotion of domiciliary, day and respite care, and development of practical support for carers. Fulfilling these objectives required new legislation which was enacted in the National Health Service and Community Care Act 1990 (NHSCCA) that came into force in 1990.

However, whilst highlighting this shift of responsibility onto informal networks of family, friends and neighbours, no corresponding funding was identified to support these groups, who would now be expected to care for those with a mental health condition, and who may have previously been subject to institutionalisation. Cooper and Lousada (2005, p.113) observe the absence of controversy, and reflect:

“Out of sight, out of mind, was the policy that informed the long era of large psychiatric institutions, and now in the context of “Care in the Community” we must ask whether or not the patient is truly to be kept in sight, and in mind”.

e. Developing care in the community

At the beginning of the 1990s a new phase of developing community mental health services emerged with the introduction of a formal framework for care planning in mental health services called the ‘Care Programme Approach’ (DH, 1990). Still relevant within current mental health services, its emphasis is on a named worker known as the ‘care coordinator’ who is responsible for coordinating the service user’s

care which must be set out in a care plan and be reviewed regularly, and importantly, take account of carers who are generally family and friends.

Under the earlier NHSCCA (1990) the role of a 'care manager' was also identified; generally a local authority social worker able to undertake assessments of service users and subsequently commission services to meet their needs. The delivery of the largely local authority role of 'care manager' in relation to the largely health role of 'care coordinator' has been operationalised in a wide range of different forms across the country. It has been implemented with variable degrees of success, from full integration between health and social care where health staff are able to commission services from local authority budgets, often set out in a formal Section 75 partnership (NHS Act 2006), to arrangements where organisational boundaries are tightly maintained and organisations are required formerly to 'refer' to one another. The work of community mental health services is thus subject to both multi professional and multi agency dynamics and 'as with marriage' these different arrangements are subject to recurring difficulties:

“which in turn have an impact on the quality of service provided. In the context of Care in the Community it is as if the period of reconnaissance or courtship has been bypassed”

(Cooper & Lousada, 2005: p.116).

The 1990s also saw prolonged and significant criticism of community care both in terms of it as a philosophy of care and the level of funding it attracted. A string of tragedies involving people with mental health issues received widespread media interest and the subsequent investigations reported on failures in community care, particularly in communication between different agencies involved in supporting service users. The most high profile incident was investigated by the Ritchie Report (1994) into the killing of Jonathan Zito by Christopher Clunis, a mental health service user, which concluded that a series of prior assaults with a knife had not been noted or communicated to all the relevant staff. The criticism within the report led to a greater emphasis on risk management, public safety and containment, and is reminiscent of Hinshelwood's (2004) argument highlighted earlier, that those patients that used to 'shuffle round' our mental hospitals are now shuffling around our streets.

f. National service framework for mental health

In 1999 a further expansion of community mental health services was laid out in the form of a 'National Service Framework' (NSF) for mental health (DH, 1999). This was supported by new funding for services, particularly in the form of: assertive outreach teams for service users who are complex and difficult to engage with, home treatment and crisis resolution teams for service users who require time limited intensive support to prevent admission to hospital, and speed up discharge; and lastly, early intervention teams to provide dedicated support to service users experiencing their first episode of a psychotic illness. The NSF also covered the role of carers which is recommended as one of its main standards:

“Local services need to pay greater attention to the needs of carers, and to the specific needs of those who care for someone with a mental health problem. This should include the assessment of each carer’s needs when requested, the agreement of a care plan which is reviewed at least annually, and the development of local networks to support carers. Carers should be made of aware of their right to request an assessment”

(NSF for Mental Health, 1999: p.71).

How far the rhetoric of 'pay greater attention to the needs of carers' actually led to qualitatively different experiences for carers is uncertain, although the urgency for change across the services is highlighted by Gilbert et al (2014, p.5):

“The scale of change was unprecedented ... the expected benefits of improved community care and evidence that suggested this would reduce the demand for beds led most providers to reduce their inpatient beds provision. Some providers closed beds in anticipation of the reduction in need”.

Although we are now several years on, the NSF for mental health (1999) still resonates through its emphasis on providing support to maintain mental health service users at home and avoiding unnecessary admissions to hospital through providing home treatment, early intervention, and assertive outreach. The implications for carers has been extensive. Although avoiding unnecessary admissions to hospital is a positive outcome, the impact on families of caring for a family member, who is possibly acutely disturbed, distressed and disinhibited, has

been flagged by carers within this research, along with the concept of 'respite', which has now largely become a redundant concept with mental health care.

g. Personalisation

In contrast to the NSF which was led by the NHS the emergence of 'personalisation' in 1996 introduced under the 'Community Care (Direct Payments) Act' (DH, 1996) lies largely within the sphere of local authorities. It comprises a range of intentions that are both strategic and related to individuals, including: enabling people to be part of their community, providing advice and guidance to everyone, putting services in place to help prevent crisis and sort out difficulties at an early stage, and where people require longer-term support services are designed and delivered with them to meet their individual needs and preferences.

Although the initial promise was radically to transform social care and specifically enable both service users and carers to access a cash budget (personal or individual) to spend on support to meet their needs, more recently, there has been a shift in the term's official usage:

"it is now also used by the government to mean people having more choice and control and a more customised service, regardless of what service or form of support they receive and however it is provided"

(Beresford, 2014: p.5).

From the perspective of carers the widening of eligibility to include carers as set out in The Care Act (2014) is another opportunity to engage mental health carers through undertaking an assessment that would identify needs that could be considered through the lens of personalisation. However in respect to mental health and carers the original promise set out in personalisation is difficult to evidence through any significant improvements, and two particular concerns have been raised.

Firstly as a result of the transfer of local authority funding from collective services, such as community-based mental health day centres (or 'drop ins') to funding going directly to individual service users, who are expected to operate a personal budget, traditional mental health day centres that received grants or block funding from local authorities have consequently declined. While many of these former day centres were not sufficiently outcome focused for their service users, they did provide a

place to meet, a warm meal, and a vital source of support for service users who had the most chronic forms of mental illness, but had limited social support.

Secondly, since the introduction of personalisation the financial circumstances of the public sector have changed markedly through the series of austerity measures since 2010, and set against the ambiguous role of personal budgets:

“they can be part of a movement for liberation, as the direct payments originally developed by the disabled people’s movement were envisaged, or part of a market-centred move to cut costs, privatise provision and rely on unpaid caring”

(Beresford, 2014: p.25).

The vulnerability of carers within the personalisation debate lies in the identification of a carer as a creative and enabling way to meet the needs of a service user but without provision of sufficient support for carers themselves. Although The Care Act (2014) removes the hierarchy between service user and carer, it is still too early to determine whether this will safeguard the good will of carers from being exploited.

h. New horizons

In recent years attention has been turned to raising the profile of mental health in general. This is many decades overdue and a long awaited acknowledgement of the ‘Cinderella’ status of mental health services, a label that was applied following the review of equivalent expenditure across a range of health settings by Goodwin (1990).

In 2009 ‘New Horizons: Towards a Shared Vision for Mental Health’ (DH, 2009) gave priority to equality and spearheaded a commitment to the notion that ‘mental health is everybody’s business’, alongside addressing stigma, improving the physical health of people with mental health problems, and personalising services which had been subject to separate legislation directed at local authorities. ‘New Horizons’ largely set out an overall approach to the delivery of care, although it did not prescribe a framework, as the NSF did, for those specific services that should be provided and importantly it was not accompanied by additional funding.

Following this 'The Health and Social Care Act' (2012) required the NHS to place mental health on a par with physical health, and the subsequent cross-government strategy 'No Health Without Mental Health' set out objectives which focused on: "championing models of service provision that support the equitable involvement of patients in treatment, management and service provision" (Gilbert et al, 2014, p.7).

i. The Francis Inquiry: carers speak out

Following the emergence of widespread failures in care, largely unearthed by complaints and concerns raised by relatives of patients, the subsequent Francis Inquiry (2013) was commissioned by the government to investigate the failings at Mid-Staffordshire NHS Foundation Trust. Recommendations have led to a series of changes across all health services including mental health provision. New codes of conduct were passed by all health organisations including the 'duty of candour' which set out responsibilities for transparency and honesty, and apologising for failings.

j. On the radar - a taster of the future in mental health care

The trajectory of mental health services continues to be away from hospital based provision and toward community models for all but the most acutely unwell service users. The following is a summary of policy and practice ideas that are still being embedded.

(i) Recovery - still prominent within mental health services is the principle of the 'recovery approach' and the emphasis on managing mental illness in a similar manner to other long term conditions, where the goal of a complete 'cure' is not realistic. Within the context of adults with long term mental health conditions 'recovery' has become a word that is pre-fixed to existing processes, for example; recovery care plan, recovery goals, and recovery college, without necessarily any significant change of approach taking place. Involvement of carers in recovery as an overarching principle is also problematic in the reliance of their continued support to make up for the absence of 'full recovery'.

(ii) Parity of Esteem – this is a call for mental health services to be funded on an equal footing with other health services. It is emerging at a time of considerable pressure across health and social care organisations and it remains to be seen

whether funding can be leveraged from 'competing' and pressurised health budgets in order to achieve parity of esteem.

(iii) Open Dialogue – is an approach that is currently emerging through pilot sites in health and social care settings in the UK with the first 'Open Dialogue' training programmes being offered to mental health professionals. Based on pioneering work carried out in the Western Lapland district in Finland, Open Dialogue is a 'network-based and language approach' specific to acute psychiatric crises. Importantly, it identifies the benefits of the identified service user, carers and professionals engaging in a 'treatment meeting' as soon as a mental health crisis is identified, and typically within 24 hours:

“all decisions about ongoing therapy, medication, and hospitalization are discussed and made while everyone is present. There are no separate staff meetings for treatment planning”

(Siekkula and Olson, 2003: p.407).

In terms of the approach that underpins the meeting, Siekkula and Olson (2003, p.410) also note that in contrast to a systemic family approach, Open Dialogue creates:

“a shared language that permits the meanings of the person's suffering to become more lucid within the immediate network”.

Although still at the stage of being piloted in the UK, the value of the service user and carers being equally engaged by professionals from the outset indicates that Open Dialogue has the potential to address some of the issues examined in this research regarding the contemporary dynamics of caring with the context of mental illness.

k. Summary

The transfer of mental health care from the former Victorian institutions into the community has been the most radical change in the development of mental health services and has been the defining feature of the last fifty years. Not only altering the physical location of care, the movement proposed that informal social networks comprising of: family, friends and neighbours, would largely assume the caring role

for service users, without any additional resources. Since the re-introduction of mental illness into the community there have been a series of national initiatives to strengthen the frameworks of care, although these have continued to assume that care is provided through family and friendship. Latterly, a spotlight has sought to highlight the inequality between mental health services and other forms of physical health care through 'parity of esteem' measures, and the degree of any success is currently awaited.

3. Caring

Within the context of mental health and the relationship between mental health professionals and carers I now turn to caring and begin with an examination of the definitions surrounding care and the activities involved in caring. Then I will go on to consider the emergence of caring within national policy, followed by consideration of the specific area of mental health.

a. What is care?

Touching on what we actually mean by 'caring' Sevenhuijsen (1998) describes it as having two senses: 'as an attitude and as a form of action'. Caring attitudes can be summed up in phrases such as: "empathy, practical knowledge, and compassion" (Sevenhuijsen, 1998: p.4).

From a psychosocial perspective Foster (2001, p.83) suggests:

"Caring for someone involves activities such as the ability to be emotionally in touch with the other person as a whole person; a readiness to consider their pain and their needs and act accordingly; and a desire to make up for any pain we may have caused them".

Within the context of public organisations the notion of 'duty of care' also emerges and this is defined by the Social Care Institute for Excellence (SCIE) with an emphasis on 'actions', and a professional acting in a manner consistent with what would be expected from a 'reasonable person' with their training and background:

"So, for example, an accountant must get their sums right and apply for the right tax-exemptions for their clients, or a surgeon must know how to carry out a certain procedure. In the same way, a care provider is expected to be

trustworthy, in accordance with their code of ethics, and apply suitable skills when carrying out care procedures”

(SCIE, Duty of Care 2012).

The use of the terms ‘unpaid carer’ or ‘informal carer’ also help to differentiate the group of people who are the family, friends, partners, neighbours or work colleagues of someone with a debilitating condition, such as mental illness, from those who ‘care’ and are paid for their work, for example mental health professionals such as doctors, social workers, nurses, and support workers. Unpaid and informal carers may be employed or occupied in any number of ways, including sometimes providing care which is delivered through living with the cared for person, or at some distance. Carers providing ‘substantial care’ which involves caring for over 35 hours per week may be entitled to claim ‘Carers Allowance’ although they are still termed unpaid carers for the purposes of this research (www.gov.uk/carers-allowance).

b. Caring concepts

From the ethics of care field a range of terms are identified in respect to what we mean when we think about caring, and this level of scrutiny serves as a useful reminder of the relative newness of the ideas surrounding care. Key terms are set out below:

Figure 2.3: Concepts of caring

Concepts of caring	Summary	Critique
‘Caring about’ and ‘caring for’	Caring about refers to how we might feel about a certain issue i.e. global warming, whereas caring for is more strongly linked with taking care of someone else, and the associated work and expenditure of energy.	The distinction continues to be slippery, for example it is possible to use ‘care for’ in a range of different contexts such as ‘I don’t care for red meat’.
Caring as an activity, as in ‘taking care of someone’	This refers to the physical activities of taking care of someone practically although it is not the same as ‘caring for them’ in the sense of having warm feelings	The activities involved in caring are vital to meet the cared for person’s dependency needs. However in an area such as mental health taking care may

	toward them.	solely involve maintaining a trusting relationship.
Attitudes of caring	Central to caring is understanding a situation from the point of view of the cared for person: their feelings, needs, desires and thoughts. A second aspect is the carer being able to care for themselves since without the maintenance of their own capabilities they will not be able to engage in caring.	From this view there is no objective or analytic appraisal of the cared for person's needs, it is solely defined through engaging with their feelings. An important contribution is the focus on the carer to look after their own wellbeing.
Care as labour	Caring is the same as any other transactions such as commercial and retail sales and does not require sensitivity to the inner world of the cared-for person.	Does not take account of the inequalities that may exist between the carer and the cared for and the vulnerability of the cared for person, and in some circumstances the carer. Unpaid carers are not held to a contract unlike many commercial exchanges.
Caring for someone and providing them with a service	Caring involves three elements: <ol style="list-style-type: none"> 1. Meeting the needs of one person by another person; 2. Face to face interaction between the carer and cared for is a crucial element; 3. The need that has been met by the carer could not have been met by the person in need. 	While consisting of three aspects of caring it does not engage with whether the carer has any warmth towards the cared for person
An expression of ethical importance	Caring signifies how we matter to one another, it transforms relationships and is the foundation for parenting, friendship, nursing, and citizenship.	Elevates the essence of caring as part of significant relationships but does not address the day to day live of carers in relation to their caring

		activities in support of people with dependencies.
Focus on knowledge and thoughtfulness and relational dimensions	Care comprises the ability and willingness to both see and hear needs, and take responsibility for these needs being met. Throughout the process care must have a relational dimension and consist of a connection between two people that is expressed in some manner.	Although the compassion which is emphasised in this description is strong the missing element is the work that is involved to ensure all the cared for person's dependency needs are met. If all of the dependency needs are not met what is the point of the relationship?
Just a motivational attitude	From an objective viewpoint the cared for person's needs are being met, rather than any focus on the inherent attitude or feelings that characterise the carer.	How do you measure whether a person's needs have actually been met? From the cared for person's perspective it is possible to see the relationship with the carer as part of the caring experience.
Dependency work	Defined in terms of work rather caring, and involves the work of caring for those who are dependent. Although rooted in the world of work, it includes a relational dimension in respect to the cared for person being vulnerable, and the carer having a special position.	The distinction with work and care appears to be more semantic than have any greater significance.

(Bubeck, 1995, Held, 2006, Kittay, 1999, Sevenhuijsen, 1998)

c. An uneasy relationship – feminism and caring

While Sevenhuijsen (1998) reminds us that care is both an attitude and an action comprising a range of qualities including: compassion, attentiveness and empathy she also highlights the 'uneasy relationship' between feminism and care and the connection with ideals of motherhood and the gendered nature of caring. This resonates with experiences of this research which attracted more interest from

women than men, and of these women, a higher proportion were older women who were undertaking the role of mother and carer in relation to their adult children, who had mental health conditions. However, on a wider societal level, and amidst the goal of women striving to achieve greater equality with men, there has been a move by some women to distance themselves from caring, and undertaking carer roles:

“Caring was depicted as dull, monotonous and traditional, and thus as an obstacle to self-fulfilment”

(Sevenhuijsen, 1998: p.5).

The battle for gender equality has followed a similar timeline, i.e. over the last fifty years, to the emergence of carers from their previous invisibility within the domestic space. The various activities connected with caring have therefore been used as one of the backdrops for gender equality issues to be played out. Feminist critiques have highlighted the risks for women of becoming the unpaid carer workforce providing support for care in the community policies, and flagged the risks to women of the welfare state breaking down, as symbolised in mental health, by the closure of the long stay psychiatric hospitals. However, this feminist approach has itself been subject to critique from other feminists within the disability movement:

“arguing for the retention of institutions which were experienced as oppressive by those admitted to them could not be the response to an analysis of the oppression experienced by informal carers”

(Barnes, 1997: p.106).

The different strands of the feminist debate illustrate an understanding of the relationship between carers and elements of the state (characterised by mental health professionals in this research) and expose the efforts to reach a ‘settlement’ between the oppressive institutions of the state being closed down, care responsibilities being passed back to families, and the impact on women. As Barnes (1997, p.107) notes:

“while caring is a ‘labour’ it is also very often a ‘labour of love’ and the carers’ lobby sought primarily to find an accommodation with the state which would enable genuine caring relationships to be maintained without the burden of care becoming overwhelming”.

d. Historic context of development of policy

As highlighted above, in the past, caring and carer roles are likely to have been inherent within society and for the most part were not identified as distinct activities and roles, as they were considered unremarkable and simply what families did.

Archambeault (2009, p.113) makes a similar point:

“40 years ago the term carer was barely in the English language. People who would now be identified as ‘carers’ would not have considered themselves in that way, or viewed themselves as belonging to a distinct group of people”.

Held (2006, p.3) also reminds us of the universal nature of caring: “every human being has been cared for as a child or would not be alive”.

In exploring the emergence of carers, and particularly those caring for adults with mental health conditions, there are connections with the earlier examination of the development of community mental health services, which to a large extent have been enabled by the efforts of carers, through familial and friendship relationships. This situation is referred to directly by the White Paper, *Caring for People* (1989, para. 2.3): “the reality is that most care is provided by family, friends and neighbours”.

e. Emerging from the invisibility of the domestic space

Beginning with caring in a generic sense Barnes (1997) reports on the work of Reverend Mary Webster, an unmarried woman who gave up her job in the 1950s to care for her elderly parents. Mary Webster wrote to *The Times* newspaper in 1963 and sought to engage the interest of the Churches in the experiences of women, largely unmarried, who had been drawn into caring for elderly parents: “because they have to earn their living, as well as undertaking the tasks of caring for others, life for them is often difficult” (cited by Barnes, 1997: p.101).

Two linked points emerge from Webster’s experience. Firstly, although women had been forced to enter the workplace to play their part in the war effort between 1939 and 1945, the prevailing view in the development of the post war welfare state was that women should be encouraged to leave the formal workplace, and resume their

pre-war traditional roles as wives and mothers. However as a consequence of the war and the demographic impact of a significant loss to a generation of men, large numbers of women found themselves as single breadwinners having to continue to work within the formal workplace, and increasingly having to juggle the need to care for their elderly parents.

Secondly, the elevation into the public arena of the experience of women, particularly single women, occurred during the development of the welfare state in the UK, and within this new political landscape, women felt more confident in raising their concerns and calling on the newly emerging post-war welfare system to consider their position.

In 1965 the 'National Council for the Single Woman and her Dependants' (NCSWD) was created with a remit to achieve legislative and policy changes which would benefit single women carers, and through its campaigning claimed some success:

“The major achievements of NCSWD are regarded as being the introduction in 1971 of the Attendance Allowance ... and in 1976, the invalid Care Allowance, paid directly to carers”

(Barnes, 1997: p.102).

Following increasing interest from women who related to the experience of caring, but were also married, widowed or divorced, in 1982 the NCSWD became: 'The National Council for Carers and their Elderly Dependants'. An important distinction in this phase of the emergence of caring was the idea of different levels of responsibility in respect to caring for various family members. Within this hierarchy there was formal acknowledgement of the impact of caring for increasingly frail older parents, in contrast to attitudes towards caring for a sick or disabled child, or for a partner who had suffered an accident or become unwell, which were all viewed as appropriate personal caring responsibilities that should be firmly managed within the setting of the family.

In 1981 the Association of Carers was founded on the principle that it should represent all carers regardless of sex, age, marital status or relationship to the person they cared for:

“there was some opposition not only from professionals who wanted things organised around the ‘condition’ of the person receiving the care, but also some members of the National Council who were unhappy about a shift away from carers of older people”

(Barnes, 1997: p.103).

A number of developments in the greater recognition of carers in the 1980s included The Disabled Persons Act (1986). This act provided the first legislative recognition of the role of carers, requiring local authorities to take account of carers’ abilities to care when assessing the needs of people seeking community care services from Social Services Departments. As we saw above in the journey through the development of mental health services, the culmination of developing recognition of caring during this period was the Griffiths Report ‘Community Care: An Agenda for Action’ (1988) and the White Paper, Caring for People: Community Care in the Next Decade and Beyond’ (1989, para 2.3) which set out the context:

“While this White Paper focuses largely on the role of statutory and independent bodies in the provision of community services, the reality is that most care is provided by family, friends and neighbours ... Helping carers to maintain their valuable contribution to the spectrum of care is both right and a sound investment”.

Continuing in the same furrow as increasing recognition and expanded entitlements, the ‘Carers (Recognition of Services) Act’ (DH, 1995) was passed in 1995. The act gave the right to a separate assessment to people providing informal care on a regular basis, to ill, elderly or disabled friends or relatives who were seeking help from Social Services. Social Services were then required to take carers’ views and the assessment into account when deciding what services to provide the person being cared for. This was followed in 2004 by ‘The Carers (Equal Opportunities) Act’ (DH, 2004) which promised to provide a firmer foundation for better practice by councils and the health service, and built on existing legislation by:

“placing a duty on local authorities to ensure that all carers know that they are entitled to an assessment of their needs, placing a duty on councils to consider a carer's outside interests (work, study or leisure) when carrying out an assessment”

(Chapter 15, para 2).

From April 2015 The Care Act (2014) came into force stating that anyone who provides unpaid care or support to an adult family member or friend is able to have a carer's assessment, irrespective of whether the person they care for has eligible needs. This means for the first time that if a carer has eligible needs of their own, they have a right to receive support.

Whilst the key milestones in the emergence of carers and caring have been reviewed, the next section will step back from the legislative framework and consider the nature of being a carer and the acts of caring.

f. Carers and the mental health system

In exploring the nature of caring within the context of mental health conditions the starting point is the impact of the disturbance that emerges from mental illness:

“mental health is, of course, dealing not only with madness but with the experiences of severe mental pain, of depression, severe anxiety and breakdown, of violence and self-destructiveness”

(Hinshelwood & Skogstad, 2002: p.13).

In terms of 'working with' people with mental health conditions Hinshelwood and Skogstad (2002, p.14) also argue that the professional's inherent interest in, and empathy for another person's mental distress is important: “these are rooted in one's own emotional development”. This suggests an attraction for working in the field of mental health which is influenced by factors related to personal development and 'life experiences', rather than a more objective 'career choice'.

Differentiated from other forms of caring, caring for someone with a mental illness which manifests itself in distress, requires the use of 'self' to provide emotional support to the person. Unlike other health conditions which may require specialist equipment such as hoists and lifts, in mental health the 'resource' is the emotional availability of the mental health professional or carer to manage and sometimes relieve whatever disturbance emerges from the long term mental health condition. Care in this context also needs to be thought about in a protective way, which may involve ensuring no harm comes to the person, or no harm is done to others as a

result of any actions or behaviour on the part of the person with the mental health condition.

g. Key typology – the three faces of carers?

A range of roles and activities to support the looked after person is represented in a framework for categorising carers (Twigg,1989) which argues that statutory workers see carers occupying one of three roles: as resources, as co-workers or as co-clients:

- As resources: this emerges from the work of Griffiths (1988) and is the perspective set out by the NHSCCA which viewed informal care as the best means of providing support to enable people to live in 'normal' environments, leaving health and social care to fulfil a residual role.
- As co-workers: sees carers as quasi or semi professionalised in which informal and unpaid carers become colleagues, and thereby create a risk of the service user being alienated.
- As co-clients (or co-service users): sees carers becoming categorised as secondary clients with rights that are similar to clients.

The thrust of The Care Act (2014) certainly appears to have reinforced the carer as 'co-client' with the eligibility for an assessment lowered and the rights to a support plan and the carer's needs being met. In the emergence of the carer as co-client there is a significant possibility of large numbers of people coming into contact with services owing to their status as carers. Is this to be viewed as extraordinary, requiring the need for services to undertake assessment and meet the needs of individual carers? Or, is this something that we should view as a necessary and reciprocal part of the human condition; to care for others and when needed, others will care for me?

h. Summary

Caring is both an attitude and a form of action and has entered into public life over the past fifty years from its previous invisibility in the domestic space. In the context of caring for someone with a mental health condition that is distressing and damages their capacity for a meaningful relationship, the need to be emotionally available is the most vital action. The various ways that services conceive of carers underlines

the risk of confusion, and of being pigeonholed in a way that is not sensitive to the carer's unique relationship with the service user and their contribution to caring.

4. Psychosocial approaches

a. Introduction

Although several research papers have sought to convey the experiences of carers within the context of mental illness (Svettini 2015, Kuipers et al 2010, McGhee and Atkinson 2010, Maskill et al 2010 and Lyons et al 2009), the lens that is provided by a psychoanalytically informed psychosocial approach uniquely enables research to be undertaken at different levels. As a methodology it is examined in chapter 2 and in this section the extensive body of psychosocial literature is examined with an explanation of how it informs the subsequent research. This will encompass 'surface' issues, such as policies and procedures, as well as engage with 'depth' issues, such as the emotional responses to caring for someone with a mental health condition which may be conscious or emerge unconsciously through the various 'defended' positions that participants seek to occupy. These 'lateral defences' such as 'splitting' and 'projection' are also part of this psychoanalytically informed psychosocial approach. Illustrating the value of this approach for investigating the caring work that is undertaken by mental health professionals and carers, Cooper and Lousada (2005, p.15) assert:

“The work of welfare is emotionally, intellectually, and practically challenging. We also assume that it entails engagement with free agents who bring complex needs, demands, ailments, predicaments, and experiences of suffering to service providers. It is in the nature of the work that it is arduous – for both provider and user”.

The psychosocial approach then, encompasses relationships, both at the conscious and unconscious levels, between individuals, groups and social movements, and according to Cooper (2009, p.440) an inherent belief:

“that each and every situation or context is unique and particular, and must be understood - 'apprehended' in its own terms”.

This then opens up access to a greater understanding of the raw, unprocessed and uncomfortable feelings that play out between mental health professionals and carers within the context of mental illness, and permits us to engage with the daily and distressing realities of caring.

In reviewing psychosocial approaches the following areas are relevant for mental health professionals and carers, and are examined in the sections below:

- Surface versus depth and left and right
- Dependency and mental illness
- Early development: The impact on adult life
- Triangles: A psychosocial view of community services
- Defended positions: Coping with distress

b. Surface versus depth and left and right

The role of the unconscious mind in constructing social realities is underlined by Clark and Hoggett (2009, p.6): “feelings and emotions shape our perception and motivation, constructing the way in which we perceive others”. Recognising this aspect of human experience opens a window that enables examination of depth issues which are relevant for understanding the relationship between mental health professionals and carers, and how they each contribute to the kaleidoscope of interactions informed by conscious and unconscious motivations and defences.

Evoking a manifestation for the surface and depth distinction Dartington (2010) describes the need for managers and professionals within health and social care organisations to approach the work with ‘two faces’: one face views the necessity to be rational, clear-headed, and financially numerate, while the other face views the complexity, emotional turmoil, and disturbance that emerges from mental illness and permeates into the lives of service users and carers. He compares this form of duality to the Roman God Janus who was shown having two faces reflecting his position at the beginning of the Roman calendar and thereby having the ability to look two ways.

Figure 2.4: Image of the two faced Roman God



The description points to the possibility of having a public outward face co-joined with a private inward face, and the potential for mental health professionals in their interactions with carers to take on one or other of these 'faces'. In response, the possibility is opened up of the carer having two faces, an outward 'keeping up appearances' face representing the surface issues of daily routines, co-joined to a private face that reflects greater emotional depth, and the reality of caring for someone with a mental health condition. The combinations of these surface and depth relationships is the fulcrum of this research project.

Wearing either one of these faces also presents different degrees of risk, with the possibility of coming too close to the pain that can emerge from mental illness and inherent within the work:

"The enterprise asks its employees to be more open, more vulnerable to one another. But in becoming more vulnerable, people compound their sense of risk. They are threatened from without and within ... Thus the stage is set for a more primitive psychology"

(Hirschhorn, 1997 cited by Dartington, 2010: p.118).

Whereas the risk of not getting close enough, of not engaging with the pain and avoiding the relational and the personal, serves to inhibit any opportunity for change and growth in either the mental health professional or carer. Cooper (2010)

comments: “the psychological intensity of these kinds of encounters change us, whether we wish for this or not” (p.432). If, as professionals or carers, we only permit ourselves to be occupied with surface issues it is unlikely that the degree of care that is needed by those who experience mental distress will be met.

c. Dependency and mental illness

Dependency is not a neutral term it involves being variously reliant on someone or something owing to an issue such as disability, for example mental illness, and the impact this has on daily life. Cooper and Lousada (2005, p.105) highlight Care in the Community policies that appeal to common sense views of dependency as ‘corrosive’ and set this against the reality of mental illness:

“The problem is that by definition mental distress defies common sense. It is a repudiation of what is common and what is sensible, and brings with it a complexity that requires engagement and understanding”.

The process of becoming a carer and engaging with ideas and values surrounding dependency, interdependency and independence also link with experiences of being part of a particular family setting. This may involve the presence of a family member being ‘different’ due to a mental health condition, and depending on the circumstances, the traumatic notion that following the emergence of mental illness family life may never be the same again.

A psychosocial approach invites us to stand back from ideas surrounding dependency, often with negative connotations, contrasting with independence which has positive associations, and consider the values we attach to particular ways of living and how they have emerged. Dartington (2010) distinguishes between different forms of dependency utilising the idea of ‘primitive’ and ‘mature’ forms of dependency. We are reminded of times, when as working adults we may indulge in primitive dependency, and: “put aside our own competences to deal with a situation and invest all competence in others” (p.42). This form of primitive dependency within the workplace can lead to pathological and destructive behaviours, for example abdicating responsibility and not taking any initiative. Within a care setting it can lead to an individual’s entire basic needs being met, i.e. dressing, eating, and toileting. While there may be situations where this is appropriate, there are also

situations where it can deny the capacity of the individual to take any independent decision making role in relation to these dependency needs, and all other activities. Within the context of a carer and cared for relationship all the decisions and responsibilities may become invested with the carer, with few opportunities for discussion or negotiation between the parties. This form of primitive dependency may have evolved through the influence of the carer, cared for person, or a combination of both. Importantly mental health professionals are in relationships with both service users and carers, requiring thoughtful navigation of attitudes towards dependency to avoid primitive relationships becoming embedded.

In contrast 'mature dependency' recognises that 'no man is an island' and: "mature relationships are grounded in the individual's developing capacity for attachment, trust, reliance on others as well as self-reliance" (Dartington, 2010: p.43).

In the context of mental illness there are risks in compartmentalising experiences surrounding dependency; with primitive equating to bad, and mature equating to good, and being unwilling to countenance anything that appears too primitive. For example, dependency in respect to mental illness does not necessarily emerge when one might expect i.e. at the onset of frail old age or following an accident. It often erupts at a time when a young adult may be going out into the world for the first time, starting a new role in the workplace, or following the birth of a child when dependency is expected to focus on the new infant, or at some other random time during adulthood. Furthermore any mental health condition is unlikely to be fleeting and transitory, may become a chronic or episodic illness, and extend over a lengthy period of time placing particular demands on the carer and professional.

d. Early development: the impact on adult life

Recognising the influence of early infant development on our capacity to manage relationships in adult life is also an essential contribution from the psychoanalytically informed psychosocial approach. Bion (1962) argues the ability of a baby to survive the intense frustrations of early life, and actually go on to thrive and develop the skills to think about one's position in relation to others in the world, is located in the nature of the early dependency experience, and availability of a 'thinking breast'. This is summarised by Waddell (2002, p.30):

“the mother brings not only her straightforwardly nurturing and loving qualities to the baby, but also her thinking self, the mental and emotional states which, in encompassing the chaos of her infant’s psychic life, establish a precondition for more integrated capacities, for a more integrated self”.

Continuing to examine the nature of dependency and its origins in our early development, Klein (1946) conceptualised a mind that successfully progressed through the early stages of development as functioning in the ‘depressive position’ and is summarised by Loshak (2013, p.50) as enabling the mind: “to recognise good and bad in one’s relationships, and oneself, without forming harsh judgements”. This is contrasted to the ‘paranoid-schizoid position’ which emerges when progress through early infant development is disrupted and is characterised by splitting the world into good and bad, leaving little space for anything in between. Elements of both positions are likely to be present in all of us at various times, and for carers, and those professionals who support them, the distinction between depressive and paranoid-schizoid positions are particularly important:

“we may be subject to paranoid functioning at times of emotional strain, and if we do not have secure internal relationships which bring a sense of trust in the world despite difficulties, we will be vulnerable to an accumulation of bad external events and to the possibility of illness”

(Loshak, 2013: p.50).

Essentially the early years of an infant’s life help to inform our relationships in later life, and potentially how we take up the role of carer and our underlying motivations. Underscoring the complexity of the emotional context of dependency and the particular triangular context of providing unpaid and professional care to an adult with mental health issues, Klein (1959, p.252) asserts:

“We are (in certain states of mind) inclined to attribute to other people – in a sense, to put into them – some of our own emotions and thoughts; and it is obvious that it will depend on how balanced or how persecuted we are whether this projection is of a friendly or hostile nature”.

Hinshelwood (2002, p.14) also suggests the idea that people employed in the helping professions, such as mental health professionals, often had the role of carer in their own family and this has become part of their own identity:

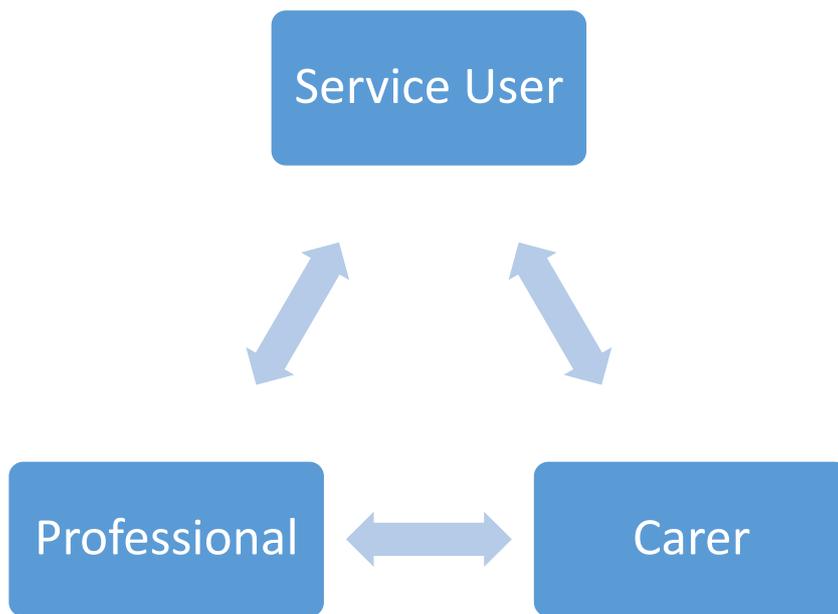
“they may be motivated by unconscious reparative wishes towards their ‘primary objects’, in particular their mother. Such wishes develop, according to psychoanalytic theory, out of a sense of guilt for one’s own destructive impulses”.

This underlines the nature of caring work in its links with fundamental human motivations that transcend categories such as carer and mental health professional. It also serves as a reminder of the idea of ‘professionalism’ founded within distinct professional structures, and associated governing bodies, which serve to mitigate or channel some of this reparative need.

e. Triangles: a psychosocial view of community services

In focusing the research on the relationship between mental health professionals and carers the exclusion of the service user, who is the recipient of the care is acknowledged. This has been a purposeful decision to enable the professional carer relationship to be honed in on, and does not in any way relegate the importance of the user perspective. The research thus provides an opportunity to shine the spotlight in a slightly different direction, taking time to think about caring, and the lives of all those who see themselves as carers within the domain of mental health. Within this system of care the symbol of a triangle is used to denote the respective relationships, and particularly the ‘Triangle of Care’ which depicts an equilateral triangle as a framework for effective mental health service provision:

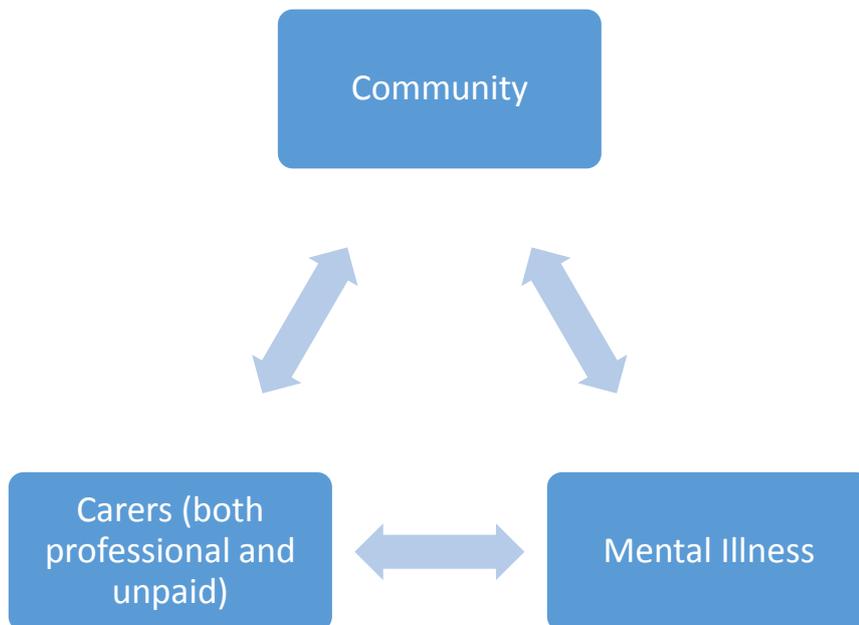
Figure 2.5: Triangle of care



(The Triangle of Care, Carers Trust & National Mental Health Development Unit, 2010)

A psychosocial perspective also values the symbol of the triangle but with a contrasting depiction of the three points, involving the following:

Figure 2.6: Psychosocial depiction of care in the community



(Foster, 1998)

In this second triangular image of mental health care, the mental health professional and carer occupy one corner, the service user (represented by mental illness) is in the second corner, while in the third corner 'community' is represented:

“all three elements need to be kept in mind if care in the community is to become a reality. Only when this is done is it possible to find a third position, that is the position to think about the system as a whole and the different relationships within it in order to avoid getting stuck in a dyadic him/her and me or us and them mode”

(Foster, 1998: p.67).

This greater visibility of people with mental illness has increased the sense of a discrepancy between the wish to cure and the modesty of what is achievable. No longer is it possible to hide away the mentally distressed by removing them from society, and no longer is it possible for family to expel the source of the disturbance from the community to the asylum. The triangle is a vivid image that enables the surfacing of this 'gap', between aspiration and what can actually be realised, and the issue of how professionals seek to manage within this space. In working with this disjuncture Cooper & Lousada (2005, p.109) highlight the challenge and importance of maintaining time for the psychosocial requirements of mental health work amidst the temptation to grab hold of the 'new', be this a new policy, new initiative, or new legislation:

“without a professional voice predicated on what they have come to know in negotiation with the voice of the user, predicated on what they need or experience, and the voice of the community predicated on the articulation of what they are willing to support, there is little chance of creating the dialogue between these different contributions necessary for the alleviation of mental distress”.

This articulation of the triangle is useful in establishing the requirement for the mental health professional to engage with both the service user and 'community' in the form of a carer who may be family, partner, friend, neighbour or work colleague. By holding onto the idea of a triangular space, the ability to find a space in which to reflect is also strengthened. Labelled the 'third position' Foster (1998, p.65) describes this space as providing:

“a capacity for seeing ourselves in interaction with others and for entertaining another point of view whilst retaining our own, for reflecting on ourselves whilst being ourselves”.

The image of hovering above oneself and seeing oneself in relation to the mental health system of service users, carers, and professionals is hugely helpful, and is essentially the quality: “of observing, being observed, and observing oneself that creates the foundations for thinking that is so essential in organisational life” (Cooper & Lousada, p.119, 2005). However amidst the disturbance that emerges from working with mental illness:

“if any one of these three aspects is excluded – split off or overlooked – the possibility of finding the third position in our thinking is lost and the system becomes dysfunctional”

(Foster, 1998: p.67).

Linked to third position thinking, and an outcome of achieving this space, is the idea of ‘containment’; a psychoanalytic term denoting the ability to remain in the depressive position with a capacity to think about and reflect on whatever emotional experience is underway, without reacting:

“we have to manage ourselves and our ambivalent feelings without resorting to projection or retaliation, at the same time managing that which is projected on to us”

(Foster, 2001: p.89).

f. The defended position: coping with distress

The psychoanalytically informed psychosocial approach provides a framework within which to examine the experiences of caring for someone with a mental illness, through the idea of defences which include: splitting, projection and turning a blind eye. The attraction of defences to an individual is that they offer a sense of protection for their own emotional equilibrium, thus enabling them to avoid being swamped by the anxiety that can emerge from caring for someone with a distressing mental illness. Defences provide professionals and carers with a kind of emotional bulwark against anxiety. While this can permit professionals and carers to keep on

caring, it can also mean introducing distance and separation from the lived experiences of the cared for person. However, in creating this form of distance, undetected risks may emerge which threaten the original aim of reducing anxiety, because even greater concerns develop.

Focusing on one form of defence, Foster (2001, p.83) describes the value of mental health professionals 'splitting off' parts of their emotional experience in order to preserve their own mental health, and reminds us that caring for someone involves:

“activities such as the ability to be emotionally in touch with the other person as a whole person; a readiness to consider their pain and their needs and act accordingly”.

This description could apply equally well to both mental health professionals and carers and highlights the challenge of caring within the context of the disturbance of mental illness, and being constantly emotionally 'in touch', although Foster (2001, p.83) underlines an important difference:

“in the professional context, 'a duty of care' reminds us that we owe this to all our clients even those who are not the sort of people we naturally feel warm towards ... we have to manage ourselves and our ambivalent feelings without resorting to projection or retaliation”.

The risks of being too defended lead to the risk of missing vital information on the wellbeing of a mental health service user, whereas constant exposure to the anxiety that emerges from mental illness in the community may lead to burn out. Signalling a middle ground, Foster (2001, p.87) highlights the possibility of temporarily retreating when the emotional experience becomes too overwhelming:

“if we can achieve a fluidity of movement between operating within the defensive system and in the depressive position, the defences – or one might say organisational retreats – may be more like benign ponds than stagnant or malignant backwaters”.

The vivid and triangular imagery that emerges from the psychosocial frameworks to denote the space in which care in the community operates is extremely useful in considering the relationship between mental health professionals and carers, amidst

the distress that emerges from mental illness, and informs the examination of interviews later in this research.

g. Organisational defences: the institution against distress

A seminal study of a large London hospital using a psychosocial approach was undertaken by Isabel Menzies (1960) with the approach later adapted to mental health settings by Hinshelwood and Skogstad (2002). In considering the relevance of the learning from both studies for my own research it is useful to pick out key psychodynamic defences that were identified and overlay them on community mental health services in 2015.

Menzies (1960, p.97) noted that the primary role of the hospital she researched was to accept and care for ill people who cannot be cared for in their own homes, whereby the nursing staff were faced with the daily reality of suffering and death, which aroused:

“very strong and mixed feelings in the nurse: pity, compassion, and love; guilt, and anxiety; hatred and resentment of the patients who arouse these strong feelings; envy of the care given to the patient”.

Within the specific context of mental health there is a difference to the general hospital studied by Menzies, as the fear of madness emerges as the key source of anxiety, rather than fear of death:

“madness has a specific quality of terror for human beings, and the fear of it is probably managed in various ways by different people ... avoidance is based on the attitude that madness comes from intimate emotional contact with others”.

(Hinshelwood, 2004: p.122)

Significant in its potential relevance for the experience of carers in community mental health settings, Menzies (1960, p.99) noted that patients and relatives have equally complicated feelings about the hospital. On occasions they are appreciative and grateful, whilst at other times: “relatives may feel demanding and critical, resenting any suggestion that the hospital implies some inadequacy in them”, and that some of the patients were actually in hospital, not because of their physical condition but

because they and their relatives: “could not tolerate the stress of their being ill at home”.

Menzies (1960, p.98) argues the situation confronting the nurse:

“bears a striking resemblance to the phantasy situations that exist in every individual in the deepest and most primitive levels of the mind”.

Menzies then draws on the work of Klein (1946, p.2) who considered the first stages of life of the human baby:

“object-relations exist from the beginning of life, the first object being the mother’s breast which to the child becomes split into a good (gratifying) and bad (frustrating) breast; this splitting results in a severance of love and hate”.

Successful navigation of this early period of life, known as the paranoid-schizoid phase of infancy, lasting from birth to around 3 months, leads to the depressive phase where the infant is able to introject or internalise the parental figure as a whole, rather than ‘split’ between good and bad. Menzies specifically focused on professional nursing students, nurses and managers and categorised a series of defences, which resonate in the present day organisation of community mental health services, and the relationship between mental health professionals and carers. The table below summarises the nature of defences identified by Menzies ((1960) and considers their relevance to present day community mental health services.

Figure 2.7: The nature of defences in present day community mental health services

Category of defence identified by Menzies	Applicability in present day community mental health services?	How it applies to the relationship between mental health professionals and carers
Splitting the nurse-patient relationship	Highly likely	This may emerge by one mental health professional i.e. ‘care coordinator’ being focused on coordinating one aspect of care, and a different professional i.e. ‘care manager’

		undertaking another part of the work. It may also emerge through one professional being allocated to the service user and a different professional allocated to the carer, or through one professional undertaking a specific intervention i.e. psychological treatment, without being aware of the wider care network.
Depersonalisation, categorisation and denial of the significance of the individual	Likely	The use of tick box lists, structured templates and care pathways based on psychiatric diagnosis take the focus away from relationship based practice. The priority may become delivering a 'package of care' that contains a prescribed range of treatments/forms of support described within the care pathway.
Detachment and denial of feelings	Highly likely	'Professional distance' rather than 'detachment' is a feature of community mental health professional practice. However the potential to become too detached and isolated from the disturbance that is generated by mental illness exists in community mental health work. There is a subsequent risk that a key issue may emerge that is undetected owing to the detachment that has taken place between the service user, carer and professional.
Attempt to eliminate decisions by ritual task-performance	Moderately likely	The risk of overly ritualised task-performance based practice is less significant in community mental health services where those daily rituals associated with inpatient areas (such as making beds) are less pronounced. However there is a risk of being too focused on a set of 'tasks' as components within a prescribed care plan, to the detriment of having a relationship with the service user and carer. Tasks might include: refer for a psychology assessment, complete a travel pass application, or liaise with a day centre. Each task may be very supportive, but

		in themselves do not provide a substitute for a meaningful relationship.
Idealization and underestimation of personal development possibilities	Moderately likely	Risk of under investment in relational practices, owing to a view that mental health professionals have inherent 'personal qualities' that cannot be developed through training.

(Cooper & Lousada (2005), Dept of Health, Caring for People: The Care Programme Approach (1990), Hinshelwood (2004), Hinshelwood & Skogstad (2002), Loshak (2013))

5. Summary and conclusions

This chapter has reviewed the literature surrounding caring within the context of mental illness and has examined the development of mental health services which were pulled, seemingly screaming and kicking, from the old long stay psychiatric asylums, into the space known as the community. Since the arrival of mental health services in the community a number of philosophies have influenced their evolution although the one constant has been the heavy reliance on the support of carers, be they family, partners, friends or neighbours. The development of the various models have at times been led by health services (National Service Framework) and at other times by Social Services (Personalisation) and this back and forth process is likely to have dissipated the necessary focus that is required to improve care. More latterly the call for mental health care to be afforded greater equality with other forms of healthcare, through the parity of esteem initiative, is timely although whether anything will alter in terms of a financial settlement is not known at this point.

Coinciding with the emergence of mental health services and service users from the asylum, carers gained greater visibility with a series of legislative acts that culminated in The Care Act (2014). Led by women, particularly single women, caring has gained traction in the national narrative, and the role has become familiar and an accepted part of life. How well this national awareness has been able to engage with the daily reality of caring is uncertain, and the impact of mental illness on the lives of carers is still submerged below the familiar headline 'support the carers'. Although recognised in national legislation, the extent to which any of these

new rights have actually changed the day to day reality for carers who live amidst the disturbance and distress of mental illness is unknown, and is a key question for this research.

Finally, in exploring the psychoanalytically informed psychosocial approach, the value of operating at both surface and depth levels was highlighted and is a unique research window. In this section the idea that 'below the surface' a dynamic world exists, containing anxiety, heightened emotions, and a battery of defences that influence individual, group and organisational behaviours, is vital for researching the relationship between mental health professionals and carers, which straddles private and public spaces. The importance of the community care 'space' being triangular was explored, and the recognition that risks emerge if any of the corners are overlooked, was a reminder that caring in the context of a mental health condition is unlikely to be successful through the sole efforts of an isolated individual.

The next chapter will seek a research methodology which most effectively enables the dynamics of caring for someone with a mental health condition to be explored.

Chapter Three

Methods Employed to Research the Experiences of Mental Health Professionals and Carers

1. Introduction

The previous chapter explored the literature relevant to the dynamics of caring including various perspectives on mental distress, the movement of mental health services into the community, growing awareness of caring from the 1960s onward, and finally the contribution of psychoanalytically informed psychosocial perspectives in understanding the dynamic relationship between mental health professionals and carers.

This chapter outlines the research methodology and begins with a brief recap of the research area, before exploring the drivers that led me to this area of study. The chapter then examines the wider theoretical framework of the research, including the psychosocial nature of the approach, before reviewing the design of the study, and the nature of the dilemmas that emerged as part of an ethical framework. In the second half of the chapter the research process is outlined, including the recruitment of participants, before going on to examine how the material that emerged was analysed. Finally, there is consideration of the structures that were available to support and supervise the research being undertaken.

In undertaking the research I have been mindful that I am not a neutral and objective investigator; I work as a manager in the area of the research and I have a range of professional and lived experiences that influence me. To support myself I have strived to take the position of a 'reflexive practitioner-researcher'. This has been supported through supervision and being part of a research support group, two spaces which have helped me to be open to both the conscious and unconscious material emerging from the research process. The idea that occupying the role of practitioner-researcher is underpinned by the notion of 'practice near' research has also been helpful through its concern for the study of relational approaches to practice and policy which requires:

“the engagement of self, and that personal change is inevitable through the work of being open to the ‘smell of the real’”

(Frogget et al, 2009: p.380).

2. Area of research

In undertaking a study of the dynamics of caring for people with long term mental health conditions three research questions were identified within the research proposal:

- How do mental health professionals and carers for people with long term mental health conditions experience each other?
- What is the nature of the lived experience of caring for someone who has a long term mental health condition?
- How do elements of sacrifice and burden, as well as satisfaction and reward manifest themselves in caring for someone with a long term mental health condition?

As can be seen in this brief summary of the research, the area of interest stretches across public and private worlds, from the domain of the formal workplace of health and social care to the private and intimate environment of family life, emotional partnerships and friendships. In my consideration of a methodology I had in mind the importance of being able to access these various public and private worlds, and in doing so, be supported to bring to the surface, material about the essence of caring for people with mental health issues, and the relationships between those that are involved in caring, be they paid or unpaid. The value of a qualitative and psychosocial approach which was able to provide coherency between the various elements of the research area, and between the individual's inner world and the wider social world that we are part of, was at the front of my mind from the outset. Frosh (2003, p.154) writes of such a psychosocial subject as:

“a meeting point of inner and outer forces, something constructed and yet constructing, a power using subject which is also subject to power, is a difficult subject to theorize, and no one has yet worked it out”

The idea of getting below the surface of everyday experience and enabling the real experiences of mental health professionals and carers to emerge is a key aim of the research. Price and Cooper's (2012, p.55) reflections on observational research resonate in their argument for the importance of the 'ordinary' and 'in between moments' and not simply looking for a 'key event':

“this shift of attention to the mundane, to what actually happened, takes considerable practice and effort”.

Continuing with the idea of getting below the surface, Waddell (1989, p.11) draws on George Elliot's novel 'Middlemarch' to describe the ways in which we seek to defend ourselves from being overwhelmed by too much human distress, and need to be protected from being overwhelmed by the extent of suffering that surrounds us:

“if we had a keen vision and feeling of all ordinary life, it would be like hearing the grass grow and the squirrel's heart beat, and we should all die of that roar that lies on the other side of silence”.

In commencing the research I was interested to find out how the idea of being defended against the 'roar that lies on the other side of silence' resonated within the relationships between professionals and carers in their care for a mental health service user. Based on elements of all of these ideas I wanted a methodology that permitted a greater understanding of the essence of caring, got below the surface, and valued my experiences as a reflexive practitioner-researcher.

3. Practitioner researcher - my background

At this early stage it is useful to share a little more about the drivers for the emergence of the research methodology used, and why certain features were prioritised. Clarke and Hoggett (2009, p.7) outline such a discipline:

“why are we interested in our research project; why choose this area and not some other? What is our investment in it and how will this affect the way we go about the research?”

In order to draw this out I want to share reflections on my 'multiple identities'; as a practitioner researcher approaching an area of interest, a senior NHS manager

within a mental health trust, and prior to taking up a management role as a qualified social worker with many years of experience working in mental health services.

My personal life has also been increasingly shaped by taking on the role of carer for a member of my own family who has become a user of mental health services, and the need for me to provide emotional support as an essential element of care.

In voicing the various experiences that have shaped both my working and personal life, and which influence my thinking about carers and mental illness, I was keen to identify a methodology that enabled me to move into a research stance that would be open and welcoming of my own subjectivities, while permitting me to surface new insights that could speak to many. Clarke and Hoggett (2009, p.3) summarise the quality of the reflexive researcher as being engaged in:

“sustained self-reflection on our methods and practice, on our emotional involvement in the research, and on the affective relationship between ourselves and the researched”.

From a methodological position reflexivity is defined by Bryman (2012, p.393) as the ability to be able to think about: “the implications of their methods, values, biases, and decisions for the knowledge of the social world they generate”. Acknowledging the importance of reflexivity, and linked with the idea of multiple identities which were referred to earlier, is the nature of power within society, and the continued inequalities of particular groups, including those characterised by race, gender, ethnicity, sexuality and disability, including mental health. Acknowledging my position in this social world as a white man holding a senior management role was a further source of reflection and discussion in supervision, and I was encouraged to take up a practitioner researcher stance in an engaging and enquiring manner. This operated at many levels, from how my choice of casual clothes could help to engage participants in talking about their experiences, whilst a formal office suit might raise barriers, through to introducing the context of the research to participants within the intimacy of a one to one interview. Again it was important to select a methodological stance that acknowledged the complexity of the human social world, and my role within this, and ‘spoke’ to the issue of engagement as a requisite to the research enquiry. From a psychosocial tradition Price and Cooper (2012, p.64) underline the knotty nature of the research environment for the researcher who:

“becomes a transference object for those inhabiting the field, as they do for her, and contributes to and alters the functioning of the field (even if marginally) as she becomes entangled in the transference – counter transference dynamics and enactments”.

Through my experiences in the workplace I have also been able to observe the complexity of relationships between statutory and non-statutory organisations and services, and between carer groups and individual workers and carers. This is an environment that is continually being shaped by performance and quality imperatives driven by national and local priorities. During the period I undertook my research a new government was formed and The Care Act (2014) came into force setting out new legislation aimed at improving the experiences of carers. In broadly the same period, the Care Quality Commission (CQC) announced a new inspection regime to evaluate health organisations in a process similar to school inspections (CQC Specialist Mental Health Services, Provider Handbook, 2015). This inspection framework operates within the context of measures to improve the quality of care.

The other experience I was able to bring to the research methodology was the accumulated experience of my work life; especially a form of ‘auto-ethnography’ the particular place that carers have held throughout my professional experience. Here again, the idea of ‘practice-near’ research supports me to step ‘outside’ my role within the workplace. It enables me to adopt a stance in relation to my experiences of community mental health work with a concern: “for the study of emotionality and relational approaches to practice and policy” and develop: “a different dimension through experience-close research” (Froggett & Briggs, 2009: p.378). In observing the increasing recognition that carers attract at a national level, I have remained curious about the junction between public and private lives, and why on one hand there is universal public support for carers and the ‘vital role’ they undertake, while on the other hand carers often appear to be personally let down by their experiences in relation to services. I have heard a mixture of messages about service delivery from various contacts with carers; from hearing about what they valued and found helpful, to how they have been left feeling marginalised and disappointed. This all forms a backdrop to the research enquiry and points to the value of interviewing both mental health professionals and carers in order to hear their accounts.

The role of carers in mental health services has always been more opaque than other areas of care; and Barnes (1998) reminds us there are no broken bones to attend to, and rarely are psychiatric hospital beds surrounded by flowers and 'get well soon' cards. In terms of methodology, this creates particular challenges in attracting research participants who may not wish to be associated with mental illness, and may not wish to be labelled as a carer and therefore come forward to share their experiences. The emphasis on the process being confidential, taking place in a containing environment, and an opportunity to 'tell your story' encourages those people who may be reluctant to make contact.

4. Philosophical foundation - how an approach was developed for the research

The next section describes how I developed my theoretical footings as a practitioner researcher and with these foundations in place, how I was able to build the methodology and analysis.

a. Ontology in my doctoral journey

From early on in my doctoral journey it helped to consider the area of research belonging within the social world, and in this sense it required a distinctly different approach from those traditionally associated with research in the natural sciences. Although the interfaces between research in the natural sciences and social world continue to be debated, the key point is whether social entities can be viewed as having an 'existence' in their own right: "whether they can and should be considered social constructions built up from the perceptions and actions of social actors" (Bryman, 2012: p.32).

Having identified the need to be in the sphere of the social world, a key ontological debate that must be navigated is the nature of social reality, whether it actually exists as an entity capable of being studied and, if it does exist, how its very essence is constructed. Connecting these fundamental questions to my area of interest, I was forced to consider issues such as:

- Do the relationships which mental health professionals have with carers actually 'exist' outside the actual contacts with one another?

- Is there anything about the behaviours and interactions between mental health professionals and carers that is 'additional' to those policies and protocols that are ascribed within the various organisations?
- Is there any material that could be surfaced that would be meaningful beyond what might be gleaned from the relevant rules, policies, regulations, statutes and law?

In drawing directly on my manager-practitioner experience I was able to recognise that there are in fact experiences, patterns, and ways of working that exist over and above the regulations for the conduct of mental health professionals and the policies for supporting carers. Indeed, the wide range of relationships that are developed between mental health professionals and carers do not appear to result from any specific policy directive, but from the 'personal' and the dynamic of two individuals coming together with a shared interest in an individual with a mental health condition. In approaching the research I also had a sense of issues constantly being discussed, negotiated and developed in a manner redolent of 'constructionism' where agreements are made, accommodations reached, and shared understandings permeated among people. As Bryman (2013, p.33) identifies: "it implies social phenomena and categories are not only produced through social interaction but that they are in a constant state of revision". This is in contrast to 'objectivism' which argues that people simply execute the rules relevant to their place in an organisation, or in wider society. It claims that organisations, or societies, have primacy, and the people that work within them merely deliver a service in the manner they have been employed to undertake:

"They learn and apply the values in the mission statement. If they do not do these things, they may be reprimanded or even fired. The organisation is therefore a constraining force that acts on and inhibits its members"

(Bryman, 2012: p.32).

While aspects of both approaches described above will apply more or less strongly in different contexts, the contributions of various social actors within the health and social care work environment aligns more consistently with a constructionist perspective.

b. Epistemology – setting the research ‘compass’

Having noted the ontological distinction between constructivism and objectivism, the next step was to set about acquiring the equivalent of a research ‘compass’ that would enable me to undertake the study, confident in the form of material that would be surfaced. At one end of the epistemological spectrum lies positivism, which elevates a version of scientific enquiry able to generate experiments that ‘prove’ facts and can then be replicated independently by others:

“phenomena are seen as independent of and unaffected by the behaviour of the researcher, consequently the researcher can be objective in his or her approach and the investigation can be viewed as value free”

(Snape and Spencer, 2003: p.13).

At the other end of the spectrum, and at odds with the premise inherent within positivism, lies interpretivism which focuses on the social world and emphasises the range of different ways of researching the nature of human social life and accurately reflecting its complexity:

“the relationship between the researcher and the social phenomena is interactive. In this case, the researcher cannot be objective and cannot produce an objective or ‘privileged’ account”

(Snape and Spencer, 2003: p.13).

Commenting on the distinction between the two approaches, Bryman (2012, p.28) regards the ‘clash’ as positivism having an explanation of human behaviour, whereas interpretivism is most concerned with: “the emphatic understanding of human action rather than with the forces (that) deemed to act on it”. From this perspective the approaches are differentiated in terms of their contrasting remits, with neither one nor the other regarded as better or worse, but more or less appropriate depending on the research context.

Returning to the focus of this examination of the relationship between mental health professionals and carers within the context of the positivism-interpretivism spectrum, it was the interpretivism approach, with the aim of enabling a deeper understanding of the experiences of mental health professionals and carers which was deemed the

most appropriate approach, with the expectation of reflexivity on my behalf. Reflexivity on behalf of the researcher ensures all the implications of methodology, values and biases are considered, and: “entails a sensitivity to the researcher’s cultural, political, and social context” (Bryman, 2012, p.393).

5. Methodology

Having established that for this research the ‘best fit’ from an ontological position is from a constructionist approach, and from an epistemological position is from a tradition of interpretivism, it is timely to examine the research methodologies that were selected to help to unpack the research questions set out in section 2 of this chapter.

a. Recapping the area of research focus

Caring for people with mental health conditions and the relationship between mental health professionals and carers was explored in Chapter 2, with recognition of the triangle, or ‘triangle of care’ comprising of the mental health service user, carer and mental health professional at respective points of the triangle. Therefore a methodology was required that was able to operate across various relationships, and bridge between the public domain of mental health professionals and the private and personal lives of carers.

In order to unravel the threads and entwined relationships involving caring and relatedness, a straightforward sociological approach would inevitably enable the emergence of useful society-wide issues that many carers face, along with the experiences of the workforce involved in the delivery of mental health services. However, it would also quickly draw attention to the limit of its remit, such as not sufficiently exploring the emotional lives of carers and professionals, and would struggle to accommodate the dynamic relationships between those individuals who live and work within the ‘triangle’.

Adopting a purely psychoanalytical or psychological approach however, would risk shining a light too harshly on the individual’s inner world, forcing the issues into a narrative that applied solely to inner emotional dynamics, with the risk of paying insufficient attention to the wider societal elements of caring which help to shape carer identities, and how carers interact with professionals and vice versa. The aim

therefore was to be able to achieve a view of all the subjects' experiences which fully engages with all of the complexity:

“people’s struggles with the constraints and possibilities of their social circumstances; their unique biographies; their creative capacities; their ethical impulses and the conditions that compromise these impulses; the vulnerability but also the robustness of human psyches in the face of painful, sometimes unbearable assaults on psychological survival”

(Hollway & Jefferson, 2013: p.143).

To avoid the pitfalls of sole reliance on either of these approaches, the research had to be invested in identifying a methodology that was able to span the psychoanalytic and social worlds that we inhabit and the selected methodology will be described below.

b. Psychosocial methodology

Clarke and Hoggett (2012) argue that the familiar split between ‘individual’ and ‘society’ is increasingly being recognised as unhelpful and suggest that the psychosocial approach brings together psychoanalytic concepts and principles to shed light on particular issues in the social sciences. This resonates directly with the field of this research where:

“there are typically many research subjects within it, all of whom can be conceptualised as having their own inner lives, enacted through their modes of relating. Members influence each other intersubjectively and unconsciously, and the observer too has no privileged uncontaminated epistemological position within the field”

(Price & Cooper, 2012: p.64).

In its claims to synthesise the inner unconscious world of an individual and the wider social world of communities and society, a methodology derived from the psychosocial approach makes available at least three analytical dimensions. Firstly the structural explanation is able to explain how certain social phenomena occur:

“psychoanalysis addresses this deficiency by recognising the role of the unconscious mind in the construction of social realities, with its suggestion

that feelings and emotions shape our perception and motivation, constructing the way in which we perceive others”

(Clarke and Hoggett, 2009, p.6).

In the second dimension Clarke and Hoggett (2009) explain: “the psychoanalytical method recognises the role of the researcher in the interpretation of realities and the way in which unconscious forces shape the research environment” (p.6). Finally, within the third dimension: “there is an integration of social, cultural, and historical factors at a conscious level, which yields information about unconscious motivations and defences” (Clarke and Hoggett, 2009, p.6). In the culmination and combination of all three analytical dimensions, the potential for a psychosocial approach is produced that enables the researcher to engage authentically with the challenge of the social world, in which: “each and every situation or context is unique and particular, and must be understood – ‘apprehended’ in its own terms” (Cooper, 2009: p.440).

6. Research design methods

a. Method 1 – Individual Interviews

The value of interviewing subjects is particularly useful where the complexity of the area being studied does not lend itself to observational approaches of the ‘natural setting’, and particularly where the carer relationship does not take place in a single physical location that can be easily ‘observed’. Ritchie and Lewis (2009, p.58) argue:

“very complex systems, processes or experiences are generally best addressed in in-depth interviews because of the depth of focus and the opportunity for clarification and detailed understanding”.

Before confirming which methods I would use I considered other approaches such as observation and action research but soon began to discount them. For example, while elements of action research may have benefits with professionals embedded inside the organisation, the research aims required the engagement of an array of carers, some of whom would be hard to engage with owing to the nature of their caring activity, and sense of stigma in being linked with mental health services. In terms of observation, the actual activity surrounding care in the context of mental health does not easily lend itself to observing a distinct or regular form of caring

activity, and is often about emotional support that is dynamic and fleeting. Any concerns about 'hard to engage' carers proved to be only partially substantiated, and although carers required prompting to attend the Focus Group they were generally very interested in volunteering to participate in the research.

Acknowledging the benefits of the interview approach permits consideration of how the interview should be conducted, and the nature of the narrative that is produced. Andrews et al (2009) highlight a number of distinctions in generating narrative from interviewing. This includes whether the stories shared by participants are representing 'internal individual states' or 'external social circumstances', and whether narratives are shaped by the 'audiences' to whom they are delivered, and if so, to what extent. This is particularly relevant for the approach I took, in acknowledging the interview narratives that emerged were valued in regard to what they conveyed about external events and experiences, as well as generating data about the individual, and their internal emotional worlds.

(i) Methodological approach to participant interviews – Free Association Narrative (FAN) Interviewing

In an earlier module of my Doctorate in Social Work I had been introduced to research methodologies and been required to experiment with a particular style as part of a marked assignment. This enabled a 'pre-pilot' and first introduced me to the Free Association Narrative (FAN) interviewing approach. For the purposes of the assignment I piloted the approach on a therapist researcher working in a recovery centre for people with long term mental health conditions. At its simplest I found the approach of '*tell me your story*' to be an elegant and straightforward way of 'releasing' information from this participant, comprising information about events and experiences, as well as how they personally felt.

In being exposed to several methodological approaches through the course of the module I realised that I had to be discerning in the selection of an approach, and had a sense of needing to become more like a 'consumer' and to exercise my choice based on as much information as possible. At this point the doctoral research methodology group was introduced to the biographical narrative interpretive model (BNIM) and I immediately saw the benefits of the approach in helping to illuminate

often poorly understood, and rarely aired, aspects of our psychosocial lives. I undertook a training course in BNIM research and quickly became acquainted with its strengths and discipline in conducting interviews, analysing text and use of panels to triangulate and strengthen findings. For a time it was an approach that I felt would be helpful in learning about my own area of interest which rests at the juncture between mental health professionals and carers, and their experiences of caring for adults with long term mental health conditions. As the initial excitement of undertaking the BNIM training course dissipated I took up a more dispassionate position, reflected on the characteristics that I required from a research methodology, and considered the strengths and weaknesses of both approaches more formally in a tutorial session.

While the BNIM model asserted its credentials in terms of rigorous pursuit of particular data derived from the narrative, the FAN interview approach had been a success in my initial pilot and a number of advantages emerged for its application in my specific field of enquiry:

- It resonated with the idea that research participants would be ‘defended subjects’ with material that was rarely spoken about, but which might be accessed by adopting a psychosocial approach that valued the slips, pauses, corrections and misunderstandings in narrative;
- It valued me as a researcher with the multiple roles and identities outlined earlier. Within the context of this complexity and risk of confusion and bias the FAN interview approach encourages reflexivity: “without examining ourselves, we run the risk of letting our unelucidated prejudices dominate our research (Finlay, 2003, p.108 cited by Hollway and Jefferson, 2013, p.157);
- Key aspects of the FAN interview approach such as follow-up and elaborating questions are able to be used flexibly and adapted so that many of the elements are able to be transferred to other settings, such as the focus group which was another part of the research design.

Having identified the suitability of the FAN interview approach I decided to undertake the interviews in two phases: In phase one I interviewed carers, and in phase two I interviewed mental health professionals. Using this phased approach permitted me to build up a body of material from the carer participants before going on to interview

mental health professionals. As the researcher I also found it helpful to hear from one group and have time to be able to digest their views and discuss them in supervision and group tutorials, before going on to hear from the second group. I first compiled data from carers, and then went on to organise meetings with professionals.

(ii) Pilot interviews

I piloted the FAN interview with both a carer and a mental health professional. The carer was an individual whom I had met several times before through her representation of carers at various meetings, and she was someone whom I felt would be able to be assertive in evaluating the interview process. At the end of the pilot she provided feedback that she had felt comfortable with the arrangements and interview structure, and also commented that it had encouraged her to share information about her caring experiences that she had seldom talked about previously, despite being involved in a range of carer initiatives. The success of the pilot meant I was able to proceed with interviewing the group of carer participants utilising the same FAN interview approach.

The pilot FAN interview with a mental health professional ended much more quickly than I had expected, and led me to ask a number of supplementary questions following their clipped responses. The pilot interview with a professional was a helpful practice run that enabled me to consider the benefits of a more relaxed interview style, although the contrast between carer and professional responses remained a theme that re-emerged at times throughout the research process.

(iii) Recruitment - Carers

Recruitment of carers was undertaken by publicising the research through a Carers, Friends and Family Reference Group, chaired by a senior executive of the NHS Trust that I work for. The Reference Group brought together carer representatives from several London boroughs, and permitted publicity about the research to be circulated. The second strand of recruitment was through an independent carers' organisation operating two carers' centres based within the community. I was able to secure attendance at a regular group for carers for people with mental health

issues to publicise the research, and a flyer was sent out to the entire membership as part of a regular bulletin (see Appendix F).

Within supervision I was able to reflect on my own anxiety about securing as diverse a group of carers as possible based on gender, age, race, and 'carer and cared for' relationships. The discussion helped me to see the response to the recruitment efforts as an important part of the data, with the response potentially being reflective of the nature of caring, and who defines themselves in these terms. At the end of the recruitment phase I was able to observe that more women than men had responded, and among these were a significant number of mothers caring for their adult children. Despite this, a range of carer relationships were represented in the responses including: partners caring for their husband/wife/partner, and sibling carer relationships.

The one carer and cared for relationship not represented in the one-to-one interviews is an adult caring for their mother or father. In terms of sampling this absence relates to the idea of 'symbolic representation': "units are chosen because they typify a circumstance or hold a characteristic that is expected or known to have salience to the subject matter under study" (Ritchie et al, 2003, p.83). In discussion with the Carers' Centre about this 'gap' it became clear that this group, adults caring for a parent with mental illness, were also under-represented at the centre, and the response to the research therefore mirrors an existing dynamic. A further reflection was whether an adult caring for their mentally unwell parent may have been too busy, perhaps simultaneously caring and employed in the formal workplace, that they were not able to commit to being interviewed for a research study.

Along with interviewing carers who lived with the cared for person, I interviewed those who maintained a carer relationship but lived separately, and in one case, at some distance. While this was not a distinction that I had considered important at the beginning of the research, it emerged as a distinguishing feature that some carers felt was significant within their experiences of caring.

(iv) Recruitment – Mental Health Professionals

As a practitioner/manager-researcher I had been excited about the strong interest shown by carers to the opportunity provided by the research to talk about their

experiences. In turning to the recruitment of professional workers I felt less positive and somewhat wary about the process. I used tutorial and supervision to reflect on the issue and why I was feeling reluctant to embark on this phase of the data collection. Although the organisation I work in is relatively large and spread over a wide geographical area, the idea of exposing myself to colleagues 'as a researcher' emerged as one element of my hesitation in engaging colleagues. It is relatively unusual for managers, let alone practitioners, to embark on research within the health and social care workplace, and in doing so I felt I was exposing myself by declaring an interest in a particular aspect of the work. I reflected that in stepping out of one role as a manager, and into another as a researcher, I was asking for help, and asking people to step forward in response to the request I was making in the recruitment poster. Stripped of the authority of management, there was also an inherent risk of being rejected and being turned down in my request for participants to come forward. A further anxiety was the possibility that participants would come forward prompted by my senior role in the organisation and as a figure of authority, with the risk that this would then distort their contribution to the research, i.e. saying what they think I want to hear.

The second element of reluctance involved my area of study. While it is familiar and on the surface seemingly straightforward: 'how carers and mental health workers experience each other', on another level touches on something that is potentially disturbing to talk about. That is, the examination of the relationship between professionals and carers, who are generally idealised by professionals who use terms such as: valuing carers, working together with carers, and being in partnership with carers. I fantasised that in publicising my research interest I was threatening the thin 'exoskeleton' that defends mental health professionals from the turmoil of mental illness: "close emotional contact is believed to cause madness, and that attitude leads to work practices (defensive techniques)" (Hinshelwood, 2004: p.122).

Supervision helped me to reflect on the basis of my discomfort and encouraged me to jump in. In order to gain interest I used a flyer and poster approach to publicise the research, and used the Trust's intranet and electronic weekly bulletin board, and identified myself as a researcher. A handful of respondents initially contacted me and I was immediately struck by their confusion about the nature of my research. Two employees whom I had never met previously responded that they were actually

carers for people with mental health issues in their own personal lives. A third worker initially indicated their interest and then asked to withdraw because they were not actually a carer in their personal life.

These confusions about carer roles and how people see themselves in relation to care were helpful to reflect on, and became part of the research data.

As well as utilising electronic means to publicise the research across the entire organisation I contacted heads of profession within the Trust, and asked them to publicise the research among their members. This supported the recruitment of a range of professionals from different backgrounds including: social work, community psychiatric nursing, medicine (consultant psychiatrist), art therapy and family therapy. Furthermore, a range of different services were also represented including: community mental health, early intervention in psychosis, acute inpatient, out-of-hours, and family therapy.

(v) Interview arrangements

Interview arrangements for both groups were similar in format. The interviews with the carers largely took place in a community based carers' centre where I was able to book a quiet and confidential space. The interviews with the professionals took place within workplace interview rooms that were separate from their actual place of work. This avoided the risk of interruptions and distractions from colleagues and work demands.

Interviews with both carers and professionals were recorded using a Dictaphone device which was later used to produce a transcript. I considered employing software technology to undertake the transcribing but found that in doing it myself I was able to become more immersed in the material, and conversant with the issues. In preparing for the interviews I was mindful of the four key aspects to FAN interviewing:

- Preparation of open ended questions;
- An inviting approach to elicit the participant's story i.e. 'tell me about your background';
- Avoid using 'why' questions;
- Use the participant's own ordering and phrasing.

This last point is elaborated on by Hollway and Jefferson (2013, p.34):

“By eliciting a narrative structured according to the principles of free association, therefore, we secure access to a person’s concerns, which would probably not be visible using a more traditional method”.

Shortly after each interview I also wrote a reflective account of the session in a manner that I adapted from previously undertaking baby observations and organisational observations (Bick, 1968, Mattinson, 1992, Hinshelwood & Skogstad, 2002). The key difference with the baby observation method was permitting myself to write very brief notes as the interview took place, which in a baby observation is intrusive, but within the context of an interview felt much more conventional, and enabled me to move from looking directly at the participant to my notebook, thereby helping engagement. These notes also enabled me to add information over and above the recording of the spoken word, for instance: adding details about the physical nature of the interview, the way the participant behaved, what they wore, and how they responded in terms of non-verbal communication. For example, in interviewing a consultant psychiatrist working within an inpatient ward setting I wrote: “bedside manner, calming and confident, might be impressive to carers?” (Reflective write up, 7:5).

(vi) Follow-up interviews

While the possibility of follow-up interviews was outlined in the information sheet, none were requested and none were carried out. In hindsight, some of the lengthier interviews, particularly with carers, may have benefited from being spread over two sessions although this carried the risk that the narrative flow would have become fragmented.

b. Method 2 – Focus Group

The focus group was arranged after both phases of the one-to-one interviews had been completed, and enabled me to introduce some of the key themes and ideas that emerged in the interviews for discussion by a wider group of participants, all involved with caring and mental health. Bryman (2012, p.502) makes the point that the focus group is a form of ‘group interview’ and draws out elements of two methods, firstly several people discussing a number of topics, and secondly:

“what has been called a focused interview, in which interviewees are selected because they are known to have been involved in particular situation and are asked about that involvement”.

Within this framework the focus group for this research incorporated characteristics of the second method as all the participants had connections with the subject material.

Unlike the one to one interview a focus group also facilitates space for individuals to disagree, argue and challenge each other:

“this process of arguing means that the researcher may stand a chance of ending up with more realistic accounts of what people think, because they are forced to think about and possibly revise their views”.

(Bryman, 2012: p.503)

Originally I had imagined three focus groups separately arranged for carers, for professionals, and for managers. Within supervision I was encouraged to re-examine the rationale behind this separation and to discuss what had been in my mind in designing the research in this manner. Through reflection within this supportive framework I was able to identify my anxiety to control and maintain separation between the parties, and my fears about the turmoil that would ensue if I brought them all together in the same room. My wish to have separation in the research design mirrors the separation that exists within health and social care organisations, including those that provide mental health services; in the boundaries that are erected between staff, carers and service users, and the policies and protocols that maintain these divisions. As a researcher and NHS manager I was therefore facing the prospect of a combined focus group that meant letting the carers ‘inside’, but also letting the professionals go ‘outside’.

Through acknowledging my anxieties about bringing carers, professionals, and managers together I was able to gain a new perspective, and to see a methodological rationale for the dynamic of uniting everyone in one group. By adapting and developing the design in this manner the combined focus group enabled me to see at first-hand how professional-carer dynamics played out within

the structure of the group, something that would not have been possible in the separate groups:

“In responding to each other, participants reveal more of their own frame of reference on the subject of study. The language they use, the emphasis they give and their general framework of understanding is more spontaneously on display”.

(Finch & Lewis, 2003, p.171)

(i) Recruitment and attendance

I realised that recruitment for a focus group would need a different approach from that of the one-to-one interviews, which had offered the security of a confidential and private space to share experiences. In contrast I was struck by the invitation potentially being viewed as exposing and something that prospective participants may actively want to avoid owing to the risk of having a difficult experience. I was also aware of my own concerns about being drawn out of researcher mode. In my reflection before recruitment I realised I was relating most strongly with the mental health professionals, and feeling worried about the possibility that they may become overly anxious and defensive if criticised by carers. I also felt worried that if the professionals were attacked then they would blame me for putting them in this position by throwing them into the ‘lion’s den’. Again it was useful to stand back from the situation and reflect on earlier discussions, including the importance of opening the focus group by re-emphasising the exploratory nature of research and the opportunity for us all to learn.

About two months before the focus group was due to take place I started a second publicity campaign within the Trust and among all the carers known to the local carers’ centre and carers’ family and friends’ reference group (see Appendix F). I wanted to ensure the focus group participants were different from those who had taken part in the interviews to enable a greater range of views to be drawn on. As well as the provision of a sandwich lunch, on the poster I highlighted that the group was an opportunity to share experiences, noted the positive nature of the group, and what it was setting out to achieve.

I arranged the session to optimise convenience for all attendees, starting in the middle of the morning at a location near to public transport, with tea and coffee on arrival, and a sandwich lunch on completion of the 90 minute session.

The need to ensure the group was sufficiently large was a key consideration, and I reviewed the literature that considers the strengths and weaknesses of large and small groups, and the inherent risk of participants committing to attend, but then not turning up:

“One major problem faced by focus group practitioners is people who agree to participate but who do not turn up on the day. It is almost impossible to control for ‘no-shows’ other than consciously over-recruiting, a strategy that is sometimes recommended”

(Bryman, 2012, p.507).

In terms of actual group sizes there is no recommended size, but the risks of too small or too large a group are material. For example in larger groups some participants may not wish to speak, whereas in a smaller group the role of the researcher may be called upon more frequently to fill the time. I will come back to this below in terms of actual arrangements for my own group.

I was also struck by the pressure to get the design ‘right first time’ and having limited opportunity to conduct a pilot focus group which would practically mean drawing together a fairly large group in order to ‘practice’. In the absence of a formal pilot I was able to use supervision to do a practice run on the running order, and to trial the case vignettes (Appendix D). The carer research assistant (examined below) also provided feedback on the case vignettes and shared her responses to each case, which permitted me to tweak and adjust the wording to ensure the maximum amount of clarity.

Professionals and carers began to sign up and I was keen to manage the arrangements tightly, and avoid the risk of commitments to attend being made and then participants dropping out shortly beforehand. To try to avoid this I contacted participants in the days before the group to confirm their attendance, and checked whether they had any special needs including dietary needs for lunch. While the professionals swiftly responded to communication from me and emailed or

telephoned me back to confirm their attendance, the carers were much harder to reach. Again, I reflected on the nature of the research environment and wondered whether this difference was due to my authority as a manager, or about the nature of working as a professional in a large organisation, or connected to the nature of being a carer where responding to emails or answerphone messages does not have the same priority.

The potential for caring in the community to be lonely and isolating was also brought home to me in organising the focus group, and I imagined each carer as no longer belonging to a 'group', but as separate individuals each with their own commitments for a range of carer activities, without organisational support structures.

When the day of the focus group arrived I had a sense of apprehension and felt both excitement and anxiety. I was anxious about whether those who had committed to attend would actually turn up: would the professionals have been distracted by organisational crises and new priorities, and would the carers find that their carer commitments could not be placed on hold while they attended.

In terms of the numbers attending the focus group my worries about 'no shows' were unjustified and the group actually comprised 16 people made up of 9 carers and 7 professionals. To my surprise carers brought other carers, and professionals who had previously indicated they were not able attend actually turned up. While the risks inherent in too large a group were at the front of my mind, the transcript of the focus group demonstrates that everyone did contribute, and while some participants appeared to say much more than others, there was in fact a fairly even spread. One structural device that helped was the division of the session into three distinct segments which permitted me as facilitator to review the work of the group regularly, before moving on to the next case vignette.

I also had a strong sense of the value of bringing together mental health professionals and carers into a single focus group, with the emphasis on sharing respective experiences. The mixing up of professionals and carers to consider case scenarios together appears to have been a framework for learning that permitted new reflections which benefited my research, as well as adding positively to the experience and knowledge of professionals and carers. The importance of careful planning and thoughtfulness in developing the arrangements for a focus group

should not be underestimated though, including making practical arrangements for good accommodation, offering refreshments, and making time for good introductions and scene setting at the beginning.

(ii) Structure of the Focus Group

Following introductions and a brief outline of the research context the focus group was divided into three main parts. Each section was based on a vignette which had been loosely drawn from real situations described in the interviews in the initial phases of the research. The third vignette was a recapping of the 'Triangle of Care' (Worthington & Rooney, 2013) and an invitation for the group, through discussion and drawing, to 'play' with the premise of the initiative that describes the key people: service user, carer and professional, as points on a triangle.

7. Supporting the research: volunteer carer research assistant

In publicising the need for carer participants to be interviewed I was contacted by a carer who showed particular interest in the research and asked to help with the project in ways other than being interviewed. We met to discuss what form this help could take and identified that supporting the arrangements for the focus group were the priority.

The volunteer carer subsequently helped with practical arrangements in setting up the focus group, shared ideas about helping to make participants feel welcome, and through ongoing discussions provided feedback on the vignettes from her perspective as a carer for close family members who have long term mental health conditions. This form of partnership, not planned at the beginning of the research, enabled contribution to the body of knowledge in a different manner. The volunteer carer research assistant became a 'sounding board' on the emerging themes from the interviews, and provided input on how they could be used as material for the focus group, in a way that would be equally understood by both carers and mental health professionals. The suggestion that I read out the vignettes and not rely on everyone to be able to read the printed sheets was invaluable, as it emerged that at least two participants would have been excluded if I had relied solely on participants reading. Furthermore, following the focus group I was able to discuss the

experience with the carer volunteer research assistant, and share reflections on the organisation, and the content of what had been shared by participants.

The involvement of the volunteer carer research assistant has associations with participatory action research, in which the development of a partnership was practical and collaborative:

“critical action research has a strong commitment to participation as well as to social analyses in the critical social science tradition that reveal the disempowerment and injustice created in industrialized societies”

(Kemmis & McTaggart, 2000, p.569).

We learnt from sharing our respective experiences and felt able to reflect on our differences, including those based on professional status, gender and race. Through discussion and sharing of written material the inclusion of a volunteer carer research assistant has significantly supported the shaping of my research.

8. Navigating research ethics and securing ethical approval

This section examines the ethical issues that arose through the research journey as well as how ethical approval was reached.

a. Ethical dilemmas on the research journey

As a practitioner-researcher I was acutely aware of the issues that arose from seeking to recruit professional participants from an organisation where I am a senior manager. In navigating the ethical dilemmas my concern was the potential, both consciously and unconsciously, to exploit my position as a manager and exert pressure based on my position within the hierarchy, rather than attracting potential participants becoming involved because it genuinely appealed to their professional interest. A closely linked anxiety involved potential participants seeing the involvement of a senior manager and therefore avoiding having anything to do with it. One of the ways I tried to avoid these pitfalls was to separate my two identities to a certain degree, therefore in advertising for volunteer participants I placed an appealing and non-corporate style poster on the organisation website and provided my name and role as researcher, without specifically including my management title. In the context of the interviews and focus group I introduced myself as an employee

of the organisation but then went on to emphasise by status as a doctoral student and my personal interest in the area of caring. I was conscious of not wishing to hide my role in the organisation, but emphasising my researcher role within the context of a programme of research.

Despite these safeguards being built into the process the possibility remained that a participant might become involved through a motivation to impress, ingratiate or convey a message to a 'senior manager' in the context of a rigid and hierarchical public sector organisation. Awareness of all of these dynamics is inherent within the FAN interview approach and the methodology helped me to engage with my emotional responses to meeting with professionals and carers alike. During an interview that I carried out with a mental health professional, working in a service that was facing a series of changes, I found myself in the role of research interviewer but also aware that the participant was emphasising the importance of their service during a stressful period within the organisation. Taking this experience to supervision permitted feelings and hunches to be examined and discussed, and served as a reminder that research in the social world is never wholly neutral.

As outlined earlier, the support from a carer volunteer research assistant provided an additional dimension to the research process. From an ethics perspective it was valuable to discuss the interest in supervision and surface some of the issues. Before the focus group I made carers aware that the space was confidential, but I was also clear that in addition to myself and mental health professionals, a carer volunteer would be present. This ensured there were no surprises for any of the focus group participants, and was a helpful reiteration of the confidential nature of the research space.

b. Securing ethical approval

Before embarking on the research it was necessary to obtain ethical approval from all the appropriate bodies involved. This included the Tavistock and Portman NHS Foundation Trust and the University of East London where I am registered as a student, and through the Integrated Research Application System (IRAS) which is a single system for managing applications for those applying for permissions and approvals for research in health and social care/community care in the UK. Once

this was in place I also sought and gained ethics approval from the NHS Mental Health Trust where I am employed.

The experiences of 'young carers' i.e. under the age of 18 years old are outside the ethical approval of this study, as well as those carers who are caring for someone with a mental health condition who are themselves under 18 years old.

9. Generalisation, sampling and validity

a. Generalisation

Before undertaking the research I considered the potential 'generalisation' from my findings. I did not set out to attract large numbers of participants as sought by many surveys within a quantitative tradition, enabling them to go on to make claims about the degree of generalisation that can emerge from their findings.

Lewis and Ritchie (2009) argue generalisation can be broken down into three concepts that should be considered when embarking on any research:

- (i) Representational generalisation refers to whether what is found in the course of research can be generalised across the wider population of which the sample is drawn;
- (ii) Inferential generalisation refers to whether the findings of the research can be generalised, or 'inferred' to other settings or contexts, beyond the one that was studied;
- (iii) Theoretical generalisation addresses the theoretical propositions, principles, or statements from the findings for more general usage.

The concept that strikes a particular chord is representational generalisation, and how what we learn from those mental health professionals and carers who participated in this study, can be generalised to a wider group of mental health professionals and carers within mental health services. Following a tradition within qualitative research, this must also be linked to considerations about validity which are noted below (under Validity).

b. Sampling

(i) Sample size

The sample size of eight mental health professionals and seven carers in addition to the focus group attended by sixteen participants is not large and reflects a tradition within qualitative research. However as in all qualitative research a balance needed to be achieved between the sample being too small and too large. If the sample becomes too large it challenges the ability to undertake deep and fine grained analysis of the richness of the data. Furthermore, a particular experience need only appear once to be identified through the analysis, and there is a risk of diminishing returns in the repetition of data. However the risks of having a sample that is too small also resonated:

“If they are, then they can easily miss key constituencies within the population, or contain too little diversity to explore the varying influences of different factors”

(Ritchie et al, 2003: p.85).

In order to manage this risk the need to be purposive in terms of the sampling is recommended, and in my design I was able to achieve a good range of diversity across factors such as carer and cared for relationships, ethnicity, age, and for the mental health professionals, their professional backgrounds and workplace settings. Other diversity factors, predominantly gender, proved more challenging and whenever this issue has emerged it has been reflected on as part of the research findings.

(ii) Selection Criteria

To achieve a greater understanding of the nature of relationships between mental health professionals and carers the sample aimed to meet two requirements. Firstly, that of symbolic representation, which refers to a participant being selected because they typify or have characteristics that are expected to have salience to the subject matter. Secondly, to have as diverse a group of participants as possible, which brings the benefits of optimising the chances of identifying the full range of factors or

features that are associated with caring within the setting of mental health, and allowing:

“some investigation of interdependency between variables such that those that are most relevant can be disengaged from those of lesser import”

(Ritchie et al, 2003: p.83).

I have set out a table of the sample in Appendices A, B and C.

c. Validity

The key aspect of validity that guided my research was achieving ‘face’ or ‘internal’ validity so that the findings which I have produced are consistent with the original research questions, and continually asking myself: “am I investigating what I claim to be investigating?”

A second aspect to validity known as external validity is linked to whether findings can be translated into wider areas, in some respects merging with aspects of generalisability that were discussed earlier.

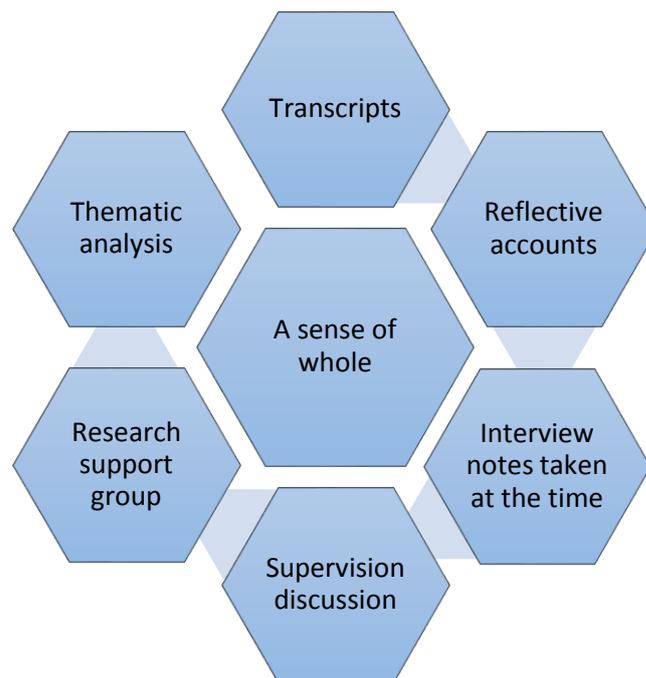
The ambition of qualitative research in respect to external validity and establishing wider ‘truths’ in social enquiry is based on confidence in the internal validity of the research findings, and unless this is in place: “then there would be little purpose in attempting ... generalisation” (Lewis & Ritchie, 2003, p.274).

10. Data Analysis

In this section I outline how I analysed the data that emerged from the one-to-one interviews and from the focus group. The material that emerged from these methodologies was captured in the following places, and depicted in Figure 3.1:

- Typed transcripts
- Reflective accounts
- Interview notes (especially for the emotional experience and other non verbal communication)
- Notes from supervision and tutorial sessions

Figure 3.1: Sources of data



The qualitative approach taken to researching mental health professional and carer experiences resulted in a range of narratives for analysis. Some overarching analytical principles provided a framework for the analysis and these will be shared next.

a. Inductive approach

The approach to the material was premised on a psychoanalytically informed psychosocial approach. While I was not a naïve researcher I refrained from predicting what themes and concepts would emerge from the data, or setting out any formal hypotheses, ahead of gathering data from the material.

b. Maintaining a sense of ‘Gestalt’

Although the material was ‘chunked’ into codes as part of the thematic analysis, the importance of maintaining a sense of the ‘whole’ inherent within the FAN interviewing approach was prioritised. ‘Gestalt’ within the context of FAN interviewing refers to the idea of maintaining a sense of the completeness and more than the sum of its parts, and encompasses subjectivity and emotionality. Within the experiences of

mental health professionals and carers this meant the importance of analysing the detail within the narratives, but also keeping hold of the larger experiences. The experience of Hollway and Jefferson (2013, p.64) resonates with my own personal research experience:

“After a whole day working on the transcripts of a particular participant we would feel inhabited by that person in the sense that our imagination was full of him or her. The impact such work had is best demonstrated by the fact that our interviewees could appear in our dreams”.

c. Awareness of the possibility of multiple interpretations

In using an interpretive approach to data analysis I was always considerate of a responsibility to draw on all my reflexive capacities, employ supervisory and tutorial space to the full, and use the material in all its various shades and textures. Awareness that this is not the territory of singular rights and wrongs, wherever possible, I shared alternative interpretations, and the selected interpretation has been discussed in relation to the actual material it has emerged from. Furthermore, where ideas have been developed and elaborated on, this is clearly stated. Squire (2008, p.50) argues researchers must continually check their evolving interpretations against the materials and actively seek out contrary cases, but also acknowledge the complex human social world:

“many researchers do not expect a single interpretation to emerge. They argue that there are multiple valid interpretations, multiple narrative ‘truths’”.

In a similar vein Hollway and Jefferson (2013, p.154) caution against ‘wild analysis’ where there are little or no grounds to make connections, and note safeguards against this: “if psychoanalytic concepts are congruent and subordinated to a holistic treatment of data”.

11. Analysis – the process

To recap briefly, the FAN interviewing approach provides both a framework for planning and undertaking research interviews, and also sets out a framework for how the data can be analysed. At its heart is the premise that there is more than the

'observable' phenomena, and that the actual words and sentences that research participants use, are only part of the data set that is available.

a. Psychoanalytically informed analysis

Establishing itself as psychoanalytically informed, FAN interviewing advocates the importance of capturing psychoanalytic material including: feelings, emotions, anxiety, transference, counter transference, and projections, and argues that this is all legitimate material available to researchers, as long as we employ the appropriate degree of reflexivity to understand and comprehend the role of self within these dynamics. The risk of not using this material is to produce research findings that merely regurgitate familiar sound bites and jargon that is presented in response to questions without any attempt to interpret the emotional response to the material.

Putting into practice the conceptual tools available within FAN interviewing was supported through regular supervision sessions and group tutorials, where material was presented, and ideas and feelings towards the narratives were discussed and reflected on.

In one group tutorial I brought two transcript extracts from interviews with a mental health professional (social worker) and from a carer (caring for his wife who had mental illness and their children). These had also been circulated prior to the session. I read out both of the extracts to the group who were then able to generate ideas, make associations, and share views about the meaning of the data.

In the case of the professional's interview the recurrent use of punitive ideas was remarked on including: 'taking away power and making decisions for families who were not able to do it for themselves'. The group also noted reliance on 'stock phrases' i.e. 'nature of the beast' to refer to mental illness, and 'get them on board' in working with carers, and shared ideas that the professional was using this language as a form of defence against the material getting too close to self.

In the case of the carer, the group played with the ideas of losses and gains, and who had lost and gained from the carer initiating a relationship with someone who was known to be struggling with obvious mental health issues at the outset. In the account of their subsequent family life the group struggled with aspects of physical care that were being described by the carer in language that used images of jungles,

forests and wildlife. Toward the end of the discussion the group acknowledged its irritation, and in sharing these feelings were then able to discuss a more complex picture of the individual in having multiple roles: partner, father and carer, and his limited options that led him to give up work to take on a caring role.

b. The defended subject

A starting point in the analytical process is the idea that we are all to a certain extent 'defended subjects' and utilise a range of approaches to defend ourselves.

Awareness of this:

“helps to guard against eliciting from interviewees ‘well worn’ stories and commonplace discourses, depleted of personal meaning and emotionally vivid experience”

(Hollway and Jefferson, 2013: p.151).

The idea of the defended subject was particularly helpful in interpreting why the FAN interviewing model appears to have caused a 'tap' of experience to be turned on in the experience of interviewing carers, whilst the same approach, when utilised with mental health professionals, needed adjustment and greater interpretation of the pauses, silences and avoidances. Through reflection and supervisory discussions, the nature of the professionals as defended subjects arose as an explanation, although at the time of the initial interviews I wondered whether the structure was adequate, and questioned my own judgement for not having prepared more questions to fill up the space as professionals sped through my interview pointers.

c. From detail to wholeness: moving back and forth

The importance of maintaining a sense of 'Gestalt' was highlighted above, and in terms of this analysis meant homing in on specific extracts of narrative emerging from participants, and developing an understanding of their experiences with their complexities and contradictions. In one carer interview 'Rhona' carer for her son, talks about her anxiety about his future as she and her husband become older. However Rhona also spoke with admiration and good humour about her son's ingenuity and resilience, and appeared visibly proud (smiling and nodding her head) of his approach to everyday problems. Although a range of themes were able to be

picked out of the details within the interview transcript, maintaining a sense of the whole of Rhona's experience was necessary as part of interpreting within the FAN interviewing approach.

d. Reflective account

Supporting the psychoanalytically informed FAN interview approach a reflective account was undertaken after each interview. This permitted ideas to be recorded, feelings to be jotted down, and the non-verbal aspects of the interview and focus group process to be captured.

For her interview, a carer called 'Maryam' arrived wearing a yellow headscarf and American sportswear in various shades of orange. In the reflective account I completed afterwards I recorded the connection I had made with the idea of a 'lioness and her lion cubs' as Maryam spoke with great authority about caring for her two sisters, both of whom had severe and longstanding mental health conditions. Working with the idea of a lioness in the analytic process, Maryam later spoke about having to 'fight' for her sisters and 'defend them'; from mental health services, from the police, and from family elders who appeared to be unable or unwilling to understand the nature of mental illness. Showing the nurturing required of a lioness, she also spoke about persuading her sisters to engage with medical treatment that was on offer for their respective mental illnesses.

Towards the end of the interview 'the lioness' spoke about wanting independence, and to removing herself from her carer commitments in order to pursue a professional course in higher education some miles from her family. The idea of the lioness stayed with me throughout, and in sharing her plans to escape from the 'enclosure' of her caring responsibilities I was left with an image of a carer far removed from the 'put upon' image often depicted. However, continuing with the idea, I was also left feeling concerned about whether Maryam had the 'survival skills' to go it alone, and whether having been taken into captivity through her carer role, she would now be able to escape as easily as she hoped.

Through adapting the FAN interviewing approach to the focus group, material was again surfaced beyond the actual spoken words. In responding to the case vignettes the carers drew on their own personal experiences of caring, and openly made

compelling connections in order to tell 'their story' to the wider group in a manner that was personal and at times disturbing. On occasions these stories made me imagine the famous 'truth and reconciliation committee' hearings in South Africa where attendees were encouraged to give testimony, and in so doing in the presence of others, were unburdened of what had been oppressive. The presence of both fellow carers and professionals appeared to be necessary in order to give gravitas to the focus group.

In contrast to the carers, the professionals were much more defended in their responses to the vignettes, sharing measured reflections only after the carers had 'spoken from the heart'. For much of the session the professionals remained in role, demonstrated by carefully crafted responses peppered with professional jargon. However, towards the end of the second vignette a discussion about carers supporting service users who are in crisis, prompted a professional to declare: 'I wish we could make it all better' (Focus group, 35). Although the actual words can be interpreted literally as a wish 'to make it all better', psychoanalytically one can see how the remark was the emotional response by this professional to the culmination of projections from carers, which had been conveyed as slights, criticisms and complaints. In this one unguarded moment, a professional acknowledges the inadequacy of so much about 'the system' and conveys a wish to resolve all the current ills.

In another exchange led by a carer reporting how difficult it was to contact her son's mental health worker and therefore ringing her in the office at 4.45pm, just before the end of the working day, a professional declares that they also 'care', and go on caring after 5 o'clock too, and in fact: *'the work actually stops me sleeping at night'*. Again, a professional momentarily appears to slip out of their professional role, responding to a perceived attack, wanting to highlight an area of professional life that is generally 'behind the scenes' and kept at bay through 'professional distance' and adherence to boundaries. We can see how the feelings of carers, caught up in despair and worry, is pushed into professionals. The professional, also feeling uncontained pushes it out again in a manner that comes across as potentially distressing to the carers, who are already uncontained. While containing the anxieties of service users, the role of professionals in containing carers is also highlighted in this exchange, and how slipping out of role can easily happen.

e. Thematic analysis: an opportunity to cross reference

Alongside the use of material that emerged from the FAN interviews and focus group, a second analytical approach was employed to add additional rigour to the work and triangulate the findings. Drawing on a thematic analysis approach, and informed by grounded theory, the transcripts, reflective accounts, notes from all the interviews, focus group and tutorial and supervision sessions were collated.

Taking a thematic analytic stance, each page was re-read and phrases or words highlighted. This established an inductive approach where I adopted an open mind about the possible themes and eventual concepts that would emerge.

Acknowledging the effort to maintain openness, Braun and Clarke (2008, p.84) caution:

“it is important to note ... that researchers cannot free themselves of their theoretical and epistemological commitments, and data are not coded in an epistemological vacuum”.

Following a process of highlighting sentences or words in the texts, these were written down verbatim on to ‘post-it’ notes, thereby generating a large set of ‘codes’ that were extracted directly from the actual material.

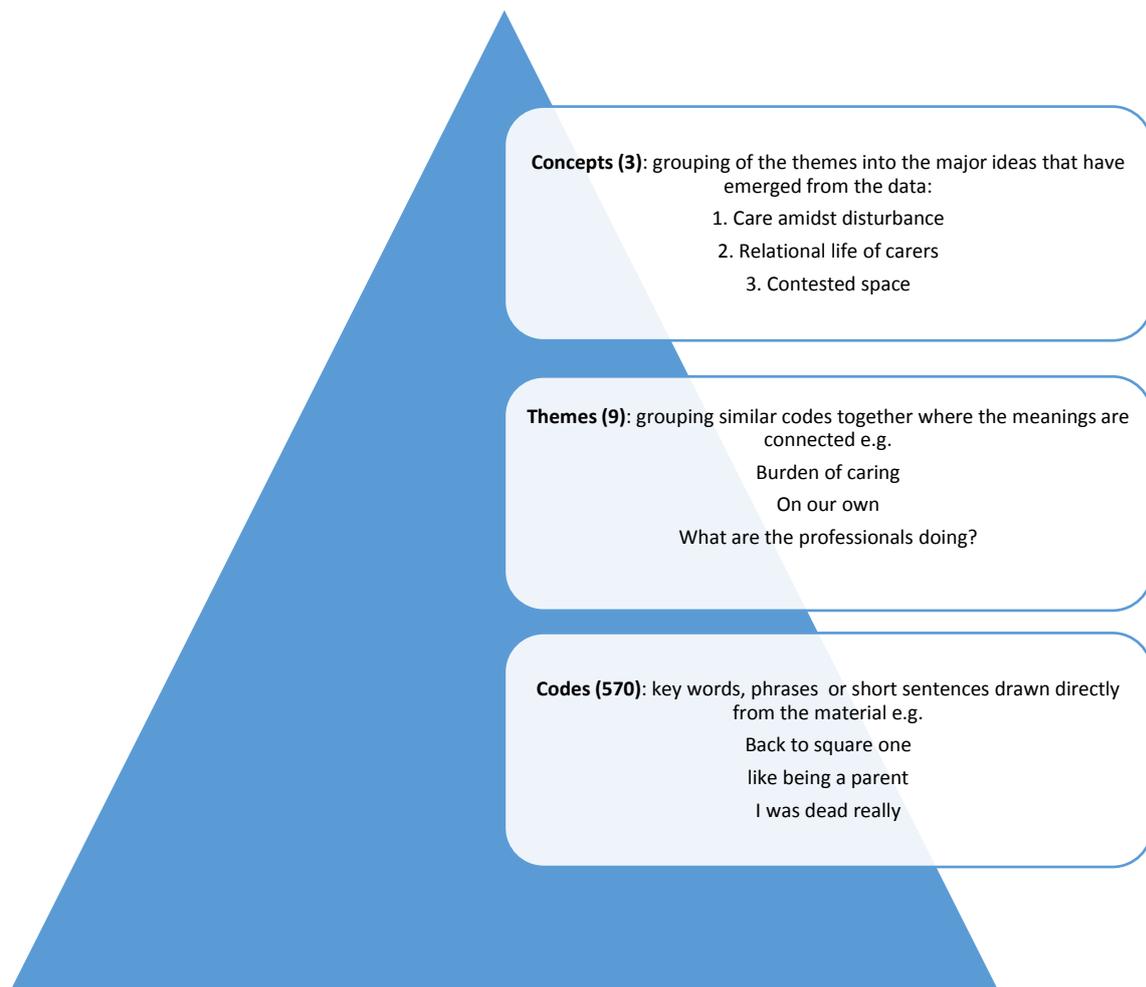
While the words or phrases might have had significance within the context of the interview or focus group, read out in isolation they can easily lose their original resonance and meaning, as the following codes demonstrate:

- Mothers stay a lot longer
- I’m more than carer I’m her father
- Without carers no one to advocate for you
- Users are carers too
- GP, he’s completely calm

To an onlooker, the above selection of codes have limited meaning outside the context they are taken from. However, having extracted the codes from the basic raw data the next stage was to bring my own knowledge of the entirety of the data, and begin to group them into provisional categories known as themes.

Twenty nine themes were initially created from the original 570 codes that were identified, and from this group, nine streamlined themes emerged. From these, the identification of three concepts surfaced as the key areas of the research, which were then able to be cross analysed and further developed with the material emerging from the FAN interviewing approach. The diagram below illustrates the method:

Figure 3.2: Thematic Analysis - Process



As this process was being finalised I used a tutorial session to share the research 'answers' I had produced, expecting to be praised for the labours that had gone into the emergence of so much information. I was rattled by the response which was that my efforts to 'boil down' my data through such a scientific approach, had resulted in an absence of meaning. While part of me knew this to be true, having heard it

verbalised in the session disturbed my sense of accomplishment and my confidence in having discovered the 'right answer' . When I had been 'chunking' the data I had become certain of the 'methodology' and the truths it would produce. However, through a process of reflection, the feedback helped me to avoid any temptation to take a 'quick win' approach to discovery within the complex psychosocial world of health and social care.

While acknowledging a role for this form of thematic analysis within qualitative research as a form of cross referencing, and an opportunity to subject the data to another form of scrutiny, I learnt that a great deal can be lost if it is the sole approach to examining complex issues. If it had been the only approach, my interpretive and reflexive influence as the researcher, would have been diminished, as well as the ability to draw on my own internal experiences of life and the workplace. Through sensitivity to my own subjectivity as a researcher-practitioner I have also been able to avoid the risk of losing the experiences of participants through their retreat into defensive positions.

The thematic approach was labour intensive, and I had in effect deconstructed the material and provided myself with a second body of analysis that needed to be worked with to inform the material I had started to secure through my FAN interview experiences. Through supervision the value of rebuilding the whole was emphasised by incorporating, adapting and using the thematic approach in conjunction with the FAN interview approach. In doing this I avoided what Cooper (2009, p.440) describes as his 'special aversion' to qualitative research:

“In which lots of people are interviewed, and then the research is written up in loosely themed groupings of quotations from the research subjects. Any effort to interrogate the meaning of these utterances further is usually met with a defensive insistence that 'What we have presented is what these people are telling us'”.

The exercise of 'dismantling' the research was tremendously useful for just that purpose, I now knew the material inside out, where the key phrases were, and where to find the words and references to feelings that actually fed into refining the themes and concepts.

f. Supervision and research support groups

The importance of support in researching the social world through a psychoanalytically informed psychosocial approach is reiterated by Hollway and Jefferson (2013, p.166): “emotional experience (in research encounters) requires reflection; for which time, containment and support of other is valuable”.

(i) Supervision

This research has been supported by regular monthly supervision from my two supervisors. The sessions were made more productive by my preparation, including: sharing a draft agenda, and circulating material from the research such as transcript extracts and reflective logs. In one supervision session the original plan of having separate focus groups for mental health professionals and carers was discussed and changes agreed upon, as reported on earlier.

The sessions were also particularly useful for studying transcripts together and combining our reflexive responses to particular exchanges. Within a supervision discussion of a transcript related to ‘Suzanne’, a community based occupational therapist working in a community mental health team, the subtlety of her intervention with a father whose son is experiencing the early onset of a mental illness had been overlooked by me. During the session we unpicked an extract of text in detail and revisited the way that Suzanne was supporting both father and son by regularly doing ‘ordinary’ things with them: going for a walk, driving in the car or visiting a café, and considered the idea of the ‘common third’ which is central to social pedagogical practice, and is about using an activity to strengthen a relationship (Boddy et al, 2006).

Unearthing this led to other ‘discoveries’ of quiet and unobtrusive interventions emerging from the transcript, and led me to alter the way I had viewed the interview.

(ii) Research support group

My tutorial group consists of four doctoral students at slightly different stages of research, although all tussling with issues around data collection and how to engage with participants. Along with fellow tutees I took it in turn to present aspects of my

data and the feedback from both peers and tutor was very helpful, particularly when having to 'defend' a particular view or explain a concept.

Learning also took place through reading and responding to material presented by other students, and reflecting on how my views contrasted with, and at other times, aligned themselves with other tutees.

12. Summary and conclusions

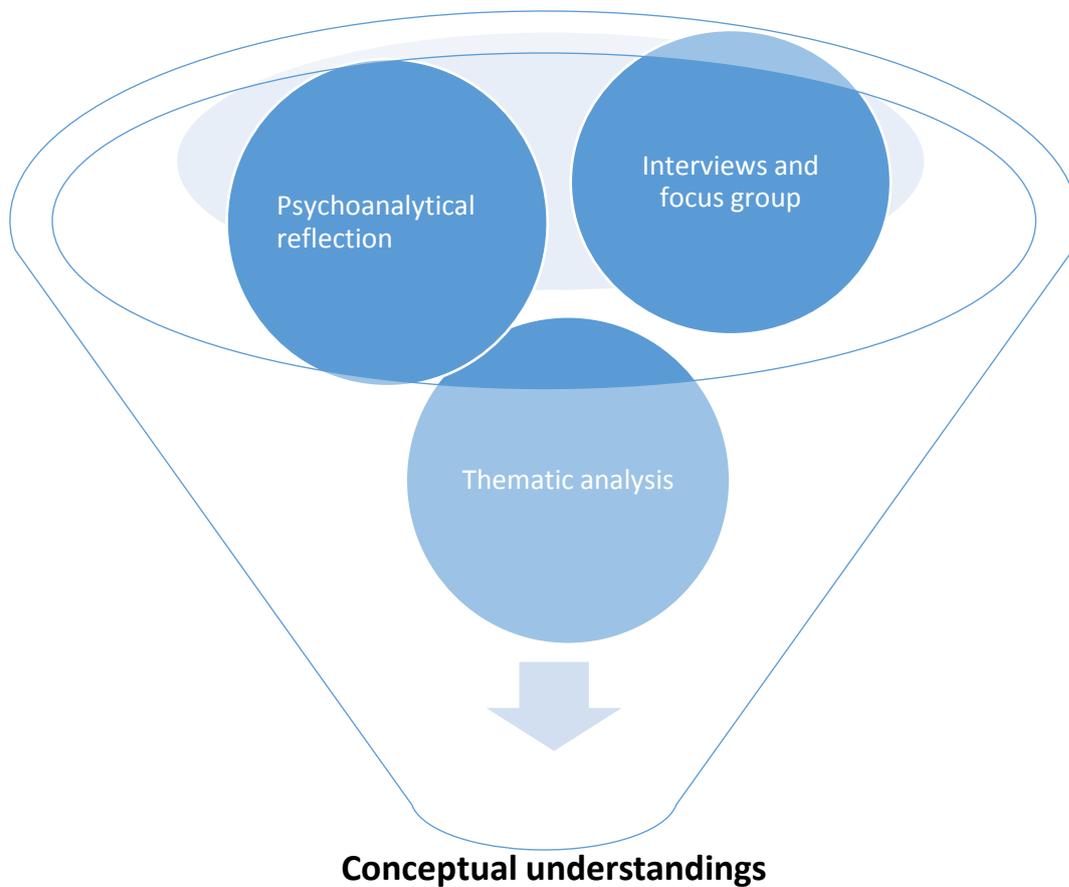
It is proposed that a specially adapted psychoanalytically informed methodology is used to examine the relationship between mental health professionals and carers. Utilising the FAN interviewing method assumes that participants are 'defended subjects' and will therefore communicate their experiences both consciously and unconsciously, and through a range of means, verbal and non-verbal. The level of complexity and defensiveness is accommodated by this psychoanalytically informed approach which operates from the premise that I am able to hold the position of reflexive researcher and be able to provide an interview and focus group environment that genuinely invites participants to engage in sharing their experiences of caring in every sense.

In order for material from these research encounters to emerge from a congruent theoretical basis, access to regular supervision is essential to enable me to discuss my reflections and test out my hypotheses. This is in addition to participating in larger group sessions with fellow doctoral students undertaking similar research methods, where ideas can be exchanged, discussed, discounted or developed. While the numbers of mental health professionals and carers involved in the research study is relatively small the focus on their lived experience of the relationship will permit new learning to emerge and highlight potential implications for future practice in the area of caring.

This is a unique and personalised methodological design that will provide a clear focus on the lived experience of carers and mental health professionals, and thus permit new learning. It values the resource that lies within the typed transcripts of all the one-to-one interviews and focus group, my notes from the interviews and focus group, and notes of supervision and research support groups. These are sources of data that not only assist with the reflective and psychoanalytical processes but

support a thematic analysis that permits 'gestalt' to be built in a different way. By breaking down a 'whole' transcript into individual data codes that are then rebuilt into themes and then concepts, the methodology permits emerging conceptual understandings to be developed in a way that enables cross referencing, and cross fertilising of ideas. The diagram below summarises the methodology:

Figure 3.3: A personalised methodology to research the dynamics of caring



Chapter Four

How do Mental Health Professionals and Carers for People with Long Term Mental Health Conditions Experience Each Other?

1. Introduction

This chapter examines the findings from the research into the relationship between carers and mental health professionals. The findings are grouped into the following themes:

- The boundary – crossing back and forth
- Understanding respective roles
- Setting reasonable expectations
- The Carers Assessment – experiences of assessing and being assessed
- Barriers in the relationship between carer and mental health professional

2. The boundary – crossing back and forth

“I was rebuffed” (Interview, transcript 4:5).

Within the larger ‘space’ that is care in the community, the idea of a ‘boundary’ around health and social care organisations can be experienced through various means: inclusion and exclusion policies, eligibility criteria, opening and closing times, and rules around geographical catchment areas. Organisational culture also contributes to the sense of a boundary being enforced and includes responsiveness to external enquiries, the priority given to customer care, and investment in the initial reception experience for service users and carers.

Carers too are able to demarcate and develop a boundary that helps to define them as a distinct group. Identifying oneself as a ‘carer’ is achieved in relation to caring for someone else based on some relational underpinning such as family membership, friendship, shared neighbourhood, or colleagueship. Membership of the group lasts as long as the caring relationship endures although the concept of being an ex-carer emerges if the cared for person recovers to the extent that caring is no longer needed, or they die. Often the sense of a boundary around services is experienced as problematic by carers and this is considered here.

Lisa, a carer for her husband, spoke about visiting him on a psychiatric inpatient unit following his becoming unwell due to a relapse of his mental illness:

“When I tried to come onto the ward with things for him, I rang them and basically said I’m coming to visit and when I was coming. They were very unforthcoming with information. It’s standard when he’s ill that he sees his loved ones as part of a conspiracy, seriously, and I would have thought mental health professionals would understand that.

So the next time I came onto the ward to bring stuff for him they didn’t let me on the ward ... There’s a sort of airlock so you’ve got an entrance and another entrance. They let me as far as the airlock and I had to decant the stuff on a chair, and I felt humiliated and I felt really upset and distressed”

(Interview, transcript C4:9).

A little later in the interview she summarises her experience of meeting the inpatient unit consultant psychiatrist, a few days after the above visit:

“Even then there was no, sort of feeling of, how on my part I was going to be supported, or informed, or looked after through the process. It was all sort of ... you’re here now and let’s get the information from you and thanks very much and bye bye”

(Interview transcript, C4:10).

At the beginning of the first session of the focus group a carer quickly took up the space to share her experiences of mental health professionals. Emily is an older woman caring for her adult son who had recently been discharged from a local psychiatric hospital:

“My son had given them permission for me to speak with them. And the social worker whenever I rung her she ... I managed to have her number ... she was never there, so I discovered if I rang her at quarter to five I got her. But the answer I got ... She said, ‘you always ring me at quarter to five’ and I said, ‘that’s the only time I can get you’, they just don’t want to let you know anything”

(Focus group transcript, C6).

The sense of a wall is palpable in these experiences shared by carers; in different ways they have attempted to break-through, and cross from outside to inside, where they perceive their loved ones to be held, sometimes physically, sometimes metaphorically within the mental health system. While the example of sharing a telephone number may not have registered as significant to the involved mental health professional, the emotional impact of this on the carer demonstrates how feelings of grievance can emerge towards mental health services, and the mental health professionals within them.

The emotional experience for me as the researcher in hearing these examples was a sharp sense of guilt and regret, and later a feeling of sadness for being part of a system that overlooks aspects of care that seem obvious for those on the outside. There was also a feeling that carers are partially inside the realms of the organisation, in contrast to interactions with service users where there is usually a degree of professional distance.

Whilst the 'airlock' was an actual and real experience for Lisa, the image of an airlock as a holding and transitional space that is neither outside nor inside is an important symbol for the position that carers occupy in being perched on the border between the two places. Confusingly for carers, at times they are permitted entry across the border, for example to bring familiar food items for an inpatient, or to attend a care review meeting. At these times the familiar refrain of 'valuing carers' and 'working in partnership with carers' is present, and in the moment, I think is genuinely believed by mental health professionals. However for carers, whenever this level of access is permitted there is a sense of: *'let's get the information from you and thanks very much and bye bye'*.

For carers, the experience that emerges suggests that they feel they have to be ingenious, and discover ways to break into the system: identifying a particular time to ring a hard to engage worker, making numerous calls despite feelings of being rebuffed, and resorting to going round and round in circles until a professional is reached.

Turning to the perspectives that emerged from mental health professionals, what comes across is the largely positive tone about the role of carers, and the absence of

any overt irritation. Mark, a nurse team manager within a community based early intervention service shared the following:

“I suppose throughout my career I’ve recognised how important carers are to our clients. In terms of Obviously being a support for them and being a kind of early alerter person. And someone who actually, genuinely loves the person they care for and want the best for them”

(Interview, transcript P2:2).

Suzanne an Occupational Therapist also working in an early intervention service remarked about her work with carers:

“they’re part of everything that I do, a lot of the work is with either the siblings or with a partner or friend who is a carer”

(Interview, transcript P4:5).

Kofi, a social worker within a community mental health team stated:

“having carers enhances your practice and can permit you to take a back seat” and: “it’s better to have a carer, without a carer or family member there is nobody to advocate for you”.

(Interview, transcript P6:5)

In a similar vein, within the focus group, the contribution of carers is recognised by a mental health professional from a psychiatric background working in a home treatment team:

“we do rely on carers an awful lot in home treatment, and not just for the feedback about what’s going on, what’s really happening, not what the patient says, but we also, I mean to some extent, rely on the carers”

(Focus group, transcript P46).

The immediate feeling is one of some disconnection between the data emerging from carers and that shared by mental health professionals. Carers are infuriated by not being sufficiently valued, symbolised by feelings of being held ‘outside’, while the mental health professionals applaud carers and comment: ‘they’re part of everything’ without having any apparent awareness of carers’ irritation about boundaries.

However, sifting further through the data from mental health professionals, the awareness of the presence of a boundary emerges. In the daily realities of her work life, Suzanne, the occupation therapist in an early intervention service ponders:

“I suppose there is only so much I can do in working with a carer directly. My priority has to be with the service user” and:

“hundreds of carers in my head, one time recently I had a carer who phoned one hundred times and again it was because of concerns with her husband and she genuinely thought he was going to do something terrible”

(Interview transcript, P4:6).

Despite the ‘working with carers’ mantra from mental health professionals, the idea of being pursued by carers also emerges and the creation of a border, which serves to help the professionals ‘survive’ and maintain a reasonable level of anxiety. If physically created the boundary might resemble a levy, like those defending low lying areas such as New Orleans, and built from huge amounts of earth that are designed to withstand flooding from tidal surges. This image dovetails with the views from carers of being rebuffed by services and the idea of the harassed mental health professional trying to fend off carers. Holding this dynamic in mind enables an understanding to surface; on one side of the boundary mental health professionals are invested in maintaining a particular script containing familiar clichés about valuing carers, while on the other side of the boundary carers become ever more frustrated and irritated in their efforts to secure contact with, and support from, mental health professionals.

A further area where the sense of a boundary emerges is language, where carers speak in raw, emotional and often critical terms, in contrast to the professionally nuanced empathic language of the mental health professionals. Talking about caring for their mentally unwell relatives at the focus group, two carers shared their dilemmas:

Stefan: “my sister is quite cunning, so that she will actually lie and she is very good at convincing workers, psychologists and social workers, so that she gets what she thinks she wants out of the system”

Judith: "They always convince you that they are not ill, the medication, I have been through this so many times with my son"

(Focus group, transcript C21, C22).

At this point in the focus group the mental health professionals did not contribute to the discussion which may be because the use of language such as 'cunning' and 'lie' are outside the remit of professional terminology. However in remaining outside these discussions there is a risk of appearing aloof and unable to empathise with the actual experience that is being conveyed through the language.

In the focus group and one-to-one interviews, the stance of the mental health professionals often conveyed a sense of a 'defended position' and an attempt to split off painful aspects of carer experiences through idealising them. Depersonalising and turning the carers into a set of stereotypes distances them, and holds them at bay, outside the organisational boundary. Illustrating this form of defence, Sam, an inpatient consultant psychiatrist described his 'natural' preference for working with families, but nonetheless classified them into one of four categories:

"families who are reasonable, and those where they are right and you are wrong, and those who are very, very helpful families and those who are over involved families"

(Interview transcript P7:8).

Echoing the idea of being perched on the boundary is reinforced by the image from Mark of the carer being an 'early alerter'. This view of carers conveys an important chink in the mind-set of mental health professionals; where they see the value in carers in their role of 'sounding the alarm' and then enabling statutory services to provide the necessary reinforcements. Being an early alerter seems to involve being set apart, both physically and emotionally, within a wider space than the rest of the support team. Again it conjures up images of the carer being isolated with the responsibilities of looking after someone with a mental illness, but being unable to draw upon support until a crisis emerges.

3. Understanding respective roles

"What are the professionals doing?"

(Interview, transcript C7:2).

Reminiscent of the work of Twigg (1989), in which she outlines at least three possible ways of viewing carers; as 'co-workers', 'co-service users' or as 'resources', uncertainty is a characteristic that emerges from mental health professionals and carers in their respective understanding of each other.

A feature of the narratives from carers is highlighted by Hamid when he remarks:

“they don't have time for carers, we're their third or fourth priority”

(Interview, transcript C7:2).

Within the focus group, Stefan, also a carer relayed:

“I've got no contact at all with the mental health workers working with my sister they seem to insist on me going to meetings, I turn up they pull in a chair for me, and I never hear from them again”

(Focus group, transcript C8).

In contrast Hannah, now retired although still caring for her adult son, looked back at her experiences of mental health professionals, and a particular crisis when her son became unwell:

“care coordinator managed to be flexible and visit nearly every day. She was more worried than me, and that helped us to help X to stay at home”

(Interview, transcript C1:3).

Later in the interview Hannah summarises what she feels is important in terms of a care coordinator (or worker): *“It's a mix of skills and personality, you have to click”* (Interview transcript C1:5).

The positive perception shared by Hannah appears to be founded on the idea of the mental health professional being available for a relationship, and the relationship 'clicking', which is a phrase often associated with significant friendships or romantic relationships. Frustrations from carers appear to emerge when their expectations for this form of empathic relationship, to help them manage their anxieties, are not met. From the feelings and emotions that emerged in the interviews and focus group, it

appears there is a degree of inconsistency in the ability of services to provide carers with a nurturing relationship with a mental health professional.

Carers also reported occasions where, despite inadequacies in the system, a relationship with a mental health professional had sustained them and helped them to cope. For example, Christine reflected on the breakdown in her son's mental health and felt she had been helped through by his care coordinator who was: "more worried than me" (Interview, transcript C1:3). Again this reflects investment on the part of the carer and the mental health professional in developing a strong relationship, in which the carer is able to appreciate how much the professional cares, and is invested in a good outcome for the service user. Despite Lisa's examples of inefficient services she softened her views when discussing certain relationships with key mental health professionals:

"The meeting with Dr K which was, I really felt, really positive because it was the first time ... D can be very violent ... and it was the first time, I don't know how he managed it, it's really difficult to talk about it and it can be really difficult to say. But somehow Dr K managed to enable me to say that and it was the first time I was able to articulate it"

(Interview, transcript C4:13).

From the interviews with other carers, there were limited examples of relationships having formed with a mental health professional that were meaningful. Caring for her two sisters, Maryam spoke about a series of experiences: not feeling listened to, a series of professionals who struggled to understand her sisters, and the inability of services to share a credible care plan. At no stage in Maryam's experience of caring is there a sense that a meaningful relationship with a professional had been formed. Any relational experience appears to be entirely absent and may be due to a range of factors, such as turnover of staff, or services straining to manage demand placed on them. On Maryam's part she may have genuinely felt mental health services were inadequate for meeting the needs of her sisters', but what comes across most acutely is the absence of a named mental health professional who was genuinely available to her, and someone she could share some of the burden with.

Turning to the perspectives of mental health professionals on their role in respect to carers, a strong degree of warmth is conveyed in the manner in which Mark relates working with the family of a service user:

“there was an atmosphere of openness and honesty, and they were ready and it was good. And I found that working as a triangle of people that care – let’s call it that – personally rewarding and clinically I felt we were a very robust team between the three of us”

(Interview, transcript P2:7).

In a similar vein, Sam, a consultant psychiatrist on an inpatient unit stated:

“It’s natural to work with carers, its automatic, I don’t even use the term carers as this pigeon holes them, its core work seeing people as part of a unit, as family”

(Interview, transcript P7:1).

In the above narratives the professionals allude to degrees of ‘naturalness’ in working with carers. Although these descriptions represent an important aspect of how professionals see their role in respect to carers, there are further factors that add both light and shade to the picture. From the focus group a ward manager adds a perspective on the nature of family life:

“Because the term carer you can split up into three: next of kin, nearest relative, a carer who is caring – or an interested relative. Because sometimes on the wards you will get four relatives who ring up separately to ask about the same person, say four times, so it’s that agreement again, who is the person you invite?”

(Focus group, transcript P30).

Kofi, a social worker with a community mental health team reflects:

“There are at least three different points of view in terms of carers and mental health, the service user the carer and the worker, and the worker is the one stuck in the middle”

(Interview, transcript P6:1).

The focus group looked specifically at the relationships between mental health professionals and carers with both parties in discussion using images and symbols to characterise them. Some participants voiced support for the image of a triangle, and Elisa, a Recovery Support Worker, working specifically with carers stated:

“I do think the triangle is good because whichever point you’re at, it’s kind of saying the carer is having communication with the service user/client and the professional”

But added:

“On our systems there are so many different things it’s like who do you involve? Do they want to be involved? And do you have their permission, and so many things”

(Focus group, transcript P38).

The focus group also grappled with how the respective carer and professional roles should be defined and summarised. Beginning with the concept of a triangle, which Woodhouse and Pengelly (1991, p.217) remind us has been around for some time:

“Triangular configurations are ubiquitous, and the dynamic forces they generate exert a powerful influence on human interaction”.

While some carers and professionals voiced strong support for the triangle as an effective symbol to reflect the relationships between mental health professionals, carers and service users, other participants articulated different models for describing the system.

Judith, a carer for her adult daughter who had been under mental health services for several years argued:

“I’d rather see the relationship as a circle. Because that’s what we do, we’re in a circle. We go round and round. As long as we hit a professional”

(Focus group, transcript C37).

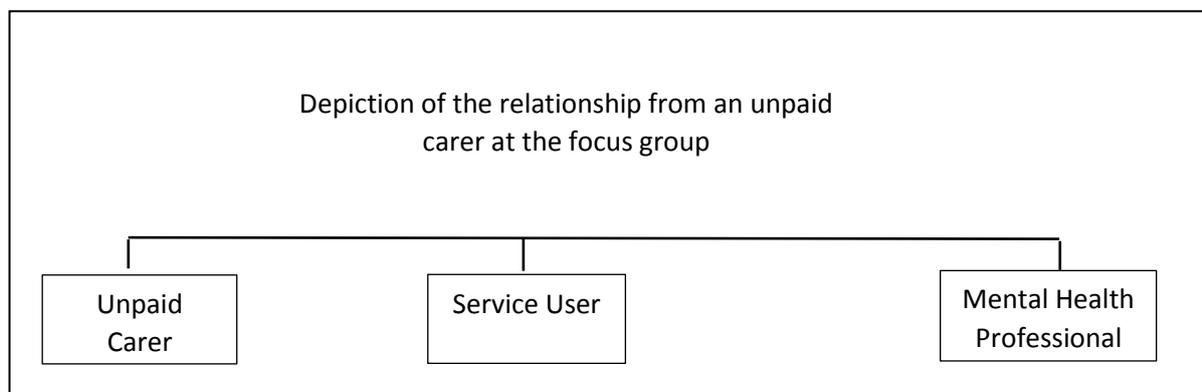
Focusing on the relationship with mental health professionals, Stefan, an unpaid carer stated:

“I actually feel like these are essentially ‘powerpoint’ (Microsoft software) symbols to describe the relationship. It’s kind of limiting, it’s limiting the understanding of a very complex relationship”

(Focus group, transcript C41).

Using the materials to draw the relationship he drew a single line with the carer at one end and the professional at the other as shown below, with the service user in the middle.

Figure 4.1: Depiction of the relationship from an unpaid carer



Pointing at the line, he stated:

“the professional is here, the carer is here, and the service user tends to be here (placed on the single line a bit closer to the carer end of the continuum). Now the professional does get access to the user, but the carer is much nearer and gets more and easier access. But the connection between the carer and the professional ... there’s not a lot of connections”.

(Focus group, transcript C42)

Criticisms from carers of the triangle, and criticism of circles and other images as being merely ‘power point symbols’ to describe what is a complex system of relatedness struck a particular chord with me, especially in its critique of the image of the triangle which has become synonymous with the work of mental health services in relation to carers. The passion and interest of carers and mental health professionals to critique the models of working, and to consider alternative

frameworks of understanding, was important in surfacing different forms of relatedness.

4. Setting reasonable expectations of services

“Why aren’t you getting them better?” (Interview, transcript C5:5).

In the above excerpt from an interview with a mental health professional, they reflect on comments from a carer (father) on the progress of his son, who has been diagnosed with mental illness while at university. Beginning with how carers articulated their expectations of services, and of mental health professionals in particular, the recurring idea of being on a journey is conveyed, with different expectations being raised at ‘pivotal’ points along the way. Maryam, a carer in her early twenties, has been caring for her two sisters since she was 11 years old and doesn’t conceal her irritation:

“They never come out with a plan for my sisters, it frustrates me. They aren’t ambitious, especially for people like my sisters who are confused and don’t understand they’re in big trouble”

(Interview, transcript C6:13).

She gave a small example of the free travel pass her sister was eligible for due to her mental illness:

“Nobody did it, I had to do it, imagine one kid and another kid having to spell out to people that they should know”

(Interview, transcript C6:13).

Other carers spoke about their contacts with mental health professionals only in association with crises and when things either psychologically or socially were at risk of breaking down. Rhona, caring for her youngest son, now in his early thirties, worried that his mental health issues would actually propel him into direct contact with inpatient mental health services with all the risks that she thought this would entail for him:

“I’ve heard some horrific stories, I mean it must be horrific for the patient you know”

(Interview, transcript C2:6).

In these examples, carer expectations veer from disappointment at the absence of ambition, to trying to avoid services intervening at all, and thereby avoid the risk of becoming another ‘horror story’. In response, mental health professionals appeared to have developed sensitivities toward the expectations that are placed on them by carers, and to have developed a range of strategies to manage them, although not always successfully. Asmita, a CPN notes:

“some families have expectations around medication and how they find out about certain forms of medication, and how it might work for some people, and then they (carers) want it for their loved one”

(Interview, transcript P5:9).

She reflected that medication didn’t necessarily work in the same way for everyone, and there was still a possibility of relapsing and becoming unwell. In my reflective log I have noted how Asmita became more open to sharing her experiences as the interview progressed. She shared insights into working with a mother and father with ambitions for their mentally unwell son to become a doctor, which she felt were never going to be realised. However I also noted how I felt in response to Asmita as the interview progressed:

“As she went on I noticed how quickly and concisely she spoke, and how self-contained she was in sitting and responding to the questions. I had a sense of her being experienced over several years, but also a feeling that questions would be answered in quite a clipped manner – in contrast to the outpouring of the carers”

(Reflective log 5:1).

Asmita shared how she approached the family:

“Carers themselves are much more informed, and I try not to add to their expectations”

(Interview, transcript P5:5).

I had a keen sense that Asmita’s sense of boundary helped her to achieve her aim of not building up expectations, and rather than this being conveyed in a cold manner, it

came across as containing, possibly due to being led by honesty which Asmita had developed over many years of working with carers.

Similarly in responding to heightened expectations, Mark a nurse manager from an Early Intervention service also shared a particular approach:

“I mean may be this is part of being manipulative but you go offering not very much to begin with and people don’t get disappointed. I guess you learn that through practice, but I don’t know whether it’s being mean with the purse strings, I’ve never really worked that one out”

(Interview, transcript P2:21).

Although expectations cross back and forth between mental health professionals and carers, there is a significant dynamic in the relationship, that establishes an expectation for the professional to make up for something that is absent in the network of care. This calls on particular skills in order to successfully navigate and may be a key motivation for managing carer expectations downwards. Advantages to dampening expectations include avoiding disappointment and avoiding any sense that the family or network has been deficient in any way. This approach, described by two experienced community mental health professionals, appears to have developed out of practical experience, rather than anything that is prescribed or widely recommended.

Lodged within all these interactions is a sense of paradox, while on one hand the prospect of recovery is the prevailing approach of mental health professionals, there has been little headway in truly curative treatments for long term severe and enduring mental illnesses such as schizophrenia. For all the participants, what came across was the chronicity of mental health conditions both carers and mental health professionals, were engaged in trying to support. However, even those carers who were at the beginning of the carer journey appear to be resigned to moderating their hopes and ambitions downwards. Donna relates how after several months of caring for her sister, diagnosed with schizophrenia and experiencing a range of distressing voices, she was unable to live in the same space, and decided to leave the former family home to become a ‘distant carer’:

“I used to say to her: ‘I’m trying to help you here’. I never hated her but: ‘I don’t know how to deal with you’. I didn’t have the knowledge with mental illness, one day I would just leave her on her own and we’d be fine, but some days I just wanted to run away”

(Interview, transcript C5:10).

Voicing a similar option, Lisa shares her perspective of her expectations:

“If I feel you know, that I can no long carry on caring we might end up separated again and he might end up admitted into the revolving door again”

(Interview, transcript C4:14).

Despite the seriousness and severity of most long term mental health conditions, professionals were keen to share instances where they believed they had met or exceeded expectations in respect to their work with carers. Working with a Muslim family where the adult son has a diagnosis of schizophrenia and is cared for by his father, Suzanne, occupational therapist working in an early intervention service recounts her approach:

“I find my appointments are very much dual ... son and dad ... because of his faith and beliefs, I suppose, like he’s had to keep it to himself. So each time I see him and his son, every fortnight, we’ll go and do something, a walk, or a drive, or for coffee, well go and do something and he’s found that very helpful”

(Interview, transcript P4:8).

The value of dampening the expectations of carers has been discussed and the subsequent interventions that involve carers can be equally modest, and almost non consequential: going out for coffee, completing a form, having a meeting that involves both the user and carer. These seemingly mundane everyday activities, coined as ‘dual’ by Suzanne, take place amidst the adversity, disturbance and chronicity of severe mental illness within families, partnerships and social networks, where sensitivity, resilience, and adopting a measured sense of hope are required.

There are some benefits of setting expectations low, as the most effective and dynamic work appears to be small in scale and founded on establishing a relationship with the carer, and whenever possible including the service user.

Marta, from her background as a family therapist describes working with a family where the adult son, recently diagnosed with the first onset of a severe mental illness, trashed his bedroom within the family home, and was unwilling to get out of bed until midday each day:

“the focus was on the consequences of the young person’s actions although not conveying it as a rejection of them. It’s easy to join the user by agreeing ‘they’re not helping you’, as well as agree with the carer ‘yes they need to be more capable’”

(Interview, transcript P8:8).

In this case, despite the carer’s anxieties about their son’s future Marta underlines the balancing act that must be navigated by the mental health professional to meet the expectation of the carer to ‘do something’. In this case the consequences in colluding with either party’s expectations may result in the engagement with the family breaking down entirely. Marta sums up the approach as ‘being curious about all stories’.

In recognition of these limited expectations the work with carers is sensitive, grounded in the everyday, and must be built on the carer and mental health professional relationship. For the professional this involves being curious about everyone’s story, quietly maintaining hope, and being honest in response to carer expectations.

5. The carer’s assessment: experiences of assessing and being assessed

“It was a really good conversation” (Interview, transcript P4:17).

During this research project, the Care Act 2014 was introduced and participants including mental health professionals and carers referred to its introduction and significance.

However, since 1995 and the introduction of the Carers (Recognition of Services) Act carers have been entitled to their own carer’s assessment separate to the assessment of the service user, and despite this existing legislative framework few carers or mental health professionals spoke about a carer’s assessment as a significant element of their experience, or work. I noticed this and wondered why.

Furthermore the benefits of a dedicated assessment specifically for carers have been widely heralded as significant in The Care Act (2014) as well as those statutes that came before it, so what will really change? Certainly at the level of grass roots mental health provision, and among carers and professionals, the opportunity that may emerge from a carer's assessment does not appear to attract similar sentiment.

Beginning with an example of a carer's assessment working well, Lisa, caring for her partner shared the following:

“the care coordinator who did the carer's assessment did it very sensitively, he did it very thoroughly, it was a really good conversation, and as I said, he said to me I've learnt all sorts of things that I didn't know and didn't ask”

However, Lisa also cautions:

“the message that I'd give is let's see some tangible results, let's see some progress on the carer's grant, or on the family therapy, or on the things I've identified as being important”

(Interview, transcript C4:17).

Lisa related how her newness to the experiences of caring for her mentally ill partner had permitted the carer's assessment to be used by her to 'tell her story', which she acknowledged contained a 'therapeutic' element through the presence of a mental health professional who was able to actively listen to her experiences. I had the sense that Lisa had experienced the assessment as containing, and through the attentiveness of the care coordinator had been enabled to tell her story in way that released her of some of those anxieties that she'd been holding onto on her own. Aside from this benefit, Lisa also cautioned me that the assessment will only be truly valuable if it brings tangible results, including services and financial benefits.

I reflected on this statement and the way I felt to be on the receiving end of it, as a practitioner-researcher. Firstly, it felt a little threatening, 'woe betide you if you don't come up with the goods'. Later I wondered about the level of investment that is placed on the carer's assessment, as both a therapeutic space to record a carer's journey and current well-being, as well as a bureaucratic procedure in terms of those statutory responsibilities set out in The Care Act (2014).

Similar to the wider group of carers, many of the carers in the research sample have been in the system for so long they were not able to pinpoint a moment when they could actually recall being assessed. In these instances the experience of caring has gone on for lengthy periods of time, and it appears to become a less pressing issue to 'unearth' the experiences of the carer and their needs in the form of a formal assessment or re-assessment. Amongst this group there is a greater feeling of resignation, of having lived with a great deal of pain for years and years, and having found a way of living with the loss that mental illness can evoke. Within the focus group this sense of longevity within the carer role emerged from these carers:

Sylvia an older woman looking after her adult son:

"I've been dealing with this for over 30 years, and as soon as he thinks he's okay, he stops taking his medication. I know the symptoms, I am there, I have to live with it"

(Focus group, transcript 20).

Suleyman a retired older man caring for his adult son:

"I've been a carer for 16 or 17 years now, and I haven't heard one carer being asked whether they, he or she, can, or are able to look after a patient"

(Focus group, transcript 30).

The benefits of engaging with a carer's assessment had not permeated among those carer participants who have been caring for the longest periods of time. Defining what the assessment process aims to achieve at this later phase of the carer journey is therefore important. On the basis of the interest and openness in sharing their respective accounts of caring at the focus group, this is the very group that may potentially most benefit from the chance to 'share their experiences' through a carer's assessment that prioritised an opportunity to open up the space for active listening on behalf of the professional.

Aside from the content of the narratives, what also emerged from the focus group and one-to-one interviews, was greater awareness of the concentrated nature of the verbalised experiences, from both carers and mental health professionals, which had not been diluted through previous opportunities to talk about their experiences. In

many cases there was a sense that the accounts were being conveyed for the first time, in a similar way to those who give testimony many years after an experience of trauma or a miscarriage of justice, of which the Truth and Reconciliation Committee in South Africa is the most widely known (Haupt & Malcolm, 2000). Although the focus group utilised case study vignettes, many of the carers took these as a cue to verbalise their own carer journey, their pain, and their ongoing efforts to maintain some semblance of normality:

“You’re the butt of being told off, you’re the butt of the cared for person’s frustrations, so you have to be extremely patient and tolerant because they’re not well people. Sometimes you have to go into another room and cry, or just disengage from the situation and talk to someone”

(Focus group, C47).

For those carers at the beginning of the journey, it appears the carer’s assessment is an important tool for permitting them to tell their story, with the added value of opening the way to receiving a service as part of The Care Act legislation. However, for others, especially those who have been in the role of carer for some time there is a need to refresh the aim of undertaking a carer’s assessment both as a formal opportunity to tell one’s own story, as well as identify needs. A dilemma in taking this approach is working with any material that emerges in respect to the carer’s ability to appropriately support the service user (who is the vulnerable person), with the likelihood that the caring role has developed, and been in place, for several years.

The confusion within the process of undertaking a carer’s assessment relates to what and who is being assessed, and specifically how much it is an assessment of the quality of care that the service user, as the vulnerable person, receives from the carer. This is an area of trepidation in the relationship between mental health professionals and carers, for while both can form an opinion of each other, it is the mental health professional who has the authority to undertake an assessment of the carer, and part of this is to consider the nature, quality and suitability of care that is provided. Depending on the relationship between the mental health professional and carer, undertaking a carer’s assessment in all these senses is challenging.

Mark from the Early Intervention Team noted:

“as a clinician I carry out carer’s assessments and I’ve found that some people don’t like the terminology of a carer’s assessment because they feel, perhaps they misunderstand the term and think perhaps that they are being assessed, and their ability to care which makes it a bit clumsy”

He also spoke about the definition of carers from the local authority (before the implementation of the Care Act 2014):

“There’s the definition of carers from the local authority that is open to interpretation so unless someone is providing something that is regular and substantial and this isn’t really defined care, then they don’t qualify for a carers assessment”

However he also noted:

“I have a much looser interpretation and I think if someone is affected by ... their thoughts about a relative or someone they care for I think they’re entitled to some form of an assessment and how they might be supported”

(Interview, transcript 2:2).

The new legislation brought in through The Care Act (2014) considerably opens up eligibility for a carer’s assessment. However as we see above, a looser definition has been in place in mental health already.

Marta sums up her understanding of the assessment process:

“It can lead to a useful and strengthened relationship between the carer and care coordinator, for example time set aside for the carer to be able to ‘tell their side of the story’”

(Interview, transcript P8:6).

The idea that the carer has ‘their side of the story’ is an interesting and useful phrase, which hints at the possibility that disagreement and contested understandings of the situation may be present. From adopting this stance the possibility re-emerges of being curious about all the stories, and engaging in actively listening to what it means to be a carer.

6. Barriers in the relationship between mental health professionals and carers

“They blocked me” (Interview, transcript P4:5).

In the above excerpt, Suzanne, an occupational therapist reflects on the instructions of a service user in a request by the professional to establish contact with their carer. It highlights a series of potential cracks that can emerge in the relationships between carers, mental health professionals and service user. These cracks may have been present before the onset of any severe and enduring mental illness, although they can be exacerbated by the disturbance that can emerge and the subsequent anxiety.

In instances where the service user, for whatever reason, is unwilling to cooperate with, or agree to information being passed to their carer, be they family or friends; mental health professionals shared their experiences of the challenges of working with these situations.

Kofi a social worker in a community mental health service:

“I’m currently working with a service user and he’s clearly stated he doesn’t want his mother to be seen as his carer. He has capacity to make this decision and it’s difficult to provide support for mother in this instance”

He sums up the dynamic and where he saw himself positioned in the network:

“At least three different points of view in terms of carers and mental health: the service user, the carer, and the worker. And the worker is the one stuck in the middle”.

(Interview, transcript P6:1)

In a Focus Group discussion about the assessment of a new service user and the involvement of their family, Jackson, working as a psychiatrist in a home treatment team notes the uncertainties and dilemmas for professionals, especially in sharing and withholding information:

“it’s the idea that we ... we get taught about confidentiality. Basic things ... like confidentiality ... and even people who are very unwell can later sue ... if they think that their confidentiality has been breached. So I think the general rule that a lot of people work on is that we only breach confidentiality if there’s a danger to the people, or the people around, or things like that”

(Focus group, transcript P10).

Suzanne, the occupational therapist within an early intervention team also flags the issue in the relationship with carers and what can get in the way:

“if the service user doesn’t perceive their loved one as being a carer and don’t want to meet ... the two examples I have are of two young people ... and they didn’t want their parents to come into the meetings ... and didn’t want them to have any information because they were their carers ... and they wouldn’t, they tried to block me ... and in both recent cases they didn’t want me to communicate with carers, or the carers to communicate with me, or to have carer’s assessment”

(Interview, transcript P4:5).

Suzanne noted that one of the ways of progressing through the impasse involved contacting a local carers’ centre who were then able to contact the carer and provide the support that was needed. Although the use of an external third party appears to have achieved a reasonable outcome, it represents the inability to work through the impasse within the triangular relationship between the user, carer and mental health professional. It is also a reminder of power and autonomy that runs through these triangular relationships, which is summarised by Suzanne:

“I suppose there is only so much I can do in working with a carer directly. My priority has to be with the service user”

(Interview, transcript P4:6).

The focus group enabled a case discussion about the sensitivities of making contact with the family of a young adult called Hassan, who was apparently becoming increasingly depressed and isolated. In the subsequent discussion both carers and mental health professionals appeared to be able to empathise with the perspective of ‘other’ and be able to hold on to the idea that all parties: worker, family, and Hassan had to work with the complexity of an emerging mental illness erupting into the life of a young man and the family he lived with. Marcia, a carer for both of her parents who have mental illness, commented on the dilemma faced by the mental health professional:

“I think she did the right thing because obviously he is her client because she needs to make an assessment and confidentiality and privacy are also a concern And obviously (there are) concerns about the relationship, the family relationship, so I think these boundaries need to be sorted out, who’s doing what around the relationship”

(Focus group, transcript C8).

The discussion, based on a case vignette and removed from the actual lived experience of any single carer or professional, made it easier for participants to take the ‘third position’, and demonstrated the value of seeing carer and professional dilemmas from alternative perspectives.

7. Summary

Although mental health services are defended by a boundary that seeks to maintain anxiety on the outside, inevitably carers find a way to breach these borders and feel aggrieved at not being prioritised. In terms of carer’s expectations, particularly those that relate to resolving the mental distress experienced by the person they are caring for, and reducing the disturbance that enters into their lives, mental health professionals shared a way of working with carers that purposely did not heighten expectations, and in fact lowered them. However carers complain of services not having ambitions for those they care for, and the possibility of division emerges. Bridging this, the importance of being curious about everyone’s stories was shared, and an approach that focuses on making small differences in undertaking seemingly mundane and everyday interventions appears to be well received by carers. Mental health professionals are able to manage many of the disappointments and losses that emerges from carers by having a strong interpersonal relationship. Finally the opportunity to enable a carer to ‘tell their story’ emerged through the creative use of a carer’s assessment, alongside the dilemmas of working alongside the rights and views that emerge from service users.

Chapter Five

What is the Nature of the Lived Experience of Caring for Someone who has a Long Term Mental Health Condition?

1. Introduction

The focus now turns to the second area of enquiry which concerns the 'lived experience' of caring for someone with a long term mental health condition. The previous chapter looked at the relationship between mental health professionals and carers, whilst this chapter focuses on the experience of caring itself, with a key interest in the everyday lives of carers. In addition to the data from carers, a wide range of data concerning the experiences of carers also emerged during the focus group and one-to-one interviews from mental health professionals, and this will also be considered to inform our understanding of caring within the context of mental illness. The lived experiences of carers also overlaps with the 'lived experience' of mental health professionals, and each experience inevitably informs the other. The possibility that there are universally shared experiences by all those involved in caring for someone with a long term mental health condition, be it unpaid or professional care, is also held in mind, and provides a further argument for including all the data.

The chapter is structured as follows:

- The nature of mental illness
- Isolation and aloneness in caring
- Relationship between the carer and cared for person
- The experience of the carer journey

2. The nature of mental illness

The nature of mental illness and its ability to infiltrate the lives of carers and mental health professionals alike, emerges powerfully from the data. Within the focus group Sylvia relayed her experiences of caring for her son who has a mental health condition leading to extreme swings in his mood:

“I’ve been through this so many times with my son. I have had the responsibility of paying off all his credit cards because I had the bailiffs come to take away all my stuff as well as his stuff, and I did this a couple of times when he’s ill, when he’s high he goes and buys things spends money on his credit card. He don’t need it and if you go now you will see things wrapped up and put under the bed. I cried myself many a night, and I think to myself: is this ever going to end?”

She reflects on the circular nature of the experience of caring:

“I’ve been dealing with this for over 30 years, and as soon as he thinks he’s okay he stops taking his medication, I know the symptoms, I am there, I have to live with it, so it is I who gets in touch with the social worker, hospital, doctors, whatever, but ah, he thinks he’s well so he stops taking his medication, so he’s back to square one, he’s gone right down the barrel again”

(Focus Group, transcript: C 22).

All of the carers, whether being interviewed on a one-to-one basis, or within the focus group, conveyed a desire for relating their own experience of mental illness in terms of outward and physical behaviours, or significant moments in relation to others, experiences that could be visibly witnessed and observed, and set within the context of family and home life. In Sylvia’s case her anxiety came flooding into the focus group as if we had travelled back in time to 30 years previously when her son had first become unwell. Other carers in the group took this as a cue, and took turns to share their own stories. There was a sense of being among ‘witnesses’ and hearing testimony, as if these carer stories had been stored away until they could be aired in a safe space and then released into the world.

Suleyman, an older man caring for his adult son, related how he was asked to take responsibility for him when he was assessed as no longer needing inpatient care and was ‘ready for discharge’:

“No discussion about what my son is suffering from, why he tried to commit suicide by slashing his throat, nothing at all. I just took him home and all I

could do was bathe him, and his wrists were cut as well, and his throat was bandaged. And I had to feed him that's all I could do"

(Focus group, transcript: C27).

Stefan shared his frustration in caring for his sister who does not believe she is unwell:

"It's my experience also, my sister is quite cunning, so that she'll actually lie and she's very good at convincing the workers, psychologists and social workers, so she gets what she thinks she wants"

(Focus group, transcript: C21).

Judith, caring for her adult daughter and Marcia, caring for both of her parents, exchange experiences:

Judith: *"The thing about severe mental illness is that you're paranoid"*.

Marcia: *"Yes, you're the butt of being told off, you're the butt for the frustrations, so you have to be extremely patient and tolerant because they're not well people. Sometimes you have to go into another room and cry"*.

Judith: *"And we're quite often ... not well either"*.

(Focus group, transcript: C47)

In addition to the disturbance that emerges from long term mental health conditions threading through the carer narratives, the experiences of mental health professionals also underlines how this disturbance is able to penetrate the whole system. Maggie, a social worker in a community mental health team, described her work with a young woman called Chloe. Chloe suffered with a long term schizophrenic mental illness in which she heard voices telling her to harm herself and leading to her scalding herself with boiling hot water and threatening to cut off parts of her body. This culminated in her being detained in hospital under the Mental Health Act and being treated against her will with a range of medication based treatments that caused her weight to increase. In response Chloe's mother had become hyper-protective of Chloe, from what she believed to be the coercive power of mental health services. She physically removed her daughter from the inpatient setting to look after her at home, and advised her daughter to stop taking any further

medication-based treatment. The breakdown in the relationship between the mental health professionals and Chloe's mother continued as more and more desperate measures were taken, and communication was taken up through legal channels. During the interview Maggie spoke of the overwhelming anxiety that had permeated the whole system, including the fear among the professionals that Chloe would one day successfully end her life, with the service being blamed:

“Particularly mums again, where they’ve been overly involved in their child’s care to the point where it’s actually a hindrance, and it’s not that helpful, I’m not saying it’s done maliciously, but for some reason they have a distorted perception of what’s wrong or right for their child. It isn’t distorted to them. It can be difficult, very difficult if you don’t get the carer on board”

(Interview, transcript P3:15).

It is not necessarily dramatic experiences that create the most disruption, but often the mundane and untoward. Rhona, carer for her adult son, talks about the nature of his condition and how it has affected their life as a family:

“He realises that something is wrong, he describes it as the left side of his brain doesn’t work. Which is not the case (laughter), not the case. And he’s not very happy today ... because people don’t understand how small things can really get to him you know because he’s really sensitive and these things happen all the time”

(Interview, transcript C2:7).

While it was not overtly referred to by carers, the stigmatising and excluding nature of mental illness also emerges in their experiences. The mental health professionals summarised this in various ways, for example, Sam the inpatient ward consultant:

“Mental illness is a condition of the soul that can affect your personality and place you at risk of losing your dignity”, and: “Physical conditions can be less mystical. Mental illness can be an enigma for people”

(Interview, reflective log P7:5).

Maggie, with a professional background as a social worker and Approved Mental Health Practitioner (AMHP) referred to mental health issues as ‘the beast’ and while

almost a throw-away line, the unspoken fear of being infected with mental illness, or possessed by this 'beast' of an illness is present. Continuing the 'infection' theme carers and professionals alike sought to highlight the characteristics of mental illness by contrasting it with physical health conditions, Maggie for example:

“The other thing about mental health is it’s not so obvious as a physical illness ... I don’t think people perceive it in the same way. So if you go in and you have a physical problem and the worker says: ‘to make you right, and to get you better we need to ...’ they’re grateful, they’re happy, you know, and, I think with mental health it’s completely the opposite”

(Interview, transcript P3:11).

Also absent is the element of gratitude and relief that can emerge from 'fixing' a physical ailment or from 'mending' a fractured bone. In the realms of a long term mental health condition the care plan does not indicate when the condition will be either cured or resolved. A further related dynamic is the feeling of time standing still from the point when the initial episode of mental illness emerged, and neither the cared for person, nor the carer being able to move on. Rhona, mother to four adult sons, reflected on her ongoing experience of caring for her youngest son, who is now nearly 30, and has a diagnosis of schizophrenia:

“My role hasn’t changed. I’m still having to do the shopping, cook the meals. Plan my activities around being there in the evening. Nothing has changed. It’s 1968 when my eldest son was born”

(Interview, transcript C2:20).

In this description it is as if Rhona and her role in the family have been held in suspension, unable to move on whilst mental illness is present within the family.

Despite the sense of disturbance, some carers demonstrate a huge commitment to really getting under the surface of their loved one's illness and trying to understand it. However, in listening to these experiences there is a sense of carers' stepping into a highly distressing space, and of the vulnerability of carers themselves. 'Lisa' described a low point in the deterioration of her husband's illness:

“He was standing in my kitchen for five hours shouting at my computer. The reason he does that, because we’ve talked about it since, is he gets a ‘feeling’ from it, and he’s there to tell the world the message, the message is usually the fact that the world is under attack and he’s there to save them, and he gets so that if only people will listen to him and could understand he could help them”

(Interview, transcript C4:4).

Of course carers respond in different ways to the disturbance that floods into their lives from a loved one suffering from mental illness. Some carers, like Lisa, decide to enter into the world of the distress to ‘work with’ the outward manifestations of the cared for person’s mental illness, sifting through the experiences, and trying to reach a greater understanding of them, despite the challenge to their own views of the world. However there are risks for carers of becoming part of the disturbance, and no longer recognising it as a manifestation of mental illness to such an extent that caring becomes harmful to their own wellbeing. In listening to Lisa’s experience, the strain of being alongside this level of enormous distress should not be underestimated, and in listening to her account I reflected on those times when professionals undertake this sensitive form of work, and the assistance they receive from organisational frameworks such as supervision, formal recording systems, and peer and professional networks, support that carers do not receive.

In contrast with Lisa, Sylvia, a carer for her son, and whom we heard from earlier, appears to try to push away and expel the unpleasant and distressing experiences. However this can be just as hazardous if carers try to defend themselves too rigidly from the disturbance that emerges from mental illness, and to expel and distance themselves from it completely. In these situations the risk of higher and higher levels of tolerance emerges, leaving the carer unaware that external help is needed.

The carers’ experiences help to explain the ‘distance’ that professionals adopt in respect to service users, and throw into sharp relief the inability for carers of achieving a similar ‘distance’, and why they are unable to use the same contained and dispassionate language adopted by professionals.

The sometimes fleeting and transitory nature of caring for someone with a mental health condition also marks it as different and unique. While caring for someone with

a physical ailment or disability may involve daily rituals around practical and physical activities, the actual carer role in mental health is much more slippery:

“Help him to have a normal life” (Interview, transcript C2:7).

“Sort out a routine” (Interview, transcript C1:5).

“Pick up on things .. go round the house making sure” (Interview, transcript C3:31).

“Take the horse to water but you can’t make it drink” (Interview, transcript C4:15).

“Like being a parent” (Interview, transcript C6:1).

“Sustain her, look after her, managing her” (Interview, transcript C7:9).

None of these carer activities can be easily quantified, measured or even necessarily observed, but within the context of the disturbance that emerges from severe mental illness, and the limitations it places on enjoying mutually productive relationships with others, they are challenging and at times highly distressing.

3. Isolation and aloneness in caring

In the consideration of isolation and aloneness in this section it is important to distinguish between the two experiences from the outset. Isolation in this context is the absence of connections to wider societal institutions or supportive frameworks such as employment and social networks, or the lack of belonging to a wider group. In contrast, aloneness is related to feelings of being on one’s own with a particular issue, in this case being a carer for someone with a mental health condition, and not having other people around to share the load.

Underlining the notion of being ‘on one’s own’, Rhona, a carer and recently retired states: *“mostly we are dealing with it on our own”*. Later in the interview she speaks about her son’s attempts to gain full-time employment after completing college. In my reflective log I’ve recorded how I observed her various feelings as she speaks: admiration for her son at his ingenuity in navigating the benefits system, anger at the unforgiving nature of the formal workplace, and finally sadness and resignation. She tells the story of Harry, her son, and his efforts to enter the world of employment:

“It amazed me, I had great difficulty getting through interviews I never got jobs. Harry sails into a job with XX Bank based in the City, a huge firm. He was there for 2 or 3 weeks on probation and then he was sacked. And he was sacked at the end of the day, nothing had happened but clearly they’d made up their mind.

Harry was so incensed they’d waited until the end of the day and made him work all day and then sacked him. May be somebody was putting off the moment, couldn’t bring themselves, but it was brutal. Well, being sacked is very brutal, I remember someone from the bank phoning, a colleague of Harry’s, phoning to see if he’d got home. I just thought that was the limit of their concern, as soon as he got home it was passed on to me and yet they created it, they hired him. I suppose they’d given him the chance, he couldn’t hack it in a huge organisation like that. And I don’t know what the problems were and I never will find out. And he was desperate to prove himself, he got a couple of other jobs after that, but they all ended after the probationary period.

It came home to me that we were on our own. They would get on with running XX Bank and we would get on with looking after Harry. And they had a clear conscience”

(Interview, transcript C2:14).

This experience connects with a particular aspect of isolation for carers within the context of mental illness, in wanting to protect the cared for person from the fear of threats from the rest of the world. Often acutely aware of the cared for person’s vulnerabilities and the stigma that arises from mental illness, carers are constantly on alert on behalf of the cared for person who may be unable or unwilling to accept their own predicament. In the case of her adult son Harry, Rhona was unable to extend her protection to the world of work, and when the experience ended so painfully she feels his pain and the sense of isolation from the wider world permeates through.

In contrast, Hamid, caring for his wife and their children, remarks on his aloneness within their relationship:

“She doesn’t recognise herself as a wife or mother. So it’s really very stressful, challenging, one day good, one day bad, one week and one month ... so many difficulties, so here I am”

(Interview, transcript, C7:9).

The loss of a loved one to any illness is shattering but with mental illness there are additional challenges. The person with the illness is present and alive but may be unable or unwilling to accept the impact on their ability to function or to relate to others. Similarly the need for support from a carer is often complicated and fraught, and may be met with a range of feelings from hostility to over-reliance.

Donna reflects that despite being one of seven siblings she has been left with the responsibility of caring for her sister, diagnosed with schizophrenia:

“Scattered all over the place, brother in Dorset and Harrow and Crawley. Out of all the family only myself, and one other brother, who lives with (my sister). We’re the only ones who deal with it, if anything bad happened – oh well”

(Interview, transcript C5:7).

Isolation from wider society was also connected with the social stigma around mental illness and the effects this can have. Mark, caring for his wife, shared how his family and friends responded to sharing news about her becoming mentally unwell:

“I mean it destroyed my friendship with people ... when I emailed to tell them what happened they just disappeared. I rang my mum and dad to tell them what was going on and their response was quite frightening: leave her don’t get involved”

(Interview, transcript C2:5).

The discrimination that results from the stigma associated with mental illness enters into family life and confronts carers. Hannah, mother to three adult sons, one of whom has a diagnosis of schizophrenia, spoke about the fear that one of her sons has of contracting the illness and it being passed on. Now married with his own children, his worries that they may ‘inherit’, through genetics or other means, an element of the madness, has meant family gatherings no longer take place and a schism in the family has opened which Hannah desperately tries to bridge.

At a public level mental illness can cause a withdrawal from social institutions and both Terry and Hamid have both left the formal workplace to take-up full-time caring roles. The isolation of carers mirrors the isolation of mental health service users to a large extent. This brings with it the impact of a general sense of increased poverty; be that financial, material or social, all associated with an inability to participate in mainstream activities. While the risks of isolation and loss of social contacts are clear, there are other ways that carers remain connected. Both Hannah and Lisa shared how they had become involved in campaigns, and joined groups involved in raising awareness of mental illness, and improving the lives of carers.

Building on the carer testimony of aloneness are narratives from mental health professionals. Suzanne, from her work in the community based early intervention service talks about 'hidden caring' and those families where there is a 'silent carer' drawing on the example of a father caring for his son who has chronic schizophrenia:

"It's an expectation in certain cultures, it's an expectation, it's just what you do, you don't ask for help from outside"

(Interview, transcript P4:8).

Suzanne notes that the family involved in the silent caring is Muslim, and it is important to flag the range of beliefs about mental illness, and expectations of caring, founded on religious, cultural and ethnic beliefs. Whilst the existence of multiple forms of discrimination is acknowledged, the research sample covered a diverse range of participants and indicates that isolation can happen regardless of cultural, ethnic and class distinctions, coming in part from the experience of caring for someone with an enduring mental health condition, and the subsequent discrimination experienced. However, the additional likelihood of other forms of oppression based on race, gender, age, class, disability and sexuality remain.

Asmita in her role as a community psychiatric nurse spoke to a different quality of aloneness in the experience of carers she was working with. She described how carers, typically parents of young adults, have large amounts of information available through the internet which created heightened expectations of what the service could achieve for the person they are caring for. She described working with a 'high achieving' family where a young adult son had been described as a 'bright child' and had showed promise until being diagnosed with a serious mental illness:

“He’s become mentally unwell and the future at university and in medicine or law, or psychology, has been lost. His mother talks about her child and the negative symptoms (of schizophrenia) are very difficult for her to deal with”

(Interview, transcript P5:11).

Asmita also noted that a number of families she is working with increasingly investigate different forms of medication on the internet, and were able talk more confidently about what they wanted for their loved ones than in the past, but:

“even with medication some people still relapse, and medication doesn’t always work”

(Interview, transcript P5:2).

These examples also highlight the manner in which mental illness can remove a family’s aspirations and ambitions for their child’s future. In these instances the wish to withdraw becomes great, as the familiar rites of passage open to many families, including: ‘A’ levels, university, and career are no longer available.

Mark, from his professional background in nursing, also discussed wider societal views about mental illness, especially prejudice and stigma, and how this affects the carer experience:

“You’re less inclined to discuss it with carers and friends and peers, and not something you’d discuss in work. And I suppose if someone had a more recognised, more socially acceptable disability perhaps they’d more readily be able to speak about it”

He reflected further:

“So there’s prejudice of society and my own prejudice that I’m not aware of about people with mental illness”

(Interview, transcript P2:22).

The ability of mental health professionals to reflect personally on their own prejudices is surfaced in this interview and in working within the field of mental health, the importance of being in touch with one’s own anxieties. Acknowledging the fear of madness within wider society it would be naïve to conclude that it stopped

at the doors of health and social care institutions. While professional distance, boundaries and individual supervision are all available to help process the anxieties that emerge from the work, the challenge is not to be underestimated. One of the threads that runs throughout all the findings from carers is the value that is placed on meaningful and supportive relationships. However, these are only available if the mental health professional is adequately supported to engage with the carer, and work alongside them to manage the distress that results from a long term mental health condition.

4. The nature of the relationship with the cared for person

The thematic analysis identified that a key aspect of the carer experience was influenced by the nature of their relationship with the cared for person, and two key concepts emerged:

Firstly, a number of narratives identified the cared for person as the source of 'the problem' which was supported by experiences such as: feeling persecuted by them, being irritated by their 'funny little ways', being aware of stress building up inside the cared for person, and the cared for persons being very demanding.

Secondly, what also emerged from the analysis was the concept of 'love in the caring relationship' which was supported by feelings such as: deep affection for the cared for person, the cared for person being a partner, relative or friend, and feeling protective of the cared for person.

These experiences could be applicable to any number of adult relationships without the additional element of the 'carer cared for' dynamic. Equally the presence of a caring element is inherent in any number of relationships, including a parent caring for an adult child, an adult child caring for a parent, one partner caring for another, one sibling caring for another, as well as caring based on friendship, being a neighbour, or being a work colleague. Within the research, mental health professionals and carers also reported instances where relationships had become strained and potentially ended owing to elements of caring, but what also emerged was the ongoing persistence of a 'carer cared for' dynamic long after the original basis of the relationship had ended. Kofi, a mental health social worker related working with an elderly service user who had identified her daughter and son-in-law as her carers. When her daughter then divorced and moved away to begin a new

relationship, her now ex son-in-law continued to provide care and support which enabled her to remain independent. While carer legislation has cemented the importance and prominence of carers within society, which is undoubtedly progress, it is also timely to point out that the use of individual identities based on 'carer' and 'cared for' labels is a constructed framework for categorising the complexity of a wide range of day to day intimate relationships:

“dependency in intimate relationships is typically mutual rather than one way, even when one party is sick, impaired or disabled. The highly restricted and one-way connotation of 'carer' and 'carer for' does not do justice to this complexity”

(Pilgrim, 2010, P86).

Accepting the essence of this critique, and acknowledging the complexity of human relationships and the complicated nature of dependency and interdependency, the research nonetheless examines caring within the context of mental illness. Possibly as a reflection of wider social factors, it is significant to note the higher number of women who volunteered to be carer participants, and the higher numbers of participants occupying the role of parent, in particular mothers of adult children with a mental health condition. Out of the seven carers interviewed, only two were men, and out of the nine carers who attended the focus group only three were men. Mental health professionals were also quick to point out the dynamic around women, and mothers in particular, who appeared to have a particular stoicism for caring. Mark, nurse team manager in an early intervention service notes:

“I have noticed that mothers tend to stay a lot longer than anyone else, and a lot longer than fathers”

(Interview, transcript P2:18).

The idea of 'staying' brings to mind the quality of resilience and the idea that mothers have a greater investment in maintaining caring relationships with their adult child, regardless of the disturbance created by the mental illness, even when others may have decided to remove themselves from the situation. Mark continued to share his views about mothers in caring roles:

“They are a lot more likely to put themselves at risk than any other family members, so perhaps there is a unique relationship between the mother and the cared for person”

(Interview, transcript P2.18)

In her interview Marta reflected on her experiences as a social worker and as a family therapist and listed categories of carer and cared for relationships. She included: those carers who undertake caring because they define themselves as ‘a good person’, those carers who undertake caring out of ‘duty’, and those who undertake caring out of a sense of commitment based on religious or other belief system (Interview, reflective log 8:6). A key determiner of the form of carer and cared for relationship seems to be the relationship that existed between the carer and the cared for person prior to the onset of the mental illness. In this sense the carer and cared for relationship between partners will inherently have different characteristics to a carer and cared for relationship between a mother and her adult son. The following example from Lisa, whose partner is diagnosed with a schizophrenic form of mental illness resulting in rapid mood swings, illustrates this. Reflecting on their relationship she noted a period of time where they parted:

“X can be very demanding and he was always interrupting me and expecting me to do things for him and I was really stressed at that time and it really stressed me out. Ahm ... so we separated”

(Interview, transcript C4:3).

Later in the interview Lisa notes how she and her partner decided to get back together and she became his carer once again. The separation and decision to resume their relationship was undoubtedly full of complexities, and although the example suggests the possibility of a degree of choice on Lisa’s behalf, it also suggests a host of dilemmas when involved in caring for someone who has a mental illness, regardless of the underlying relationship.

Meanwhile, Maryam, caring for her siblings, one older and one younger, referred to them in the following terms:

“They’re my babies and I’ve had to protect them”

(Interview, transcript C6:11).

She noted a key change occurred when she decided to move out of the family home, where she had previously been available full-time as a carer to her sisters:

“I lived with my sisters until I was 22 years old and now I live separately. When we all lived together it was like eternity, it was exhausting and unbearable”

(Interview, transcript C6:15).

Although not without its difficulties, Maryam’s separation from her sisters by physically removing herself from the family home, appears to be part of a dynamic that is associated with widely recognised social norms about gaining independence and separation. However Hamid, married to Sonya who suffers from a range of psychotic symptoms, and caring for his two children, conveyed a contrasting sense of agency:

“This is my destiny, I accept it till the children grow up, then I’ll see, I’ll be 60 or 70 years old by then, I’ll have a year”

(Interview, transcript C7:9).

In contrast with Hamid’s summary of his limited options, Donna, caring for her adult sister, relates how she made a decision to leave the family home where she had provided care for her mentally unwell sister following the death of her parents, who had previously been the carers. Now describing herself as a ‘distant carer’ she related how she and her husband had decided to move several miles away as a direct consequence of the increasingly challenging experience of caring:

“I had to have counselling, I tried to tidy up the place with her agreement, I spoke with my family about the counselling and they suggested things. I spoke with my GP who advised: move away or leave the house, and try to get care for her when you’re gone”

(Interview, transcript C5:3).

With a background in social work and family therapy, Marta stated there was an essential element of reciprocity or ‘pragmatism’ in all caring relationships:

“with siblings it might be, ‘I’m doing this for you now, but what are you doing for me?’”

However, within a parent - adult child relationship she noted:

“there is less expectation around reciprocity, with parents there is a sense of ‘til death us do part’, whereas with other relationships they can be more easily ended”

(Interview, transcript P8:5).

Interest from mothers in attending the focus group was particularly strong, although the inclusion from a father caring for his son, alludes to the idea of parental tenacity in caring, and supports the point made by Marta above. Cross-cutting any commitment based on familial ties, a discussion of a vignette at the focus group involved the commitment of ‘Rachel’ in caring for her boyfriend (‘Andrew’) at the point of his discharge from hospital. The vignette highlighted the uncertain nature of the partnership and whether the couple had in fact broken up or not. This uncertainty became something of a preoccupation of the group. Dora, a family therapy mental health professional notes:

“I still don’t actually know who is in a relationship with whom. So, um, I suppose I was confused and wondering how to clarify that, but we’ve got that Rachel went to his discharge meeting ... so I wondered, how did she get there? Who invited her? So I guess those are the things that I’m interested in; when and how and who is defining their relationship. So I was just interested ... this is a big confusion”

(Focus group, transcript P24).

Olivia, a carer for a sibling responded in a manner that addresses what might have been happening for the carer in the vignette, and spoke for the actual experience of being a carer which may have been overlooked by the professionals in their preoccupation to establish certainty:

“they just expected him to return home to her, and to help with money until he gets his benefits to start with. If that’s the expectations that are put on her she’ll probably feel, that if she says anything, if she says contrary to that, she

may feel she is responsible for him deteriorating in his health. So she may feel that it's best that she just comes along, and helps him improve and move on"

(Focus group, transcript C33).

Through sharing this 'carer' perspective, the irritation within the group around the status of a particular individual in the life of another was neutralised. From her role as a carer, Olivia was able to reflect on something previously unseen in the detail of the scenario, and pushes the legalistic perspectives of the group to one side. In contrast she hooks on to other dynamics; while there is pressure to discharge Andrew from hospital, Olivia talks to something about the essence of caring, the sense of responsibility that a carer has for a cared for person, regardless of the familial or relationship connections, and something that speaks to a fundamental aspect of human nature.

During her one to one interview Marta picks up on a similar point and reflects on the nature of her case work:

"There are occasions where if it wasn't for the existence of the carer – cared for relationships, the relationship would probably have broken down, and the couple are actually a couple because of the ongoing caring relationship"

(Interview, transcript P8:10).

Commitment within the role of carer appears to be related to the degree of mobility on the carer's behalf and the nature of the obligations that exist within the relationship, and are informed by the familial relationship between the carer and cared for. Carers may also have a sense of responsibility that endures beyond the lifetime of the actual relationship, and this is something that mental health professionals can work with, being mindful not to exploit it by assuming care continues unchanged. Many carers also report loving, supportive and creative experiences in the lives they share with the cared for person, and these qualities should not be overlooked by professionals who may become focused on issues involving dependency.

5. Carer experience as a journey

The 'lived experience' for many carers has been seen as a journey. Through the thematic analysis, the frequency of mental health professionals and carers talking about how mental illness impacts a family or network emerged strongly. Examples include: *'had to start afresh with a 'new' person'* (carer), *'shock as I'd been looking forward to retirement'* (carer), *'partly to blame as it was my fault'* (carer), and *'carers need to be aware of whether they really want to be carers'* (mental health professional). Alongside the data on becoming a carer, the idea of pivotal points on the journey also emerges, which are largely occasions when things go wrong: *'they didn't want to let me know anything'* (carer), *'I really didn't know how to get help'* (carer), and *'we do rely on carers'* (mental health professional). For carers the starting point of the journey seems to shape the way they subsequently engage with support from mental health services, and a number of accounts feature feelings of shock, loss and ongoing bewilderment at the impact of mental illness on the lives of carers.

However, this is not the case for all carer and cared for relationships and two participants (Hamid and Lisa) appear to have started a relationship knowing that their partners experienced mental illness. For Lisa, this seemed to be part of her partner's 'character', she was aware that he took treatment for a significant mental illness, and had regular reviews with a mental health professional. In Hamid's case, he also knew from the outset there would be role for him in being his wife's carer and noted he was aware of a 'chemical imbalance' in her brain:

"my destiny, I accept it, until the children grow up"

(Interview, transcript C7:9).

Setting aside the motives that influence carers, the initial experience appears to be one of shock and disbelief, and having to learn about a whole new world very quickly. Once this initial phase of shock lessens a series of 'firsts' take place, almost like induction to a new organisation, and these may include: first visit to a psychiatric hospital, first care coordinator, and first meeting with a psychiatrist.

As the journey continues, the key pivotal points, are often mostly associated with interactions with mental health and other statutory professionals. In particular these

include: care plan review meetings, discharge from hospital meetings, receiving an aspect of information about a particular diagnostic label, or hearing advice about an aspect of the mental health condition. For example, Terry spoke about being offered a council flat in a tall tower block and the worry of his wife committing suicide, and Maryam talked about calling the police when she became worried about her sister's health deteriorating.

With those carers who have been caring for many years a degree of acceptance or stoicism appears to emerge. Hannah, Rhona and Suleyman, all caring for adult children for several years, appear to have adopted a particular position, where their outward feelings of loss have dissipated, and their role is now one of 'protector' with an eye on ensuring everything is as well as it can be, ahead of a time when they are no longer able to care. This phase of the journey also appears to convey a sense of resignation, and a more melancholic worry about the future for the vulnerable person they care for.

For other carers the idea of a linear journey with a starting point and hoped for end point is not their view of their experience. In the focus group carers spoke about being in a circular existence:

"I'd rather see it as a circle. Because that's what we do, we're in a circle. We go round and round"

(Focus group C37).

Mental health professionals also spoke about the experience of carers and identified distinct stages of the journey, adding there was a sense that new carers were able to be influenced much more than those who were in the midst of the role. Discussing carer support groups, Suzanne, an occupational therapist, remarked:

"often hear feedback at different training events about how negative their contact with services were, and how they've never been told anything and all that, and I think that's often carers who have been around for a while and not recent carers"

(Interview, transcript P4:7).

In listening to Suzanne's description of her work with carers I recall feeling impressed by her commitment, and initially wanted to brush over her categorisation of 'around for a while' and 'recent' carers. The suggestion is that the 'around for a while' group are a lost cause in terms of support and altering their perception, while the recent group can be influenced to much greater effect. I had a feeling that Suzanne spoke for a familiar dynamic in services that grabs hold of the new, and focuses its energy where the greatest leverage can be gained. Perhaps those amidst the long haul of caring represent failure, and the diversion to the 'new' carers is a defence by professionals from straying too close to the pain that has entered into the lives of carers, who support those with long term severe and enduring mental illnesses.

In terms of the analogy of a journey, the end point in terms of the relationship between carers and mental health professionals is the process of discharge from services. However, for carers the experience of discharge was not viewed as the point where illness had been cured, nor when identified needs had been met or concerns resolved. The potential for discharge to be seen as something to be celebrated was not welcomed, and in fact was viewed as another pivotal point when things could potentially go wrong. Both Terry and Lisa spoke about their fights with mental health services to overturn a decision to discharge their respected partners, and they both conveyed a sharp sense of being let down. Lisa remarked:

“this was hit the roof time for me ... I used terms like you're failing in your duty of care and so on ... and it had the desired effect I'm pleased to say because I immediately got an appointment”

(Interview, transcript C4:13).

A key issue in the process of discharge is the stark distinction it makes in the different relationships that carers and mental health professionals have in relation to the service user. Depending on the relational status between the carer and the cared for person, the caring elements of the relationship will endure throughout their lives. In contrast, the involvement of statutory services is based on meeting criteria set out in policies and protocols. The challenge with mental illness is that there is rarely an obvious full recovery, and therefore the risks of carers feeling let down and abandoned are increased.

6. Summary

In the examination of findings related to the lived experience of caring for someone who has a mental health condition, mental illness is described by one professional as 'a condition of the soul'. A spectrum of disabilities emerge from mental illness that push their way into carer lives, and at the fulcrum is the challenge of having a meaningful relationship with someone whose identity has been damaged by the disturbance of mental illness. Through the existence of a caring relationship this frequently leads to a series of consequences for the service user and carer that includes loss, isolation, marginalisation and practical hardship as employment and housing becomes harder to secure. Threading through the experience of carers is also an existential dimension to the initial shock of mental illness erupting in their social network, and the loss of the future they were expecting. This process is compared to a 'journey' in which we learn from carers that encounters with mental health professionals are pivotal points along the way. Recognising the significance of these contacts for carers enables professionals to consider how they invest in developing a 'space' that enables expectations to be regularly discussed, and how they encourage honest discussions that enable frustrations and concerns to be shared.

Chapter Six

How do Elements of Sacrifice and Burden, as well as Satisfaction and Reward Manifest Themselves in Caring for Someone with a Long Term Mental Health Condition?

1. Introduction

In this chapter I examine and analyse the data regarding those elements of caring associated with sacrifice and burden and then go on to consider the data associated with satisfaction and reward. Prior to this it is useful to define the key terms, and briefly examining the background and value of this particular framework for understanding caring.

2. Definitions of key terms

Defining sacrifice, burden, satisfaction and reward is a useful starting point to explore more accurately how these experiences feature in the lives of carers and mental health professionals:

- a. **Sacrifice** refers to an act of giving up something you value for the sake of something more important.
- b. **Burden** refers to a heavy load, a cause of hardship, worry, or grief. To load someone with something that is heavy.
- c. **Satisfaction** refers to the state of being pleased because one's needs have been met or one has achieved something.
- d. **Reward** refers to a thing given in recognition of service, effort, or achievement and can be a show of appreciation.

(Oxford English Dictionary, 2013)

3. Value of the framework utilising sacrifice, burden, satisfaction and reward

The framework set out in this chapter is based on contrasting emotional responses that may be felt during the experience of caring for someone with a mental health condition; the acute feelings associated with making a sacrifice on behalf of someone else, and the potential for caring to be drawn out and for feelings to

develop from being burdened, are in contrast to the prospect of caring being rewarding, and a source of satisfaction. The framework is drawn on my 'lived experiences' as a profession and latterly as a carer for a close family member.

As carers have emerged into public awareness, both statutory and voluntary sector services have responded through the provision of services which aim to be restorative and reduce the hardship that can result from undertaking caring responsibilities. In contrast to public dialogues that often emphasise the burden of caring, and hence the need to support carer 'wellbeing', the idea that caring might be inherently rewarding and satisfying is more elusive in our national dialogue. Research too has frequently twinned 'caring' with 'burden', for example:

- 'Can we identify the factors influencing the burden on family members of patients with schizophrenia?', Lowyck et al (2001)
- 'Burden of care and general health in families of patients with schizophrenia', Gutierrez-Maldonado et al (2005)
- 'The Burden of Sympathy: How families cope with mental illness', Karp (2001)

The flexibility of the framework also permits data to be drawn out of the research material and be understood from a psychosocial perspective, through making links between the inner worlds of carers and mental health professionals and wider societal responses towards carers. The different aspects of the framework also represent polarities in respect to caring for someone with a mental health condition, through the likely layers of experience that were examined in earlier chapters, which may include becoming marginalised and stigmatised by one's association with mental illness, and the subsequent risk of becoming an invisible carer.

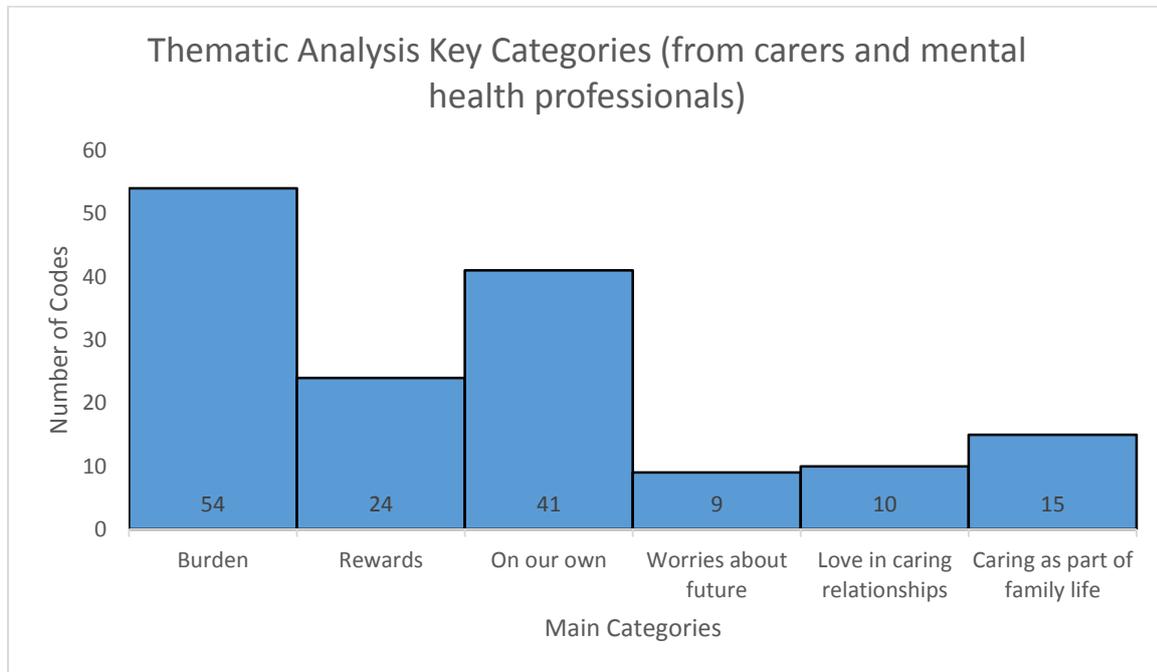
4. Perspectives drawn from thematic analysis

In setting out to review the data in this area it is useful to reflect on the thematic analysis that I undertook. This included all the data sources, and identified 'codes' i.e. key words or phrases, which then translated into themes i.e. 'burden of caring' and 'rewards of caring'.

Themes referring to the burden of caring attracted significantly more codes (54) than those that referred to the rewards of caring (24). This is helpful data which has been cross referenced with an overall examination of the experience of caring that

emerged from the one to one interviews and focus group, and contributes to our overall understanding of those aspects of sacrifice and burden, as well as satisfaction and reward.

Figure 6.1: Thematic analysis – burden and reward



5. Sacrifice and burden

a. Sacrifice

The notion of sacrifice has a strong sense of being linked to a single act, or a series of events, than the longer term experience associated with the definition of burden.

Surfacing carer data that connects to the notion of sacrifice, Hamid spoke as follows:

“I gave up my job, and resigned, and look after this lady (his wife) mentally, physically and emotionally, I mean it was really, really very hard to accept first, that I am a carer, because, I had ambitions to achieve, and I didn’t. I was working in X company as a supervisor within the whole department working in maintenance, security, and looking forward to becoming promoted to manager at that time. But I had to resign.

I have to resign because I feel that if I stay I will jeopardise the life of my children, and so I have two choices, either look after this lady, and you

maintain her well-being, and the children's safety, or you go looking for money. And then the family will be taken and we'll be shattered, and we'll have double troubles. I started understanding what care means"

(Interview, transcript C7:1).

In this extract Hamid points to the dilemma of continuing to be employed within the formal workplace with all the opportunities for professional development, versus meeting the needs of his wife, who has a mental health condition, and the needs of their two children. Hamid speaks to a keen sense of having to 'sacrifice' his job and career to take on the role of carer.

Terry, living with and caring for his long term partner also refers to numerous 'losses' as part of becoming a carer from the outset of establishing their relationship:

"It destroyed my friendship with people, they just disappeared. Occasionally we would get an email from one of them and then it would die down and I'd hear nothing. I rang my mum and dad at times to tell them what was going on. Their response was quite frightening ... things like 'leave her, don't get involved'. And that hurt, when my own parents turned around and don't support you. And tell you to leave and walk away"

(Interview, transcript C3:4).

Later in the interview Terry talks about his own physical health issues and the advice from his GP to take painkillers to ease the discomfort:

"I know if I take them I won't have 'the edge' I'll miss something (in being a carer). And that's the sacrifice we make as carers, it's that choice. It can be the wrong choice but it's the choice we make. It's the sacrifice"

(Interview, transcript C3:27).

Although I did not introduce the idea of sacrifice as a theme in the interviews, both Hamid and Terry spoke of a sense of giving up something for the advantage of another. The existence of 'another' is important, and in both instances it is the cared for person, as well as the children in the case of Hamid. There is also a keen sense of a decision having to be made, and important consequences flowing from deciding one way or another. In Hamid's case he is clear about the loss of his job and all the

associated opportunities, but also alludes to the risk of losing his family if he does not care for his wife, who is also the mother of their two children. While he therefore portrays the issue in terms of sacrifice, he has ultimately weighed up his various options and reached a decision which he feels is the best for him in all his circumstances.

Within both scenarios we can also see that each carer derived something from their decision, and it was not entirely a selfless or sacrificial process. Both men continue to be carers but also have relationships with the women they chose to be with, and in both cases were aware of the existence of mental illness when they entered into the relationships.

From her background in social work and family therapy work Marta reflected on carer motivation and shared a schematic framework for understanding some of the issues:

“Firstly, the idea that ‘I’m a good person’, and this may involve ethical and religious beliefs, and secondly a belief in duty i.e. ‘it’s my duty to care for this person’, and thirdly ‘I’m stuck with this’, and this may also involve religious or other beliefs that state i.e. ‘this is what we do’”

(Interview, transcript P8:7).

She also spoke about the differences between mental health professionals and carers, and questioned whether there was actually such a thing as ‘altruism’: “the unselfish concern for the needs of others” (Oxford English Dictionary, 2013):

“Care that’s provided by professional people is due to being paid, with the motivation from family and friends coming from closeness, and the feelings that emerge from caring”

(Interview, transcript P8:7).

This critique of the meanings associated with ‘sacrifice’ strengthen the idea that one must comprehend all of the choices that surround caring, and what these mean to all the individuals involved in care. In this sense the motivation for mental health professionals may be financial recompense, satisfaction from the reward of making a difference, and the association with a professional group that has wider recognition and status. Turning to the carers, the motivations may appear to be connected with

sacrifice, although this becomes less clear in the context of the existence of emotionally supportive relationships that contain elements of reciprocity.

b. Burden

Burden alludes to a much more extended experience than the sense of an acute or significant pivotal moment, or moments, which are linked to the notion of sacrifice. From the perspective of mental illness, Kuipers (1996) cites Goldberg and Huxley (1980) who defined the burden of care in simple terms as: “the effect of the patient upon the family” (p.215). Within the context of this reflection the carers who have been caring the longest, appear to have been able to talk most clearly.

Commencing with Hannah, now retired but still caring for her adult son, she noted:

“We can’t do things, we’re a middle class family but we can’t go on trips around the place. I can’t do that, or I feel I can’t do that. You’re only as happy as your unhappiest child”

(Interview, transcript C1:6).

Rhona, also mother to an adult son with mental illness, continues to work part-time and reflects on her situation:

“I was made aware of it recently because I go to a class every Thursday and somebody at the class ... oh I think we were asked what we were especially happy about or something like that, and somebody at the class said that now she has retired and her children have grown up that she can do whatever she wants and that really brought it home ... I thought what would that look like?”

(Interview, transcript C2:1)

Donna, caring for her sister with a chronic form of schizophrenia found the experience of caring for her overwhelming, and as noted earlier, took a decision to move to another town. Before doing so she spoke about her experiences, and the theme of burden permeates:

“She’d spend most of her time in her room, and then when she came into the living room she’d be: ‘what do you want?’ She could be rude sometimes and I’d hear her laughing and ask her what she was laughing at”.

(Interview, transcript C5:2)

Terry adds a further element to the idea of the burden of caring in flagging a distinction between those carers who do and do not live with the person they are caring for. He equates this distinction with a level of dependency, with a greater burden levied on those carers who reside with the cared for person:

“they do a job the same way that I do, and obviously they want their people to be more independent .. that’s okay if the person is able to, the person doesn’t have some form of dependency”.

(Interview, transcript C3:30).

The impression of a hierarchy within caring emerges premised on levels of burden, in which the need to live with the cared for person signifies a particular level of dependency, and therefore burden. Terry’s reference to his carer role as his ‘job’ is also relevant and suggests a degree of commitment from carers comparable to having a formal job within the workplace.

There is also a keen sense of carers having to live with situations they would not have chosen, and decisions being worked through within a range of emotions; from melancholic ruminations over the loss of the retirement that had been imagined, to the more explicit experience of giving up a job in order to resume a full-time caring role. Finally though, Donna articulates her experience of living in the same house as her sister who has mental illness, and openly discusses how she found the role of carer to be too burdensome. Rather than remain burdened she illustrates how she exercised a choice by physically removing herself from the situation, now coordinating care from a distance, rather than providing it herself. This is further examined below in considering the data from the mental health professionals.

A further area that links to burden is the increasing use of ‘intensive home treatment’ (multiple visits by professionals for a short period of time) to care for mental health service users as an alternative to hospital admission. This is used particularly when a crisis emerges, or when there is a breakdown in functioning that leads to consideration for the need for admission to hospital. While avoiding unnecessary admissions is laudable, a result of this shift is the need for families to support the

service user in the same way that inpatient ward staff support acutely unwell people. A doctor working within a home treatment team noted:

“We rely on carers a bit like the staff on the ward, get out of bed, get dressed, get something to eat. We have done all that without really thinking about whether carers do have enough knowledge to be able to cope day to day. We assume it. We say: ‘can you do this, can you do that?’”

(Focus Group, transcript, P48).

The intensity of the emotional support involved in this level of caring in the community is a further dynamic that risks engulfing the entire family or social network of carers who become, by default, an alternative team of inpatient staff assigned to help the disturbed individual regain a sense of equilibrium. Within this community ‘space’ is the opportunity for people with mental illness to avoid hospital admissions, which can be highly disruptive in their lives. However, this form of treatment can result in an extra burden on the social network, and mental health professionals do not always recognise the extent of the imposition levied on carers.

Aligned to the idea of burden the feelings most commonly held by carers are more closely linked with a sense of sadness, resignation, and loss, and are often aligned to being socially marginalised, and of becoming more reclusive in order to deal with the circumstances of caring for someone with mental illness. Although only in her twenties, Maryam, a carer for two siblings shared the following:

“You have to smile at some level, all my friends are in their forties they’re the only people I can connect with. I’ve lost those years of my life, I’m young but I’m old”

(Interview, transcript, C6:5).

This is also linked with a wish, at times, from the carer to set themselves apart, and linked with wider social dynamics of stigma and discrimination which can actively push people to take up a marginal and less visible place in society, ‘not seen and not heard’.

Mental health professionals also appeared to be in touch with the burdens involved in the lives of carers. Kofi, a social worker on the community team spoke to the idea

of carers working in an environment of distress: *“Carers get the brunt of it”* (Interview, transcript P6:7). Suzanne, an occupational therapist gave an example of a case of a young man diagnosed with the early onset of a psychotic illness and the care provided by his mother:

“Her son was very psychotic and very unwell, and ... she’d been sort of holding it, been the strength for a number of years ... and before he was known to services, and I did a Carers Assessment and it took an hour and a half and she cried for all of it”

(Interview, transcript P4:7).

The sense of burden conveyed in this narrative is added to in the reflections from Mark, also working within an early intervention service:

“I think if people find the carer role difficult they will remove themselves from that environment. It unusual that parents do, and I have noticed that mothers stay a lot longer than anyone else, and a lot longer than fathers”

(Interview, transcript P2:18).

Although the focus has been on the burden carried by carers the data also touches on the experiences of mental health professionals. As a group they are defended by a number of strategies which became apparent in their brevity in responding to open questions, and their reliance on professional language that sought to distance them from any pain. Examples included the use of familiar clichés to describe their engagement with carers such as ‘carers are part of everything I do’. However toward the end of the focus group, after hearing about the burdensome experiences of carers and their sense of being ‘on call’ twenty four hours seven days a week, in contrast to professionals who *‘go home at 5.00pm’*, Fintan, a community psychiatric nurse reacts:

“Yes, I know someone said that at the end of the day we go home and that’s it. But sometimes it keeps me awake at night, but it doesn’t stop at 5 o’clock, it goes on. Because we worry, have we done all the right things?”

(Focus group, transcript P50).

For a moment the professional mask is removed and the professionals are able to share the burden that they also feel in supporting people with long term mental health conditions.

Examples of sacrifice and burden experienced by carers have been shared along with examples of the burdensome nature of caring from the perspective of mental health professionals. The idea of a kind of ‘carer agency’ has also been touched on, where depending on your status in relation to the cared for person, it is sometimes possible to step aside, or remove oneself from carer duties.

6. Satisfaction and reward

Although the thematic analysis indicated fewer instances of satisfaction and reward in the experience of caring than those experiences linked to burden, it surfaced data that conveyed the closeness of relationships between carers and the cared for person in categories such as ‘love in caring relationships’, ‘caring as part of family life’, and ‘rewards of caring’.

a. Satisfaction

Returning to the interview narratives of Hannah and Rhona, both mothers, and both of whom experience being burdened by caring, the data also reveals other features that force us to consider a deeper more complex understanding of the carer experience. The following three vignettes shared by Rhona illustrate the possibility of elements of satisfaction in caring for her adult son:

- i. In his efforts to secure state benefits due to being unable to secure a job she recalls:

“He’s very good at going through all those hoops, he registered himself as self-employed, and sent off all the paperwork and they accepted it and now he gets less benefit and realises he has to work more and that’s where we are now”

(Interview, transcript C2:10).

- ii. On having a son who is at home and unable to work due to his long term mental illness:

“And we go out together, on Monday we went to see the (outdoor event), I wouldn’t do that if it wasn’t for him. So it’s a little strange taking a 30 year old out to things, oh and we go to art exhibitions because he’s keen on art being a designer”

(Interview, transcript C2:17).

- iii. On an aspect of his mental illness, Rhona laughs when she relates the following:

“Well I don’t know, we’re all the same we’ve got our standards. His standards are beyond realistic. Grandiosity was one of the terms that Dr X used”

(Interview, transcript C2:17).

Hannah also looks back at her experiences of caring and presents a degree of satisfaction in having established ‘safeguards’ for him in terms of accommodation and finances, and from protecting him from his siblings who don’t have the same sympathies or understanding of his mental illness. While acknowledging her other children, she spoke with particular emotion and fondness when she shared the following: *“We love him very much”* (Interview, transcript, C1:2).

Representing two sides of the same coin, the satisfaction that can be gained from providing protection is also picked up in Terry’s experiences of caring for his wife:

“Just keeping an eye on her it’s basically knowing that I managed to keep her alive through a psychotic episode and then the authorities can kick in to do their work. And trying to give her a life and trying to encourage her to have a life”

(Interview, transcript C3:31).

In the focus group, Judith, a carer for her adult daughter challenges a professional in their advice about housing, and describes how she had to intervene at one particular crisis point in her daughter’s life. In my reflective log afterwards I noted how she spoke with so much authority and pride in protecting her daughter that she commanded the attention of the group:

“My daughter was evicted from a hostel, and they wanted to send her on her own to the homeless person’s unit. Well in fact they did, and she got turned away, and then the social worker went with her and they got turned away. Her needs were too high, even if you’ve got four people looking after you, they should all be involved in her care”

(Focus group, transcript C29).

Aspects of satisfaction are generally quieter and more difficult to discern than those experiences of burden that can be prompted by the opportunity, in an interview or focus group, to share experiences. Examples of satisfaction also emerge from a context of adversity, where in spite of challenges and difficulties carers have persevered and continued to support the cared for person, even to the extent of celebrating some of the deficits that have caused the concern in the first place.

Amidst the often private world of caring within the context of mental health the issues which frequently bubble up involve experiences of loss, and the apparent absence of satisfaction and reward is marked. The stigma associated with mental illness also infects the wellbeing of carers. Further, it can be difficult to identify any sense of satisfaction emerging from the activities of caring. This is confirmed in data from mental health professionals:

“I don’t know what it says about me but I found it a bit of a shock to think that caring can be satisfying .. perhaps I’ve lost something .. it’s a bit of a surprise, but yes some people probably do”

(Interview, transcript P2:17).

Despite expressing surprise that carers could derive satisfaction from caring, Mark was able to talk at length about memorable and professionally satisfying occasions when he had been able to put his ‘family work’ training into practice with a family: “personally rewarding and satisfying, clinically I felt we were a very robust team between the three of us” (Interview, transcript 2:7).

b. Reward

Briefly recapping, reward refers to something that can be actually recognised and experienced as a way of marking appreciation for some form of effort or achievement.

At the end of the focus group the group of carers all stayed behind and ate a sandwich lunch together. There was a real sense of camaraderie between them all, and the conversations ranged from sharing experiences about caring to specific problems they were having, as well as offering advice and tips drawn from their own lived experiences of caring. The experience was a reminder of the impact of the disturbance of mental illness on all those around, and the importance of drawing some degree of reward from the act of companionship with others in similarly distressing situations. In this sense I have reflected on the therapeutic dimension of the focus group for the carers, and the reward it provided them in being able to 'tell their story'.

In contrast to the carers, all the professionals left as soon as the formal part of the focus group ended, highlighting the sense of boundaries and distance that exists in the space in which care in the community operates.

During the focus group and one-to-one interviews, carers shared how the experience of caring for someone with a mental health condition had brought particular rewards by providing them with certain expertise and recognition of their expertise. Rhona, caring for her son shared that she has become involved in sitting on mental health review tribunals, and Lisa, caring for her partner, has become increasingly involved in campaigning for carer rights in the local area.

In a group tutorial reflecting on the carer experience of Hamid (who cares for his wife and their children), the group questioned whether amidst all the sacrifices and burdens, Hamid benefited from other rewards within the relationship. Rewards that may have outweighed the burdens of caring. The group noted that Hamid was aware of the existence of a mental health condition when he met his partner, and had made a series of choices to enter in to the relationship. This behaviour demonstrates an additional complexity in the relationship between a carer and the cared for person, and the possibility of various motivations.

7. Summary

The use of a framework based on 'sacrifice, burden, satisfaction and reward' has permitted these specific feelings to be differentiated, pulled out of the data, and examined in relation to each other. The emotional pain of maintaining a caring relationship with someone with a mental health condition emerges most strongly through a sense of burden: never being able to 'leave the work of caring', always on edge, and contrasted to professionals who are able to 'go home', although they also remain 'on edge'. In some cases carers revealed that the experience of caring had been too much, and they had needed to remove themselves physically from the disturbance, although remain 'in touch' in a different way. Much more difficult to discern have been the elements of satisfaction and reward derived from the role of being a carer for someone who has a mental health condition. Where feelings of satisfaction and reward emerged from carers, they were not primary, but fell out of the descriptions of caring amidst the adversity and disturbance of mental illness, and specifically from the anxiety that emerges from feeling constantly responsible for, and protective of, those they care for.

Chapter Seven

A Discussion of the Study's Findings and Implications for Policy, Practice and Research

1. Introduction

Through successive carer-focused legislation, a stronger light has been shone on carers and the scale of their contribution through caring activities. This research, utilising a psychosocial approach, has examined caring for adults with mental health conditions and the relationship between mental health professionals and carers within this specific context. In parallel with the greater prominence of carers within society, mental health services have moved from a model of segregation within large psychiatric asylums to 'care in the community'. A further element of the research, therefore, examines what the shift to care in the community has achieved in respect to the relationship between statutory mental health services and carers; most likely to be a partner, relative or friend of a mental health service user.

The following discussion distils the findings from the previous chapters through three key conceptual understandings. Although closely linked, each one relates to different aspects of the experience of caring, be it professional or unpaid, for someone with a long term mental health condition.

- **'Care amidst the disturbance of mental illness'** addresses how mental health professionals and carers are able to continue to care within the context of the chaos that is caused by the manifestation of mental illness in social relationships.
- **'Relational life of carers'** crystallises an argument that relationships are at the heart of the carer experience and can be developed through a more reflexive approach.
- **'Contested space – lonesome and crowded'** considers how caring for someone with a long term mental health condition is undertaken in a contested psychosocial space which is at times crowded, and at other times vacant and lonesome. Amidst this space, often depicted as a triangle, carers and mental health professionals occupy particular roles and the shifting ability to see oneself in relation to others is examined.

Following exploration of each of the conceptual understandings, and building on existing knowledge, the chapter sets out suggestions and proposals for developing a more meaningful relationship between mental health professionals and carers.

2. Care amidst the disturbance of mental illness

“Madness has a specific quality of terror for human beings”

(Hinshelwood, 2004: p.122).

An outcome of the closure of the former psychiatric asylums dotted around the edges of towns and cities across the UK, was that mental health conditions were no longer ‘out of sight and out of mind’. The anxiety that emerges from mental illness was therefore re-introduced into society. Although the policy change coincided with advances in medical knowledge such as the introduction of new forms of medication, ambitions to cure or effectively treat chronic forms of mental health conditions, remain unrealised. The move of mental health services into the community is supported by this research, but what also emerges are the largely hidden experiences of carers who are inadequately supported, despite public awareness of carers being greater than ever.

Jones (2002) reminds us that family and friends of those experiencing mental illness were closely involved with the development of the former psychiatric asylum system, and viewed hospitalisation as an appropriate resource to be drawn on in the event of a relative becoming too demanding to manage at home. Acknowledging this position underlines the range of viewpoints, and for some families the option of ‘removal’ from family life was seen as the most appropriate response to a relative developing a mental health condition. It is also necessary to question all the labels that are used. So in being described as a ‘carer’ it is necessary to note:

“caring for others can stem from less noble motives, such as the urge to meddle or to control others. It can also simply follow from one’s love or involvement with others, or from concern with their well-being”

(Sevenhuijsen, 1998, p.20).

It may also take place without any real choice being open to the carer, who assumes the role because there is nobody else who is able, or present.

Similarly, mental health professionals can be drawn to working with vulnerable people by a range of motivations, including the hope of making a difference through the application of their professional expertise. Equally, different levels of professional competence exist and people can become demotivated and stressed, and this can lead to less positive outcomes for service users and carers.

a. The nature of disturbance

Life never being the same again is the picture gleaned from the harrowing narratives from carers, following a family member, partner or friend developing a mental health condition:

'he was standing in the kitchen for five hours shouting at the computer .. the message is the world is under attack' (Lisa, interview, transcript C4:4).

'completely unattached from reality doesn't want to live, wants to commit suicide' (Hamid, interview, transcript C7:11).

'I managed to keep her alive through a psychotic episode' (Terry, interview, transcript C3:31).

'They always convince you that they're not ill, I've been through this so many times' (Sylvia, focus group C21).

'My sister is quite cunning, she'll actually lie' (Stefan, focus group C20).

'Why he tried to commit suicide by slashing his throat?' (Suleyman, focus group C27).

The accounts emerge from their everyday lives being alongside someone with a severe and long term mental health condition.

Although more guarded in their responses, mental health professionals also shared how the disturbance that emerges from mental illness came into the work:

'Mental illness is a condition of the soul ... and places you at risk of losing your dignity' (Sam, interview transcript, P7:5).

'The beast' (Maggie, interview transcript, P3:11).

'It doesn't stop at 5 o'clock, it goes on. Because we worry have we done all the right things?' (Fintan, focus group, P50).

'I just wish everything could be a lot better' (Jackson, focus group, P35).

In referring to the notion of 'disturbance' this can relate to a number of factors and in the case of someone experiencing a severe and enduring mental health condition, which includes schizophrenia, mania, personality disorder and chronic forms of depression, it relates to a spectrum of symptoms that disrupt the sufferer's ability to function and participate in relationships with others. These include: mood swings, unjustified suspicion or mistrust known as 'paranoia', depression, hallucinations and suicidal thoughts, extreme tiredness, and self-neglect. In terms of schizophrenia the effects can include:

"Finding that their thinking has been affected (thoughts may become blocked, thoughts may feel as if they are not a person's own), being totally convinced about unlikely or bizarre ideas (delusions), and hearing or seeing things that others do not hear or see, such as voices (hallucinations)"

(Ramsay et al, 2001, p.16)

Hinshelwood (2004, p.8) also describes how serious mental illnesses damage the ability of the sufferer to have a sense of 'meaning' about the world, and the disturbance that emerges from this degree of impairment cannot be solely isolated to the sufferer:

"the capacity to understand things in real ways and with reflective thought is hampered in the condition, and that spreads to those who care".

The narratives that emerged from carers and professionals are indicative of the sense of psychological and emotional 'breakdown' that sits at the heart of mental illness, which then infiltrates and fractures the relationships of those around them, and is underlined by Cooper and Lousada (2005, p.110):

"mental distress manifest themselves in absent, distorted, or damaged social relationships, which are the basis of psychological nourishment and mental health".

Drawing on my own practitioner-researcher perspective, the disturbance that emerges from mental illness erupted at all levels within the 'community' during one

random selected week at work, and led to huge levels of anxiety entering into the organisation that affected the ability of myself and colleagues to think:

- A Local Authority Councillor contacted me and complained about a mental health service user being discharged from a local psychiatric hospital and being allowed to return to their flat in the community and then ‘trash it’. The councillor had witnessed the smashed windows and broken door during a walk-about in a local estate and had received reports from anxious neighbours, some of whom had children. The enquiry was not neutral but a ‘complaint’ about the damage to the property and the waste of Council resources. As a senior manager representing community mental health services I felt attacked by the enquiry, and a sense of hate and outrage being projected on to me. In response I felt an overwhelming anxiety to push the persecution away and find someone, anyone, to blame; the ward for discharging the patient, the care coordinator for not preventing the flat from getting into such disrepair, and the consultant psychiatrist for not alerting me to the risks.
- In the same week a patient died while being monitored within one of the inpatient wards. A few weeks earlier the patient’s father had made frantic calls to the 24 hour mental health crisis line to try to arrange for his son to be given support. Earlier he had taken him to the local Accident and Emergency Department but had given up waiting to be seen after 5 hours, and eventually returned home and contacted the local police after his son became agitated and threatening. The cause of death was determined to be natural causes, but certainly complicated by his deteriorating mental health. When dealing with the aftermath of this tragedy I reflected on the interviews with carers for this research project. How can a senior manager working inside the institutions of health and social care also come to feel powerless?
- A 24 year old man was sentenced to an indeterminate admission to a secure hospital setting due to reasons of insanity after a catastrophic breakdown in his mental health resulting in him killing an 82 year woman in her back garden, and chopping off her head with a machete. The London Evening Standard reprinted photos taken from a police helicopter, and ran the story on its front page: “*Chilling police helicopter video shows mentally ill man*”

rampage through north London gardens moments after decapitating great grandmother". Evidence (Taylor & Gunn, 1999) shows no greater likelihood of violence from someone with a mental health problem although fear of mental illness continues to be strong within the wider public conscience. While chronic and severe forms of mental illness remain largely hidden, more 'acceptable' forms of mental illness such as depression and anxiety are increasingly evident through anti-stigma campaigning endorsed by celebrities. When it comes to mental illnesses that take away aspects of an individual's personality, such as schizophrenia, they are still 'out of sight and out of mind' except when a serious incident erupts, and mental illness returns to public consciousness with all the recriminations of failing services.

The quality of relationship between mental health professionals and carers are reflective of their respective defended positions in relation to the huge anxiety emerging from mental illness, and borne in large measure by the carers. While the nature of mental health work situated within the community requires defence mechanisms, including a sense of boundary and a degree of detachment, these should not be to the detriment of caring work. These mechanics are discussed next along with reflections on how they can be overcome.

b. Alive to fear: failure, dependency and madness

Although they may be offered treatment and interventions from medics, psychologists, psychodynamic counsellors and social workers, mental health service users are rarely completely cured. They continue to experience multiple oppressions such as poorer physical health, sub-standard housing, limited employment opportunities, fewer meaningful personal relationships, and wider social stigma. The generalised poverty that emerges from the result of experiencing severe and enduring mental illness also leaks into the lives of those around such as carers and mental health professionals (Ali et al, 2012; McAuliffe et, 2014).

Amidst this atmosphere of limited success and frequent failure, expectations of health and social care organisations are issued from Government regulators such as the Care Quality Commission (CQC) to provide high quality services that are: 'responsive, safe and effective' and 'outcomes' that make a difference. Although

these are 'givens' there is an underlying 'chronic' anxiety within this area of welfare work that is associated with dependency:

“An apparently neutral concept of dependency is nevertheless surrounded and coloured by ethical debate, psychological theory, and political philosophy, so that it may seem to emerge as not neutral at all: dependency bad – independence good”

(Dartington, 2010, p.41).

Amidst the disturbance of mental illness the anxiety of failure and the subsequent fear of dependency runs in parallel with the fear of mental illness itself:

“anyone working with such patients will experience (consciously or unconsciously) the fear of being contaminated by such feelings and losing control over themselves”

(Hinshelwood & Skogstad, 2002, p.13).

These parallel fears of failure and dependency and of succumbing to madness encourage a battery of defensive systems that interfere with how carers and mental health professionals are able to relate to each other. These fears and defences are examined next.

(i) Professional distance

While carers utilised the opportunity within the focus group to critique both the strengths and weaknesses of mental health services, mental health professionals appeared unwilling to undertake a similar critique of services, or the respective contributions from carers. Menzies (1960, p.102) identified this particular form of response as part of a battery of defence systems that surround institutions, as the detachment and denial of feelings:

“a necessary psychological task for the entrant into any profession that works with people is the development of adequate professional detachment”.

An uneasy asymmetry emerged during the focus group in which the carers appears to be comfortable in talking 'from the heart' about their encounters with mental health services, whereas the professionals, for the most part, maintained a sense of professional distance. This is perhaps reflective of wider mental health services,

where carers may feel less constrained, and more free to speak about their experiences, while mental health professionals, for the most part, maintain a degree of detachment.

Similarly, within the one-to-one interviews carers were eager to share the totality of their experience of services; aspects that had been painful and unhelpful, and those that helped. On the other hand, many of the narratives that emerged from the mental health professionals appeared to be restrained, nuanced, and cautious, and reliant on language that was embedded in professional jargon. A degree of authenticity seems to be missing from the following views shared by professionals:

“we value carers and work with them” (Mark, interview transcript P2:11).

“it’s natural to work with families” (Sam, interview transcript P7:2).

“there’s no such thing as a challenging carer” (Suzanne, interview transcript P4:10).

There is a sense of professionals surrounding themselves in a cloak of carefully crafted narratives: highly professionalised language, jargon, and deference to carers in order to avoid any risk of submerging ‘below the surface’ to talk about what it really means to them to ‘work with’ the material that comes from being a carer for someone with a severe and enduring mental health condition.

I suggest one aspect is a fear of getting too close to the disturbance that mental illness pushes into carers, and their professional skills are therefore attuned to protecting them from this specific threat to their sense of equilibrium:

“social defence systems are a way of maintaining a status quo. However, while providing us with relief from the roller coaster of emotion arising from alternating persecutory and depressive anxieties, they keep us static, hindering us from moving on”

(Foster, 2001: p.87).

Despite the heavy investment in maintaining professional distance and a formal façade toward carers, the mask slipped in the focus group and provided a glimpse into a feeling of persecution, and the need for professionals to retreat into a defensive system:

“We let people down and we hear about it all the time, I just just wish everything could be a lot better”

(Jackson, focus group 35).

Such defensiveness leads to protective practices in respect to working with carers. For example, to avoid disappointment mental health professionals engage families with low expectations about what can be achieved to restore mental health. Like many defence mechanisms, this has limited success as it is responded to by fierce criticism from carers who feel their loved ones are being let down. Menzies’ (1960, p.99) study reminds us that families of patients have complicated feelings:

“relatives may also be demanding and critical, the more so because they resent the feeling that hospitalization implies inadequacies in themselves”.

In order to forge stronger relationships between mental health professionals and carers, acknowledgement of the disturbance that emerges from severe and enduring mental illness must be engaged with in an honest manner. This is challenging work as it risks identifying the service user as the source of all the problems, and if not done appropriately can promote a sense of scapegoating. However, reluctance to take these risks, and engage in meaningful dialogue about the nature of mental illness and its effects, leads to unsatisfactory and confused relationships between professionals and carers. The essence of the disturbance is the context for the professional involvement and the need for care, and therefore the potential for this disturbance to find its way into everyday life must be given space to be openly discussed. This cannot be a one off discussion, and should be qualitatively similar in its aims to a professional supervisory framework, which permits both the mental health professional and carer to feel contained, and enable caring to continue based on an honest estimation of what can be achieved.

(ii) Turning a blind ‘professional’ eye: the idealisation of carers

A familiar narrative emerged from mental health professionals when describing their experience of carers and this largely manifested itself in praising carers, listing their epic contributions, and noting how challenging their lives are. These views were conveyed as a homage to carers in which their sacrifice was everything. As an interviewer, I felt these professional summations acted like a barrier that undermined

my opportunity for a more realistic view of carers and their contribution, which would inevitably contain elements of light and shade. One mental health professional reported with utmost conviction: 'there is no such thing as a challenging carer'.

The deployment of descriptions of carers in such ultra-positive terms is consistent with the psychoanalytical term of 'idealisation' where it becomes possible to 'turn a blind eye' to those things that are too painful to think about. Drawing on his clinical work, Steiner (1985, p.169) highlights the attractiveness of the position:

“yet all the information pointing to the seriousness of the situation is available and we seem to have to avoid drawing the unhappy conclusions which a realistic appraisal would demand. We can only carry on our lives as normal by turning a blind eye”.

The attraction of disengaging from the painful experiences that often dominate the lives of carers is a reduction of anxiety for the professional in the short term. However, the risks of looking the other way and turning a blind eye, is that professionals may lose the potential for a mutually supportive relationship, and a vital element in caring for a mental health service user in the community.

A sense of confusion also manifests itself in carers being subject to extensive praise from professionals, but also held at arms' length and valued largely as an 'early alert' system for when things start to go wrong. This conjures up the image of the carer as 'messenger' running between professional and service user, a role frequently linked with conveying bad news, and the object of blame through being the carrier of information nobody wants to hear.

(iii) 'It's not us, it's them': the value of splitting

Splitting is an psychoanalytic process which enables us to project our bad thoughts and feelings onto someone else, resulting in us feeling, for the time being relieved, but the other person feeling bad. Focusing specifically on the mental health professionals, the use of splitting was evident in the categorisation of carers. This permitted the professionals to push elements of badness onto the carers. Examples included 'toxic families' (Sam) and 'overbearing mums' (Maggie); while others depersonalised them further by referring to them as simply a group 'out there'. Amidst the disturbance of mental illness it is not surprising that mental health

professionals use various defensive mechanisms to shield themselves from the burden of exposure to the emotional lives of carers. Foster (2001, p.87) also notes the value in certain forms of splitting which allow a 'retreat' from the effects of mental distress: "providing us with relief from the roller coaster of emotion". However, a risk of employing such defence systems is they hinder the opportunity to deal with and confront the anxiety. In the case of mental health, this may result in avoiding an honest conversation with a carer about the inability of services to restore the cared-for person to normal functioning. The conclusion of the examination of nurses' social defences in a large general hospital in the 1950s resonates with the findings of this research:

"a main characteristic of which is that they facilitate the evasion of anxiety, but contribute little to its true modification and reduction"

(Menzies, 1960: p.117).

Another risk in not being fully engaged with the emotional life of carers, in both the good and bad aspects, is that valuable data about the well-being of the patient and the effectiveness of the support that is available, is lost. Risk, in all its many facets, is a source of considerable anxiety amidst care in the community, and managing this by deploying defences that maintain too much distance also resonates with Menzies' argument that social defences do not ultimately work.

c. Caring amidst distress: the defended carer

While the focus thus far has been on the professionals' attempts to defend themselves from the sources of disturbance, carers also utilise defences. Out of the disturbance of mental illness a range of feelings emerged from carers specifically in respect to the role of mental health professionals. These spanned from gratitude and respect, to resentment, disappointment and fundamental questioning, summed up in the complaint: 'what are the professionals doing?' By shifting the focus on to 'what are the professionals doing', attention is drawn away from asking: 'what are the carers doing?' This latter question feels both disrespectful and reasonable, although its intentions emerge from a wish to negotiate the organisation of care for a mental health service user. As a practitioner-researcher I also recognise my own hesitancy and anxiety in setting down the question: 'what are the carers doing?'

Another psychodynamic defence helps to illuminate this area where, in the face of intense and unmanageable experiences, the anxiety created can be emotionally projected on to someone else, and thereby relieve some of the pressure, albeit temporarily. For those who are the recipients of such anxiety there is a risk that it is not processed properly and that they will subsequently feel overwhelmed and anxious. Through a carer projecting on to a mental health professional, and vice versa, there is an inherent risk that neither party is able to tolerate the anxieties of the other. This then prevents the opportunity to have an open and honest discussion and results in the carer's role in the cared for person's life being relegated, with the censure of mental health services becoming the defining issue.

For those carers who were at the beginning of their journey their anxiety emerged in relation to the responsiveness of services, and whether communication was appropriate. All of these 'surface' issues are vital components of good quality care. What took more time to unearth were those 'depth' issues at the heart of the carer's lived experience, such as the existential agony they found themselves in, through becoming a carer for someone who could no longer provide a satisfying relationship due to the presence of mental illness. At the end of her interview Lisa, caring for her partner, reflected on whether she could remain in a relationship with him, and in the last few minutes of the interview spoke candidly about life: 'as if the world has come to an end because it is just too much stress'. Similarly in the interview with Maryam, she shared several examples of being let down by services in her care of her siblings. However, at the end of the interview she revealed how living in the same home had been: 'exhausting, unbearable'.

d. Implications for the future

In his investigation of shame within the process of caring for a loved one with mental illness, Jones (2003) finds the existence of shameful feelings as being a 'very intimate and private emotion', with which this research concurs. However this research proposes that shame is one among a constellation of emotions including: anger, despair, loss and disappointment that can feel impossible to voice when you are defined by your role as 'carer'. The more subtle expression of feelings from mental health professionals indicates the existence of a spectrum of hidden emotions within this group too.

Reflecting on implications for the future, the need to support mental health professionals and carers to strive for more open and honest dialogue appears to be important. This is incorporated in a proposed framework titled 'Being Alongside' for professional and carer relationships outlined in the final section of this chapter. Being available to talk with honesty about the disturbance involved in caring starts to open up the possibility of identifying ways to share the load. This might begin with acknowledgement that services are unlikely to provide the 'cure' that carers really want, opening a discussion about more realistic goals.

It is also important to acknowledge the existence of the carer's deeply ambivalent feelings towards the person being cared for, and amidst the existential predicament that has arisen, to ask the carer: 'what do you want?' Through permitting the surfacing of such honest dialogue, mental health professionals and carers can develop supportive relationships that permit them to rally around a vision of 'good enough' care.

3. The relational life of carers

"All phases of the care process have relational dimensions"

(Sevenhuijsen, 1998: p.15).

We have explored how the disturbance that emerges from mental illness infiltrates the daily lives of families and friends, as well as mental health professionals, and while the nature of caring is frequently described through a range of physical activities, the essence of caring amidst the presence of mental illness is essentially rooted within the world of emotions:

"caring for someone involves activities such as the ability to be emotionally in touch with the other person as a whole person; a readiness to consider their pain and their needs and act accordingly; and a desire to make up for any pain we may have caused them"

(Foster, 2001: p.83).

In the case of a mental health service user the experience of being 'in touch' at an emotional level may at times be impossible or agonisingly painful, and take the carer and mental health professional into the service user's own world of persecutory,

delusional or fragmented thoughts and feelings. On a daily basis, through their personal closeness, these realities leave carers as the bulwark against the disturbance, as they struggle to maintain a degree of emotional equilibrium:

“we should not forget that there is a kind of emotional contagion, ... in which parts of mad people can actually infiltrate into the identity of carers and others”

(Hinshelwood, 2004: p.28).

Through the experience of being alongside this form of emotional disturbance, carers interviewed in this research frequently spoke about ‘the issue’ residing with the looked after person and the heavy burden of caring for them: ‘his life is a misery’ (Rhona, parent), ‘she tripped into psychosis’ (Terry, partner) and ‘devious and cunning’ (Stefan, sibling). For many carers the burden is too much and they report feelings of being under great strain: ‘I don’t know how to deal with mental illness’ (Donna, sibling), ‘I’ve lost those years, a lost chunk of my life’ (Maryam, sibling) and ‘I’m living with a level of stress that I find uncomfortable’ (Lisa, partner).

Amidst the turmoil and distress created by mental health conditions, what emerges most profoundly is the importance of a meaningful relationship with a mental health professional.

a. Relationships – the relationship is the service and the service is the relationship

Carers described mental health services predominantly through their different experiences of relationships with mental health professionals. In essence, from the carer’s perspective, the relationship is the service and the service is the relationship. This is reminiscent of reflections by Cooper and Lousada (2005, p.110) who state:

“whatever the modality of treatment, the capacity for relationship is, in one way or another, what informs mental health intervention”.

At one stage or another all the carers referred to the essence of the relationship they had formed with a mental health professional, through comments such as: ‘you have to click’ (Hannah, parent), and through meetings with key mental health professionals which were described as pivotal points: ‘there was a particularly helpful

doctor' (Lisa, partner). In contrast when expected relationships don't materialise, and closeness is not achieved, the sense of a void and dissatisfaction is significant. In talking generically about services Maryam, (caring for her sisters) remarked: 'they have their way and it sucks'. Also noticeable were those moments when carers felt 'at sea' with the burden of care and this was referenced by the absence of a meaningful relationship with a mental health professional: 'professionals come only when I really can't cope' (Hamid, husband).

While much more nuanced and defended, mental health professionals spoke about how 'natural' it was to work with carers, although they went on to relate instances of being 'inundated' with calls from anxious carers (Suzanne, Occupational Therapist), working with someone who: 'claimed to be a carer' (Mark, community psychiatric nurse), and working with: 'families who are unreasonable, where they are right and you are wrong, ...and over involved families' (Sam, inpatient consultant).

b. Why relationships matter

From an ethics of care perspective, care can be broken down into two parts, described as care as 'practice' and care as 'value':

"care must concern itself with the effectiveness of its effort to meet needs but also with the motives with which care is provided"

(Held, 2006: p.36).

Beginning with care as practice, needs are responded to through a range of different ways by the carer, and through this process, standards of care begin to be able to be described and trust can begin to emerge between the carer and the cared for person. In contrast, the essence of care as 'value' is exemplified through 'caring relations':

"We can ask if persons are attentive and responsive to each other's needs or indifferent and self-absorbed"

(Held, 2006, p.42).

Stripping back the concept of caring underlines the importance of relational activities that incorporate both 'physical' and 'emotional' practice and value the underlying relationship. While the carer may be an inherently good, bad or indifferent individual,

the key focus is on the caring relations, and not the character of the carer themselves:

“we may resist reducing care to a virtue if by that we refer only to the dispositions of individual persons, since caring is so much a matter of the relations between them. We value caring persons in caring relations”

(Held, 2006, p.38).

Amidst the tumultuous emotions that surround caring and mental health conditions a focus on the essence of caring, valuing caring persons in caring relations, is underlined. Hinshelwood (2004, p.7) also underlines the importance of caring and the weight of responsibility that is placed on the carer: “the most stress comes when the work involves caring for other people”.

The challenging relational context of caring for someone with a mental health condition is highlighted by Barnes (1997) who reminds us that there are no psychiatric hospital beds surrounded by ‘get well’ cards and flowers. Within the findings of this research the stigma and fear that mental illness provokes seeped into the relationships between carers and mental health professionals and was demonstrated in the descriptions of ‘hidden carers’, and the responsibility that carers convey in needing to ‘protect’ their loved ones from harm.

Waddell (1989) stands back from the emotions that swirl around the work of health and social care agencies to ask ‘what does helping really mean?’ To begin to answer the question Waddell (1988, p.14) proposes the value of a model, drawn from parenting, that can be transferred in to the work of caring professionals: “not so different, in some ways, from the difficulty of being a parent”, in which she identifies two positions in the face of the metaphysical and often highly destructive pain that can erupt in family systems owing to mental illness. Through referencing parent and infant relationships Waddell identifies these respective positions as ‘serving’ and ‘servicing’, and this research proposes that the framework has relevance for carers, as well as professionals (as explore below).

A further reflection on the relationship is the need to be honest about the pain and disturbance that result from mental illness, with an awareness that this is not the same as denigrating and criticising the individual service user. The fear of being

criticised for being open about the pain of mental illness should not prevent professionals and carers from being open, honest and unfiltered in talking about it. The learning that emerged from the one-to-one interviews was that, given the opportunity to talk, carers benefit from the chance to share their experiences. If the nature of the disturbance is not at the heart of conversations between professionals and carers, then there is a risk of turning a blind eye which could lead to ever more disturbance and distress.

c. Drawing on parenting literature to inform caring relationships

‘Servicing’ involves action, doing, and responding: “with the illusion that needs can always be met through material or practical resources” (Waddell, 1989, p. 20). In contrast ‘serving’ links to the idea of ‘thinking about thinking’ which involves:

“The capacity for thinking about emotional experiences which enables the individual to learn, thereby becoming a different person with different capabilities from the person of the past”

(Waddell, 1989: p.25).

In Chapter 5 the following carers were introduced:

(i) Sylvia

Sylvia is a middle aged woman who has spent over 30 years caring for her adult son who has a form of mental illness that leads to manic episodes:

“I’ve been through it so many times with my son. I have had the responsibility of paying off his credit cards because I had the bailiffs come to take away all my stuff as well as his stuff”

(Focus group, transcript C22).

(ii) Rhona

Rhona has recently retired and has been caring for her adult son for around 12 years and spoke about her worries for his future:

“I’m not totally tied watching his movements and I’ve even braced myself against the worst possible scenario that could be a repeat of the suicide

attempt. I've braced myself against the possibility that, you know, it will be his decision, his choice"

(Interview, transcript C2:20).

Sylvia shares glimpses into the pain she has endured in caring for her son for his entire adult life. Faced with her own retirement from the workplace she fears that her previous means of caring for him, similar to idea of servicing the disturbance that emerges from mental illness, is no longer available. Amidst her new situation Sylvia is able to acknowledge that even when the option of servicing was available, neither she nor her son were ultimately able to escape from the pain: *'I cried myself many a night'*. Within the focus group Sylvia projected her anxiety into the group as if it had started earlier that day, not a lifetime before. I noted in my reflective log: *'she spoke at a fast pace, with a sharp note of anger in her voice, projecting her anxiety into the group and provoking others who quickly reacted by offering advice on how she could handle the dilemma'*.

In contrast, Rhona seems to have arrived at a different place, and to be occupying a 'depressive position' which permits greater space to consider a response in line with serving:

"In this state of mind one is able to recognise good and bad in one's relationships, and in oneself, without forming harsh judgements. The capacity to forgive and thus to reinstate in memory lost figures and to repair damaged internal relationships is an important aspect of human development and growth of personality"

(Loshak, 2013: p.50).

Rhona conveys a sense of responding to her son's mental illness through adopting a containing role that involves listening and taking in, rather than being pressurised to act. Waddell (1988) notes the argument is not necessarily for 'inaction' but that 'non-action' may at times be the most helpful response.

In her approach to caring Sylvia has invested in elements of 'servicing' the needs of her son, and responding to his manic spending by paying off his credit card debts. In contrast, Rhona appears to have reached a point where she is able to accept, and reflect on her son's disturbed state of mind, and to ultimately live with and think

about the pain without reacting. Using another of Waddell's concepts influenced by Bion (1962) and the nurturing that is required by a new born baby, Rhona appears to have established a sense of 'holding' her adult son:

"I do not, however, mean 'passivity', which could represent to the child an active rejection of the need to communicate and experience relief, but rather a responsive presence which is active and transformative"

(Waddell, 1989, p.19).

In neither case does there appear to have been a specific professional intervention to promote a particular approach. Rhona seems to have been able to draw on her personal experiences, and in Sylvia's case, her way of coping has gone on for over 30 years without any form of professional intervention, be it advice, training, coaching, or the chance to tell her story through a carer's assessment.

d. A repertoire of skills

In the development of relationships, mental health professionals also demonstrated a repertoire of serving skills within the minutiae of everyday contacts. In sharing her work to support the mother of a young woman who had been diagnosed with the first onset of a psychotic mental illness, Suzanne working in a community mental health team, described the assessment: "her reaction after it, actually it had been so much about her (mother) and how much she had been suffering over the years".

Suzanne's initial inclination in the research interview had been to 'brush over' the work, which resonates with the idea that the everyday interactions between professionals and carers are valued to a lesser degree than direct work with a service user. It also highlights the challenge of quantifying the value of ordinary and everyday things that often have the biggest impact on the ability of carers to continue caring.

In a second example Suzanne highlighted the value of the seemingly mundane and shared the story of a regular commitment she has to go out to a café, or for a drive, with a father and his young adult son, who has been diagnosed with schizophrenia. Undertaking these everyday activities requires an extensive set of 'hidden' professional skills that lead to meaningful relationships being developed, and caring to be enacted, as social situations are navigated together by the professional, carer

and user. The work also resonates with the distinction between servicing and serving and the value of taking in all the elements of the situation faced by a service user and carer, and thoughtfully responding to them.

e. Investing in the emotional work

“It is so much easier to become the patients’ advocate rather than inhabit the more complex and conflictual role of clinician”

(Cooper and Lousada, 2005: p.113).

The above argument, aimed at mental health professionals, is a reminder of the distinction between professionals, with their clinical skills such as assessment, communication, care planning, and risk management, and the role of carers. In the focus group the unfiltered emotional outpourings from carers were responded to by the mental health professionals, acting largely according to the boundaries of their professional groups. Although observing these differences is important, and a reminder that professional relationships are not personal relationships, when applied without sensitivity, the growth of a meaningful relationship between a professional and carer can be inhibited. The focus on professionally acquired clinical skills distinguishes professionals from ‘unpaid care’ which is largely based on relational commitments, often familial or partnership-based. In contrast, professional relationships are based on a set of clinical skills, overseen by membership of a professional body and the employment contracts with the respective employer. Highlighting these differences, one carer pointed out the commitment she had made to her husband when she recited her marriage vows which she had spoken in public: *‘in sickness and in health, death do us do part’*.

Contrasting perspectives between professionals and carers emerged at the focus group during discussion of a vignette (Appendix D, vignette 2), which described the commitment of a young woman to caring for her former boyfriend at the point of his discharge from hospital. The case also highlighted the uncertain nature of the relationship, and whether the couple had in fact broken up shortly before the hospital admission. This uncertainty became a preoccupation and source of great irritability, characterised by the professionals seeking clear answers: ‘Who was in a relationship with whom?’ In contrast the carers were sanguine about establishing the ‘official’ status of the relationship, explaining that the carer may simply:

“feel that it’s best that she just comes along to the discharge meeting, and help him improve”

(Olivia, Focus group C32).

From the discussion it is apparent that the presence of a relational context, and a feeling of care, is sufficient to tip someone into the role of carer, and subsequently take on the associated caring actions. From this perspective the existence of a need in one person, matched with a feeling of caring in another, is the foundation of a caring relationship, regardless of any other labels that may be applied.

These qualities, which characterise all healthy carer and service user relationships, push away legalistic perspectives, and speak to a more existential issue related to feelings of responsibility for a fellow human being:

“Responsibility for other people is the greatest responsibility felt by humans. Perhaps responsibility is a biological inheritance, due to becoming a social species”

(Hinshelwood, 2004: p.7).

In the focus group these feelings were demonstrated to the consternation of mental health professionals, and without recourse to organisational policies, and regardless of familial or relationship connections. Stripping back the layers of caring to a fundamental base in the relatedness between human beings helps to re-connect caring with the possibility of satisfaction and reward. Although the possibility of burden and sacrifice is also present, and at times overwhelming, there can be something fundamentally satisfying, and potentially rewarding, in caring for someone who needs support.

Identifying the distinction between the personal relationship that exists between the carer and service user, and the contractually-based relationship that exists between the professional and service user and professional and carer, helps to avoid confusion and permits honest conversations to open up about expectations. A common complaint from carers in the focus group was their ‘twenty four seven’ and ‘round-the-clock’ commitment in contrast to their perception of ‘nine to five’ professionals. While carers may always feel envious of the boundaries ‘enjoyed’ by professionals, clarity about what a carer can expect of a professional, and what a

professional can expect of a carer is a strong place to begin the relationship. Undertaking this form of 'expectations check-list' serves as a reminder to everyone involved that the role of the mental health professional is different from that of a family member, and enables them to adjust their expectations accordingly.

f. 'Being Alongside' – drawing together elements of 'good enough' caring

Winnicott (1960, p.145) identified the idea that small infants require 'good enough' care:

"The good-enough mother meets the omnipotence of the infant and to some extent makes sense of it. She does this repeatedly".

Mindfulness of the essence of caring for a young infant helps to inform the nature of caring in the lives of people with severe and enduring mental illness. There are times when action is the appropriate response, and when practical, material or financial support is what is required, which was demonstrated in the distinction between serving and servicing earlier in this section. However, caring within the context of mental illness must also involve the mental health professional and carer being in touch with the disturbance, and working together to be able to respond in a containing manner. This means resisting an automatic urge 'to do something' and, in a timely manner, respond in a way that acknowledges the disturbance, and take a safe, considered and measured way forward:

"to receive, to undergo, psychically to digest, whatever is expressed at the time; genuinely to be 'continent and cognizant of one's own infantile emotions' and, with those in mind, to respond accordingly".

(Waddell, 1989, p.20)

g. Implications for practice

These forms of containing behaviour are helpful for everyone in the service user's network, both carers and mental health professionals, and it is proposed that these different elements of caring within the context of mental illness form an approach that is captured in the idea of 'being alongside'. Being alongside recognises that the optimum caring relationship with the service user is directly related to the strength of the relationship between the professional and the carer and involves the following:

- Discerning those anxieties that need to be digested and those that need a more immediate response;
- Honesty about the nature of mental illness and what is realistic;
- Expectations revisited regularly, and if helpful use of a check-list to avoid disappointment;
- Value the seemingly mundane and recognising that the everyday is the environment where caring is undertaken.

4. Contested Space – Lonesome and Crowded

‘Knowing my place helped to create the structure for which I had been searching’

(Edwards, 2002: p.81).

A wisdom has evolved that caring for people with mental illness in the community can be understood through the image of a triangle in which the key actors; service user, carer, and mental health professional are represented in each corner. Considerable benefits have emerged from the ‘Triangle of Care’ (2009) programme, particularly through the prominence it has given to the contribution of carers. However, the psychosocial ‘space’ in which caring for someone with a mental health condition is undertaken remains fragile, fraught with anxiety, and contested by those who occupy it. In considering the idea of ‘space’ it is defined as: “a continuous area or expanse that is free or unoccupied” (Oxford English Dictionary, 2013), and for those professionals and carers who enter into its expanse, the atmosphere is dominated by the disturbance that is generated by mental illness making it demanding and lonely both at the same time. Despite its expansiveness the space is also segregated. It is physically located in the community, and relationally comprises the mental health service user, carer and mental health professional. However, there is little in the way of guidance or information on where one can venture within the space which leads to it being contested. So, within the space there are ‘places’ that have particular rules of entry and expected forms of behaviour, and in considering the idea of ‘place’ it is defined as: “a particular position or area, occupied by or set aside for someone or something” (Oxford English Dictionary, 2013). Access to certain places within the wider space depends on one’s status,

and for carers, access to professional places is sometimes permitted, and at other times not.

The idea of a contested space links with Winnicott's (1951, p.230) description of the space between the inner subjective world of individuals and the external objective world, in which an additional area of human experience exists:

“there is the third part of the life of a human being, a part that we cannot ignore, an intermediate area of experiencing, to which inner reality and external life both contribute”.

This will be discussed in the sections below.

a. An ambiguous space and place

Within the caring space ambiguity thrives in the relationship between mental health professional and carer, and uncertainty abounds about what to expect from one another. This emerged in the findings from carers who complained that they were the third or fourth priority for professionals, and wondered aloud ‘what are they doing?’ In response, mental health professionals spoke warmly about carers being ‘partners’ but at other times as being peripheral and forming part of an ‘early warning system’ for when services need to become more involved. In the focus group the sense of disconnection and fragmentation within the space also emerged, when carers underlined their availability ‘around the clock’ in contrast to mental health professionals who ‘went home’. Professionals felt attacked by this summary of their commitment and while the exchange provoked a reaction that momentarily led to the professional mask slipping, it had significance in the realisation amongst the group that professionals have a choice to remove themselves, while the carers do not have the same option. The plea from the professionals that they do go on caring beyond 5pm prompted no verbal response from carers, perhaps indicating that their point had been made. Hoggett (2015, p.57) reminds us that aside from social defences against anxiety:

“there are many others – hope, resentment, love, envy and so forth – that can easily overwhelm us. It follows that we defend ourselves not just against anxiety, but against any experience that threatens to overwhelm us”.

From their particular position within the contested space, the relationship between mental health professionals and carers surfaces painful realities that are difficult to tolerate, and by drawing attention to their inability to 'go home' the carers highlight their personal and emotional bonds to the source of the disturbance. It is also a sobering reminder that within the space of caring for someone with a mental health condition there are few chances to experience gratitude for 'making a difference' or to celebrate a successful course of treatment: "in mental healthcare there is inevitably a lot of feelings of failure floating around" (Hinshelwood, 2004: p.36). Similarly, within a space largely devoid of success the entry of professional expertise also stirs up defensive feelings among the carers: "they envy nurses their skill and jealously resent the nurses' intimate contact with their patient" (Menzies, 1960: p.99).

b. The airlock – the limbo life of a carer

One way that mental health professionals defend themselves from becoming overwhelmed by the emotional experience of working with mentally disturbed people is attempt to physically restrict access into their professional places within the larger space. In chapter four the experience of a carer visiting her partner on an inpatient psychiatric unit and being trapped in an airlock, being neither inside nor outside, was examined.

Erecting boundaries, either physically or psychically, is a familiar defence: "madness is kept in patients and sanity in staff and rigid barriers are created to prevent contamination" (Hinshelwood and Skogstad, 2002: p.8). Lisa's airlock experience also provides a link to a largely unspoken 'fear of contagion' from mental illness within the mental health staff team, and how carers represent a risk through breaching the strict boundary between the well and unwell. Again this reinforces the notion of a 'contested space' marked out by 'prohibited zones' that segregate mental health professionals from service users, but frequently leave carers in a confusing space, being neither service users nor professionals.

Within a space that is founded on 'them and us' defences that are reinforced through professional structures, the presence of carers prompts confused responses. On the one hand an inpatient consultant interviewed as part of the research stated: "It's natural to work with carers, it's automatic, I don't even use the word carer" suggesting their 'insider status', while on the other hand he related his categorisation

of carers: “families who are unreasonable, they are right and you are wrong, and very helpful families, and over involved families”, which pushes carers back to being outsiders. Similarly, an occupational therapist working in a community mental health team related how carers are: “part of everything I do” (inside the boundary) while also acknowledging being ‘hounded’ by carers (outsider the boundary).

The theme of accessibility and inaccessibility within the space emerged strongly within the focus group adding to the notion of competition for time and the right to information:

“We go round and round for as long as it takes to hit a professional. Unless we get to have communication with patients all around it still won’t work will it? No matter what shape it is”.

(Focus group transcript, C37)

The sense of going round and round and the idea of ‘hitting’ a professional is suggestive of desperation on the part of the carers, in their struggle to make meaningful contact within the expansive and lonely space. It also resonates with the idea of a ‘transitional space’ which proposes a place between the inner world of an individual and the outer world of society, where the key actors: carer, mental health professional, and service user are seeking to establish a culture of living with each other:

“infants and children and adults take external reality in, as clothing for their dreams, and they project themselves into external objects and people and enrich external reality by their imaginative perceptions”

(Winnicott, 1989: p.57).

Young (1994) emphasises that the transitional space is more than the ‘commerce’ between the inner and outer worlds, and evolves in early child development through the infant’s ability to separate successfully from the maternal figure. If a secure base is in place and there are no concerns about illness, then separation is likely. This permits the infant to distinguish the world as a separate entity or ‘not me’, and therefore enables an interchange between inner and outer reality, with each being enriched by the other. However, within the contested space of community mental health we know that the presence of a service user with a mental health condition

introduces severe limitations to the capacity to manage the inner and outer realities, with the result that disturbance can infiltrate into all relationships, professionals and carers:

“while physical illness can be seen as separate from the person’s identity (something ‘one has’), mental illness is experienced much more as part of, or catastrophically affecting a person’s identity”

(Hinshelwood & Skogstad, 2002: p.13).

Proposals for how this challenge can be worked with are examined next.

c. Reconceptualising the triangle: ‘there is no such thing as a service user’

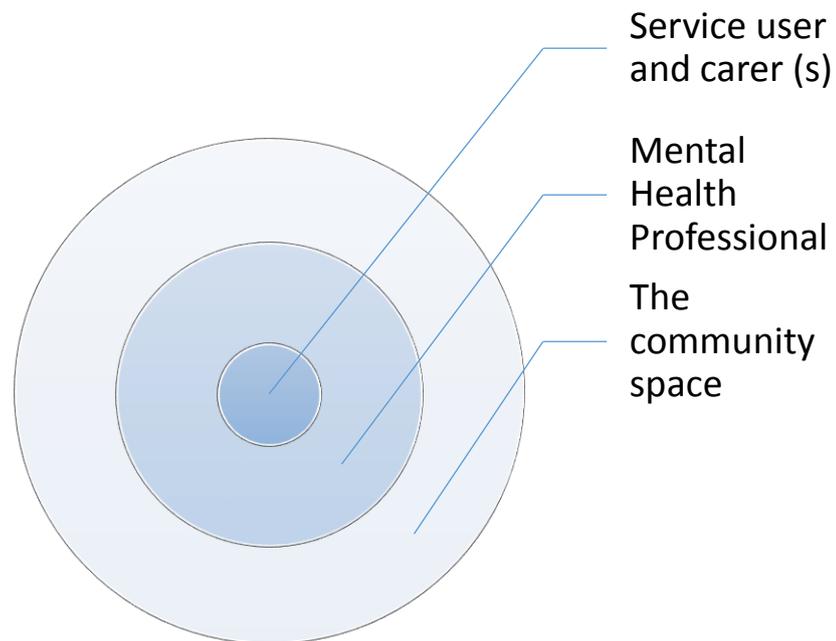
Set within the contested space of caring and mental illness, a sense of isolation and disconnection has emerged at the heart of the relationship between the professional and carer. An alternative way of conceptualising the relationship is proposed by this research by drawing on ideas from early childhood:

“there is no such thing as an infant, meaning, of course, that whenever one finds an infant one finds maternal care, and without maternal care there would be no infant”

(Winnicott, 1960: p.39).

In the same way that a parent and infant must be seen as two elements within one system, the service user and carer can be viewed as aspects of one system in which there is no such thing as a ‘mental health service user’ only a mental health service user and his or her carer(s). This is shown in Figure 7.1 ‘The Caring Space’ below:

Figure 7.1: The caring space



A proposed framework for reconceptualising the relationship between professional, carer and service user puts to one side the carer occupying their own particular category, and implies that they and the service user are part of one and the same system that is affected by mental illness. This is denoted by the circle at the centre of Figure 7.1 above.

Surrounding, supporting and alongside the service user and carer network is the mental health professional(s) who occupies the next circle, and finally both circles are located within the community. The value of the service user and carer being co-located in a 'single system' is an opportunity to engage with the essence of the issue; which is the disturbance that arises from a mental health condition in the context of the social network. It is also an important reframing of the current arrangement which situates a vulnerable person in the isolated role of 'service user', who then becomes the overriding focus of the service.

The role of the mental health professional within this framework is not to 'prioritise' the service user, but to prioritise the service user and the carer as a unit that is characterised by a relationship. In his reflections on dependency Dartington (2010) argues that nobody is entirely independent and the proposed framework engages

with the notion that we are all connected to someone in a mature form of dependency, and that mental health service users, as vulnerable people, must be engaged with by mental health professionals through the system they are part of, and which struggles to contain their distress.

This proposal suggests that changing the psychosocial framework of caring for people with mental health conditions can achieve more meaningful relationships between user, carer and professional. In altering the focus from service user in one corner of the triangle and carer in the other, to service user and carer both being in the same 'space', the disturbance that mental illness creates is equally acknowledged for the user and the carer. The absence of structures to contain those that operate within this space is discussed next.

d. A proposed new way of thinking – the 'Mini Community Institution'

The proposal from this research is for a psychoanalytically informed psychosocial structure for supporting carers and professionals, which cares for people with mental health conditions in a contained manner, drawing on the idea that the relationship between the service user, carer, and professional is actually a 'mini community institution' in its own right.

'Containment' describes the capacity of the care taking mother to be attentive to, and tolerant of the needs and distress of the infant, and to reassure the infant that she can manage these feelings and respond in a considered manner (Sandler, 1988). Applied to the context of community mental health care there is a need for the structures to play a similar role to the maternal object in managing the distress that emerges from enduring mental health conditions:

“in which chaotic bits of an individual are, first, understood and managed by workers in the system. Subsequently – if possible – they are internalized by the individual, having been transformed into something that feels understandable and manageable”

(Foster & Roberts, 1998: p.4).

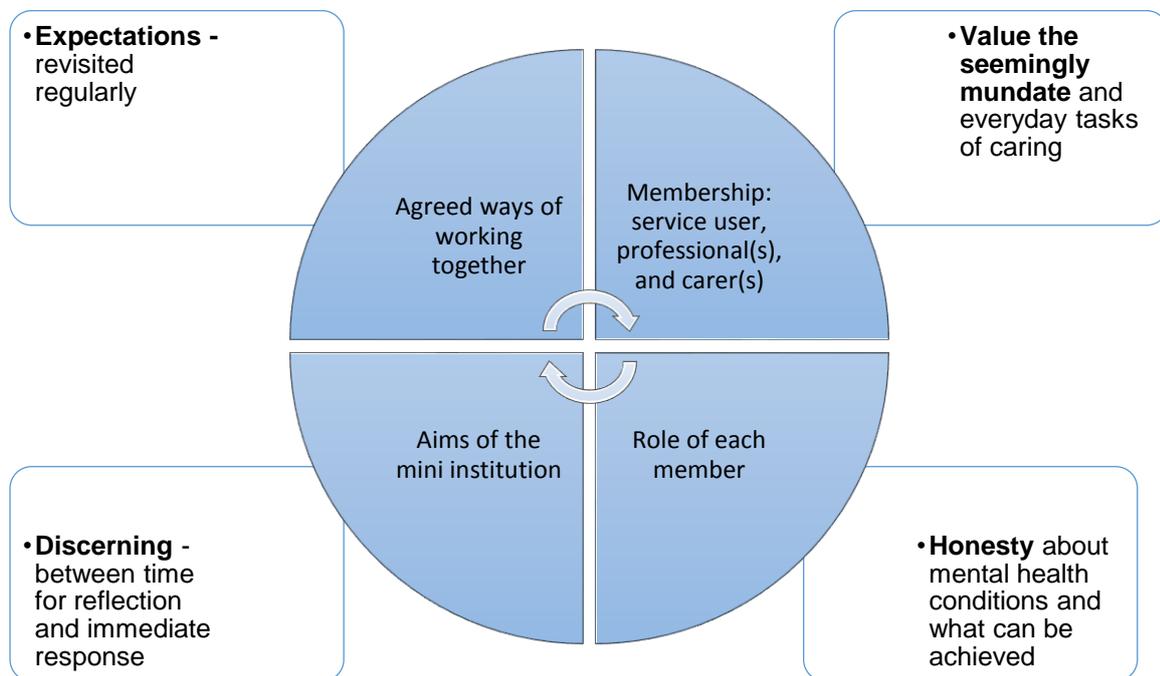
This proposed new structure for community mental health care is in contrast to the existing arrangements based on the 'Care Programme Approach' (DH, 1990) policy framework, and which involve a mental health professional 'care coordinating' or

'case managing' the care of an individual service user. Reconceptualising this space proposes an evolution from the current 'approach' to build a new conceptual structure with characteristics of an institution or organisation. Like an organisation, it incorporates governance processes to enable it to contain anxiety. This idea of the 'mini community institution' also redraws the contested space into a new form: an institutional structure, which has a membership, aims, a governance framework, and policies and protocols which oversee the experiences of the care.

Reconceptualising the space in this manner also underlines the importance of relationships between service users, carers and professionals, through all becoming members of the mini institution, who jointly develop: the aims of the institution, its constitution, expectations of members, care planning, the risk assessment processes, and all the other areas that need agreement.

From the conceptual understanding examined earlier in this chapter, and the ideas discussed around 'being alongside' (section 2), we also know that to support the structures of the mini community institution key components of care are needed to support someone with a mental health condition successfully. These include: discerning what needs immediate action and what needs time to be digested, honesty about what can be achieved, expectations being discussed and regularly revisited, and recognising the minutiae of the everyday tasks of caring. Figure 7.2 below therefore combines the structure of the mini community institution (central circle) with those of 'being alongside' that form the key components of a caring relationship (surrounding boxes):

Figure 7.2 – Mini community institution and the key components of care



(i) Membership of the mini-institution

The members of the mini community institution are the service user, carer(s), and mental health professional(s).

(ii) Aims of the mini institution

The key aim is to meet the needs of the service user and to agree together how this will best be done.

Inevitably, depending on individual circumstances, there will be a range of different aims, tasks and goals within each mini community institution. The primary focus is always supporting the service user and ensuring the carer and mental health professional work together within the institution to achieve this successfully, and receive the support they need to undertake this task.

In the current community mental health arrangements the mental health professional utilises a care plan to outline the priorities in supporting the mental health service user. Although the value of this is not opposed by this proposed model the benefit of the mini community organisation is that the service user, carer and professional are

brought together as 'the membership' to agree the key aims. Armstrong (2015, p.13) notes the complexity of this process in large institutions such as hospitals: "in many institutions there will be more than one principal goal or value, and its definition may be contested, leading to conflict".

(iii) Constitution of the mini-institution - setting out the way it works

Relationships are at the heart of the mini community institution and the work is largely conducted through meetings. Depending on the nature of the agenda, meetings may involve all the members being invited such as when a care plan has to be agreed. Equally one-to-one encounters can take place where appropriate such as the routine completion of paperwork by the user and professional.

Some mini community institutions will begin and end in a brief period of time as the service user recovers from mental illness, and is discharged from services. However for those service users who have a long term mental health condition it is likely that the mini community institution will operate for a significant amount of time, with professionals and carers potentially leaving and joining to ensure care is maintained around the service user. The institutional model recognises the fears of dependency but acknowledges from the outset that the institution will continue for as long as it is necessary to provide support.

(iv) Role of each member

Each of the members of the mini community institution has a role with certain rights and responsibilities. These must be discussed on convening the institution in the presence of the minimum membership of service user, carer and mental health professional, and be described in the form of job descriptions, which reflect the idea of having a clear sense of expectations within the caring relationships between the mental health professional, carer and service user. It is important that all members should understand and agree the primary aims of the institution.

The institution will need to set formal processes to manage inevitable differences of opinion.

During its existence, the institution will need to consider and agree on a range of issues, such as: growing concern about the wellbeing of the service user, the possible need to consider a different form of treatment, the decision making rights of

the mental health professional in order to maintain a sense of safety, the rights of the service user to set out their wishes in a plan that can be considered in the eventuality of becoming unwell, and the wishes of the carer in being updated on progress by the mental health professional.

(v) Agreed ways of working together

The members of the mini community institution are encouraged to set out their ideas for how the institution will operate, such as: preferred ways of communicating, frequency of meetings, and managing differences. The agreed ways of working should build on the key components of the caring framework: 'being alongside'. As outlined in Figure 7.2 above, this sets out: discerning between those anxieties that need to be digested and those that need a more immediate response, honesty about the nature of mental illness and what is realistic, agreeing expectations and re-visiting them regularly, if helpful use of a expectations check list, and valuing the seemingly mundane and everyday minutiae that comprises caring activities.

The focus group undertaken as part of this research served as an example of an 'institution in practice' where a group of mental health professionals and carers were brought together to discuss their views on three case vignettes. The space was designed to be containing, there was a time limit, and rules were imposed around not talking over each other. As convener of the focus group I had authority to move discussions on, and both carers and mental health professionals cooperated with the framework. Support for the members of the mini community institution in agreeing how they will work together can be gained from some of the principles that have influenced mental health therapeutic communities. This includes the recognition that mental disturbance is not only located in the individual, but can affect the network around the service user, and a particular principle that assists the forming stage of the institution is the idea of 'democracy':

“not in a populist sense of 'we are all equal in all respects' but more one of 'we are all in this together'”

(Wilson et al, 2011: p.602).

A further element of agreeing ways of working involves the process to be undertaken if the institution stops fulfilling its aims, according to any of the members. At the

setting up of the institution an escalation process will be agreed that is open to members to ensure such issues are dealt with.

5. Summary and conclusion

This discussion has examined three conceptual understandings: care amidst the disturbance of mental illness, relational life of carers and the contested space in which care is provided. These enabled a range of research findings to be discussed in relation to existing knowledge, and for a number of implications for future practice and policy within the context of mental health services to emerge. Of these, three key proposals are made and are summarised below.

The key qualities of the professional - carer relationship have been captured and summarised in a proposed framework called 'being alongside' which denotes an approach that avoids 'doing to' or 'doing for'. It involves a professional and carer relationship that has both emotional and practical components, and is based on: discerning what is urgent and what needs further reflection, honesty about what can realistically be achieved for someone who has a mental health condition, agreeing expectations, and valuing the seemingly mundane and everyday aspects of caring practice.

Secondly, the benefits of adopting an alternative approach to the traditional triangular framework of: service user, carer and mental health professional relationship is proposed. A new model is described, which recognises that all service users, even the most isolated, are part of a network, whether this be family, friends, or neighbours. Consequently, 'there is no such thing as a service user' is an approach that proposes professional engagement must recognise and work with the service user *and* carer(s), on the basis that they are two elements of one system. To be effective this is the 'system' that must be supported by mental health professionals, and not the individual service user in isolation from their carer(s).

Thirdly, the proposal for reconceptualising the space in which care is undertaken as a 'mini community institution' is examined. Within the 'contested space' which care in the community operates in, the proposed mini institution creates a containing place to enable the service user, carer and mental health professional to form relationships with one another and more successfully support the service user. This is based on findings from this research, which indicate the relationship between the

mental health professional and carer is pivotal in providing a strong framework to support the cared for person. The current arrangements struggle to provide an appropriate space and the mini community institution draws on the ability of institutions to be containers of anxiety, through being attentive and reassuring. As an institution it is also able to accommodate the caring frameworks of 'being alongside' and 'no such thing as a service user' that are noted above.

Chapter Eight

Conclusion

1. Research context

“The most stress comes when the work involves caring for other people – i.e. being responsible for others. Responsibility for other people is the greatest responsibility felt by people”

(Hinshelwood, 2004: p.7).

The more I have researched the dynamics of caring, the more I have become aware of the significance of the shift away from caring for mentally ill people in the old institutions and into the community. Of particular poignancy is that in fighting for their closure, which was absolutely the right thing to do, an inadequate settlement was reached with carers, which has affected their relationship with mental health professionals, and hampered the ability to provide good enough care to service users.

Prior to care in the community, the State had a role in segregating the sane from the insane. For those who were too disturbed to be looked after at home, and for others who could, but where their family chose otherwise, incarceration was available to manage the object of distress. For some service users this form of separation from society provided ‘asylum’ in a positive way, but for most users incarceration stripped them of their individuality and their dignity, and undermined their prospects to return to the community. The closure of these institutions is endorsed by this study, and any return to a model of incarceration or segregation is not proposed. The assumption from the outset of this research, and which has not been altered by the findings, is that people with mental health conditions, except those with the most severe forms or in periods of acute crisis, are, on the whole, most appropriately supported in the community by their family and friends, and by professionals as necessary. However, the research has also identified that the space in which care in the community is provided is often lonesome and isolated, and frequently devoid of meaningful relationships that are needed to make it work.

2. Reflections on the research process and learning

Building on these assumptions, this psychoanalytically informed psychosocial research has considered the relationship that mental health professionals have with carers, who are generally a relative, friend, or partner, and their combined experiences of caring within this challenging space. Research data was derived through interviewing carers and mental health professionals, and bringing together carers and professionals into a combined focus group. Combining the two groups into one single focus group was vitally important. This enabled me to congregate professionals and carers around a series of vignettes and research their respective responses within the shared space.

Use of the free association narrative (FAN) interview approach also supported me to be both reflexive and attentive to my own emotional responses to the participants and their narratives. This was cross-referenced by a thematic analysis of the data that further strengthened the findings. The collection of data and analysis was supported by both regular supervision and a research support group that enabled me to share research dilemmas, and support fellow doctoral students with their research issues.

The material that emerged from carers was raw, emotional, and highly personal, and conveyed the harrowing nature of being alongside someone with a distressing and incurable mental health condition on a daily basis. In remaining in close proximity to such distress and continuing to care, the question that screams out is: 'how do you do it?' Mental health professionals are also affected by the pain that emerges from someone experiencing mental illness, and the impact of this on carers.

The material that emerged from professionals was conveyed in more nuanced ways and through numerous defences including splitting and idealising carers, enabling them to 'turn a blind eye' (Steiner, 1985). The outcome of these defences permits the professionals to maintain some distance from the intolerable pain experienced by carers, although it does not help in the greater enterprise of supporting service users, and inevitably leads to carers feeling frustrated and confused. As a researcher I also found the sophisticated defences employed by mental health professionals frustrating, as the anxiety that lay on the other side of the defence mechanisms only occasionally appeared. In recognising this feeling in myself I

initially felt the research method was inadequate to dislodge the data, but through further reflection and discussion in supervision I came to appreciate that my feelings were likely to be mirroring those of the carers when they came up against the professional boundary. This is a powerful example of the benefit of the FAN interviewing method in the value it gives to these psychoanalytical dynamics, and for appreciating them as research material: “they are the richest and most valuable means of accessing the unconscious dimensions of the field of study” (Price and Cooper, 2012: p.64).

3. Summary of findings

The research identifies that caring for mentally ill people in the community takes place in a psychosocial space that is often expansive and lonely. Any feeling of order is constantly subject to attack from the disturbance that emerges from mental illness. While the distress is located in the service user it causes those carers and professionals around them to become anxious and seek to defend themselves from the prospect of somebody close to them, and who they feel a sense of responsibility for, losing their mind. The loss of one’s mind has an equivalence with death.

Mental illness remains highly stigmatising and carers are often hidden and isolated in caring for someone who may be unable to maintain a personal relationship, or participate in the daily rituals of life, due to the damaging nature of their mental health condition. Within this context the availability of a meaningful relationship with a mental health professional is seen as pivotal by carers. Although mental health professionals recognise the support that carers provide, their priority is to maintain their focus on the service user. This can leave the carer on the periphery, rather than recognising they are a major part of the system that is affected by the disturbance arising from mental illness.

Within this contested space professionals and carers experience only fragmented and partial relationships with each other, in which carers often feel rejected and unsupported, and professionals feel burdened and attacked. The professionals are clear about their boundaries in regard to service users but are often confused in relating to carers. Carers can experience a sense of limbo, finding themselves in a lonesome and ambiguous space. Typically professionals seek ways to limit their exposure to the anxiety that carers live with, although these defences generally lead

to more irritation and the loss of an opportunity to work together. When the mental health professional and carer are able to form a meaningful relationship it appears they are able to support each other, and be more effective in their shared aim of supporting the service user.

4. Messages from the research - implications of learning for future developments in community mental health

In this research I have developed proposals for improving how community mental health care is delivered. Through the research I have taken particular account of the experiences of mental health professionals and carers who work together to provide care for the service user. The proposals are set out below:

a. 'Being alongside' - relationships form the basis of the work and must be more valued

Relationships form the basis of the work and should be conceptualised as 'being alongside'. Being alongside acknowledges the distress that emerges from caring for someone with a long term mental health condition and how the presence of a meaningful relationship makes all the differences. The framework of 'being alongside' also underlines the relationship is not based on an imbalance of power ('doing to' or 'doing for') but is based on the following:

- Discernment – professional and carer working together to distinguish between those anxieties that need an immediate response, and those that benefit from a longer period of reflection before responding;
- Honesty - between the professional and carer about the nature of mental illness and what is realistic;
- Expectations - discussed at the beginning and regularly revisited with acknowledgement that disappointment is possible due to the inherent nature of long term mental health conditions;
- Valuing - the seemingly mundane and every day minutiae is the environment where care is undertaken.

b. There is no such thing as a service user

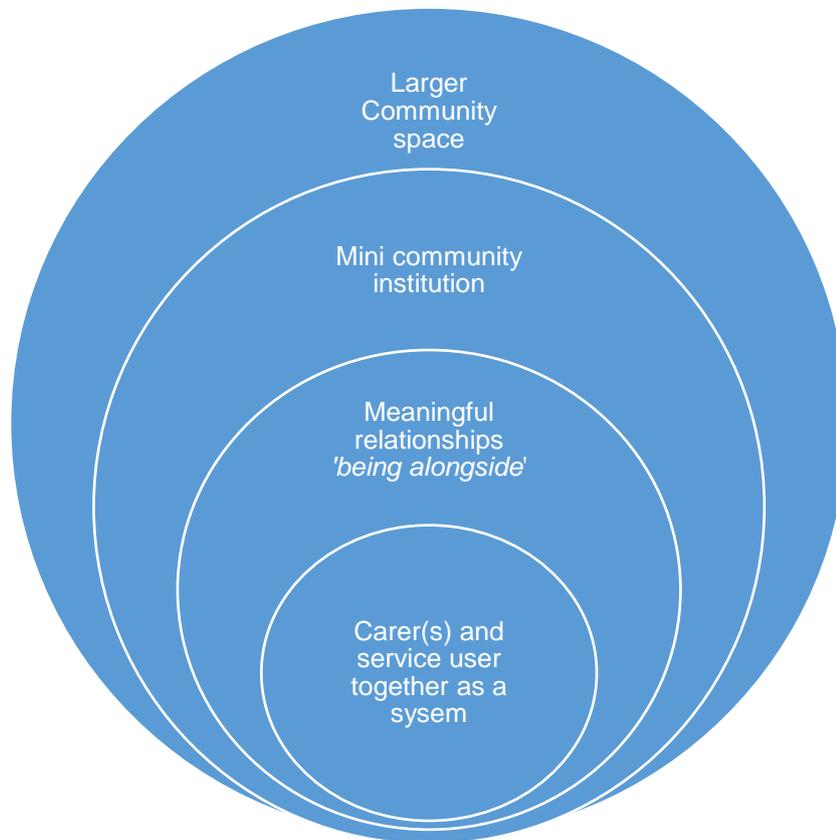
Community mental health work should be re-focused on the vulnerable mental health service user *and* their carer. In the same way that Winnicott (1960) argued there is no such thing as an infant, only an infant in relation to maternal care, there is also no such thing as a service user, only a service user in relation to their own care network. Even the most isolated, disturbed and dissociated person has a connection to someone, and sole focus on the service user contributes to the fragmentary nature of relationships that characterise community mental health care. The proposal also draws strength from the goal of reaching a state of 'mature dependency' where it is recognised that: "no man is an island, entire of itself" (Dartington, 2010: p.43).

c. Mini community institutions - reconceptualising community mental health work

In order to provide a containing place for professional and carer relationships, 'mini community institutions' should be developed. The proposal is that each mini community institution surrounds and supports each network of care, containing a service user, carer(s) and mental health professional(s). Through this new way of organising community mental health work the current Care Programme Approach (1990) is reconceptualised enabling the service user, carer and professional to become 'members' inside the boundaries of the institution, and work together to support its primary aim of supporting the service user. Similar to other institutions it has a governance structure and constitution, and although everyone is a member and knows the aims, not everyone has the same role, or decision making powers.

The proposals reconceptualise the space in which care in the community is undertaken as shown in Figure 8.1 below:

Figure 8.1: Reconceptualised community space for caring for people with mental health conditions



5. A summary of the messages

The research strongly supports recent changes in legislation (The Care Act, 2014) and the result for carers (their greater eligibility for an assessment and for a support plan, and for services to meet identified eligible needs). However this will still do little to change the emotional experience of caring for someone who is living amidst the turmoil and distress of a long term mental health condition – the harrowing and incurable nature of mental illness itself cannot be altered by The Care Act. What can improve the experience is recognition that the disturbance that emerges from a mental health condition affects the lives of everyone close to the service user, and being able to access a meaningful relationship with a mental health professional is the beginning of a containing structure. ‘There is no such thing as a service user’ illustrates how services are hampered by their isolated approach to working with a

vulnerable mental health service user in isolation from those carers around them, who are most likely to be family, friends or neighbours. The space in which care is undertaken can be lonely and disturbing, and the establishment of a mini community institution provides a containing structure for user, carer and professional relationships to flourish.

6. New areas for research

Reflecting on the implications that have arisen from this research into the dynamics of caring for people with long term mental health conditions, the areas that are indicated as having potential for new learning include:

- (i) The benefits of professionals and carers learning together in the form of a combined focus group is indicated to be a powerful and containing structure for sharing respective experiences and learning. There is also a cathartic element to the structure. The use of anonymous vignettes permits discussion by the entire group without issues becoming personal.
- (ii) The strong response from parents' caring for adult children indicates that research into this experience would be valuable, especially as parents become elderly and increasingly unable to care, as many of the participants in this research indicated.
- (iii) The space in which care is undertaken is constantly changing and the dispersed nature of present day family life in the UK is very different from the idea of community when 'Care in the Community' initially emerged. How can different ways of working, over dispersed social networks, provide the meaningful relationships that are needed by carers and professionals in their support of a mental health service user?
- (iv) In parenting there is an expectation that any burdens and sacrifices at the beginning gradually become outweighed by satisfaction and reward. This balance is not the same in caring for someone with a long term mental health condition, and further research into the respective journeys would also be interesting.

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Appendix A: Participants - Carers

Carers – One to one interviews

Number	Name	Relationship (with cared for)	Gender	Ethnicity	Live with?	Brief Synopsis
1	Hannah (Pilot interview)	Mother	F	White British	No	Now retired but continues to campaign for carer rights, and has cared for adult son for 20 plus years since he was a young adult and diagnosed with a severe and enduring mental illness. Recently supported him to move into his own accommodation
2	Rhona	Mother	F	White Irish	Yes	Works part-time and cares for adult son since he was a diagnosed with Schizophrenia in his late teens.
3	Terry	Partner	M	White British	Yes	No longer employed in the formal workplace and cares for his long term partner who he met prior to her becoming unwell with a severe and enduring mental illness.
4	Lisa	Wife	F	White British	Yes	Left formal employment at the point that caring role was becoming increasingly demanding. Although needing more frequent and lengthy admissions into hospital for his mental illness, Lisa's husband has now returned to employment.
5	Donna	Sister	F	White other	No	Became a carer for her adult sister at the point her parents' passed away. Lived in the family home as a carer for several months and then decided to move out and move

						away due to the stresses of caring. Now sees herself as a distant carer.
6	Maryam	Sister	F	Asian	No	Cares for her older and younger sisters who both have psychotic forms of mental illness necessitating periods of time in hospital due to break-downs in mental functioning.
7	Hamid	Husband	M	Asian	Yes	Aware of his wife's mental illness when he met her and they subsequently married. They now have three children together and Hamid has given up work to provide sufficient care to his wife and children.

Appendix B: Participants - Mental Health Professionals

Mental Health Professionals – One to one interviews

Number	Name	Gender	Ethnicity	Professional Background	Area of work
1	Bea (Pilot interview)	F	White British	Music Therapy	Arts Therapy
2	Mark	M	White British	Nurse Manager	Early Intervention Service
3	Maggie	F	White Irish	Social work manager	Out of hours emergency duty team
4	Suzanne	F	White British	Occupational Therapist	Early Intervention Service
5	Asmita	F	Asian	Community Psychiatric Nurse	Community Mental Health Team
6	Kofi	M	Black Caribbean	Social worker	Community Mental Health Team
7	Sam	M	White Irish	Consultant Psychiatrist	Psychiatric Inpatient Unit
8	Marta	F	White British	Social worker and Family Therapist	Family Therapy service

Appendix C: Participants - Focus Group

Carers and Mental Health Professionals - Focus Group participants

The focus group participants are outlined below:

Unpaid Carers

Number	Name	Relationship	Gender	Ethnicity	Live with cared for person?	Brief synopsis
1	Stefan	Brother	M	White European	No	Cares for sister who lives in a North London borough
2	Marcia	Daughter	F	Asian	Yes	Cares for both of her parents who have mental health issues alongside a range of physical health concerns
3	Judith	Mother	F	White British	No	Cares for her adult daughter who has been known to mental health services for several years
4	Sylvia	Mother	F	White British	No	Cares for her son who recently left hospital to reside in a residential mental health unit
5	Annie	Mother	F	White European	No	Cares for her middle aged son who has been known to mental health services for his entire adult life
6	Olivia	Sister and friend	F	Black African	No	Cares for a sibling with severe and enduring mental illness
7	Emily	Mother	F	White British	No	Cares for her son who has lived in a range of inpatient and supported housing schemes in the community
8	Suleyman	Father	M	Asian	Yes	Cares for his adult son for over 20 years who has

						made attempts to take his own life
9	Soloman	Husband	M	Middle eastern	Yes	Cares for his wife

Mental Health Professionals

Number	Name	Gender	Ethnicity	Professional background	Area of work
1	Elisa	F	Asian	Recovery Support Worker	Community Mental Health Team
2	Kate	F	White British	Student Nurse	Early Intervention Service
3	Fintan	M	White Irish	Community Psychiatric Nurse	Community Mental Health Team
4	Alvin	M	Asian	Nurse - Manager	Psychiatric Inpatient Unit
5	Ken	M	Asian	Community Psychiatric Nurse	Early Intervention Service
6	Harvey	M	White British	Psychiatrist	Home Treatment Team
7	Dora	F	White British	Social worker	Family Therapy Department

Appendix D: Focus Group Vignettes

Vignette 1

Focus Group

19th February 2015

Jane is a worker on a mental health team and has been asked to do an assessment of Hassan, a 22 year old man following a referral letter from the GP setting out worries about Hassan's mental health, including the possibility of him hearing voices.

On the referral letter is Hassan's mobile telephone number and Jane calls it. The phone is actually answered by Hassan's mother, Mrs A, who says she's really pleased to hear from the service because she's been worried about her son for the last 6 months following poor exam results at University. She says he has been spending increasing amounts of time on his own in his bedroom, and the family are worried that he's become depressed and distant from everyone. Jane asks to speak with Hassan, and after a few moments he comes to the phone. Although she tries to encourage him to talk on the phone he appears irritable and asks what his mother has said about him.

With some reluctance he agrees to see Jane at the family home.

Two days later Jane arrives on time, and Mrs A and her eldest son Mo answer the door.

Jane is shown into the family sitting room and Mrs A and Mo start to talk about their worries, saying that Hassan went out after a family argument earlier that morning, and they don't know when he'll be back.

Jane thanks them for sharing their concerns, and at that point Hassan arrives home. Seeing Jane and his mother and older brother talking in the sitting room he shouts at them to get out. Mrs A starts to cry and Mo walks out of the room.

At this point Jane also decides to leave the house but hands Hassan her work card with her telephone contact details on it, and asks that they keep in touch – possibly meeting next time outside the family home. Hassan nods.

Vignette 2

Focus Group

19th February 2015

Rachel has started to attend a weekly group at the local carers centre and has been finding life particularly difficult since Andrew her partner was brought into the local psychiatric hospital through an involuntary admission under the Mental Health Act. She mentions that Andrew had moved out of their shared home a few weeks before the admission, and she talks at the carer group about the experience of visiting him on the ward:

“I took two buses to get to the psychiatric hospital and had a huge shopping bag of Andrew’s favourite food. When I got to the ward the nursing staff wanted to search my bags and wouldn’t let me in until they’d gone through everything. Then to cap it all I found out that Andrew had been moved to another ward the night before, but nobody had told me. Apparently they’ve got his Mum on the system as his next of kin. When I did eventually see him I could tell he still wasn’t well, you know, he was saying odd things that I just knew he wouldn’t say if he was properly well. I asked to speak to the ward doctor, and I’ve been waiting for him to ring me for two days”.

Two weeks later Rachel talks again about her experience of services:

“I went to Andrew’s Care Programme Approach discharge meeting last week. Without any discussion they just expected me to let him return home to me, and to help him with money until his benefits start again. I feel like I’m the care plan. They said he didn’t need to be in hospital any longer, so I had to contact my boss and take emergency leave from work for a week. I was worried about Andrew being at home on his own all day without me. The home treatment team has been visiting everyday but the only trouble is it’s a different person who visits each day, and I can’t keep up with them. I can see that Andrew just tells them what he wants them to hear”.

Rachel returns to the carer group a few weeks later:

“Andrew and I are breaking up. We’re still living together and I’m continuing to care for him but it just isn’t working out. He says he feels much better now, and so has

stopped taking his medication, but I know what's going to happen. I just don't know what to do next".

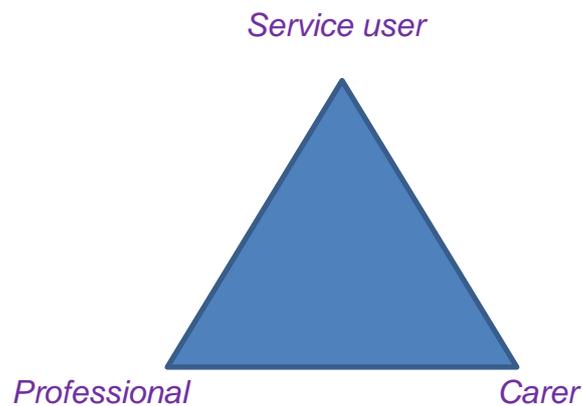
Vignette 3

Focus Group

19th February 2015

The idea of a triangle has been proposed as a way of showing how the collaboration between a mental health professional, service user and carer should take place. This is a three way relationship between the service user, carer, and mental health professional with everyone being heard and all parties influencing decisions.

1. How useful is the triangle in describing the relationships between mental health professionals and carers?
2. Is the triangle helpful in understanding the lived experience of caring for someone with a long term mental health condition?
3. Is there a shape or image that describes the relationships better?



Appendix E: Extract of Thematic Analysis

Research Analysis								
Number	Codes	Code reference			Carer or Worker?	Discussed in supervision or Group Tutorial?	Themes	Concepts
		Participant Identity	Source	Page Number				
1	Mums again	Maggie	Transcript	1	W - 3	Yes	Mothers as carers	
2	Mother is carer in society	Maggie	Field Notes	9	W - 3	Yes	Mothers as carers	
3	Mothers stay a lot longer	Mark	Transcript	18	W - 2	Yes	Mothers as carers	
4	Mothers talk about their 'child'	Asmita	Reflective write-up	4	W - 5	Yes	Mothers as carers	
5	Must be a nightmare for the mum	Worker 9	Transcript	10	W - Focus Group	Yes	Mothers as carers	
6	Completely dependent on mum	Suzanne	Transcript	13	W - 4	Yes	Mothers as carers	
7	Mums protect their children	Maggie	Field Notes	1	W - 3	Yes	Mothers as carers	
8	No discussion what my son is suffering from	Carer 13	Transcript	27	C - Focus Group	Yes	Family life	
9	They're their children but they're adults	Maggie	Field Notes	9	W - 3	Yes	Family life	
10	Getting out from under - never get parent-child	Hannah	Field Notes	8	C - 1	Yes	Family life	
11	Doesn't recognise herself as mother or wife	Hamid	Field Notes	9	C - 7	Yes	Family life	
12	Set into a carer - cared for dynamic	Marta	Reflective write-up	2	W - 8	Yes	Family life	
13	Familys come together	Marta	Reflective write-up	1	W - 8	Yes	Family life	
14	Family all scattered	Donna	Field Notes	7	C - 5	Yes	Family life	
15	Family work	Suzanne	Transcript	3	W - 4	Yes	Family life	
16	Continued to be a carer ... with new wife	Kofi	Reflective write-up	4	W - 6	Yes	Family life	
17	Family work - iron out disagreements	Worker 15	Transcript	33	W - Focus Group	Yes	Family life	
18	She's another child herself	Hamid	Field Notes	5	C - 7	Yes	Family life	
19	Carer relationship remained (after divorce)	Kofi	Reflective write-up	4	W - 6	Yes	Family life	
20	Uncertain future and loss	Asmita	Reflective write-up	2	W - 5	No	Family life	
21	Like being a parent	Maryam	Reflective write-up	1	C - 6	Yes	Family life	
22	Not like to clean their teeth (like children)	Suzanne	Field Notes	1	W - 4		Family life	
23	Difficult for parents	Suzanne	Transcript	9	W - 4	Yes	Family life	
24	I'm more than carer, I'm father	Hamid	Field Notes	9	C - 7	Yes	Family life	
25	Depends what we mean by carer	Asmita	Reflective write-up	1	W - 5	No	Defining who is a carer	
26	Nearest relative not always the carer	Maggie	Field Notes	1	W 3	Yes	Defining who is a carer	
27	Recognised as a carer	Kofi	Field Notes	10	W - 6	Yes	Defining who is a carer	
28	Term: 'Carer'	Suzanne	Transcript	2	W - 4	Yes	Defining who is a carer	
29	Recognition	Mark	Transcript	18	W - 2	Yes	Defining who is a carer	
30	Fluid label could get in the way	Marta	Reflective write-up	2	W - 8	Yes	Defining who is a carer	
31	Regular and substantial definition	Mark	Transcript	4	W - 2	Yes	Defining who is a carer	
32	Carer and Next of Kin don't enjoy rights	Kofi	Reflective write-up	4	W - 6	Yes	Defining who is a carer	
33	Who is in a relationship with whom?	Worker 17	Transcript	24	W - Focus Group	Yes	Defining who is a carer	
34	Next of Kin is who they want it to be	Carer 5	Transcript	24	C - Focus Group	Yes	Defining who is a carer	
35	Who is defining their relationship?	Worker 17	Transcript	24	W - Focus Group	Yes	Defining who is a carer	
36	Obliged to recognise	Mark	Transcript	3	W - 2	Yes	Defining who is a carer	
37	Big confusion things got really conflated	Worker 17	Transcript	24	W - Focus Group	Yes	Defining who is a carer	
38	Carer split into 3: NOK, NR, carer	Worker 14	Transcript	31	W - Focus Group	Yes	Defining who is a carer	
39	Don't have to live with someone to be their carer	Carer 5	Transcript	32	C - Focus Group	Yes	Defining who is a carer	
40	Language is muddled	Suzanne	Transcript	1	W - 4	Yes	Defining who is a carer	
41	Entitled	Mark	Transcript	4	W - 2	Yes	Defining who is a carer	
42	What sort of relationship do they have?	Worker 17	Transcript	32	W - Focus Group	Yes	Defining who is a carer	
43	Consenting	Suzanne	Transcript	18	W - 4	Yes	Defining who is a carer	
44	Wanting recognition more than anything else	Mark	Transcript	10	W - 2	Yes	Defining who is a carer	
45	Legal framework	Kofi	Field Notes	4	W - 6	Yes	Defining who is a carer	
46	No such thing as a baby only mother and baby	Sam	Reflective write-up	6	W - 7	Yes	Defining who is a carer	
47	Officially didn't recognise	Mark	Transcript	6	W - 2	Yes	Defining who is a carer	
48	Claiming to be a carer	Mark	Transcript	2	W - 2	Yes	Defining who is a carer	
49	Clear definition?	Kofi	Field Notes	2	W - 6	Yes	Defining who is a carer	
50	Are they/aren't they carers?	Kofi	Reflective write-up	4	W - 6	Yes	Defining who is a carer	
51	Carers not recognising themselves as carers	Asmita	Reflective write-up	2	W - 5	Yes	Defining who is a carer	
52	We take over a bit	Maggie	Field Notes	11	W - 3	Yes	Taking control	
53	If she just comes along (with the professionals plans)	Carer 8	Transcript	33	C - Focus Group	Yes	Taking control	
54	Have to make a decision forceful	Maggie	Field Notes	6	W - 3	Yes	Taking control	
55	Mediator of power	Mark	Transcript	7	W - 2	Yes	Taking control	
56	Remove themselves	Mark	Field Notes	6	W - 2	Yes	Taking control	
57	Permission from service user	Kofi	Reflective write-up	3	W - 6	Yes	Taking control	
58	Mediator	Mark	Field Notes	3	W - 2	Yes	Taking control	
59	Safety of not including the carer	Suzanne	Transcript	17	W - 4	Yes	Taking control	
60	Relinquishing carer role	Maggie	Field Notes	2	W - 3	Yes	Taking control	

Appendix F: Information Sheets

Information Sheet 1 – Focus Group Attendees

August 2013

Information Sheet (Focus Group attendees)

Research Title

The contemporary dynamics of caring - An in depth qualitative study of the relationship between paid and unpaid carers of people with long term mental health conditions.

Introduction

My name is Jeremy Walsh and I work full-time for South West London and St Georges Mental Health NHS Trust. I am also undertaking a Doctorate in Social Work at The Tavistock and Portman NHS Foundation Trust in association with the University of East London, and as part of the doctoral programme I am undertaking a research project on the role of carers for people with long term mental health conditions.

The overall aim of the research is to develop a greater understanding of the experiences of carers who support people with long term mental health conditions, and within this broad subject of caring, three specific areas of enquiry have been identified for the research:

1. The relationships between professional people in caring roles, and unpaid carers for people with long term mental health conditions;
2. The lived experience of caring for a friend, partner, parent, sibling, child, or neighbour who has a long term mental health condition and how the role of professional people in caring roles affects this;
3. The experience of caring for someone with a long term mental health condition as being a burden as well as satisfying and how professional people in caring roles, and unpaid carers, manage these experiences.

Defining who is a carer

The definition of caring within the context of mental health is wide, and caring can comprise of emotional support, as well as physical and practical forms of assistance.

In defining who is a 'paid carer' the nature of the roles undertaken by a range of professional people in mental health services; including psychiatry, social work, nursing, occupational therapy and psychology, form the paid carer category.

The definition of who is an 'unpaid carer' is also wide, and for this research I am defining it as anyone who defines themselves as a carer and attends the XX Carers Centre, and provides support to someone with a long term mental health condition. In relation to the person with the mental health condition, as an unpaid carer you could be a family member, friend, or neighbour, although you must be over 18 years of age.

Gathering information from professional people in caring roles

In order to gain an insight into the experiences of paid carers providing care to people with mental health issues I have identified the value of discussing carer experiences within the context of a focus group. The focus groups will be facilitated by me as the lead investigator and will take place within the XX Carers Centre or a confidential meeting room within the XX mental health trust. To help with analysing the information afterwards the group has ended, the sessions will be taped recorded via a recording device, and I will also take notes as the focus group proceeds. The focus group is likely to take no more than one and a half hours.

The focus group will not entail a formal series of specific questions, but is likely to begin with an open invitation for attendees to share their experiences of being a professional person in a caring role or a family member, friend or neighbour of someone with a long term mental health condition. As the focus group develops I may ask additional questions about respective roles, although the group will largely be led attendees discussing their experiences of being carers and of supporting carers.

Use of the information

The information that emerges from the focus groups will form valuable data for the research project that aims to gather a range of individual narrative accounts from both paid and unpaid carers. The information that emerges from the focus groups may also be used to illustrate points in the written research report, but will not be identifiable to any one individual participant, and will be confidential with any identifying details that arise in the interview anonymised.

Support following the focus group

I realise that in having the opportunity to discuss your experiences of being a professional person in a caring role, or an unpaid carer that difficult and emotional issues may emerge. In order to provide an opportunity to talk further and identify support should it be needed, I will be available both in person, and on the telephone, after the focus group has ended.

Thank you for considering taking part in this research project and for more information at this point please contact me via telephone or email at:

- jeremy.walsh@swlstg-tr.nhs.uk
- 0203 513 5420

Jeremy Walsh

Lead researcher

Version 1.1 dated 6 January 2014 Informal Carers

Information Sheet 2 – Carers

August 2013

Information Sheet

Research Title

The contemporary dynamics of caring - An in depth qualitative study of the relationship between paid and unpaid carers of people with long term mental health conditions.

Introduction

My name is Jeremy Walsh and I work full-time for South West London and St Georges Mental Health NHS Trust. I am also undertaking a Doctorate in Social Work at The Tavistock and Portman NHS Foundation Trust in association with the University of East London, and as part of the doctoral programme I am undertaking a research project on the role of carers for people with long term mental health conditions.

The overall aim of the research is to develop a greater understanding of the experiences of carers who support people with long term mental health conditions, and within this broad subject of caring, three specific areas of enquiry have been identified for the research:

1. The relationships between professional people in caring roles, and unpaid carers for people with long term mental health conditions;
2. The lived experience of caring for a friend, partner, parent, sibling, child, or neighbour who has a long term mental health condition and how the role of professional people in caring roles affects this;
3. The experience of caring for someone with a long term mental health condition as being a burden as well as satisfying and how professional people in caring roles, and unpaid carers, manage these experiences.

Defining who is a carer

Within mental health services the definition of who is an 'unpaid carer' is quite wide, and for this research I am defining it as anyone who defines themselves as a carer and attends the XX Carers Centre, and provides support to someone with a long term mental health condition. In relation to the person with the mental health condition you could be a family member, friend, or neighbour although you must be over 18 years of age.

Gathering information from carers

In order to gain an insight into the experiences of carers providing care to people with mental health issues I have identified the value of interviewing carers on a one to one basis. The interviews will be carried out by me as the lead investigator and will take place at the XX Carer Centre offices. To help with analysing the information afterwards the interviews will be taped recorded via a recording device, and I will also take notes as the interview progresses. The interview is likely to take approximately one and a half hours, and I may ask you if you would be prepared to meet with me for a second follow-up interview following the first interview.

The interview will not entail a formal series of specific questions, but is likely to begin with an open invitation for you to share your experience of being a carer. As the interview develops I may ask additional questions about your role as a carer, although the interview will largely be led by you talking to me about your experiences as a carer.

Use of the information

The information that emerges from the interviews will form valuable data for the research project that aims to gather a range of individual narrative accounts from unpaid carers; including family, friends and neighbours of people with long term mental health conditions. The information that emerges from the interviews may be used to illustrate points in the written research report, but will not be identifiable to any one individual participant, and will be confidential with any identifying details that arise in the interview anonymised.

Support following the interview

I realise that in having the opportunity to discuss your experiences of being a carer that difficult and emotional issues may emerge. Along with a carer support worker from the XX Carers Centre I will be available both in person, and on the telephone, if you wish to talk about any of the issues that arise during your interview.

Thank you for considering taking part in this research project and for more information at this point please contact me via telephone or email at:

jeremy.walsh@swlstg-tr.nhs.uk or 0203 513 5420

Jeremy Walsh

Lead researcher

Appendix G: Consent Form

Version 1.4 dated 6 January 2014

Consent Form

Contemporary dynamics of caring – An in depth qualitative study of the relationship between paid and unpaid carers of people with long term mental health conditions

Thank you for considering taking part in this research. If you have any questions please ask a member of the research team before you decide to take part. The team is as follows:

- **Jeremy Walsh, Chief Researcher**
Tel 020 3513 5420 or via email Jeremy.walsh@swlstg-tr.nhs.uk
- **Gillian Ruch, Lead Supervisor**
Tel 020 7435 2058 or via email gruch@tavi-port.nhs.uk
- **Helen Hingley-Jones, Secondary Supervisor**
Tel 020 8938 2476 or via email hhingleyjones@tavi-port.nhs.uk

You will be given a copy of this consent form to keep and refer to at any time.

Once you have agreed to participate in the study you have a 'cooling off' period of fourteen days in which to change your mind, and indicate you no longer wish to be involved.

Over and above the 14 days cooling off period you may decide you no longer wish to participate at any point, and the researcher will check your willingness to continue to be involved before the focus group commences.

Please tick 'Yes' or 'No' box as applicable:

	Question	Yes	No
1	I confirm that I have read and understood the information sheet dated (version). for the above study.		
2	I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.		
3	I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my support or care or legal rights being affected.		
4	I understand that if I withdraw from the study the data collected up to that point will be destroyed.		
5	I agree to the interview being audio recorded so that my comments can be typed up and used as research data.		
6	I agree to take part in the study		
7	I understand that data from the study may be looked at by regulatory authorities or by persons from the Trust where it is relevant to my taking part in this research. I give permission for these persons to have access to this data.		

Name of Participant (please print): _____

Signed _____ **Date** _____

Name of Researcher: Jeremy Walsh

Signed _____ **Date** _____

SCHOOL OF HEALTH, SPORT AND BIOSCIENCE
Dean: Professor Neville Punchard PhD FIBMS FHEA
uel.ac.uk/hsb

School Office



Mr Jeremy Walsh
28 Vestris Road
London
SE23 2EE

18 February 2015

Dear Mr Walsh

**University of East London/The Tavistock and Portman NHS Foundation Trust:
research ethics**

Study Title: *Contemporary dynamics of caring – An in depth qualitative study of the relationship between paid and unpaid carers of people with long term mental health conditions*

I am writing to inform you that the University Research Ethics Committee (UREC) has received a copy of your IRAS application and R&D approval letter, which you submitted to the Chair of UREC, Professor Neville Punchard. Please take this letter as written confirmation that had UREC had seen this IRAS application and approval at the time, then it would have noted and approved it. However, this does not place you in exactly the same position you would have been in had clearance been obtained in advance. Therefore, when responding to any questioning regarding the ethical aspects of your research, you must of course make reference to and explain these developments in an open and transparent way.

For the avoidance of any doubt, or misunderstanding, please note that the content of this letter extends only to those matters relating to the granting of ethical clearance. If there are any other outstanding procedural matters, which need to be attended to, they will be dealt with entirely separately as they fall entirely outside the remit of our University Research Ethics Committee.

Stratford Campus, Water Lane, Stratford, London E15 4LZ
Tel: +44 (0)20 8223 4477 Fax: +44 (0)20 8223 4965
Email: hsb.pa@uel.ac.uk



If you are in any doubt about whether, or not, there are any other outstanding matters you should contact Mr William Bannister at the Tavistock and Portman NHS Foundation Trust (e-mail WBannister@tavi-port.nhs.uk).

Yours sincerely



Professor Neville Punchard

c.c. Mr Malcolm Allen, Dean of Postgraduate Studies, Tavistock and Portman NHS Foundation Trust
Mr Will Bannister, Associate Director, Education and Training, Tavistock and Portman NHS Foundation Trust
Professor John J Joughin, Vice-Chancellor, University of East London
Mr David G Woodhouse, Associate Head of Governance and Legal Services