

Exploring the meaning of caring:

how informal caring for somebody experiencing mental health difficulties,
and the language used to talk about it, are understood by carers, family
members, mental health service-users, and professionals

by

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A thesis submitted to the University of Birmingham
for the degree of Doctor of Philosophy

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September 2011

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Abstract

While much is known about caring and mental health difficulties from a broad range of theoretical perspectives, less is known about the lived experience of caring for a relative experiencing mental health difficulties. This thesis therefore adds to the developing literature in this area by taking a phenomenological approach to understanding the meaning of caring as described by service-users, carers, family members, and mental health professionals, in their own words. For these participants, the language of caring was presented as problematic. On the one hand, it was helpful, linked to being valued, visible, and opening up access to help and support; while on the other, it was seen as threatening to the primary relational qualities of the pre-existing close relationships that had led to taking on caring responsibilities in the first place. In terms of the implications for mental health service design and delivery, a family-sensitive ethos involving open communication and information sharing was seen as essential in developing meaningful relationships between service-users, their families, and professionals, to the benefit of all concerned. Supporting familial relationships in a way that goes beyond simple characterisations of ‘carer’ and ‘cared-for’, focusing on the essential relatedness of the family system, and helping families to develop their own resources and resilience, was also seen as a key way in which mental health services could support the service-users and families they work with.

Key words: caring; mental health difficulties; serious mental illness; interpretative phenomenological analysis; multi-perspectival design; focus groups; written emotional disclosure.

Dedication

Dedication

For all those who have helped me along the way,
I couldn't have done it without your encouragement and support.

Special thanks to Jason, always there for me.

Acknowledgements

This research would not have been possible without the support of the mental health service-users, carers, family members, and professionals who shared their experiences and time with me for the benefit of this project. I am also extremely grateful for the support I received from carers' support groups, mental health services, and the University of Birmingham to promote this research.

I would also like to express my sincere gratitude for the ceaseless encouragement, support, and guidance offered by my research supervisor, Dr Michael Larkin. I am also pleased to acknowledge Dr Gráinne Fadden, and the Meriden Family Programme team in encouraging and supporting me to undertake this research.

This research was granted ethical approval by the [REDACTED] and the [REDACTED]. I am grateful for each committee's time and valuable comments in guiding this research.

I am pleased to acknowledge that this research was awarded financial support from the Economic and Social Research Council.

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Chapter 1

Introduction

This research hopes to add to the developing literature on informal (unpaid) care that is offered to people experiencing mental health difficulties, particularly by focusing on the relationship between the carer and cared-for, and the ways in which mental health services respond to this. This research therefore aims to explore the ways in which carers, family members, service-users and mental health professionals make sense of their experiences of being affected directly or indirectly by mental health difficulties, informal caregiving and recovery, and the language used to describe these things.

1.1 Chapter 1: Introduction

The overall aim of this research is provide a greater experiential base from which to better understand the implications of taking on a caring role for somebody experiencing mental health difficulties. In linking together issues concerning identity, family relationships, stigma, the positive aspects of caring, and the interface between informal care and mental health services, this research will present multiple perspectives on caring. It is hoped that this research will have practical implications for the way in which mental health services are both designed and delivered. An outline the ways in which this research attempts to address these aims is presented below.

1.2 Chapter 2: Conceptual overview of the literature concerning caring and mental health difficulties

This chapter provides an overview of the literature concerning caring and mental health difficulties. Consideration is given to what is known about who takes on a caring role when

somebody needs help and support in relation to mental health difficulties. The literature suggests that although caring can be burdensome and stressful, it can also be a positive and rewarding experience. As the number of carers seems set to increase in the coming years, greater emphasis is being given to finding out more about the experience of caring and what can be done to support carers to help them with their caring responsibilities. This overview therefore examines some of the strengths and weaknesses of work done in this area, and identifies gaps in the literature, in order to consider what is already known about the experience of caring, and how research in this area might be developed.

1.3 Chapter 3: Literature review: Exploring the meaning of the caring experience

Much has been written about informal caring and mental health difficulties, some of which has begun to look at the lived experience of such carers. Phenomenology's core concerns are with what the experience of being human is like and how we make sense of, and make meaning from, our everyday lives. It would therefore seem to be a particularly relevant approach for helping to develop an understanding of caring from a range of perspectives. This chapter focuses on literature that has taken a phenomenological approach to the study of informal caring for people experiencing mental health difficulties. It considers its strengths and weaknesses, implications for clinical practice, and potential opportunities for future research. The application of phenomenological methods is further discussed in Chapter 4.

1.4 Chapter 4: Taking an interpretative phenomenological approach to the study of the experience of caring for somebody experiencing mental health difficulties

Following the literature overview and review chapters, this chapter outlines the key phenomenological approaches typically employed in psychological research. The rationale for employing an interpretative phenomenological approach to the study of caring for somebody

experiencing mental health difficulties is outlined. The primary research questions that will guide this research are also presented.

1.5 Chapter 5: Exploring the meaning of carers' experiences of caring for somebody experiencing mental health difficulties, and the language of care

This chapter explores the ways in which carers (who attend carers' support groups) understand and make sense of the language of care; and their personal experience of caring for somebody experiencing mental health difficulties. This chapter examines what carers think of the terminology associated with the type of care they provide, whether or not they think it applies to themselves, and how it impacts on their lives.

Recruitment was carried out through advertising this research at carers' support groups in the English Midlands, UK. The carers who participated in this study therefore identified themselves as carers at the time of taking part, and had been attending support groups for varying amounts of time. All participants were caring for a relative (e.g. adult child, parent) and reported that their relatives had been given a psychiatric diagnosis (e.g. psychosis, bipolar disorder, dementia etc.). Eleven individuals took part over three focus groups, which each lasted for approximately 1 hour 30 minutes.

Analysis identified six key themes in the data that focused on the idea that being an informal carer...: is a useful label?; is a choice?; can mean identifying other carers and finding support in others' experiences; means taking on responsibilities that blur the lines with formal care; means having to deal with (un)professional conduct; and can present concerns about the future. While many of the experiences shared indicated significant agreement on many issues, there were also some stark differences of opinion between participants. For these carers, this label was often something that was difficult to identify with, being both a help and a hindrance at times.

1.6 Chapter 6: Exploring the meaning of service-users' and carers' experiences of first-episode psychosis

This chapter explores service-users' and carers' experiences of first-episode psychosis. Where work in this area has been carried out it tends to have been from either service-users' or carers' perspectives. This study therefore employs a dual-perspective design to further explore the issues that are pertinent to both groups.

Data were collected from eight community-based, Early Intervention service-users (three male, five female, aged from 18-33 years, mean age 23 years) and eight carers (one male, seven female, aged from late-30s to mid-50s). Seven of the carers cared for a child, whilst one cared for a spouse, experiencing early psychosis. All participants were based in the English Midlands, UK.

Analysis suggested that issues around identity and loss were key concerns for both service-users and carers, particularly in relation to the impact of early psychosis on the service-user's personality, i.e. who they used to be, and who they could be in the future. There also seemed to be striking similarities between service-users' and carers' concerns with adapting to a change in difficult circumstances and dealing with future uncertainty, with both groups expressing concerns about, and hopes for, the future. A key difference between the groups centred on a sense of conflict about the potential causes of mental health difficulties. For the most part the service-users did not express their thoughts about why they might have become unwell, whereas the carers tended to focus far more on the possible causes of their relative's condition, often describing concerns about their own role in the development of mental health difficulties.

1.7 Chapter 7: Exploring the meaning of a family's experiences of being affected by mental health difficulties

This chapter examines what it is like to be part of a family affected by mental health difficulties. A family group was identified by an Early Intervention service in the English Midlands, UK. Four family members took part, each completing an interview with the researcher that lasted for approximately one hour. Although the family were identified because one member of the family was currently engaged with Early Intervention services, there was a wider family history of diagnosed psychiatric disorder (bipolar disorder).

Family members shared their understanding of mental health difficulties, and talked about their impact on family life over the years. Although difficulties and challenges were presented, there was also a sense of learning and development. Family members talked about the knowledge and skills they have picked up, opportunities that have arisen, and personal developments in softer skills, such as, empathy and compassion. As a family system, the key features of the experiences presented centred on: making sense of what happened to Luke when he became unwell; making sense of the ways in which family roles and relationships had been impacted by mental health difficulties (choice, detachment, role reversal and replacement); the impact of chronic and acute experiences of mental health difficulties on family members' sense of self; and sources of support outside the family.

1.8 Chapter 8: Exploring the meaning of mental health professionals' experiences of working with carers of people experiencing mental health difficulties, and the language of care

This chapter investigates mental health professionals' experiences of identifying, engaging with, and maintaining relationships with the families and carers of people that are referred to Early Intervention services. Recruitment was carried out through advertising this research at the team

bases of Early Intervention services operating in the English Midlands, UK. A total of 18 individuals, from a range of professional backgrounds, took part in three focus groups which each lasted for approximately one hour.

Findings suggested that mental health professionals sometimes faced conflict between being open and inclusive, viewing everybody a service-user might have contact with as a potential carer, and having to manage finite resources. Analysis identified four themes in the data: Doing more than is normal within relationships; “I’m not a carer, I’m a wife”: labelling and identity; The impact of the carer label on family relationships; and Development of staff relationships with carers and families. Overall the groups seemed to present an understanding of caring that seemed better defined by experience than circumstances, for example, not all parents are necessarily carers, but carers will most likely be doing more than the norm, feeling a sense of burden from their activities, and/or not being able to go about their own lives in the way that they used to, or would like to.

1.9 Chapter 9: Synthesis of service-users’, carers’, family members’, and mental health professionals’ experiences of caring and mental health difficulties

This chapter brings together what has been learnt about caring and mental health difficulties throughout the previous chapters of this thesis. The findings presented in Chapters 5-8 are synthesised to highlight what this research is able to offer in terms of developing an understanding of how service-users, carers, families, and mental health professionals make sense of caring and mental health difficulties, and the language used to talk about these things. The implications of this research for mental health care design and delivery are considered, highlighting the importance of communication, information sharing, and the benefits of services that are guided by a family-sensitive ethos. Methodological issues and reflections on the research process are discussed, including reflections on the multi-perspectival design, and use of different data collection methods.

The limitations of this research and the ways in which research in this area might be developed are also considered.

References and appendices follow Chapter 9.

Chapter 2

Conceptual overview of the literature concerning caring and mental health difficulties

2.1 Abstract

Consideration is given to what is known about who takes on a caring role when somebody needs help and support in relation to mental health difficulties. The literature suggests that although caring can be burdensome and stressful, it can also be a positive and valued experience. As the number of carers seems set to expand in the coming years, greater emphasis is being given to finding out more about the experience of caring and what can be done to support carers to help them with their caring responsibilities. This overview therefore sets out to further explore what is already known about the experience of caring and how research in this area might be developed.

The literature on caring and mental health difficulties is introduced before moving on to a systematic review of the phenomenological work that has been carried out in this area (Chapter 3). A smaller number of papers considered particularly relevant to the current research are then identified and discussed in further detail with regard to the lived experience of caring. These papers are then further considered in terms of their methodological approach.

Much of the work that has been carried out in this area draws on parental carers' experiences, with a smaller number of studies also including spouses or cohabitants, other family members or close friends. The experience of caring seems to be often conceptualised in terms of 'psychic loss' (Miller, 1996), with carers facing the loss of a relative who is replaced by a new, vulnerable, needy person. There are also indicators that carers' identity is impacted by caring responsibilities and this can have implications for family relationships.

This research seeks to further explore the meaning of caring through the inclusion of mental health service-user, carer, family member, and mental health professionals' perspectives. It aims to explore the ways in which the language of caring is understood from these perspectives and the ways in which identity and family relationships are affected when somebody becomes a carer.

2.2 Context of the overview: Exploring the meaning of caring

The overall aim of this research is to provide a greater experiential base from which to better understand the implications of taking on a caring role for somebody experiencing mental health difficulties. The focus of this research will therefore focus on relationships that have been affected (directly e.g. service users, or indirectly e.g. carers) by mental health difficulties. For the purposes of this research 'mental health difficulties' will be used to define a range of psychological difficulties that are often also conceptualised as serious or severe mental illness. As these terms are typically quite vague and open to a range of definitions themselves (Ruggeri *et al.*, 2000), they will be further discussed below, along with greater detail about the nature of the conditions represented in this research. In linking together issues around identity, family relationships, and the positive aspects of caring, this research aims to build up a more holistic picture of caring that will have practical implications for the ways in which mental health services are both designed and delivered.

In order to accomplish this aim, what is known about the experience of caring for somebody experiencing mental health difficulties must first be considered. This chapter will therefore focus on what is known about being a carer and the impact it has on family relationships, the types of research that have been used to address these questions, and how this research might go about deepening the understanding of these complex relationships for the benefit of mental health service-users, their families and friends, and services.

2.3 What is known about being a carer and the impact it has on relationships in the family?

2.3.1 Who cares?

“Do you look after or give any help or support to family members, friends or neighbours or others because of: long-term physical or mental ill-health or disability or problems related to old-age?”

(Question included in the 2001 UK Census, Buckner & Yeandle, 2007)

It has been estimated that there are almost 6 million carers in the UK who provide help and support for family, friends and neighbours. The economic value of this care can be estimated at £87 billion per annum, a figure that is only set to rise in the coming years as the number of carers, and the cost of care, continue to increase (Buckner & Yeandle, 2007). The authors also suggest that, “...the enormous economic value of the contribution that carers make ... when added to its huge but incalculable non-economic value it is clear that providing adequate support for carers which enables them to care, as well as have what others take for granted – access to work, income, education, leisure and participation in everyday life - is essential, cost-effective, and in everyone’s best interests.” (Buckner & Yeandle, 2007, p. 5).

The provision of informal care is therefore a growing concern and increasingly the subject of research. For the purposes of this research, the word ‘carer’ will be used to denote an informal, or unpaid, carer taking on caring responsibilities for a family member, friend or neighbour. This is in contrast to formal care, which would include health care professionals, institutions and treatment programmes. As informal care may cover a vast array of conditions that might require the help and support of a relative, the focus of this research will primarily be concerned with carers of people experiencing mental health difficulties. Pickens (1998) offered a discussion of the origins of these

definitions and a historical perspective on the differences between informal and formal care of those with psychiatric disorders. The author provided an overview of formal and informal care for individuals with serious mental illness as it has changed over the years in the United States, which is comparable with the experience of the United Kingdom. Failures in early care were outlined, considering the emergence of asylums, the mental hygiene movement, and the Depression, and moving towards deinstitutionalisation and community care. Further exploration of the role of the family was presented, ending with the current move towards greater collaboration between formal and informal carers. Pickens highlighted the tensions that have existed in the relationship between families and professional care systems, citing blame, resentment, and neglect as often being key sources of difficulty. Indeed, the development of inclusive, collaborative, meaningful partnerships between formal (i.e. mental health professionals) and informal carers has been the focus of a number of campaigns and research studies (e.g. the Royal College of Psychiatrists' 'Partners in Care' campaign launched in 2004; the 'Carers in Partnership' Community Interest Company which began operating in 2007; Fadden, Shooter & Holsgrove, 2005). However, while it is clear that professionals are increasingly becoming aware of the important role that families play in supporting their relatives, and in helping professionals to do their jobs, there is evidence to suggest that this relationship is not always satisfactory (see also Pinfold & Corry, 2003).

Mental health services and carers' organisations typically offer broad definitions of what a 'carer' is, many of which generally concur with the National Service Framework for Mental Health's definition which identifies carers as individuals who provide regular and substantial care for a person on CPA (Care Programme Approach) (Department of Health, 1999). Estimates of the number of mental health carers in Britain vary from 125 000 (Department of Health, 1999) to 1.5 million (Pinfold & Corry, 2003). Following a survey of carers, the leading mental health charity, Rethink, reported that the 'typical' carer was a woman, in her sixties, usually a mother, caring for a man, usually a son in his late thirties, for a period of around 14 years (Pinfold & Corry, 2003). These figures, particularly relating to carers' gender and age, seem to be broadly in line with other studies on caring more generally (Singleton *et al.*, 2002; McKie, Bowlby & Gregory, 2001;

Magliano *et al.*, 1998). However, it is worth remembering that carers, although likely to be older adults, can in fact be part of virtually any demographic and that they may also have their own health concerns which mean that they might also be considered cared-for individuals. In terms of the number of hours of care that are being provided, the Princess Royal Trust for Carers (2000) suggested that 42% of carers provide between one and nine hours of care per week, while 31% care for 50 hours or more. However, unlike other carers, mental health carers might not be actively caring all the time, for example during periods where the person they care for is relatively stable and free of symptoms. This, along with the stigma associated with mental health difficulties, can make it difficult for carers to access the help and support that is available to them. Further figures from the Princess Royal Trust for Carers (2000) suggested that 65% of carers reported receiving no support whatsoever.

The words ‘mental illness’ are used to describe a vast array of conditions and symptoms and are often synonymous with other general terms such as, ‘mental health’, ‘mental or psychiatric disorder’, ‘psychological distress’, through to more specific diagnoses like, ‘schizophrenia’, ‘bipolar disorder’ and ‘depression’. While these are among the most common terms to come up when performing general searches for information on mental illness, other more specific searches for conditions like dementia, brain injury, learning disabilities, anxiety disorders, and eating disorders also yield a wealth of information that is available to the general public. Vast amounts of research are carried out into specific conditions, and so, as with narrowing the discussion of carers down to informal mental health carers, it is therefore necessary to narrow the field yet further to be more specific about the scope of ‘psychiatric disorder’ that can be covered by this research.

2.3.2 *What is ‘care’?*

There would seem to be little doubt that there are a great number of individuals in society who are offering help and support to people in need because of long-term physical or mental health or disability or problems relating to old-age. While the vague definitions of carers go some way to

highlighting the nature of 'care' it is worth considering the language and conceptualisations of 'care' in greater detail here.

Care is both a noun and a verb and can be variously applied to a great many areas of life. As a noun, 'care' can denote "the provision of what is necessary for the health, welfare, maintenance, and protection of someone or something; protective custody or guardianship provided by a local authority for children whose parents are dead or unable to look after them properly; serious attention or consideration applied to doing something correctly or to avoid damage or risk; an object of concern; or a feeling of or occasion for anxiety." (Oxford English Dictionary, 2011). While as a verb, 'care' is defined as to: "feel concern or interest; attach importance to something; feel affection or liking; like or be willing to do or have something; (care for) look after and provide for the needs of." (Oxford English Dictionary, 2011). So, the word 'care' might be used to describe anything from, providing help and support for another's welfare needs; to a local authority institution (e.g. to be placed in *care*); from the experience of not having a *care* in the world; through to enquiring whether another would *care* for some tea. For the purposes of this research, the focus of care will be on the informal care and support that people offer when a relative becomes unwell.

Caregiving interactions are therefore the primary interest of this research, though these will inevitably be bound up in definitions of 'care' in its broader senses, for example, as concern, affection, or a formalised system. Caregiving is essential to the human experience as infants are unable to survive without the care of others, typically (though not necessarily) parents. Caregiver-infant interactions play an important part in enabling infants to acquire basic social skills and attachments to others. Being part of society will typically lead to a range of opportunities for caring relationships and caregiving experiences throughout an individual's lifespan. So caring might therefore be thought of as a somewhat universal experience. So what is it about caring for a person with long-term physical or mental health needs, disability, or problems associated with old age, that is different to common, everyday experiences of caregiving?

As noted in the previous section, the caregiving that is of interest to this research is characterised by long-term health difficulties and is of immense economic value to society. The type of support that might be offered when somebody experiences mental health difficulties is thought to be considerably different to that of caregiving where such health concerns are not present. However, as previously noted, carers are often family members, friends or neighbours, where there would already commonly be an element of caregiving occurring. How these relationships are impacted when a person becomes mentally unwell and the ways in which ‘caring’ becomes more of an issue are therefore primary concerns of this research. While the term ‘carer’ will be used to denote informal carers of people experiencing mental health difficulties, ‘care’ will therefore be concerned with caregiving, particularly in relation to carers’ thoughts, feelings and behaviours towards supporting a person experiencing mental health difficulties.

2.3.3 Exploring caring and mental health difficulties from an experiential perspective

The primary focus of this research is caring for a person experiencing serious mental health difficulties, or severe mental illness, though it must be acknowledged that this in itself is a vague term with no clear, singular definition (Ruggeri *et al.*, 2000; Slade, Powell & Strathdee, 1996). However, it is generally thought to include those with psychosis, a condition whereby individuals experience a loss of contact with reality, generally occurring episodically, and characterised by unusual beliefs and possibly hallucinations, often also including impaired insight, motivation and communication. So, in seeking to explore the meaning of caring, it is these types of experiences, rather than specific diagnoses, or disorder categorisations, that are of primary interest to the present research. Consequently, this research will focus on those individuals where the cared-for person experiences psychosis, bipolar disorder, or depression, where some of those factors identified in experiences of psychosis (e.g. impaired insight, motivation and communication) may also be a common feature of an individual’s experiences. It is important to draw attention to this here as it will impact upon the literature reviewed and participants recruited for the present research. Choosing to focus on these types of experiences, and not assuming that diagnostic categories are

necessarily the best way of defining psychological difficulties, will make it possible to recruit a sample that is reasonably homogeneous in type of experience, but sufficiently broad to gather a range of different perspectives on the experience of caring. This focus on experiences, rather than psychiatric diagnoses, has been a key characteristic of recent psychological writing on mental health, considering alternative ways of conceptualising mental health difficulties (e.g. Boyle, 1990; Bentall, 2003).

It is acknowledged that thinking about the self through our experience of the world is just one way of conceptualising identity. There is a wide and varied literature considering how we understand the self, including perspectives on the embodied self, the impact of the social world and how our unconscious might shape identity. However, our subjective experience of the world is also a defining factor in our sense of being. To be a person is to experience oneself as being in the world, someone who can engage with and influence the world, and who possesses awareness of thoughts, feelings and actions in the world (Smith, Flowers & Larkin, 2009; for further discussion of the origins of phenomenology and exploration of 'being in the world' as developed by Heidegger and Merleau-Ponty, see Langdrige, 2007). Through these experiences we come to develop our sense of self and our place in the world. Trevarthen (2002) suggested that, from birth, infants coordinate information-seeking and object-using behaviours, intimately sharing expressions of emotion with parents (immediate caregivers). The author went on to describe the 'narrative musicality' of these interactions, highlighting the way that, "All these lay the foundations for learning how to speak about what is already consciously shared. We see that human sense of things, with all its potential for cultural elaboration, is somehow born in us, seeking affirmation in human company." (Trevarthen, 2002, p. 161).

This research is interested in how the experience of caring on an informal basis, a fundamentally social activity, impacts upon individuals and families. It therefore seeks to address questions like: What is it like to care for a relative experiencing mental health difficulties?; At what point does an individual become 'a carer'?; and How does being 'a carer' impact on other aspects of the self? As

noted above, for many people, caring is something that they just do instinctively, perhaps as a natural extension of a previous caring, close relationship. So, how does this impact on carers' experience of their own autonomy and the choices that they are able to make? In exploring how to go about answering these questions, consideration must be given to how research can address the study of experience. Phenomenology is a philosophical approach often employed in psychology to study conscious awareness. It is predominantly concerned with what the subjective experience of something is like, rather than what is empirically measurable. So, in seeking to explore the meaning of caring for carers, families, service-users and professionals, a phenomenological research design will encourage detailed first-person accounts through which more might be understood about the daily, lived experience of caring. The application of a phenomenological approach to this type of research will be explored in further detail as the literature review progresses. However, it is worth further considering here how else we might conceptualise caring from a psychological perspective.

One consequence of phenomenology's influence on psychology was the development of the humanistic approach which focuses on the idea that humans strive to achieve personal growth, motivated by a need for self-actualisation. The roots of this approach lie in existentialism, which assumes that human beings are self-aware, able to make decisions and take responsibility for themselves. In humanism, there is a focus on the 'here and now' and on how we develop through personal growth and fulfilment. At a time when psychology was dominated by ideas about motivation being driven by basic physiological needs, Maslow (1954) acknowledged these but sought to go beyond them, including psychological needs. Maslow proposed a five-level hierarchy of needs. At the bottom are those needs that are considered essential for survival (e.g. food, water and sleep). The next level is concerned with safety (a secure, predictable environment, relatively free from physical and psychological anxiety), which is followed by a need for love and belonging. The fourth level identifies the need for esteem, which is related to having the respect of others and confidence in the self. Finally, at the top of the hierarchy is self-actualisation which centres on fulfilling one's potential, which Maslow famously summarised as, "what a man (sic) *can* be, he

(sic) *must* be” (Maslow, 1954, p. 123). Although Maslow’s theory is not without its limitations, it does provide a useful starting point for thinking about why individuals might be motivated to take on a caring role, and the implications it might have for self-concept. Existential and humanistic approaches to psychology are very much concerned with the notion that we can understand ourselves through the examination of our experience. Phenomenology is therefore valuable to these approaches, being interested in accounts of individuals’ conscious experience of being in the world. While phenomenology will be explored in more detail in Chapters 3 and 4, it is first worth considering, here, how individuals go about fulfilling their potential, the potential consequences of these activities for well-being, and how these things might relate to caring.

One framework which builds upon the idea of meeting these basic needs by thinking about the development of self through experience is self determination theory. This theoretical framework provides a way of thinking about personality growth and development, viewing humans as active, growth-orientated organisms that innately engage in, and seek out, challenges in their environments, attempting to actualise their potentialities, capacities and sensibilities (Deci & Ryan, 2002). In exploring the integrating self and conscious experience, Hodgins & Knee (2002, p. 87) suggest that in seeking to address our basic psychological needs, “...there is a basic human tendency to proceed toward higher-order organisation. The organismic integration process through which this tendency is actualised involves aspects of the self becoming more complex and interrelated with one another and with aspects of the social world.” The way in which we seek to achieve this is described through self determination theory’s focus on innate human psychological needs for autonomy (being the perceived origin of one’s own behaviour), competence (feeling effective in one’s own interactions with the environment), and relatedness (feeling connected to others, to caring for and being cared for by others; belongingness).

It is not difficult to see how taking on a caring role for somebody who needs help and support can lead to both the carer’s and cared-for’s needs being met. As noted above, caring often takes place in the context of pre-existing, close relationships and can be clearly linked with all aspects of

Maslow's hierarchy: survival, safety, love and belonging, esteem, and self-actualisation. The satisfaction of basic needs is believed to promote healthy psychological development, and to result in a self that is integrated, authentic, and congruent with intrinsic aspects of the core self. So, in choosing to care for another in need of support, the need for autonomy (e.g. I can choose to help you), competence (e.g. I can use and develop my skills and compassion to help you), and relatedness (e.g. I can connect to you and care for you in a meaningful relationship) might be met. It might therefore be expected that caring and being cared for, something that is typically quite central to all human experience, would be a good way to achieve self-actualisation. However, we know that not all carers choose to take on the role and that there are a great many challenges that carers often face. So how might these impact on the integration of the caring experience with the self? What if autonomy, competence and relatedness, rather than being developed, are instead threatened by feelings of duty, responsibility, reciprocity, love and devotion? Sometimes, behaviour is influenced, not by integrated needs, but by external environmental pressures, such as, societal expectations about the ways in which we should care for those more vulnerable than ourselves. Individuals might easily find themselves in a caring role but with little sense of self-determination, struggling to integrate a whole new set of expectations within the current sense of self. Such circumstances can lead to a lack of fulfilment of basic needs which could lead to ego-invested self-structures, a false self, based not on self-worth, but on doing activities in certain ways, or being perceived by others in certain ways (Hodgins & Knee, 2002). So, in becoming a carer without choosing to do so, individuals might feel external pressure to perform in certain ways, or to be seen by others as nurturing and supportive, which instead of being personally fulfilling, might leave them vulnerable. It is therefore important to develop an understanding of how carers come to understand their role so that better support might be offered to facilitate the successful integration of caring with sense of self. In supporting carers to develop and maintain a sense of autonomy, competence and relatedness in their daily lives, it is hoped that health and well-being outcomes might be improved for carers, their cared-for relatives and wider familial networks.

2.3.4 *Caring can be difficult...*

There are a number of difficulties that are often associated with taking on an informal caring role. Financial burden may be an issue with carers making a commitment to future poverty as a result of giving up income, employment prospects and pension rights. Increased social isolation might also occur as carers' time, and other resources, are taken up by their caring activities. A prospective, population-based study of carers and non-carers, found that carers are especially at risk for psychological distress and adverse health effects (Hirst, 2005). A number of studies have explored certain constructs that are often associated with caring, for example, stress, burden and coping, more often than not attempting to measure and quantify these difficulties, developing specialised validated scales (e.g. assessing coping strategies, Magliano *et al.*, 1996; family attitudes and burden, Morosini *et al.*, 1991; see also Oyebode, 2003 for a discussion of other well-known measures of carer burden and stress).

However, although high levels of burden may be experienced, there is evidence to suggest that this is not stable, but rather subject to change (for example, during times of crisis), and requiring continual adjustment to the relationship between carer and cared-for (Caqueo-Urizar & Gutiérrez-Maldonado, 2006; Oyebode, 2003). This has implications for being able to predict burden and the possible responses to it, and demonstrates the need to be sensitive to carers' needs at different times, avoiding assumptions about the burden they may be facing at any given time.

Of course, much of the research exploring burden has also considered what might help in reducing it. Magliano and colleagues (1998) pointed to increasingly sophisticated understandings of what contributes to, or protects against burden, identifying coping and social support as key factors relating to burden experienced. In a study that covered five European countries, the authors found that relatives experienced higher levels of burden when they had poor coping resources and reduced social support. This suggested that work should be done with families to ameliorate such difficulties and reduce stigma. However, while the importance of having good social networks and

support would seem to be a somewhat protective factor against burden, a comparison of family burden in long-term schizophrenia versus physical disorders highlighted an important difference. Findings suggested that social support and help in emergencies concerning the cared-for person were dramatically lower among relatives of those with schizophrenia than among those of people with physical disorders (Magliano *et al.*, 2005). Indeed, lower levels of burden in the physical health groups were related to a number of factors including the high social acceptance and understanding of the conditions of the patients with physical diseases, with the general public commonly considering these illnesses as independent of an individual's will. The authors went on to note that, in their study, schizophrenia appeared to be different from the other groups in a number of ways. They note that 17% of relatives reported difficulties inviting people into their home, and that there was a clear link between reduction in relatives' social network and increased levels of burden only in the schizophrenia group. This was reported to be partly indicative of stigma relating to schizophrenia. The patient's poor functioning may result in families avoiding social contact. Also, these families received less support from professionals, which meant it was likely they were too overwhelmed and exhausted by caring responsibilities to engage in their social networks. There is also evidence to suggest that, in psychosis, family interventions have a positive effect on relatives' burden, psychological distress, the relationship between service-user and relative, and family functioning (Cuijpers, 1999; Lobban & Barrowclough, 2009).

So, there is much evidence to suggest that mental health carers often face considerable burden and that their own health and well-being can be seriously impaired as a result (Maurin & Boyd, 1990; Fadden, Bebbington & Kuipers, 1987). Indeed, as Oyebode (2003, p. 52) noted, the needs of carers should be addressed because a failure to do so may lead "...health services to find themselves with two patients to support where previously there was only one, supported by a carer." As the prevalence of mental illness and the number of carers are estimated to increase in the coming years, this clearly has implications for health services' already stretched resources.

2.3.5 ...but it's not all burden and stress; caring can be positive too

There is an increasing awareness of the positive impact that involving families and carers in formal care can have on service-users, families, carers and mental health services. Greater involvement has been linked to fewer and less severe relapses, reduced hospital admissions and shorter stays in hospital (Pilling *et al.*, 2002; Pitschel-Walz *et al.*, 2002; Barbato & D'Avanzo, 2000). Reductions in stress and burden, and improved coping in carers has also been shown to be a positive outcome of greater involvement in the care offered by mental health services (Perlick *et al.*, 2006). There is also evidence to suggest that while family burden is an overarching dimension of the family experience of mental illness, experiences of burden can be a force for building resilience in both the family unit, and personally, as individual family members (Marsh *et al.*, 1996). However, Marsh and colleagues noted how even when responding positively to research questions, family members often responded by portraying "an anguished struggle to survive" (1996, p. 7). This demonstrates the need for those who listen to carers' and family members' stories to go beyond the negative descriptions to attend more closely to those areas where change has been constructive. In doing so, those factors that support the development of resilience can be encouraged and further supported.

Dwyer and Miller (1990) suggested that carer burden may be reduced where a sense of reciprocity exists between the carer and cared-for person. Indeed, a number of studies have explored the role of reciprocity in caregiving (e.g. Graham & Bassett, 2006; Heiker, 2007). Walmsley (1993, p.129), researching experiences of women with learning difficulties in caring roles, suggested that, "...drawing a clear distinction between carer and dependent is frequently impossible; both parties in the caring relationship both give and receive. There can be reciprocity and interdependence. Care and dependence are seen as false dichotomies". One study exploring caregiver burden from a social exchange perspective suggested that different role relationships will have an effect on perceptions of burden, and that the norms of obligation and reciprocity should be especially salient in parent-adult child, and spousal relationships (Thiede-Call, Finch, Huck & Kane, 1999). The

authors outlined the four key assumptions of social exchange theory, described by Molm and Cook (1995): that people depend on one another for the things they value, people behave in ways that increase the outcomes they value and decrease the outcomes they do not value, people engage in ongoing, mutually contingent exchanges with specific partners over time, and all outcomes obey a principle of satiation. They used the example of caring to illustrate this: i.e. when only small amounts of care are provided that do not interfere with other responsibilities and routines, small additions of time and tasks devoted to care will be unlikely to have a significant impact on feelings of burden. However, if a great deal of care is required that does interfere with other areas of the caregiver's life, each additional need may well have a big impact on the caregivers perception of burden (Thiede-Call *et al.*, 1999, p. 689). The authors also draw on Baltes and Baltes' (1990) work that suggests that over time, "Motives and incentives underlying nonmaterial exchanges shift from the exchange of information to the exchange of emotional rewards" (Thiede-Call *et al.*, 1999, p. 690). Therefore, the quality of relationships, a sense of belonging and closeness to others is the primary reward sought. The literature would therefore seem to suggest that carers and cared-for individuals should be considered together if we are to understand more about the experience of caring in difficult circumstances. Reid, Moss and Hyman (2005) provided a brief overview of social exchange, reciprocity and equity theories as they can be applied to caregiving burden, exploring the benefits of a greater sense of balance in the give-and-take that exists in relationships. They went on to explore the effect of reciprocity, carer self-esteem and motivation on the experience of carer burden suggesting that intervention strategies aimed at fostering reciprocity should be employed.

2.3.6 *Caring for carers*

The Department of Health highlighted four key areas for service provision for carers: supporting and advising carers; providing information; ensuring breaks from caring; psychosocial interventions (Department of Health, 2003). It went on to report that effective service delivery should stem from services being: positive and inclusive; flexible and individualised; accessible and

responsive, and integrated and co-ordinated. Indeed, many carers reported that access to information, financial support, and breaks in caring, are vital in helping them to manage the impact of caring on their lives (Kelly, 2007). However, in order for carers to access services that are available to support them in their caring role, individuals who are providing regular and substantial care to a relative must first identify themselves as ‘carers’ as opposed to simply being loving or concerned family members or friends.

One of the difficulties in carrying out research into informal caring is that carers can be difficult to identify and engage in studies. Unlike mental health service-users who have their own notes and records kept about them, carers are often engaged with on a more informal basis. A research report from the Princess Royal Trust for Carers suggested that the majority of carers struggle on alone, unaware that there is help available to them (Kelly, 2007). However, where help and support for carers were taken up, it would seem that carer support groups were considered most useful offering valuable peer-to-peer support (Pinfold & Corry, 2003). Pinfold and Corry’s research strongly recommended that outside agencies, both in the statutory and voluntary sectors, should become more aware of carers’ existing peer-to-peer support networks of family, friends and other carers if they are to be effective in delivering help and support to carers. The Department of Health also acknowledged the importance of support groups noting that, “...they often demonstrate to carers that they are not on their own, and often have a ‘campaigning’ dimension which can be effective in informing and improving local services. Some care groups organise social outings and events.” (Department of Health, 2003, p. 16). This guidance clearly stated that, “...carer support services and workers should assist this self-help and mutual support work and avoid undermining or cutting across it” (Department of Health, 2003). Such groups may also be of use in terms of signposting carers to other help and support services available to them.

In light of the positive evidence for the inclusion of families and carers in their relatives’ care *and* what is known about the difficulties carers often face, there is still evidence to suggest that meaningful collaboration between carers and mental health services is not always achieved

(Pickens, 1998). In 2004, the Royal College of Psychiatrists (RCP) launched their 'Partners in Care' campaign with the aim of highlighting the problems faced by carers and encouraging true partnership between carers, service-users and professionals. Dr. Mike Shooter, then president of the RCP, made the following statement which is publicly available on the campaign's website, "Carers are an integral part of the patient's support system... They are the ones with the day-to-day experience of the patient's condition, and they carry the most intimate responsibility for the patient's welfare... The carer's voice in decision making about admission and discharge is ignored at everyone's peril – and yet so often is." (Shooter, 2004). This campaign sparked a number of activities including research among carers, information materials (checklists, leaflets, training materials) and 'Carers Week', an annual event to raise awareness of carers' issues. While this campaign has gone some way to highlighting the need for meaningful partnerships between service-users, informal carers and professionals, it would seem that barriers to effective collaboration still exist. One of those most often cited is confidentiality and how to deal with situations where service-users do not consent to their information being shared with carers. This has led to increasing research in this area considering the ethical dilemmas that might be faced, and best practice guidelines when such situations arise (Szmukler & Bloch, 1997; Slade *et al.*, 2007). Developing ways of accessing and deepening our understanding of carers' lived experience, so that meaningful, effective relationships can be built and sustained during difficult times would therefore seem to be an important factor in recognising the value of informal carers and the contribution they make.

2.3.7 What is the experience of caring like and what can we learn about it?

As previously noted in the literature, many studies have explored the lived experience of family caregivers of relatives experiencing mental health difficulties, and many of these have used quantitative methods, seeking to categorise and measure different aspects of experience (for example, stress, burden and coping) (Chang & Horrocks, 2006). While this can go some way to providing an understanding of the extent to which carers report that they are affected by these

things, getting to the rich lived experience of what it is like to take on a caring role requires a different approach. Where this type of research has been carried out, the findings suggest that it can make a valuable contribution to the development of more effective mental health services. Indeed, Player and Leggatt (1999, p. 30) recommend that “...mental health professionals should learn about and value the lived experience of consumers and carers if best-practice is to be achieved.” So, the value to mental health professionals of developing an understanding of the rich, detailed, and often complex lived experience of caring, seems clear. There is also evidence to suggest that the increasing adoption of the term ‘carer’ can be problematic, and that those who take on caring responsibilities do not always identify with the term (Molyneaux, Butchard, Simpson & Murray, 2011). There is therefore a case to be made for asking individuals who care for relatives what they think of the language associated with informal care, and how it impacts on their daily lives. Also, as so many people are affected by caring and mental health difficulties, exploring the meaning of caring would surely also benefit the general population.

There would therefore seem to be a strong case for further exploring how families, carers, service-users and mental health professionals understand and identify with the language of informal care and the implications this has for making sense of identity, and interpersonal relationships, as well as the benefits and rewards that taking on a caring role might bring. This research therefore aims to explore the meaning of caring through multiple perspectives, utilising qualitative methodology to inform research design and analysis. This thesis will therefore present a review of the literature concerning the lived experience of caring (Chapter 3), and present the rationale for taking an interpretative phenomenological approach to exploring the meaning of caring (Chapter 4). Data collected from participants including: self-identified carers attending support groups (Chapter 5); service-users and carers in contact with Early Intervention services (Chapter 6); a family affected by mental health difficulties (Chapter 7); and mental health professionals working in Early Intervention services (Chapter 8), will be presented and discussed as individual research studies. Consideration and synthesis of the multi-perspective, phenomenological design of this research will be considered in Chapter 9. What these chapters contribute to the literature on caring will be

further discussed, and their strengths and limitations considered. The implications for mental health services will also be explored.

Chapter 3

Literature review: Exploring the meaning of the caring experience

3.1 Abstract

As outlined in the previous chapter, much has been written about informal caring and mental health difficulties, some of which has begun to look at the lived experience of such carers. However, there is considerably less literature that specifically focuses on this from a phenomenological perspective. Phenomenology is a philosophical approach to the study of experience that was initiated by Edmund Husserl at the beginning of the twentieth century. Much has been written about the history and development of the phenomenological method, and its adaptation and application in psychology (see Willig, 2008; Smith *et al.*, 2009; Giorgi & Giorgi, 2003). Phenomenology's core concerns are with what the experience of being human is like and how we make sense of, and make meaning from, our everyday lives. It would therefore seem to be a particularly relevant approach for helping to develop an understanding of caring from a range of perspectives. The purpose of this chapter is to therefore review the extant literature in this area, exploring its strengths and weaknesses, and implications for clinical practice, and to identify potential opportunities for future research. While the application of phenomenological methods is discussed further in Chapter 4, this chapter will now focus on literature that has taken a phenomenological approach to the study of informal care for people experiencing mental health difficulties.

3.2 Research strategy

Electronic searches for papers taking a phenomenological approach to caring and mental health difficulties were undertaken using the Web of Knowledge bibliographic databases: Science Citation Index Expanded (SCI-EXPANDED - 1899-present), the Social Sciences Citation Index (SSCI -1898-present), the Conference Proceedings Citation Index - Science (CPCI-S - 1990-present), the Conference Proceedings Citation Index - Social Science & Humanities (CPCI-SSH - 1990-present). Another search was also undertaken of the Ovid bibliographic databases: PsychINFO (1806-1996) but no further relevant literature was identified. Searches were limited to English language studies but were not limited by time-frame.

The following search terms were employed:

- [Phenomenolog* OR Experienc*]
AND
- [Caring OR Car* OR Caregiv* OR Care-giv*]
AND
- [Mental ill* OR Psychological distress]

(* represents any word beginning with that prefix.)

The terms phenomenology and experience (and their derivatives) were chosen for the research strategy as they are closely bound together. Phenomenology is essentially concerned with everyday experience, yet is not the only approach to its study. It was hoped that by using both of these terms, a broader range of papers exploring the experience of caring would be identified. For example, those using loosely phenomenological approaches, like grounded theory, might refer to

experience without necessarily referring to phenomenology. These papers could then be checked for relevance to the present research.

Results were combined and checked for relevance to taking a phenomenological approach to the informal care of those experiencing mental health difficulties which meant that 78 papers were identified. Two of the 78 papers were identified as presenting a review or overview of a particular topic (Galovski & Lyons, 2004; Reine *et al.*, 2003) but neither were considered relevant to the present research (their foci being on post traumatic stress disorder in combat veterans and an overview of measurement instruments for caregiver burden respectively). Of the 26 papers that were considered relevant (those that took a phenomenological approach to the study of caring for somebody experiencing mental health difficulties), three others were identified through their references. Other papers that were picked up by the search terms but rejected for lack of relevance included studies that explored experience via questionnaire, studies that were purely from a service-user's perspective, or about the phenomenology of illness itself. For a summary of the relevant 29 papers see Appendix 1. This summary includes details such as: sample size; method of data collection; approach to data analysis; key themes identified; key findings; and relevance to this research.

3.3 Overview of the literature on phenomenology, caring, and mental health difficulties

Much of the literature focused on family caregivers, i.e. those who are directly related to, or a partner, or spouse, of the person they care for. Many of the studies were concerned with parental carers of an ill child (e.g. Osborne & Coyle, 2002; Tuck, du Mont, Evans & Shupe, 1997) though there were a few that specifically explored the experience of young carers (those under the age of 18 years) (e.g. Bolas, van Wersch & Flynn, 2007). Two papers were also identified that specifically focused on the experience of fathers, both those caring for an adult child with schizophrenia (Howard, 1998), and those fathers experiencing psychosis themselves (Evenson, Rhodes, Feigenbaum & Solly, 2008). While the second of these papers was not specifically

relevant to carers' experiences of supporting somebody experiencing mental health difficulties, it did help to highlight that to date there has been less research specifically focusing on fathers' experiences compared with those studies exploring mothers' or parents' experiences, but that this is a growing area of interest to researchers.

Individual papers also focused on a range of illness categorisations, some quite broad, others more specific, including: serious/severe mental illness (Champlin, 2009); chronic mental illness (Jeon & Madjar, 1998); mental illness (any diagnosed mental disorder) (e.g. Chang & Horrocks, 2006); first-episode psychosis (e.g. Penny, Newton & Larkin, 2009); schizophrenia (e.g. Huang, Sun, Yen & Fu, 2008); bipolar affective disorder (Tranvåg & Kristoffersen, 2008); depression (e.g. Hight, McNair, Davenport & Hickie, 2004); dementia (e.g. Phinney & Chesla, 2003); and eating disorders (e.g. Huke & Slade, 2006). Others had recruited carers of people where the cared-for person may be experiencing different types of illness, not just specific to mental illness. For example, Efraimsson, Höglund and Sandman (2001) explored patients' and carers' lived experiences of caring at home in cases where the patients suffered from diseases such as diabetes, heart and vascular disorders, Alzheimer's disease, renal failure and stroke. However, they did not differentiate between these illnesses when reporting the findings of their study. The authors reported that their findings showed experiences of home care nursing were associated with changes that affect well-being, habits, relationships and the home, and that such changes in the life situation were interpreted as long-lasting and trying. These findings seemed to be consistent with the wider literature on caring, again making a case for nursing interventions that are sensitive to the unique experiences of service-users and families.

In order to explore in greater depth the lived experience of caring for somebody experiencing mental health difficulties, some of the papers identified in this review's search strategy appeared to be more relevant to the present research than others. It is therefore necessary to consider the focus of the papers identified, and to separate out those that are a more specialised literature (e.g. specific carer role perspectives; psychological disorder categorisations; experience of interventions or

service models; or cultural emphases). However, it is noted that some papers may cover more than one specific focus, such as, ‘understanding the impact of an Assertive Outreach Team on couples’ experiences of caring for adult children with psychosis’ (Wane, Larkin, Earl-Gray & Smith, 2009). This paper explored a range of quite specific issues (couple’s perspectives, parents’ perspectives; mental illness in adult children, and psychosis). However, these things were framed within attempts to understand these things as they are impacted by a particular service model (i.e. an Assertive Outreach team).

As noted above, a number of papers set out to explore what it is like to care for or live with someone experiencing mental health difficulties from a particular carers’ perspective (e.g. parent, spouse, young carer) or a particular illness/disorder perspective (e.g. psychosis, bipolar disorder, depression). Some papers set out to try and address specific experiences within the caring role. For example, Harris, Pistrang & Barker (2006) specifically looked at what kinds of support people with depression valued from their partners, and what happens when their partners try to help, while Czuchta and McCay (2001) were interested in trying to understand help-seeking behaviours in parents of individuals experiencing a first-episode of psychosis. Others were more specifically interested in the relationships between family members when one of them becomes ill (e.g. Champlin, 2009; Jones, 2006). A number of these papers also reflected on the move towards community care and the impact this has had on the family and friends of those who experience mental health difficulties, highlighting the increasing wealth of experience that exists and the potential benefits of developing a better understanding of this experience (e.g. awareness of attitudes towards informal and formal caring, reduced stigma, better education available). As a reflection of the literature on mental health caring more generally, while these papers often focused on factors like burden, stress, and relapse rates, there is also evidence to suggest that not all caregiving leads to experiences of excessive burden and that caregiving in families is a reciprocal process (Pejlert, 2001).

Many of these studies, in setting out to explore the lived experience of taking on a caring role for a relative, went on to consider the implications of their findings for mental health service provision, making a case for greater understanding of experience as a way to help identify carers' needs. The idea being that services can be designed and delivered to meet these needs to the benefit of service-users, carers and families, services, and the wider communities in which they exist. Sin, Moone and Wellman (2005), specifically identified their aim of understanding the experiences of caring for a young adult experiencing early-onset psychosis as being a key factor in developing an early intervention in psychosis service. Other papers focused more specifically on experiences relating to previous interactions with professional mental health services, for example, the impact of assertive outreach on couples caring for children (Wane *et al.*, 2009); receiving Behavioural Family Therapy (Campbell, 2004); perceptions of frequent psychiatric rehospitalisations (Downs-George & Cobb-Howell, 1996); and mothers' experiences of being excluded from acute psychiatric settings (Wilkinson & McAndrew, 2008).

While much of the literature published in the English language focused on typically Western models and understanding of mental health difficulties, a number of papers utilised a phenomenological perspective to explore caring and mental illness from a particular cultural perspective, for example, British Pakistani families' experiences of support from an Early Intervention Service for First-Episode Psychosis (Penny *et al.*, 2009); the experiences of carers in Taiwanese culture who have long-term schizophrenia in their families (Huang, Hung, Sun, Lin & Chen, 2009); Buddhist family caregiving for the seriously mentally ill in Thailand (Sethabouppha & Kane, 2005); illness perspectives of Thais diagnosed with schizophrenia and their family members (Sanseeha *et al.*, 2009); lived experience of Chinese family caregivers (Chang & Horrocks, 2006); and views of patients and caregivers on the cultural attribution of mental ill health suffering in Chinese societies (Hsiao, Klimidis, Minas & Tan, 2006). These papers considered the implications for providing culturally-sensitive services in order to facilitate appropriate interventions and improve clinical outcomes. Indeed, Penny and colleagues (2009, p. 969) noted the significance of the role that qualitative research can play in exploring these issues,

“...because it allows us to understand more about the context, complexity, and variability of people’s experiences and concerns and partly because it does not rely on a prior formulation of what those experiences and concerns might be.” It can therefore go some way to avoid imposing Western explanations of mental illness on carers’ experience, getting carers to tell their stories in their own words in a way that is meaningful to them.

3.4 What does the literature tell us about the lived experience of caring for somebody experiencing mental health difficulties?

As noted in the above outline, the literature search strategy identified a broad range of papers exploring different aspects of caring experiences focusing on different types of carer perspectives; psychological disorder categorisations; or cultural emphases. As the focus of this research project is exploring the meaning of caring, particularly focusing on how the language around caring is experienced by those who care for somebody experiencing mental health difficulties, the literature review will now explore some of the most relevant papers in greater depth. Those 29 papers identified in the literature search as having a specific focus on caring from a phenomenological perspective were further reduced to 12 that seemed particularly pertinent to this research. These papers are first considered in terms of content and what they tell us about the lived experience of caring. This part will consider how qualitative work might be synthesised to explore the sorts of themes that are identified, and what seems to be both common and different in the reported findings. Discussion of the methodological issues associated with the papers identified follows this section. This will cover issues like: sampling; and assessing quality in qualitative work.

The 12 papers that were included for further discussion in this section were those exploring: caring and daily lived experience; living with a person experiencing mental health difficulties; caring and family relationships; help-seeking and support experiences. Details of which papers were identified in the literature review that were deemed particularly relevant to this research are given in Appendix 1.

Seventeen of the papers identified in the initial search were excluded on the grounds that their foci were the subject of their own, more specific, literatures which, although of interest in their own right, are beyond the remit of the present research. These foci included: exploring caring more widely than the perspective of mental health carers (e.g. mental and physical health carers); experiences of particular interventions (e.g. Behavioural Family Therapy) or mental health service models (e.g. Assertive Outreach; Home care nursing; Rehospitalisation; Acute psychiatric settings); a specific cultural focus to the exploration of the lived experience of caring; the experience of carers who also have a diagnosed psychiatric disorder (e.g. fathers experiencing psychosis); specific conditions other than psychosis, bipolar disorder, or serious mental illness (e.g. dementia; eating disorders).

Taking a phenomenological perspective, all of the papers identified as being of particular relevance to this research focused on some aspect of the lived experience of taking on a caring role for somebody experiencing serious mental health difficulties. It therefore seems worthwhile to explore what some of the key similarities and differences in these experiences might be, as well as who was recruited and how the data were collected. Consideration must therefore be given to the ways in which the findings from qualitative studies might be synthesised to further knowledge and understanding of phenomena. How best to go about combining the findings of qualitative studies in a particular area brings to mind the type of meta-analyses that are more commonly found in quantitative research. However, in qualitative research the very methods that enable the analysis of rich, detailed personal accounts that are typically led by what is meaningful to the participant, coupled with the integral role of the analyst in the process, can pose certain difficulties when attempting to synthesise research findings. Indeed, as Jones (2004, p. 96) suggested, "...this rush to imitate quantitative procedures is producing a kind of 'mission drift' in many qualitative 'systematic' research reviews.", whereby the key qualities that qualitative research has to offer are being lost as methods better suited to reviews of quantitative studies (e.g. 'check lists', 'standards' and 'hierarchies of evidence') are applied to qualitative work. The author then went on to outline recent developments in the systematic review of qualitative research and propose a way forward

for systematic narrative reviews with a view to an, "...opening up of the possibilities in interpretation, rather than relying solely upon the primary researcher's interpretation of the materials" (Jones, 2004, p. 103). A series of useful questions for starting to think about reflecting on qualitative studies were proposed, considering things like: transparency (how clearly the stages of the research process are described); limitations; how well the research process is described; how well the cultural context is accounted for; how the study is presented; how language is used; what the theoretical background might be; ethics; and usefulness and the contribution the work might make to the literature and society. In thinking about these issues, the 12 phenomenologically-focused papers that were considered particularly relevant to this study will now be explored in more detail (specific methodological issues will be explored in the following section).

First it is worth considering the caring backgrounds from which participants were recruited. Eight of the papers focused on parental carers; in six of these, this fact is clearly identified in their titles, the other two require further reading before this focus becomes apparent. Of the two papers that recruited parental carers but make no mention of it in the title, one focused on the needs of young adults (Sin *et al.*, 2005); while the other revealed that participants were mostly parental carers, but one participant was highlighted as a daughter caring for an ageing parent (Jeon & Madjar, 1998).

While a number of the studies made reference to parental carers, only one of these specifically explored the experience of fathers. Howard (1998) set out to describe the lived experience of fathers of adult children with schizophrenia, looking at the extent to which they engage in caregiving. Themes identified were: "Crisis", "Learning, coping and acceptance", "Involvement in care", "Unresolved issues" and "Severity of event". The discussion of these themes suggested that the caring experience was severely stressful for these fathers and that the descriptions given were not unlike those of lifelong maternal care for adult children with schizophrenia (as reported by Howard, 1994). The fathers who participated in this study, although being quite fundamentally involved in caregiving, attributed most of the primary caregiving to their spouses. It is interesting to note that in a study about fathers, it is still their partners/spouses (i.e. mothers) that were

identified as the primary caregivers. Another paper focused specifically on women living with sons diagnosed with schizophrenia (Chaffey & Fossey, 2004). Five themes were identified, starting with: “It’s a whole new thing” which detailed descriptions of carers’ confusion as the illness developed. “The need to provide support” detailed how accessing healthcare support, monitoring and protecting their sons became a major part of the caring experience. Taking responsibility for helping their sons with everyday tasks was also a feature of this theme. The authors highlighted how “The situation just evolved” describes the way that some participants talked about caring as an extension of mothering, with some going on to describe a process of learning to differentiate between mothering and caregiving. This theme also covered carers learning coping strategies through their own experiences, highlighting the importance of putting measures in place to protect one’s own well-being. The theme of “Much of our life focused on him” considered the impact of mothers living with their sons on their daily lives. While mothers noted having little time available for things like housework, relaxing, or doing the things they would like to do, the loss of quality time with other family members was also considered. The final theme noted by the authors was “Don’t get too optimistic” which also refers to loss, and the feelings of sadness which were described “...as being like nothing else they had experienced” (Chaffey & Fossey, 2004, p. 204).

Loss seems to be something of a common feature to many experiences of caring and will be considered further as this discussion develops. In Chaffey and Fossey’s (2004) paper this theme about being wary of optimism also accounted for feelings of anger at not being taken seriously prior to diagnosis and lack of consultation with professionals about the care offered. The uncertainty and unpredictability associated with the condition were also described as challenging, making it difficult to plan for the future. Again, dealing with uncertainty also seemed to be characteristic of the experience of caring for a person experiencing mental health difficulties and is certainly a feature of many of the papers highlighted in this review. The authors acknowledged that previous research has examined the stresses for families caring for people experiencing mental illness, more typically involving mothers than other family members. The authors also noted that

while parents and other primary caregivers in support programmes were approached about the project, six women volunteered to participate. This seems to indicate that, in line with previous research findings, it is mothers that are typically taking on the primary caring role for people experiencing mental health difficulties. So, although female carers, particularly mothers, are well represented in research it would seem that this is a reasonably accurate reflection of the general caring population.

Two papers focused specifically on couples or spousal/partner carers, which was clearly identified in the titles using terms like ‘couples’ experiences of...’ (Harris *et al.*, 2006), and ‘experience of being a spouse/cohabitant of...’ (Tranvåg & Kristoffersen, 2008). The remaining two papers reported participants as being from a range of roles, including, parents, spouses, family members or friends (Champlin, 2009; Hight *et al.*, 2004). . So in going on to explore the nature of the experiences of informal carers, it is clear that most of these relate to parental carers, though others, typically close family members, are represented in some studies. This seems to reflect the figures given by carers’ organisations concerning who is likely to become an informal carer. But it also highlights gaps and potential areas for further research with different carer populations. For example, consideration might be given to exploring if, and in what ways, the experience of caring might be different for these different populations, helping to identify how best to meet their individual needs. Indeed, there is evidence to suggest that the needs of carers and service-users, though often grouped together, can vary significantly and even conflict at times (e.g. Fadden *et al.*, 2005). There is therefore a case to be made for exploring a range of perceptions in a way that gives voice to those who may not always feel heard.

With regard to exploring what the experience of informal caring is like, Champlin (2009) conceptualises the experience as “being there” for the person experiencing difficulties. There was a specific focus on the caring and caretaking relationship between the person experiencing mental health difficulties and their informal carer, from the perspective of the carer. Champlin’s study identified eight key themes as being central to the experience of caring. The first, “Accepting the

changed other and grieving the loss of who the other once was” revealed that this was common among participants but that they varied in how they came to do this and how much time it took them to reach acceptance. This was seen as a key feature of the experience of “being there” for another with serious mental illness. The “Taking action in challenging circumstances” theme typically involved help-seeking for the person who was ill and sometimes involved making tough decisions and participants suspending their own feelings in order to take action.

Champlin (2009) referred to a persistent feature of “being there for another with serious mental illness” as seeing no permanent resolution to their situation. This formed the basis of the “Recognizing the ongoing, never-ending and sometimes unpredictable nature of the experience” theme, emphasising unpredictability and the subsequent weariness that is experienced. The theme “Feeling isolated” was used to describe the loneliness felt by participants as their own social networks diminished and “Having ambiguity of the heart” was used to describe participants’ uncertainty about the best way to proceed to help their relative which at times would induce fear, anxiety or even terror. Features of waiting that were deemed to be different from ordinary waiting were highlighted in the theme, “Experiencing the tension of waiting”. This theme was concerned with vigilance, watching the person for signs of changes in behaviours, waiting to see if the person would deteriorate. The theme of “Knowing the other well” was very much concerned with participants’ emphasis on the fact that they felt they knew their relative better than anyone else and the fact that this was both a good and bad thing. On the one hand, it enabled them to notice small changes quickly, seeking help when needed, but on the other, it sometimes made it difficult to intervene for fear of being seen as pushy and interfering. Finally, the theme “Caring for the other” was used to highlight the fact that participants cared deeply for their relatives and were committed to “being there” for them on a long-term basis. These themes were discussed in relation to Mayeroff’s (1971) caring paradigm, Champlin used this to highlight the importance of devotion as an essential component of caring. The author went on to highlight that although participants sometimes found it difficult and challenging to maintain the “being there” relationship, “...they

described being able to remain steady in their devotion to their loved one.” (Champlin, 2009, p. 1532).

Loss and grief were also a key feature of other studies. Osborne and Coyle (2002) specifically explored parental responses to adult children with schizophrenia in relation to conceptualisations of loss and grief. The authors highlighted what Miller (1996) termed ‘psychic loss’ to describe the sense of loss felt by a parent for the pre-morbid version of their child, and the loss of their potential for the future. A series of case studies were presented through which themes (derived from interpretative phenomenological analysis) around uncertainty, interpreting illness, coping, continuity of the person and aspirations for the future were presented. The findings suggested that parental responses of loss and grief in such circumstances centred on the loss of the pre-morbid version of their child and suggestions were made with regard to the implications for counselling psychology, particularly in terms of providing facilitative environments for parents to explore these feelings. A number of other papers also reported notable findings relating to loss and grief. As we have seen, Champlin (2009) emphasised the importance of accepting change and achieving this by going through a grief process that is different to that experienced when somebody dies. The dichotomy between losing someone, while at the same time gaining another who needed them in different ways, was described as challenging, and although the experience of loss and grief was common amongst participants, they often differed in the way that they had come to accept the changed other. Tranvåg and Kristoffersen (2008) also reported the emergence of a theme (derived through a phenomenological-hermeneutic method of analysis) that they called “Grief over loss”. In this case, it was the loss of a spouse/cohabitant that was the source of grief. The authors reported participants felt that their relative had been taken away from them and that they had been deprived of the security and future that they had thought they would enjoy. This grief also extended to the implications for children’s stability and security in the relationship.

As noted above, a sense of loss of a relative, as well as things like a loss of stability and security have been identified across a number of papers. Highet and colleagues (2004) again identified

loss, not as a specific theme, but as something that seemed to be a feature of caring more generally. The title of their paper, ““How much more can we lose?”: carer and family perspectives on living with a person with depression” identified five themes from a series of focus groups with carers, family members or partners of people experiencing depression. The “Direct impacts of depression on carers” were reported to be intense and persistent. Carers reported that they were often unprepared for the impact that the illness would have on their family, work and social life. Adverse effects on the carers’ health and well-being were thought to be related to the intensity of the caring relationship and the lack of reprieve from it. So here, the authors seemed to be saying something about carers experiencing a profound change in their daily lives, indicating a prior sense of ease that has been lost at the expense of something more challenging. Loss figured more centrally in the theme of “Impacts of depression on intimate relationships” where a clear sense of the lost other was highlighted. The theme of “Lack of broader social support” highlighted a further loss with regard to social networks as friendship relationships diminished for a variety of reasons. The amount of time and effort involved in caring, the person not wanting to go out socially, fear of contamination, others not knowing what to say, and stigma, were all highlighted through a series of short quotes from the data and reflected findings from other studies. The theme of “Lack of respect or engagement by healthcare providers” reflected carers’ experiences of having social difficulties compounded by poor experiences with providers. A sense of unnecessary exclusion was highlighted, drawing attention to the need for better communication and partnership working. Finally, “The importance of support groups/agencies” theme stressed a crucial role for effective support networks, particularly with regard to gaining information, sharing experiences and overcoming social isolation.

However, although a common feature of many papers in this area, it is noted that the transformation of a relative was not always conceptualised in terms of loss and grief. Tuck and colleagues (1997) introduced their theme of “Transformation of the loved child” noting that what might have been seen as promising has turned into something sinister, perhaps with a diagnosis and grim prognosis. Here the authors drew on what they described as “...echoes [of] folkloric tales of

the changeling, in which the fairies steal a charming or pretty child and replace it with a strange and ugly infant (the changeling) who will never mature” (Tuck *et al.*, 1997, p. 121). Despite this, the authors also referred to parents’ recognition of a core identity which is occasionally seen. The implications for the acceptance of this ‘changeling’ are not fully discussed but the authors do go on to explore other themes including: “Living with constantly changing levels of hope” of which grief was a feature. In addition to thinking about the person experiencing mental health difficulties as the changed other, Tuck and colleagues (1997) also explicitly picked up on identity issues experienced by carers. They identify the theme of “Preserving identity”, noting how parental caregivers’ beliefs about themselves were challenged as a result of dealing with their child’s difficulties. The authors highlighted the importance of maintaining a sense of being separate from the cared-for person, both for the carer and the cared-for person.

In exploring the experience of caring for somebody experiencing mental health difficulties, all of the papers referred to the caring role as being supportive of another who needs help. Two of the papers seemed to be particularly concerned with the specifics of help-seeking and support processes. Czuchta and McCay (2001) employed a mixed-methods design to explore help-seeking for parents of individuals experiencing a first-episode of psychosis. The qualitative component of their research, identified three overarching themes that were common to all of their five participants. The first, “Evolving change: what does it mean?” outlined the way in which parents noticed changes in their children, the ways they engaged in attempting to understand these changes and the challenges of managing these changes. The theme of “Continuous help-seeking” reflected parents often having to persuade both their children, and healthcare professionals, that help was needed. The third theme of “The help-seeking experience: impact on parents” was characterised by disruption to the family, illness recognition: need for understanding and support, parental beliefs associated with the illness and range of emotional responses to the help-seeking experience. The authors reported that participants used a variety of ways of seeking help, including turning to non-health professionals, friends, and even the police in times of crisis.

Also in the help-seeking and support area of interest, Harris and colleagues (2006) explored couple's experiences of the support process in depression. They identified ten themes that they grouped into two domains. The first related to the challenges couples faced over the course of a depressive episode and included the themes, "Bafflement", "Battling through – coping with a family emergency", coping with the "Long grey periods", "Starting to swim again – the recovery phase", and "The threat of relapse". The second domain related to the support process and included the themes: "Stumbling along", "Walking on eggshells", "Communication in depression – a "Catch 22"?", "Working together", and "Managing one's feelings as a 'helper'". The authors reported that participants' accounts of the support process were characterised by a sense of bewilderment and struggle and that participants talked about their use of trial and error and the need to tread carefully for fear of doing harm. Effective support highlighted the importance of trust, acceptance and open communication, having the opportunity to talk openly, without being judged or criticized, things typically considered to be integral to relationships under normal circumstances as well as during episodes of depression. Overall the findings supported the inclusion of partners in psychological interventions for depression. This paper therefore seemed to pick up the threads that commonly ran through a number of the other papers, concerning acceptance, working to develop an understanding of the situation, and fear of doing something that will make the situation worse, but from a different caring perspective.

Following on from the themes that have been mentioned above, including acceptance of and "being there" for a person experiencing mental health difficulties, Jeon and Madjar (1998) reported two main themes centred on temporality (to "Live each day as it comes") and relationality (to "Look at the world through the other's window"). The idea of "living each day as it comes" appeared to stem from carers' experience of time as being less predictable and less certain than it would be for those who are not engaged in caring for a person experiencing chronic mental illness. Caregivers would have to deal with unfamiliar, frightening and unpredictable behaviours and events much of which came down to learning through trial and error, a common feature of much other research in this area. Again, as with other studies, these carers reported some difficulties in

dealings with mental health professionals, but noted that community support groups were more helpful. Grief for the loss of the past, present and future potential was also experienced, focusing not only on personal losses, but also what the person experiencing mental health difficulties had lost. “Self-preservation through time out” (Jeon & Madjar, 1998, p. 700), described the realisation that carers needed to take time to attend to their own needs if they were to continue to be able to meet the needs of their relatives.

This identification of taking time for oneself fits in with developments in supporting carers, encouraging them to have carers’ assessments of their own needs to enable them to maintain their own health and well-being. In exploring relationality and family caring, the authors (Jeon & Madjar, 1998) reflected on the interpersonal process between the carer and cared-for. However, this relationship is only one part of the way in which carers relate to the world and undoubtedly other family and wider social relationships will be affected. The authors suggested that carers are sensitive to how their relatives experience the world, feeling the need to make the world more accepting and tolerant. They went on to suggest that being constantly reminded that life is more difficult for the person experiencing mental illness can help, in some cases, to “...sustain a generosity of spirit that was quite remarkable” (Jeon & Madjar, 1998, p.701). Sadly, in common with a number of other studies, a number of caregivers expressed feelings of anger and isolation, hurt and disappointment, where health professionals were concerned. The authors suggested that, “...it is important that health professionals appreciate the temporal and relational qualities of family caring, which are different from the essential qualities of professional caring” (Jeon & Madjar, 1998, p. 704).

While papers that focused on experiences of a particular type of intervention (e.g. Behavioural Family Therapy) or service model (e.g. Assertive Outreach) were excluded from further analysis in the review, one paper was included that explicitly stated an interest in developing services in its title (Sin *et al.*, 2005). However, the authors set out to explore carers’ experiences of caring for a young adult diagnosed with first-episode psychosis *and* their needs in relation to the development

of an early intervention for psychosis service. Six themes were identified: “Living together”; “Caring extensively and intensively”; “Knowing and caring”; “The search for normalizing activities”; “Support in caring”; and “Adjusting to the caring role”. The authors reported that the overall findings suggested that all the carers were providing comprehensive practical, emotional and financial support which is consistent with the wider literature. Although this is the only paper to be so explicit about these aims, all of the others made reference to some consideration of the implications for specific interventions, health professionals or health services.

Indeed, all of the papers highlighted the benefits of developing a greater understanding of carers’ experiences so as to be better able to support their needs and therefore offer better family-sensitive services. In particular, Pejler’s (2001, p. 194) study of parents’ narratives suggests that “...mental health professionals need to be aware of their own attitudes and treatment of families, improve their cooperation with, and support to families, and provide opportunities for family members to meet one another.” The author identified a cultural conflict between the family system and the care system, on the one hand, threatening the parental role, while on the other, providing comfort and confidence. Themes are concerned with: “Living with sorrow, anguish and constant worry”; “Living with guilt and shame”; “Being in a relationship with nurses/care: comfort and hardships”; “Coming to terms with difficulties”; and “Hoping for a better life for the son/daughter”. The long-term nature and perseverance associated with the caring role were discussed and the author noted that the findings were related to parental devotion to the adult child citing Howard (1994) and Tuck and colleagues (1997). As noted above, Champlin (2009) also discussed her findings in relation to theoretical frameworks about devotion, citing Mayeroff’s (1971) work on the subject.

In taking a narrative synthesis approach to the literature identified, several striking characteristics seem to have been identified. The experiences of carers seemed to be very much concerned with a process of accepting and adjusting to significant, often challenging, changes to daily life. Feelings of uncertainty and unpredictability can be difficult to manage and contribute significantly to perceived stress and burden. Developing coping strategies, and managing help-seeking and

support were often also key features of being able to accept and adjust to changes in family life when a relative becomes unwell. Experiences of caring for a person experiencing mental health difficulties often seemed to focus on loss and grief, and issues around a relative transforming into someone who is unrecognisable to their former self can also present significant difficulties for family members and carers.

Many of the studies focused on the experiences of parental carers, particularly mothers. This seemed to reflect what is known about who is providing the majority of informal care but it also highlights the need to explore a range of caring experiences if a greater understanding about the meaning of caring is to be developed. Other features, such as, identity, loss and grief, learning by doing, support and help-seeking, and coping strategies seemed to feature heavily in many accounts of experiences of caring for a person experiencing mental health difficulties. Also, all of the papers made some reference to clinical practice, supporting the view that greater involvement and meaningful collaboration between families and professionals is to be encouraged. All of these studies focused predominantly on the carers' perspective, even in those papers where couples participated. While this provides a solid base from which to understand the experience of caring, it might also be useful to look at the wider relational context in which carers operate, moving towards multi-perspective research design. In seeking to address some of these issues, this research therefore aims to recruit carers from a range of backgrounds, as well as including service-users', family members' and mental health professionals' perspectives to explore the meaning of caring. In addition to these issues, further discussion of the more specific methodological issues will now be undertaken.

3.5 Methodological issues

As noted above, unlike the use of validated scales in quantitative research, the specific experiences explored, combined with the methods used to collect and analyse the data, do not easily lend themselves to a process like meta-analysis (the integration of data from a number of independent

studies), and care should be taken to be sensitive to the differences in qualitative work. Through the development of rigorous phenomenological work, research can gradually begin to explore what is strikingly common or different in experiences. The aim of this research is therefore to contribute to the growing literature on the lived experience of caring for somebody experiencing mental health difficulties. It is hoped this will be achieved through developing a more holistic picture of how the situation is understood by carers and family members, service-users and mental health professionals. However, it is important to note that this picture will never be a finished masterpiece, carefully defined and applicable to all carers. Rather, it will be a fluid pencil sketch, changing over time as carers and service-users transition through their lives, and mental health service provision develops.

Where phenomenological work in this area has been carried out, different studies have often employed different techniques to analyse their data including: interpretative phenomenological analysis; descriptive phenomenology; phenomenological-hermeneutic analysis; thematic analysis; narrative analysis; constant comparative analysis; and responsive reader analysis. Typically each paper made some reference to taking a phenomenological perspective and went on to briefly outline, or simply give a reference for, any specific theoretical and analytical frameworks used (for example, interpretative phenomenological analysis as described by Smith & Osborn, 2003; Ricoeur's phenomenological hermeneutics as described by Lindseth & Norberg, 2004; narratives analysed according to Colaizzi's seven steps method, 1978). Of all the papers identified, all but one used an exclusively qualitative methodology. Czuchta & McCay (2001) used a mixed-methods (quantitative and qualitative components) design to explore parents' experiences of help-seeking, using measures pertaining to perceived stigma, thresholds of parental burden, uncertainty in illness and help-seeking indicators. The authors briefly outlined their rationale for employing a mixed-methods design as a way of extending, complementing and validating each other's findings. While the authors found that the results of their quantitative and qualitative components did indeed complement and support each other, they did not offer any detailed reflections on taking a mixed-methods approach, instead seeming to let the results speak for themselves in this respect.

As is typical of qualitative research, the sample size of each study tended to be far smaller than would be expected in quantitative work (samples ranged from 4-37 participants). The majority of the studies included a range of 4-18 participants and employed individual interviews or interviews with couples to collect data. It is noted that none of the authors offered any real reflection on the size of their samples, and there does not seem to be a clear pattern in the sample size and method of data collection. In the case of the study that recruited 37 participants (Highet *et al.*, 2004), structured focus groups were facilitated with twelve groups where the range was 5-8 participants, and the mean attendance 6 participants. However, it is worth noting the total number of participants to give an idea of the individual, idiographic accounts that were being attended to, as well as to provide information about the group dynamics. Although the details above only pertain to the studies that were considered to have the greater relevance to the present research, a summary of the analytical methodologies used in all of the phenomenologically-focused papers considered in this literature review is given in Appendix 1.

In carrying out any research, consideration must be given to assessing the quality of the work. As it is neither possible, nor desirable, to apply the sorts of concrete checks and balances that might be applied to quantitative research, the assessment of quality and rigour in qualitative work must therefore be approached in a way that is sensitive to its ethos. Indeed, there has been a move towards developing specific criteria for evaluating qualitative research, the development of which can be seen in qualitative methods textbooks and more recent papers (e.g. Murray & Chamberlain; 1999; Barker, Pistrang & Elliott, 2002; Parker, 2004; Smith *et al.*, 2009). A summary of the papers that are particularly relevant to this research in terms of Yardley's (2000) principles for assessing the quality of qualitative research is given in Appendix 2. The papers are therefore considered in terms of: sensitivity to context (e.g. appropriateness of method, awareness of existing literature, participant extracts); commitment and rigour (e.g. appropriateness of sample, completeness of analysis); transparency and coherence (e.g. clarity of research process stages; details of interview schedule; outline of analytic process); and impact and importance (e.g. interest, importance, use).

As noted above, researchers have a wide range of methodological approaches to draw on within phenomenology, let alone qualitative research more generally. In the papers selected for this review, all employed an appropriate methodological approach to the study of lived experience. However, it is noted that authors took quite different approaches to the information they provided about these approaches and their theoretical underpinnings in relation to their work. Most were clear about these links, plainly providing a rationale for proceeding in a particular way. For example, Osborne and Coyle (2002) outlined taking an idiographic approach to the analysis of their interview data, building up to producing detailed accounts of parental responses to adult children with schizophrenia. The authors went on to briefly outline the process of interpretative phenomenological analysis, referencing Smith (1996) and Smith and colleagues (1997; 1999) as the key proponents of this approach. Others, however, were less clear. For example, Hight and colleagues (2004) took a thematic analysis approach to their data on carer and family perspectives of living with a person with depression. Although the authors had selected an appropriate approach to their data they did not discuss their reasons for doing so. This begs the question, if a plausible, interesting, useful account of the data is produced, to what extent does the reader need to be informed as to the methodological underpinnings and analytic framework that the work is based upon? While it may not be strictly necessary to provide these details, discussing them in relation to particular research certainly helps the reader to understand the process and have confidence in the findings and the author's abilities as a competent analyst. It helps to give the reader a sense of the commitment of the authors to the data, where they are coming from and what they are hoping to achieve. It also speaks to the transparency and coherence of the work, enabling the reader to think about the research design more completely.

While all authors outlined the broad details of their recruitment criteria and the demographic details of their participants, many did not go on to discuss these factors in relation to their findings. Sometimes issues relating to sampling were addressed when considering the limitations of the studies but there would seem to be room for greater consideration of participant context, as well as analyst reflexivity (the analyst's awareness of their impact on the analytic process, including the

research context and relevant personal thoughts and feelings) in many of the papers. Some authors made brief references to the use of field notes or reflective diaries to enhance the analytic process (Chaffey & Fossey, 2004; Huang *et al.*, 2008) though the value of these was typically not discussed in any detail. With regard to the interview schedule, or questions posed to participants, half of the papers gave details of the questions or broad areas covered. Where sample questions or prompts were not provided, some authors made reference to initial interviews informing follow-up interviews (e.g. Jeon & Madjar, 1998) or more generally described the overall aims of the interview (e.g. "...to elicit responses exploring the loved one's condition", Osborne & Coyle, 2002). As qualitative interview schedules can often vary dependent on participants' responses, it may be argued that it is not that helpful to include them. However, the inclusion of sample questions can help the reader get a feel for how the topic under investigation was approached by the researcher. Also, while the prompts may be of limited use to the reader, their inclusion and some researcher reflection on their use might indeed prove more interesting and valuable.

3.6 Discussion and implications for this research

Where phenomenological work has explored the experience of caring for somebody experiencing mental health difficulties, it has tended to focus solely on carer perspectives, with the exception of a small number of studies that have sought to also include the cared-for person's or other family members' experiences (e.g. Harris *et al.*, 2006; Wane *et al.*, 2009; Penny *et al.*, 2009; Campbell, 2004). A case can therefore be made for exploring the experience of caring by further setting carers' experiences within the context of wider family members', service-users' and healthcare professionals' perspectives. Although it is important to attend to carers' experiences in their own right, multi-perspective research designs may well be useful in helping to develop a more holistic picture of caring.

Much of the research in this area seemed keen to highlight the need for better family-sensitive services, making a case for greater inclusion, collaboration and meaningful partnership working

between carers and mental health professionals. The very nature of this type of research lends itself to small sample sizes with homogeneous populations. This can lead to questions being raised about the generalisability of its findings to wider practice. Rather than see this as a weakness of qualitative work, it could be argued that it is in fact a key strength, so long as results are interpreted carefully and within the context of the wider literature. Attending closely to individual experiences, drawing out what is both similar and different across accounts can help develop our understanding of the lived experience of caring. In exploring these accounts, the context of the participants' personal development throughout their lifespan, changes in societal attitudes and developments in services should be carefully considered. Therefore, as these things develop and change over time, so research in this area must develop along with them, if research is to accurately reflect current experiences and future best practice.

While the research identified in this review offers a range of perspectives on the lived experience of caring, little, if anything, was made of the way in which the language of caring is understood by carers, service-users or professionals. There is a separate literature exploring the discourse of caring (e.g. Heaton, 1999; O'Connor, 2007; Molyneaux *et al.*, 2011). However, it would seem that the link between experience and representation has not been made, and there is therefore a gap in the literature for exploring the language associated with informal care from a phenomenological perspective. Within the wider context of the literature on caring, a number of papers can be found to make the distinction between formal (professional) and informal (non-professional) care. So, although this might help us to identify unpaid, family members or friends who become carers, it does little to tell us how or why people come to be in the role, what they themselves understand by the term carer, and what it feels like to be called a carer. There would therefore seem to be a case for further exploring this from a phenomenological perspective.

Also, from a methodological perspective, the majority of the relevant phenomenological papers identified in this review utilised interviews (typically semi-structured and conducted with individuals). Only one study employed focus groups to collect data. Individual interviews are

typically the preferred way of capturing rich, detailed, first-person accounts of experience in qualitative research, but that is not to say other methods cannot be employed successfully, especially where shared experiences are sought. There is therefore scope for exploring different data collection methods in phenomenological work. In doing so, consideration will be given to thinking about taking a phenomenological approach to research design, not simply applying its principles at analysis stage. This research therefore seeks to explore the experience of a range of service-users, carers and family members, and mental health professionals to explore the meaning of caring. How to go about this task is the subject of the following chapter.

Chapter 4

Taking an interpretative phenomenological approach to the study of the experience of caring for somebody experiencing mental health difficulties

4.1 Abstract

In the context of the literature on caring presented in the previous chapters, this chapter outlines the key phenomenological approaches typically employed in psychological research. The case is made for employing an interpretative phenomenological approach to the study of caring for somebody experiencing mental health difficulties. The primary research questions that will guide this research are also presented.

4.2 Taking a phenomenological approach to the study of caring

All qualitative research seeks to explore language in some way, seeking richness, depth and detail. Sometimes it is people's perceptions and experiences that are of primary interest, while at others it is the use of language itself that is the key feature. Qualitative research can therefore be thought of as being broadly divisible into two main traditions: phenomenology and constructionism. However, that is not to say that these traditions are mutually exclusive, rather there is much diversity within, and overlap between, them. Essentially, phenomenology is a philosophical approach to the study of experience that focuses on understanding and meaning-making, taking the view that multiple perspectives are not only possible, but equally valid. Constructionist approaches seek to explore how language itself is used in social interactions and how it is affected by history, culture and social structure. As outlined in Chapter 3, there is a strong case to be made for taking a phenomenological approach to the study of informal care. If we want to find out about the lived experience of caring, and how people make sense of these experiences, phenomenology

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can guide the research process, encouraging carers to share their own experiences in their own words, highlighting what is really meaningful to them.

The philosophical background and development of phenomenology is the subject of a great many books and articles and has been eloquently summarised in a number of theory and methods texts (e.g. Smith *et al.*, 2009). Barker, Pistrang and Elliott, (2002) highlighted the fact that growing interest in phenomenological research has led to a great many variations in phenomenological research methods, going on to further describe four of the most commonly encountered by clinical psychologists. Mindful of the subject of this research, i.e. exploring the meaning of caring: how informal caring, and the language used to talk about it, are experienced by carers, family members, mental health service-users and professionals, it is worth considering these approaches here also.

4.2.1 Empirical phenomenology

This approach to phenomenological psychology aims to take a systematic approach to in-depth analysis with a view to describing the fundamental features of an experience. Giorgi, Wertz and Fischer are thought to be key figures in its development (see Barker *et al.*, 2002). In applying the phenomenological method, bracketing and describing are the central processes applied to the data. Bracketing relates to attempts to set aside personal assumptions and expectations. As these are often hidden, reflection is required in order to identify and remove oneself from the phenomenon under investigation so as to see it from an outsiders' perspective. Statements are therefore not interrogated with a view to establishing facts or the truth, rather they are interpreted as statements about an experience of the world which is personal to the individual. While it may be impossible to entirely rid ourselves of our assumptions and expectations, careful reflection on their existence and potential impact on the research process can, and should, be taken into account.

Description is also a feature of the phenomenological method. In an approach that seeks to discover meaning and develop understanding of a phenomenon, descriptions of experience, rather

than explanations for it, are given priority. In undertaking the process outlined above, the ultimate aim is to better understand a thing's essence, the very attributes that make an object or a substance what it is.

4.2.2 Grounded theory

Grounded theory is a qualitative approach that seeks to go beyond rich descriptions of data to generate theory. This approach was developed by sociologists Glaser and Strauss (1967) who sought to challenge the dominant quantitative paradigm of the time. The approach seems to have been taken up by psychologists in the 1980s and has been developed by authors like Charmaz (1991; 2003). In taking a grounded theory approach, the aim is to develop one or more categories that capture the essence of the phenomenon under investigation. The approach is inductive, with the methodology being shaped by the research process as it develops, but with a commitment to explanatory-level accounts. Grounded theory therefore involves the systematic generation of theory, starting with individual cases and building up to create more abstract conceptual categories that offer an explanation of the data. These categories synthesise the data and allow for the development of a theoretical analysis (Charmaz, 2003). In taking a grounded theory approach, methods of data collection are flexible, being shaped by the findings as the research progresses, with the analyst pursuing what they feel to be the most relevant or interesting material. The overall purpose is therefore to develop a theoretical analysis of the data that is relevant to the topic under investigation.

4.2.3 Hermeneutic approaches

Hermeneutics is the theory of interpretation and therefore adds something to empirical phenomenology, seeking to go beyond surface meaning derived from description, to the interpretation of implicit or unconscious meanings embedded in individuals' accounts of their experiences. As noted in Chapter 3, a number of the papers identified in the literature review (e.g.

Pejlert, 2001; Jeon & Madjar, 1998; Tranvåg & Kristoffersen, 2008) made use of phenomenological-hermeneutic methodology citing authors such as, Ricoeur (1976) and Van Manen (1990).

4.2.4 Interpretative phenomenological analysis

Interpretative phenomenological analysis (IPA) has been rapidly developing since the mid-1990s, driven by the work of Smith (1996; 2004). The approach began in health psychology, though it is becoming increasingly popular in other areas of psychology, as well as social sciences more generally. Indeed, the literature review highlighted that of the twenty-nine phenomenological papers identified, eight employed IPA.

In taking a psychological approach to the exploration of experience and meaning, this approach draws on phenomenology (the study of experience), hermeneutics (the theory of interpretation) and idiography (the particular, focusing on detail and context). The focus of IPA studies is therefore on personal meaning and sense-making, encouraging participants to express what is important to them in terms of their particular lived experience. So, in order to find out how caring and mental health difficulties, and the language used to talk about these things, are experienced (directly or indirectly) by carers, family members, service-users and professionals, IPA offers a structured, yet flexible, approach to research design. Prior to the current research, the researcher successfully utilised an IPA approach to explore carers' experiences of engaging with mental health services, with data gathered from those attending carers' support groups. This research informed the present study which has been designed in line with phenomenology's philosophical principles. The rationale for taking an interpretative phenomenological approach to the present research is presented below.

4.3 Taking an interpretative phenomenological approach to the study of caring

Although IPA is very much concerned with the analysis of experiential data it is important to be aware that it is an approach to research, not just an analysis technique. It offers a way for researchers to explore people's major life experiences by attempting to interpret the ways in which people make sense of their lifeworld, that which is immediately and directly experienced in everyday life. In choosing IPA, the researcher is therefore choosing to find out more about how people experience something in a way that allows them to express their concerns in their own way. So, as identified above, while much is known about informal caring and mental health difficulties from a broad range of theoretical perspectives, less is known about the actual lived experience of carers as described in their own words. There is little doubt that taking on a caring role for somebody experiencing mental health difficulties can have a dramatic impact upon the carers themselves, family members, friends and the person directly experiencing psychological difficulties. What is less well understood is how carers make sense of their transition into this role and the changes that result from this.

IPA assumes that data is able to tell us something about people's involvement with the world and how they go about making sense of it. In order to access this type of data, the researcher needs to apply a phenomenological approach from the beginning, developing research questions that focus on how people understand their experiences, probing them to explore rather than explain their lifeworlds. In order to find out more about the lived experience of informal carers, this research will utilise data collected from family members, carers, mental health service-users and professionals, to try to build up a more holistic picture of caring. In order to be a 'carer', there must also be a 'cared-for' and it would therefore seem prudent to explore the experiences of service-users (the cared-for) and staff members (formal, paid carers) to find out a more about the relationships between these people and their implications for informal caring. Research questions should therefore be directed towards eliciting meaning, not to set out to test a hypothesis as such, as reflected in this study's primary research questions (see below).

In order to access the type of detailed, experience-rich data required for IPA research, one-to-one participant-researcher semi-structured or unstructured interviews are typically considered to be the exemplary method of data collection, allowing the participant to talk and the researcher to listen and gently guide the interview where necessary. As the IPA approach continues to develop, other types of data collection methods, for example, focus groups and written accounts are being used to good effect (Smith, 1999a; Palmer, Larkin, de Visser & Fadden, 2010).

Carers, service-users and mental health professionals can be difficult populations to access. Even in cases where individuals may be easily identified, engaging them as research participants can be difficult for a number of reasons (for example, lack of interest, over-research in certain areas, time constraints). Utilising a range of data collection methods therefore offers a number of advantages over interviews alone. This research will therefore employ interviews, focus groups and written accounts to collect experiential data from participants. As focus groups and written accounts are less well-used than interviews, this will also offer the opportunity to reflect on the development of their use with the IPA approach, hopefully offering something of methodological interest to the literature.

This research hopes to add to the developing literature on informal caregiving and mental health difficulties, particularly by focusing on the relationship between the carer and cared-for, and the ways in which services respond to this. This research therefore aims to explore the ways in which carers, family members, service-users and mental health professionals make sense of their experiences of mental health difficulties, informal caregiving and recovery, and the language used to describe these things. In order to accomplish these aims, the following primary research questions have been developed:

4.3.1 Primary research questions

1. What are the perspectives of service-users, carers, family members and mental health professionals on the experience of being (directly or indirectly) affected by mental health difficulties, recovery and caregiving and how do they relate to one another?
2. How is taking on an informal caring role for a family member understood to affect family relationships?
3. How do informal carers come to be identified as such?

These questions will be addressed in the following chapters. Chapter 5 examines carers' experiences of caring for a relative experiencing mental health difficulties, and their understanding of the language associated with informal care. Chapter 6 considers the dual perspectives of service-users and carers by exploring their experiences of a first episode of psychosis. One family's experiences of mental health difficulties are the focus of Chapter 7, and mental health professionals' experiences of identifying and working with families and carers are the subject of Chapter 8. Further consideration of how this range of experiences relate to each other, and the literature on caring more generally, is presented in Chapter 9.

Chapter 5

Exploring the meaning of carers' experiences of caring for somebody experiencing mental health difficulties, and the language of care

5.1 Abstract

The aim of this chapter is to explore how carers experience caring for somebody experiencing mental health difficulties, and the language associated with informal (unpaid) care. Data were collected from 11 carers over three focus groups to explore personal experiences of what it is like to be an informal carer for somebody experiencing mental health difficulties. A semi-structured set of prompts was used to elicit carers' daily lived experiences, though they were encouraged to focus on the things that were important to them and lead the discussion as much as possible themselves. The carers provided rich, detailed accounts of their experiences, seeming to want to take advantage of a forum in which to share their stories.

An interpretative phenomenological approach to design and analysis was employed, attending to some of the issues that are often associated with focus group data (Palmer, Larkin, de Visser & Fadden, 2010). Analysis identified six key themes in the data that focused on the idea that being a carer...: is a useful label?; is a choice?; can mean identifying other carers and finding support in others' experiences; means taking on responsibilities that blur the lines with formal care; means having to deal with (un)professional conduct; can present concerns about the future. While many of the shared experiences indicated significant agreement on many issues, there were also some stark differences of opinion between participants. For these carers, the label was often something that was difficult to identify with, being both a help, and a hindrance, at times.

5.2 Introduction

This chapter sets out to explore the daily lived experience of caring for a relative experiencing mental health difficulties. It also seeks to examine the ways in which self-identified carers come to be aware of the language associated with informal caring, what they think about it, and how they use it in relation to their own experiences. In analysing data from previous research with carers of people experiencing mental health difficulties, the researcher (MP) became aware that often carers would dispute whether the term was applicable to themselves, preferring instead to think of themselves as doing what any concerned relative or friend would do. O'Connor's (2007) work exploring the positioning process in how people come to self-identify as carers suggested that recognition of oneself as a carer is a result of interactions with others. Therefore, family members will often see the work they are doing as being part and parcel of their relationship. O'Connor went on to suggest that benefits of self-identifying as a carer include a sense of connection with others, greater ease in accessing services, and rewards resulting in positive societal sanctioning of the carer role. However, there may also be challenges associated with accepting the carer role, including the other person's needs superseding one's own, distancing in the relational role, and a challenge to the power dynamics of the relationship. O'Connor's work suggested that there is a case to be made for self-identifying as a carer in that it can be important in helping people to recognise the scale of the task they have taken on, and in developing self-care strategies.

However, there is a growing body of literature to suggest that the term 'carer' might well be failing people who take on caring responsibilities when a relative becomes unwell (Molyneaux *et al.*, 2011). Molyneaux and colleagues (2011) also highlighted evidence which suggested that there are particular complications in the field of informal care for mental health issues, because carers often struggle with complex emotions, such as fear, bewilderment and resentment (e.g. Karp & Tanarugsachock, 2000). Using the term 'carer' could even be detrimental to the relationships in which caring takes place (e.g. Henderson, 2001). Indeed, there is little doubt that this terminology has become entrenched in discourse about caring (Heaton, 1999), as well as in policy and practice

through a series of government White Papers, Department of Health charters and the introduction of the Carers Act (Department of Health, 1995).

There is evidence to suggest that formal care services commonly utilise this language, while carers themselves may be ambivalent about the term (Molyneaux *et al.*, 2011; O'Connor, 2007). Although questions are being asked about the utility of the term 'carer', there is still relatively little known about how the process of labelling carers in this way impacts on the experience of caring. There therefore seemed to be a gap in the literature for a phenomenological approach to the experience of becoming known as a carer, both in terms of self-identification, and identification by others. If carers are to be able to access the help and support that is available to them, there is an argument to be made for asking them what they think of the terminology used, and to explore how they would go about defining what a carer is. Of course, definitions do already exist, but as previously noted (see Chapters 2 and 3) they tend to be vague, and inclusive to the point of applying to everybody at some stage of their lives. So how do people distinguish between caring about and, by extension, for, a relative; and being a carer? Being a 'carer', as opposed to simply being a caring person, seems to require some element of long-term ill-health, disability, or old age, though this covers a huge variety of potential circumstances. In order for carers to be able to take advantage of what is available to them, and in turn to make sure that what is available really meets their needs, consideration must be given to ensuring that carers are aware of this status, that it is helpful to them, and valued by others.

Chapter 5 therefore seeks to address the following research questions:

1. What is the daily lived experience of informal caring for somebody experiencing mental health difficulties like?
2. How is the language associated with informal caregiving understood by carers themselves?
3. How do informal carers come to be identified as such?

5.3 Method

5.3.1 Participants

Data were collected from carers who attended support groups across the English Midlands, UK. A total of 11 participants, each caring for a relative, took part in three focus groups (details summarised in Table 5.1). Group 1 consisted of five participants, while Groups 2 and 3 were made up of three participants each. Further details of group composition are discussed in greater detail below.

Table 5.1: Overview of carers' demographic details

Gender	Age range (years)	Ethnic background	Relative cared for	Length of time in caring role
6 x Female	1 x 26-35	7 x White British	6 x Adult child	Range: 3-40 years
5 x Male	3 x 36-45	1 x White Irish	3 x Parent	Mean: 20.6 years
	2 x 46-55	1 x Asian - Indian	2 x Grandparent	
	2 x 56-65	1 x Asian - Other		
	3 x 65+	1 x Other		

Participants reported that their relatives had received diagnoses of schizophrenia, bipolar disorder, depression, and dementia. While full diagnostic criteria are detailed in the Diagnostic and Statistical Manual for Mental Disorders, Fourth Edition (American Psychiatric Association) it is worth noting here the key characteristics of these conditions as they might be understood by those outside of the mental health professions. The NHS Choices website (2011, www.nhs.uk) provides health information to the general public, offering a search facility for a range of health conditions. Schizophrenia is described as a psychotic illness which may result in people not being able to distinguish their own thoughts and ideas from reality. Hallucinations, delusions, muddled thoughts or changes in behaviour may be a feature of experiences of schizophrenia. Bipolar disorder is

characterised as a condition that affects a person's moods, swinging from one extreme to another, including episodes of depression (feeling very low) and mania (feeling very high). Depression is characterised by a wide variety of symptoms including lasting feelings of sadness, hopelessness, loss of interest in things that used to be enjoyable, feeling tired, experiencing aches and pains, and at its most severe, feeling suicidal. Dementia is described as a syndrome (a group of related symptoms) that is associated with an ongoing decline of the brain and its abilities (including memory, thinking, language, understanding and judgement). People experiencing dementia may have problems controlling their emotions or behaving appropriately in social situations. These conditions are therefore all characterised by changes to thinking, feelings and behaviour that will have a significant impact on a person's life. It is noted that some relatives experienced a range of difficulties (e.g. schizophrenia and dementia). As some of the participants' demographic details are quite specific, and may therefore be used to identify them, the exact composition of each group and further demographic details will not be given to protect anonymity. An outline of the composition of the groups is given below, and consideration of the positions adopted by participants is further discussed in the discussion section.

5.3.2 Data collection

Focus groups were set up to elicit carers' experiences of what it is like to be an informal carer for somebody experiencing mental health difficulties. Each group was facilitated by the researcher (MP) who recruited three convenience sampled groups (minimum of three participants) from a number of carers' support groups operating across the English Midlands, UK. The facilitators of carers' support groups were approached by the researcher who supplied posters and information leaflets to advertise this research to potential participants (see Appendices 3 and 4). Interested individuals were encouraged to contact the researcher, who would then provide more information (including a participant information sheet, see Appendix 5) about the research project. All groups were held at the University of Birmingham. Participants were informed that each group would last for about an hour but it is noted that each group overran quite significantly (groups lasted from

approximately 1 hour 30 minutes to 1 hour 50 minutes). The discussions were audio-recorded and transcribed verbatim for analysis. All participants were given pseudonyms during the transcription process.

The researcher used a prompt sheet (see Figure 5.1 below) to start the discussion and keep participants focused on the topic of caring, though participants were encouraged to express what was important and meaningful to them. The prompts were developed by the researcher following previous research with carers, which indicated that carers often expressed a sense of confusion and conflict in terms of thinking about themselves in the language which is typically used by carers' groups and mental health services (Palmer, 2007). The researcher therefore considered what these carers had said and what was available in the literature to develop the prompts for this research.

5.3.3 Data analysis

Data were analysed using interpretative phenomenological analysis. A protocol for using IPA with focus group data (Palmer, Larkin, de Visser & Fadden, 2010; see Appendix 6) was used; which was itself developed from Smith's work on IPA (Smith, 1996; 2004). Each transcript was first analysed to explore what was especially meaningful to participants in each group, and how participants were interacting with each other. Emerging themes were identified for each group and these analyses were then integrated to develop an understanding of the meaning of caring across the groups. Key similarities and differences were considered within the wider context of self-identified carers of people experiencing mental health difficulties. A short extract of worked data is presented in Appendix 7 to illustrate the initial steps in the data analysis process.

Figure 5.1: Prompt sheet for focus groups with carers**Focus group prompts:**

NB. The below are prompts only. The Chief Investigator will rephrase/prompt for more detail as appropriate during each individual interview.

1. When and where did you first come across the term 'carer' (used by professionals, used by friends, found it on the internet/literature)?
2. What do you understand by the term 'carer'?/What responsibilities/expectations do you associate with 'caring'?
3. Do you feel that this term applies to yourselves?
4. Would you prefer a different term to be used? What do you think might be a better term?
5. Are there any benefits or disadvantages to people using the term 'carer'? What might these be?
6. What key information/advice would you want to pass on to people who are new to 'caring'?
7. What makes you feel more/less like a 'carer' (e.g. at times of crisis; when in contact with services)?? Is there conflict between being a parent/spouse/sibling and being a 'carer' – what causes this and how do you think it could be resolved?
8. Does the person you care for have a 'main carer'? Is this role taken on by yourself? Is this role taken on by somebody else (who and what is their relation to the person who is ill/yourself, e.g. another family member etc.)?
9. Do you feel that being labelled a 'carer' has been more of a help or a hindrance (e.g. opened up new avenues of support/led to discrimination)
10. How do you think mental health services perceive carers?
11. What can carers offer to mental health care?
12. How do you think the media perceives carers? Are there specific issues associated with mental health?
13. How do you think the general public perceives carers? Are there specific issues associated with mental health?
14. Has being in a caring role had an impact on your employment prospects/finances/your own health/your friendships and social networks?
15. Are you aware of organisations that offer help and support to carers? How did you find out about these? Do you have contact with such organisations – in what capacity?
16. Are you a member of any groups specifically aimed at carers (e.g. support groups)? If yes, what prompted you to join such a group; what impact has this had on you?; If no, what has stopped you from joining such a group?

Ethical approval for this study was granted by the University of Birmingham's Life and Health Sciences Ethical Review Committee. All participants were sent written information about the study and discussed what would be involved in participation with the researcher prior to taking part. All participants were aged over 18 years, had capacity to understand the nature and purpose of this research, and gave written informed consent to participate.

5.3.4 Outline of focus group composition

In order to set the group discussions in context, consideration should be given to the positions adopted by participants within their groups. A brief outline of each group is therefore presented while being mindful of protecting participants' anonymity.

Group 1 (five participants: Theresa, Noel, Edward, Ellie & Robert)

Theresa, Noel, Edward and Ellie were all around retirement age, and had been caring for an adult child who had received a psychiatric diagnosis and been experiencing difficulties for a number of years. Robert was considerably younger than the other members of the group. He cared for a grandparent who had also been given a psychiatric diagnosis, and had experienced difficulties for a long period of time. All of the participants attended carers' support groups and some found that they had met each other before (also, Edward and Ellie were a married couple).

Theresa seemed to take on something of a spokesperson role in the group. This seemed to reflect her position as a mother, long-term carer, trained nurse, and someone who had been involved in setting up and running carers' support groups. She was also actively involved in supporting a number of younger individuals experiencing mental health difficulties who looked to her, as an experienced carer, for advice and support in their daily lives. Although not dominant in terms of speaking, Theresa did come across as someone who had experienced a lot to do with caring over the years. As group members shared their personal experiences of caring, particularly in sharing

some of the more challenging aspects, she said, "...I mean, this is our story and we can multiply it a hundred times can't we?". This seemed indicative of her position as someone who is known for advocating for carers, using inclusive language, and promoting greater awareness of carers' issues.

While all of the participants had been caring on a long-term basis, their primary concerns did differ. For example, Noel, Edward and Ellie, acknowledged that they were getting older, and spent some time talking about their concerns for the future and what would happen when they were no longer around to offer help and support to their children. For Robert, the youngest of the group, concerns about employment were more important to his personal circumstances.

Group 2 (three participants: Dawn, Frank & Anne)

Dawn and Frank were both caring for a parent, while Anne was caring for a grandparent. All of the cared-for individuals had received a psychiatric diagnosis and experienced difficulties for a number of years. For Dawn, caring had been part of her life from a very young age, supporting her mother, and at times her younger siblings. Frank came to caring a bit later as his father's problems started later in life. Anne was newer to caring, taking over caring responsibilities from other family members. None of the participants had previously met.

As participants shared their experiences, many similarities around difficulties and challenges were revealed. However, as in Group 1, some of the differences in personal circumstances led to a range of concerns being expressed throughout the discussion. Reflecting on the ways that they each came to caring had an impact on ideas about caring as a choice that people are free to make. Anne talked about a clear decision making process in taking on caring responsibilities, while Dawn and Frank talked about their experiences of caring more in terms of duty, reciprocity and devotion (i.e. it's just what you do, you don't really have a choice in the matter). For Dawn and Frank, their concerns also focused on planning for when their parent was no longer around, thinking about the impact it would have on them after having such a close, intimate relationship over many years.

Group 3 (three participants: Lynne, Dan & Marie)

Lynne and Dan had both been in the position of caring for an adult child, while Marie was caring for her mother. Lynne and Dan had previously met at a local carers' support group, but neither had met Marie before.

Of the three groups, the personal experiences of this group seemed to be the most different from each other, though a number of key similarities were identified despite the circumstances in which they occurred being different. A key similarity in their stories was that all of them agreed that they only started to realise that they could be considered 'carers' rather late into their experiences. They also agreed that they had all lost out at some point because they had not realised the label applied to them.

5.3.5 Context in which themes are set: carers' support groups

All participants attended carers' support groups within the English Midlands, UK, though some attended more regularly, and were more active in the caring community, than others. In attending carers' support groups, it may be that these carers were used to sharing their experiences with others, and so were particularly willing to take part in this type of research. Convenience sampling from a range of support groups was utilised by the researcher to employ a constructed groups design. In composing each focus group of carers who had typically not met before, it was hoped that participants would share their personal experiences, as opposed to telling a group story about caring. It is noted that two participants who attended Group 1 were a married couple, but the researcher felt that this would not be problematic to the focus group, and did not want to turn away either participant who were both keen to attend together. Also, it became apparent to the researcher, as the groups met up, that a number of the other participants had previously met. However, this did not seem to lead to convergence on a particular presentation of caring within groups where this was the case. Indeed, in all three of the groups, participants shared personal

experiences that reflected a range of similarities and also some stark differences. However, it is also noted that it is possible that some participants may have held back certain things for a variety of reasons, which may have included not wanting to seem very different from other group members. Most of the participants who took part in these focus groups cared for adult children, though the range of caring experiences also included parents and grandparents. Consequently, many participants' experiences of caring reflected parent-child relationships, though it is acknowledged that the experience of caring is likely to be very different depending on whether a parent is caring for a child or a child is caring for a parent. Although the researcher did not plan for this focus on parent-child relationships, it did add another level of homogeneity to the sample. Overall, each participant seemed comfortable in sharing their own experiences in relation to the researcher's, and each others', prompts, expressing both similarities and differences in rich detail.

It is noted that many carers do not attend support groups and that these people might have both similar and different experiences to those presented in this research. The participants in Group 3 reflected on this during their discussion. In response, the researcher briefly outlined the other aspects of this research that seek to engage with some of those carers who do not attend support groups. Elsewhere in the thesis, the experiences of carers who are newer to the role and might not realise that they are carers, or attend support groups, are included (see Chapter 6, service-users' and carers' experiences of first-episode psychosis; Chapter 7, a family's experiences of being affected by mental health difficulties and being in contact with the Early Intervention team). It is noted that recruiting such carers poses difficulties and may require others, such as mental health professionals, to identify them as potential participants in this research.

It is also noted that the themes presented are set in the context of experiences that have often been challenging. These experiences, about caring relationships between family members, are often bound up in conflicting emotions as participants share stories that highlight love, devotion, reciprocity and guilt. As previously noted (see Chapters 2 and 3), carers often face a range of difficulties, including financial burden and social isolation. Indeed, a number of the participants

talked about their financial concerns and that they thought that others do not really understand their caring responsibilities, even perceiving caring negatively. However, these stories seemed to be very much bound up in the overall sense of what it is to be a carer, and have therefore been incorporated into other themes. Six key themes were identified in the data concerned with what is like to be an informal carer for a person experiencing mental health difficulties. A summary of these themes is presented below (Table 5.2), and they are subsequently explored in further detail with extracts from the group discussions.

5.4 Themes

An outline of the themes derived from the carers' focus group data is presented in Table 5.2 and the themes are further explored below. These themes focus on what it is like to be an informal carer of a person experiencing mental health difficulties, and how the language used to talk about these things is understood.

Table 5.2: Summary of themes derived from carers' focus groups

Being an informal carer...	Key components of the theme
...is a useful label?	<ul style="list-style-type: none"> • 'Carer' means different things to different people • Some are more so than others • 'Carer' opens doors • 'Carer' stigmatises people • 'Carer' can reinforce sick and carer roles
...is a choice?	<ul style="list-style-type: none"> • The primacy of familial relationships – love, duty, reciprocity, guilt, choice
...can mean identifying other carers and finding support in others' experiences	<ul style="list-style-type: none"> • Helping others realise that they are carers • Experiences of carers' support groups
...means taking on responsibilities that blur the lines with formal care	<ul style="list-style-type: none"> • Having to learn information and skills, provide professionalised care • We know these people better than any professional • Implications for family relationships
...means having to deal with (un)professional conduct	<ul style="list-style-type: none"> • Communication – being shut out • Good and bad professionals – disparity • Services are too reactive and incident driven
...can present concerns about the future	<ul style="list-style-type: none"> • What happens after we're gone? • What happens after they're gone?

5.4.1 Being an informal carer... is a useful label?

In terms of thinking about being labelled a 'carer' the participants were prompted to think about the language used around informal care and the impact it had on them. Dan summed up what he saw as a key difficulty with the term:

Dan I think the term helps the NHS... because it's a sort of catch-all thing from the NHS side... they need something like the term carer, but from our side we see it, you know, we either don't understand it or we see it as a completely

different thing you know, sibling, daughter, parent, so obviously we do things naturally because obviously... we obviously feel that that's our role, now I know it doesn't happen in all families, some, there's, they want nothing to do with it, you know.

(Group 3)

While participants went on to offer generally broad descriptions of what a carer is and does, there was a sense that there is a certain level of input and support involved, and this is more than would be done for a person who was not experiencing mental health difficulties. Rather than try to quantify it, participants shared their stories as a way of demonstrating the sorts of things that would qualify one as a carer. As noted in the Chapters 2 and 3, carers often take on increasing responsibilities for financial support, medication management, household chores, encouraging participation in activities, and childcare. However, the differences between people's responsibilities can be startling, as Noel noted after taking part in another research project:

Noel ...and the stories that came out from the twenty people really opened my eyes as well, you know, you think you've got problems yourself but some of these people have got immense problems.

(Group 1)

However, in other discussions, participants considered the idea that some 'carers' might not be doing as much, but might still think of themselves as carers, using the label to take advantage of the support available:

Dawn Yes, and I've said, I think a lot of people, they seem to think that, "ooh, I'll be a carer, they're getting all these perks and all these benefits"...

Anne It's not the case is it, not the case?

[Murmur of laughter]

Dawn ...and everybody, because I've met, I mean even like at the [Carers' forum], you know, and some people, they're clearly not carers, they care about the person, but they might only go and visit them every six-months or every seven-months...

Frank Yeah

Anne A carer, you have to do thirty-five hours don't you?

Frank Mmm

Dawn Well, that's what you're supposed to be...

Anne Yeah

Dawn ...to claim, to get carers' allowance you have to be caring five hours a day, now some people will say, "Ooh, I'm a carer, you know, I go and wash so-and-so's sheets every month, or, I'll go and visit this old lady every three-months" so it's what impact it has on you.

(Group 2)

Here, the group talked about the fact some people might be attracted by the "perks" and "benefits" available to carers, but that in reality accessing help, and financial support in particular, can be very difficult. The legitimacy of these carers was questioned here, at least in relation to the amount of hours which one is "supposed" to put into caring. Despite this, ideas about the amount of effort involved, and the impact of caring upon one's own life seemed to be more important to these

carers. As Dawn also noted, caring *about* the person is not necessarily the same as 'being a carer'. So, it would seem that identifying carers is not clear cut. The label is both valued and contested, and as such it can be abused. There was also some brief discussion about the potential for caring to become a sort of lifestyle choice. Dawn drew on the experiences of other people she knew, to illustrate how the label of carer can be difficult to give up, and may lead to excessive control over the cared-for person:

Dawn I mean, another carer I know who's got two disabled children, some carers will, don't want to let go of caring because some of them, if you've got two disabled children or three children, up to the age of 18, you're in control of all their money, finances, and once they get to 18, and some people don't like to let go because they, it can become a lifestyle, you know.

(Group 2)

However, all the participants in this research cared for people who had experienced mental health difficulties for a number of years. Although the number of years spent in a caring role ranged from 3-40 years (mean 20.6 years), this reflected a number of younger carers taking over the role from other relatives, and the cared-for person had typically been unwell for quite some time. In the relationships with these carers, the role of 'service-user' was therefore long-term and well-established. Conditions were seen as chronic, to be managed as well as they could be. Consequently, many of the carers had become established in the caring role and there was a sense that these service-user/carer roles would endure for the foreseeable future.

A number of the participants seemed to be somewhat conflicted about applying the label to themselves. Some found it difficult to personally identify with the term, feeling slightly uncomfortable with it, or seeing themselves more as concerned relatives than carers. Marie acknowledged that this was something she struggled with, but highlighted that the label could present difficulties as well as benefits:

Marie ...initially with me it felt as though I was being disloyal to me as a daughter, to my mother as a daughter by saying that I was a carer, because my, I'm not a carer, I'm her daughter and I love her and I'm doing this for her, not because, the label makes you feel slightly detached from the situation sometimes, it's like negative.

(Group 3)

Marie But doors do open if you say you're a carer, and, you will get access to certain services.

(Group 3)

Marie had experience of caring from an early age. She discussed the difficulties she had faced in getting the services she wanted for her mother and the support she needed for herself at times. Marie also talked about the impact of the carer label on her ability to cope and manage her responsibilities on a personal level:

Marie I think it may sometimes, take away a little bit of the guilt when you feel as though you're not coping, you think, when I think of myself as just being a daughter, and then I would think, "God, I can't cope with this", or "I'm really struggling", and I'd feel like I was failing, whereas when you're given a, a thing, of, you're actually a carer, then you realise, oh, there's an additional responsibility on you, which is different to just me being a daughter and I can ask for help, and I can, without feeling as though I'm failing, because there's a lot I've struggled with over the years, the fact that, I've failed her, or I'm not doing something right.

(Group 3)

However, aside from the benefits, the label can also have negative consequences in some situations. Marie, who acknowledged that she had benefitted from seeing herself as a carer, had also experienced discrimination in the workplace because of this:

Marie I hardly ever share with anyone that I care for my mum, that she's got a mental illness, because I've found that it's just treated so negatively, the whole arena of mental illness is treated negatively and when you're working as well, people don't want to employ someone who's a carer, because they worry that you're going to be off doing this, or off doing that, so I find it's a secretive thing that I've still got to do, you know, I'm like a secretive carer, and I don't like raising my voice about it, I don't like saying it because it has negative implications on other aspects of my life.

(Group 3)

Marie later went on to talk about taking a career break, and the consequences of telling people about her caring responsibilities. She wanted to return to the workplace, and went on to say how she approached a few people she used to work with to find out about potential vacancies. She expressed her frustration at being told that the demands of the job might be too stressful for her to manage on top of her caring responsibilities. Marie was not the only person to suffer discrimination in the workplace as a result of being a carer. For Robert (Group 1), returning to the workplace (after giving up his profession to become a carer), posed similar difficulties to those faced by Marie. Robert talked about potential employers wanting to know what he had spent his time doing, and feeling that if he told people he had been caring full-time he would not be seen as a suitable candidate. Theresa commented that this stigmatises carers and they both talked about employment being important in terms of independence (Group 1). In Group 2, Anne, who was taking a career break at the time of the focus group, talked about the impact of revealing her role (as a carer) to others:

Anne ...because I've always worked... so you know when you sort of go out into society and say like, "Oh hi, how are you? What's your name? What do you do?" People always ask what you do, and I've never really noticed that before, until now, that like, I don't actually do it anyway, I've just,

something that I've realised then I don't do, but I definitely don't now, but then when you say, like, "What do you do?", oh, erm, "Oh, I'm a lawyer", "I'm a doctor", "You're a carer, oh okay, yeah, so er..." and then it's that then that's the conversation, and I don't know how the caring thing is perceived, I don't know if it's like, care assistant? Or you're not really doing anything, you're just at home, unemployed and you're really just not doing anything [Laughs].

(Group 2)

Here, it was not employers that were the source of the discrimination (as for Marie and Robert), rather in Anne's experience, it was the reactions of wider society that were perceived as negative. Anne talked about knowing what she had to do within the caring role, but being unprepared for how it would affect her as an individual and how others would perceive her. This sense of being perceived negatively seemed to link in with Marie's experiences of being a "secretive carer" (Group 3), and being careful who she talked to about her role. Marie also shared her perception that people seem to be afraid of mental illness, and that mental health, more than other conditions, seemed to be a target for stigma. Lynne also talked about being careful what she says to people when asked how her daughter is getting on:

Lynne It's kind of like, you know, the socially acceptable response isn't it, because, if you met somebody, and it depends who it is obviously... but at the end of the day, you know, when I think of some of the things that we've been through, they just wouldn't want to hear it.

(Group 3)

So, although certain benefits may be derived from identifying with the label of 'carer', there is also the potential for prejudice and stigma to negatively impact on carers' experiences. When prompted to think about what it is like to be called a 'carer', Dawn talked about sometimes finding the term

“patronising” (Group 3). This happened towards the end of the discussion and Dawn did not expand much on her assertion, instead letting her previous testimony explain why she felt this way (devoting time and energy to caring with little or no support from services). The label ‘carer’, designating the provision of informal care, can also seem belittling as far as employment goes. A number of participants shared experiences of employers and wider society often seeming to perceive caring as, “not really doing anything” as Anne put it (Group 2). Frank also highlighted how carers themselves can reduce the role, almost without realising it. He talked about a time he met a prominent figure in carers’ campaigning at a conference:

Frank Yes, yeah, and erm, I said to [Him/her], after the conference, and the talk that [S/he] was doing about you know, the set up of it, and erm, [S/he] says, “Oh, you make a lot of good points”, [S/he] says, “Have you got a business card?”, I said, “A business card?”, I said, “I’m only a carer”, [S/he] says, “You’re not *just* a carer, don’t ever say that”.

(Group 2)

This extract highlights the way in which carers themselves can internalise a diminished role, being “just” or “only” a carer, which is at odds with current attempts to value what carers contribute to society (as noted in Chapter 2, e.g. Buckner and Yeandle, 2007). If carers are to be valued by society, and able to take advantage of what is available to them, the language of informal care needs to be made accessible and acceptable to carers, as Dan said:

Dan Haven’t we all lost out, the people in this room, because we didn’t think of ourselves as carers enough to say, “We’re carers, therefore we tick a certain box, therefore we, we’re entitled to certain, a different type of, erm, service?”, and because we didn’t think of ourselves as carers, erm, we never sort of ticked that box, therefore we didn’t get the service we were entitled to.

(Group 3)

While Dan was referring to the stories he had heard in his particular group, his comment captured the central concern of this theme, echoing many of the participants' experiences of having difficulties identifying with the term 'carer' at one time or another, and struggling to get help and support when it was needed.

5.4.2 Being an informal carer... is a choice?

When asked to describe what a carer is, participants talked about familial relationships and how love, duty, reciprocity and guilt are closely bound up in the experience of caring. While this might be true to some extent in all close relationships, there were certain things about the presence of mental health difficulties that made these things more pronounced. The ways in which participants had come to identify with the term were therefore closely linked with how they came to take on caring responsibilities, and how these were maintained over time. Most of the participants talked in quite general terms about taking on extra support responsibilities around the onset of disorder-related behaviours. Only one participant explicitly expressed having made a choice to care. In exploring ideas about choice, it is worth considering how participants viewed the role of carer in the wider context of their lives. Dawn talked about the expectations placed on families with regard to caring, and noted that there have been changes over the years:

Dawn Although I can see why it's changed because, in the past a lot of families was expected, "Well it's your relative", you know, I've heard that myself as well, "Well it's your relative so you should be looking after them", so I suppose that's why the government's changed, because carers are recognised now, so, I suppose that's why, the carer is important, but I do feel myself, personally that, we're all turning into carers and there's no mums and dads, brothers and sisters, sons and daughters because we're all becoming carers.

(Group 2)

Here, Dawn set out the idea that the label 'carer' has gained in importance over the years, something that is reflected in the literature (Fine, 2004). However, Dawn pointed out that in gaining importance and recognition, the label seems to be becoming more powerful than familial roles, and this isn't necessarily a good thing. This is also something that seemed to be a key issue for a number of participants. For example, in Group 3, Lynne and Dan both noted that they saw themselves as supporting their children as parents, not carers. Indeed, they both talked about how the word 'carer' had come to them rather late in their experiences, and they expressed ideas about how it might have been helpful to be aware of the label earlier in order to access help and support:

Dan ...because, parent, in my mind is, you know, it takes priority over carer, I was a parent, as far as I can see, it's, you know, it's your prime duty to look after your children if they're the ones that are ill, so I didn't really come across the term carer until I started to identify it, you know, that's what we were all the time, and erm, as such, I think it would have been useful for us to have had more contact, and erm, had the benefit of knowing that we were his carers, in that sort of category, and therefore had whatever came with that status.

(Group 3)

While these extracts link in with the previous theme which questions the usefulness of labelling carers, they also highlight the sense that carers themselves prefer to think of themselves as loving and concerned relatives. Indeed, it is these pre-existing relationships that are often the very basis for taking on caring responsibilities when somebody becomes unwell. Agreeing with this sense of caring as an extension of a pre-existing close relationship, Marie talked about caring for her mother from a young age, only realising years down the line that she might be considered a carer (Group 3). So, although these participants had a range of caring experiences, coming to caring at different times in their lives, they had a common experience of only coming to realise that they were carers a number of years into their experiences. In Group 1, Ellie talked about her daughter asking her about her role as a carer:

Ellie Well, no, my daughter, she has said to us, she's said, er, "Are you my carer mum?" [Pause] and I said, "What do you mean, your carer?", I says, "Well we do care for you, because we're the only ones," [adopts voice of her daughter] "I don't want you to be my carer" she says, she says, "I want you to come as mum and dad, and not do anything here".

(Group 1)

Again, this extract highlights the sense that the primary familial relationship takes priority, and that the term carer can cause confusion and discomfort between family members. Noel went on to talk about service-users not wanting to feel different from others, and having a carer was a sure way to mark somebody out as different:

Noel I don't think they [service-users] like to feel different from other people which is why they don't, sort of, but we never had a problem with my son about that, he knows that we help him and do certain things... and I think it's that they don't like to feel different from other people.

(Group 1)

The participants in Group 1 all shared stories of taking on caring responsibilities because of a sense of love, reciprocity and duty to a relative, though some were more explicit, and gave more details about how they came to see themselves as carers than others. There was a general sense amongst all participants in Groups 1 and 3 that caring is just something that you do (almost inevitably), involving something a bit different to what you were doing before (relating to changes in mental health), in normal pre-existing family relationships. A major departure from this overall view was expressed by the participants in Group 2, where there was some division in opinion within the group over whether or not caring is a choice.

At the beginning of their discussion, the participants in Group 2 each briefly outlined their introduction to caring. Dawn and Frank both cared for parents, while Anne cared for her grandmother. Dawn talked about only recently being identified as a carer by health professionals, having previously thought of carers as those who were being paid to do a job, for example, care assistants. Dawn also talked about family members not recognising themselves as carers, which she said meant there are "hidden carers" in society (Group 2). Frank agreed, going on to set the scene for his story:

Frank That's it, I'm still like that, I don't, you know, it's, the way I look at it, if it wasn't for my dad, because, my mum's dead, er, but if it wasn't for my dad I wouldn't be here, so you know, he's looked after me, and you do that back.

(Group 2)

Frank clearly outlined reciprocity as a key factor in him becoming a carer, something that you just do for each other as part of a close relationship. Anne talked about taking a different approach to the others, talking about how she made a decision with her family to take on caring responsibilities now that her grandmother needed help and support on a daily basis. The group continued their discussion, sharing their stories, but the idea of choosing to become a carer recurred later when Anne clearly set out her motivation for caring:

Anne ...it's a choice I've made, I'm able to do it, and, because no matter what, I do, this is my opinion [aside, clarifying for the group], I do believe it's a choice, our choice is to do that even though, even though, at the time, sometimes when you started doing it, and whatever, it didn't seem like a choice, it is always a human's choice, because you could leave.

(Group 2)

Anne was very clear to point out that she was expressing her own opinion, and Dawn and Frank both expressed uncertainty about her views. Although it was clear that they felt differently themselves, they gave Anne the opportunity to speak, and tried to relate ideas about choice to their own experiences. Dawn mentioned that she had always promised her mother she would not put her into a residential home, and that she had achieved this goal, to which Anne responded, "So that's then your choice isn't it?" (Group 2). Dawn initially agreed, but then tried to qualify her experience as being her choice, but not really her choice. Dawn talked about residential care not being good enough, or being too expensive, implying that there was never a real (attractive) choice about going down that route. Frank agreed with Dawn's sentiments here, later going on to outline the circumstances that led to his father going into residential care:

Frank ...my father... he only went in [to residential care] for respite care, but the council were insisting, you know that, they'd got to have all this [domestic repair] work done [on his own home]... and the work was only supposed to take them two-weeks, and it took... near enough seven, and by that time he'd got that settled, he decided he didn't want to come home, now [a few] years down the line, I still find that really hard to deal with, because between me and my sister who were caring for him, we feel like, well we've done something wrong, and there's days when I'm sitting with dad, and he's watching his [Comedy] films, or he's just staring at me, you feel like there's a look in his eye, you know, as if to say, "This is your fault", you know, and, [Pause] he probably isn't.

(Group 2)

Frank talked about the transition, from his father moving from his own home to residential care, being a decision that he felt was ultimately beyond his control. He felt he never made a choice about his father going into long-term residential care, but circumstances transpired to make this happen, and this was something that both he and his sister found difficult to deal with at times. In

trying to strengthen her position that caring isn't really a choice, Dawn recounted the story of a mother she knew, who had young disabled children who need to live with her, saying that she had not got a choice because they are her children. Anne responded with:

Anne I think, I still think, not to sound cold, I still think it's a choice, it is, it is a choice, it's like, no matter how hard we can look at it, you could still walk away, any human being could walk away from another human being at some stage.

(Group 2)

Here the group seemed to be at an impasse, with Anne firmly believing caring is a choice, and Dawn and Frank taking the view that it isn't really a choice, it's just something you have to do for a relative in need. While Anne acknowledged that her point of view might sound "cold", she did set the context for her belief that caring is a choice:

Anne So then, that way [choosing to care], that stops you from becoming bitter.

(Group 2)

Here, Anne talked about the development of a coping strategy that works for her. She seemed to be saying that framing caring as a choice gives one more control over it, thus increasing one's sense of autonomy. However, while Anne firmly asserted that taking on the role was her choice, she also acknowledged that a number of other family members had difficult relationships with her grandmother, and that her choice had also been influenced by being in a position to be able to take a career break. So, although participants often seemed to acknowledge the existentialist perspective that individuals are always free to make choices, they also presented a range of experiences that illustrated the potentially negative impact of caring and mental health difficulties on feeling able to make attractive choices.

5.4.3 Being an informal carer... can mean identifying other carers and finding support in others' experiences

As noted above, participants spent a lot of time reflecting on what a carer is, thinking about their own experiences and how they came to be identified as carers themselves. While a number of participants admitted to being identified as carers by others (e.g. social workers), some also discussed times when they had identified other carers themselves. As Group 1 got underway, Theresa talked about her introduction to caring (seeing it as an extension of her parental and nursing roles), and the importance of getting others to realise that they are carers too:

Theresa Well for me it was very easy because I took up nursing in any case, you're a carer, once you do that, but... the difficulty you have in getting it across to people that they are carers, is if you've got, say an elderly person who needs a certain amount of attention, the next door neighbour's handy and helpful and friendly, comes across, then one day I turn round to someone and said, "You're a carer", she says, "No I'm not". I said, "Yes you are my love, you go in the morning, you see that she's got her tea, you see her during the day, give her a hand when she's having a bath and sort of make sure...", [in the tone of other woman speaking] "That's not being a carer". So, okay, what is being a carer?

(Group 1)

For Theresa, being a carer was closely linked with her choice of profession, blurring the lines between formal and informal care. She broadly identified the criteria for being a carer as being handy, helpful and friendly, spending time with those in need and giving them a hand. She also highlighted that others might question her assessment of themselves as carers, something also picked up by Marie in Group 3:

Marie I remember telling a friend of mine... she's been working quite intensively to look after [Her parent]... but I remember raising it with her, that she was a carer, erm, about a couple of years ago, and that was just new to her, she thought, "I'm not a carer, this is my [Parent], my [Parent's] ill and it didn't, it's very different", and I was like, "No, you're a carer like I am a carer" and trying to get people to understand that concept because, if someone in your family's ill, or anything happens, it's your automatic response, with a lot of people, is you look after that person.

(Group 3)

In addition to participants' stories about how they came to be identified as carers, these extracts further highlight the difficulties that carers face in identifying themselves in this way. Offering help and support to relatives in need is generally presented as an "automatic" response for most people, not sparking consideration of the "concept" of caring until explicitly stated by another person. However, as outlined in the previous theme, Group 2 had a lively discussion about the notion of choice in taking on caring responsibilities. In any case, it seemed that for some carers, identifying others in a similar position to themselves, and communicating this, was another aspect of the role, seeking to benefit those less aware of the role than themselves.

In addition to identifying others as carers, identifying *with* other carers was another feature of caring for many participants. This was somewhat unsurprising considering the participants were recruited through carers' support groups. However, it was noted that not all views on such groups were positive. A number of participants found attending support groups valuable, giving them time and space to interact with other carers, sharing stories and experiences that made them feel less isolated and alone, for example:

Lynne ...and that's just useful because you, meeting people in similar situations, that have had similar experiences, and, and that maybe can point you into a direction, for some additional support or whatever.

(Group 3)

Robert ...we have like coffee mornings... when we get different organisations to come in and talk to the main carers, and we also have like, er, er, workshops like... and we also, er, [exercise and relaxation] right, so the carers right, when they're, if they can spare a couple of hours right, they can always have like a peace of mind to themselves, which is very important.

(Group 1)

In Group 2, Frank and Dawn shared positive experiences of carers' support groups. For Frank, deriving empathy and understanding from others, and being with people who could relate to one another, was important. However, although Dawn had had good experiences herself, she was also somewhat cautious about support groups, thinking about matching carers to the groups that would best suit their needs. She talked about the needs of young carers, and differences between conditions like learning disabilities, psychosis and bipolar disorder, suggesting that going to the wrong sort of group could be unhelpful. She also recounted a story of a lady who came along to one of the support groups she attended:

Dawn I mean I know one lady, and she came along to the carers group, and she was a bit quiet, and I said to her, "Are you okay?", she says, "I haven't slept all night with my son, he's driving me up the wall", she said, "I was so depressed", she says, "And I feel even more bloody depressed coming here, and I won't be coming back!", so for some carers it's good, everybody's different.

(Group 2)

For some participants, support groups were extremely valuable, while others were ambivalent about them, or had even had negative experiences. For those who liked such groups, value seemed to be derived from: taking time out for oneself, away from the caring environment; and having the opportunity to empathise with others, sharing experiences. Being part of the caring community can also be a way of reducing social isolation which can often be a feature of the caring experience, as summed up by Dawn and echoed by others:

Dawn ...I became very dependent because, I don't have many friends, when you are a carer for a long time you lose contact with everybody.

(Group 2)

5.4.4 Being an informal carer... means taking on responsibilities that blur the lines with formal care

A key feature of taking on a caring role seemed to be offering care that is more than would be expected in a normal pre-existing close relationship, sometimes to the point of offering highly skilled, medicalised care. Throughout the groups, participants talked about learning, seeking out information, and developing practical skills to help their relatives. Noel likened his experience to a train journey which began after his son became unwell while away at university:

Noel ...but he landed on us at home, we were obviously bemused by it all and bewildered, and we started on the long train, this was about twenty-five years ago... on the long train of learning about medication, you know, what he should do, shouldn't do, you know, the benefits system, the whole thing of caring.

(Group 1)

Right from the beginning, Noel seemed to set up his perception of caring as a large, amorphous entity: “the whole thing of caring” which he was still grappling with twenty-five years down the line. As noted in the previous themes about labelling and choice, it seems as if it should be easy to define what a carer is, yet it encompasses such a variety of experiences it is actually very difficult to describe it succinctly, without resorting to vague definitions that could almost apply to everybody. Part of this seems to be linked with the boundaries between what is a ‘normal’ level of caring in any given relationship, and what it is about being a carer that goes beyond this. Also, in taking on these extra caring responsibilities, the boundaries between informal and formal care can become blurred. As Anne noted, her ability to take a more detached, professionalised approach towards caring for her grandmother helped them both get through what needed to be done:

Anne ...I’m able to go into that professional role because I know that this is what I’ve got to do this, this is what we’ve got to do at this time... and, just to get it done and there’s no, there’s no bantering and bartering, and stuff as what they like to do with the medication.

(Group 2)

Dawn also talked about the ways in which being close to the person you care for can impact on the type of care you are able to provide, and the group expressed agreement:

Dawn Mmm, I mean even my daughter, she’s a [professional who works in mental health] and her and her nan will be arguing and shouting and I’d say, “I hope you don’t talk to your clients like that! What would your manager say?!” [adopts voice of daughter] “Oh mum, you know, it’s different when I’m at work! I’m a very good [professional]” which she is...

Frank Yes

Anne It's hard...

Dawn ...she is

Anne ...it's hard when it's personal though isn't it?

Frank Yeah

(Group 2)

This also linked in with Dawn's experiences of knowing a number of professionals who were also carers, and the idea that the boundaries between informal and formal care are not always clear cut. For Dawn, the level of practical skill she had acquired was a source of amazement to both her and her mother as she recounted learning how to undertake complicated procedures. Other participants also talked about learning by doing, and being forced to take a trial and error approach to some aspects of caring through simply not knowing what else to do. Frank talked about the power of information and the efforts he put into researching his father's condition and medication. He outlined how his knowledge had informed the professional care offered to his father and that he felt a sense of achievement from being able to contribute in this way (though he also found it hard to believe that the professionals did not seem to be aware of some of the things he told them). In this discussion thread, Dawn made a case for it sometimes being better not to know certain things, suggesting that too much information can overwhelm and scare carers. There was therefore the suggestion that information should be shared at a pace that is set by service-users and their families, with opportunities for questions, and the sharing of information materials (e.g. leaflets, books, websites etc.), that family members feel most comfortable with, being provided by professionals.

Indistinct boundaries between informal and formal care can also impact on close family relationships. Dan talked about his relationship with his son, and how good communication and

information sharing could help families and professionals develop a better understanding of what is going on when a person becomes unwell:

Dan ...that's something else, we, as parents, we know these people, far better than a psychiatrist can judge, I think, in an hour or so, and erm, but we need the right questions and the right prompts and people to ask us things to lead us down, to get more information out of us because we don't know what you, as psychiatrists, want to know.

(Group 3)

This also links in with participants' experiences of feeling that nobody cared for their relative as much as they did, or would bother to offer the level of help and support necessary in the way that they did. This was also highlighted in discussions about the future, and what would happen when carers were no longer around to offer support (this is further discussed in the subsequent theme about concerns about the future). The needs of service-users and carers were often described as being bound up together, something that is also reflected in the literature. However, while these needs might well be closely linked, there may also be key differences that need to be addressed (e.g. Fadden *et al.*, 2005). Noel summed this up after talking about the help he has received recently to support his son:

Noel ...and then there were our needs, you know, there's the needs of the patient as it were and then the needs of the carer, which are inextricably linked.

(Group 1)

5.4.5 Being an informal carer... means having to deal with (un)professional conduct

Another key feature of being an informal carer seemed to be linked with the trials and tribulations of navigating the formal care system and relationships with mental health professionals. All of the participants expressed some level of dissatisfaction with mental health and social services. For

some, poor experiences had gradually given way, over time, to more positive ones, usually as a result of a lot of “fighting”, “pushing”, “screaming and shouting”. Participants’ concerns about services seemed to be chiefly linked to: poor communication; disparity between good and bad professionals; and services being too reactive and incident driven.

Concerns about not being listened to were raised by a number of participants throughout the groups. This links with the previous theme which highlighted the fact that carers have expertise in their situation, often knowing the service-user better than most, and being in a position to offer and accept information that will help in the overall package of care. For many participants, a sense of being “shut out” from involvement in formal care seemed to make it difficult to manage their informal caring responsibilities. A number of carers discussed their beliefs that their knowledge and skills might be perceived as threatening by professionals, leading to friction in relationships. Robert talked about his experiences of learning new skills, as well as trying to use knowledge and skills gained in other areas of his life, within his caring role:

Robert I've actually been on some training right, that I've actually done on, er, like voluntary basis, right, and that's where I actually learnt that from right, and when I actually told the other team, er they were quite, er, stroppy with me, because that's, because I don't come from a caring background, because I come from [another professional] background right, so caring right, er, it's not and they'd invited, because I used to sit on management on the other side right, and so when I, er, transferred my skills on this side, they don't like it er, because it's like me basically telling them what to do, and they don't like that.

(Group 1)

Disparity between good and bad professional conduct was also an issue, with a number of participants citing unprofessional conduct as presenting difficulties. In Group 2, social workers took the brunt of Frank's disdain for professionals, after a particularly difficult set of experiences

around the time his father was making the transition into residential care. He told his story of having to make a complaint after being treated badly, and being told that action would be taken. He then found out that another person was also having a poor experience with the same professional and questioned what services were doing in allowing this sort of thing to continue. The group discussed the idea that professionals often have stressful jobs, acknowledging that nobody is perfect, but also that maybe not everybody working in mental health is well suited to the role:

Anne ...you know, somebody, some people, sometimes they do go into roles maybe that isn't totally suited to them.

(Group 2)

This idea of personal suitability, and professionals not considering their impact on difficult situations, was echoed particularly strongly by Dan in Group 3. Dan talked about his experience of professionals coming to his house to go through the sectioning procedure (to be hospitalised under the Mental Health Act) with his son:

Dan ...erm, but my first impression was that, you know, they do say that the psychiatrists are the odd ones, but [S/he] seemed to go out of [His/her] way to be just that, but [S/he] hadn't really given much thought to [His/her] sense of dress, and [S/he] was lax, and hanging, draped over the furniture [leans back in chair with arms spread out and over the back to demonstrate]... so I thought, that's a good impression, [clothes looking dishevelled], oh right, this is the professional!

(Group 3)

However, in amongst many stories of difficult and challenging encounters with "the system" and particular professionals, a number of participants had also had some good experiences. Dawn

talked about feeling included in her mother's multidisciplinary team, and supported to help make decisions about her mother's care. Marie described having a "strong team" of people around her mother now, which relieved some of the pressure on her:

Marie You have to fight sometimes for the best people, like I had to fight for a, decent social worker, and now she's got a decent social worker, and I had to fight for a decent psychiatrist, and now she's got a decent psychiatrist, but it shouldn't be that, there should be good and bad people in a profession... most psychiatrists, or most social workers should be able to do, but it's not, there's huge disparity, and her care is managed, and her case is managed quite well now, she's in a good place now, but I've had to fight to get her into a good place.

(Group 3)

There was a strong sense across the groups that getting good formal care was reliant, in part, on informal carers putting in a lot of effort, working hard to overcome the challenges presented by the huge variation that exists between professionals and services. In addition to disparity between professionals, services were often seen as being overly reactive, and incident-driven. In Group 1, Noel and Edward both talked about waiting for a crisis to happen:

Noel ...and I went up to the surgery and spoke to the doctor and then the consultant, and a social worker, and in those days it was a case of, well, it's their life, they're over 18 or whatever it is, we, you can't, they can do what they like, they don't, refuse medication they can do, and that was the problem we had, and then I got hold of the consultant and I really gave him a roasting, I said, "Look, you're ruining not just his life, ours."

(Group 1)

Edward To a point, but you see, we've just got to a situation where our daughter won't actually take any medication, she's had enough, and that's it, she's rebelled, you see, we can't do any more about it, we've just got to wait, and if there is a problem we've got to pick up the pieces, that's the problem.

(Group 1)

These extracts very much highlight the impact that crisis situations can have on family members, having their lives "ruined" and being left to "pick up the pieces". As Marie summarised:

Marie And it's a very reactive service, it pushes you to the point where you have to have, er, disasters before it takes you seriously, and we have to get to crisis point, and I hate that, because crisis point stresses the whole family.

(Group 3)

Good experiences with formal care systems (professionals and services), were very much linked to open, honest communication and information sharing. Unfortunately, having a good experience of formal care was all too often linked to previous challenging experiences. Participants talked about having to go to a lot of effort to get their point of view heard (even though they felt they had valuable information because they know the service-user so well). Difficulties in communication often resulted in stress and tension which participants felt could be easily avoided if professionals were more willing to listen to them.

5.4.6 Being an informal carer... can present concerns about the future

Concerns about the future were expressed by a number of participants. In Group 1, Edward, Ellie and Noel were worried about how their children would get on in the world after they had passed away. While this may be true to some extent for most parents, there seemed to be the sense that

the things that they did for their children would not be easily picked up, or monitored, by others, which could lead to difficulties. Edward and Noel both highlighted financial concerns for their children, with Noel also picking up on issues around medication management and efforts to widen his son's social circle:

Noel ...what happens when we're gone? Who's going to dole out so much money so he doesn't get into debt? Erm, make sure he takes his medication each day? He comes round to us for an evening meal and the medication is taken in front of us before he leaves that night... so, it's all those things, erm, occupying him now, we're getting him involved with, involved with more people, and little societies and this sort of thing so that'll gradually help, but he needs somebody to make sure that he's looking after the house, [Charitable Trust] may do that with him once or twice a week, and somebody to dole out the money, I believe social services would do that for you, er, they do it with several people in [local area], erm, particularly when it comes to holidays, you know, they'll, there's an amount in the account, or they would do it, er, to help you, er, but, you know, you can only set up as much as you can in advance, otherwise, then it's like the captain of a new ship, he's on his own, you know, after that.

(Group 1)

Here, Noel suggested that charities and social services might be able to help with some things, but that they would not put the same amount of effort into caring as he and his wife did. Later in the conversation, Ellie picked up on Noel's descriptions of the amount of effort involved, and the close bond that can be associated with, caring for a relative:

Ellie I think I worry, to when, when they're left, you know, that it, that is my biggest worry, when, you know, if we're not around to, supervise [Laughs] because I don't think anybody cares.

(Group 1)

This extract reemphasises a point that Theresa raised earlier in the group, saying that you can't expect a stranger to put the same amount of input into caring as a relative would. This seemed to tap into the fundamental sense of what an informal carer is, and what is offered in comparison to formal care. In contrast to participants' thinking about 'after *we're* gone', two others, in the position of caring for a parent, also considered what would happen 'after *they're* gone'. In Group 2, Dawn described a project she took part in that aims to open a dialogue about living and dying. Throughout the discussion, Dawn talked about how her mother being unwell had been a big part of her life and she mentioned that others are concerned about how she will manage when her mother passes away:

Dawn I've done things, a lot of things with [bereavement group] and erm, even they said to me, you know, and I think, "Who do I turn to?", you know like... but it is going to be difficult, because she's always been part of my life and I do think, you know like, eventually that mum will die, and you know, what do I do?

(Group 2)

Frank also acknowledged that while it could be a while away yet, he has also thought about how he will handle the situation when the time comes. They both agreed that, while most children will have to face the fact that their parents will not be around forever, there is something a bit different about their situation as carers, linked to the amount of time and input they have had into their parents' lives. Dawn talked about involving herself in activities and the importance of finding

things to fill her time, which Frank agreed with. Dan also brought up an interesting point about caring relationships between parents and children as children grow older:

Dan This is an important thing isn't it really, for parents particularly, but carers in general anyway, you want to know how it's going to span out for the future, what's going to happen, they might be safe and secure at the moment, and controlled, um, but for the future, you really want to know that the services and support's going to be there, because when we knew he was ill, obviously we were worried about, [His] future, the fact that perhaps when we were older he wouldn't be able to look after us as we might have expected, like, perhaps parents do, and that he's going to need care, as well, beyond us, I mean, we could make financial arrangements to make sure, perhaps at least he'd have a roof over his head, but, you know, we just couldn't really see how he'd ever manage that, or manage himself.

(Group 3)

While thinking about what happens after either the carer, or the cared-for person, is no longer around, was important to a number of carers, others did not mention it. This could be because they simply hadn't found themselves in a position to think much about it, or perhaps because they did not want to talk about this particular subject with the group. However, concerns about the future were not just limited to discussions about end of life. As noted above, Robert (Group 1) and Marie (Group 3) expressed concerns about future employment prospects, citing stigma around caring as a particular problem. Lynne (Group 3) also talked about her concerns for her daughter's future, thinking about how she would be able to support her daughter, and have some input into her life when her accommodation situation changed and she was more independent in the community.

5.5 Discussion

5.5.1 Reflections on carers' participation in research focus groups

All of the participants engaged with discussions about caring, and shared their personal experiences for the benefit of this research, with a view to improving things for other families affected by mental health difficulties. As previously noted, all of the discussion groups overran by at least 30 minutes more than the proposed time of one hour. The researcher was mindful of the time throughout, advising participants when the one hour mark was approaching, but all participants seemed happy to continue past this point. Only one participant left a little bit earlier than the others but this was due to a prior engagement, not as a result of no longer wishing to participate. All participants were courteous towards each other, taking turns and generally not talking over one another. Participants interacted well with each other, responding to each others' stories as well as prompts from the researcher as the groups progressed.

Participants in each of the groups seemed to find a lot of common ground between them, while at the same time sharing unique experiences. Where disagreement occurred, group members listened to each other, and rather than attempt to suggest that the other participant was wrong in any way, would go on to express their own opinion instead. Participants would also sometimes preface their comments with statements like, 'in my opinion' to make the point that they were aware that others might think differently about things. There was never a sense of animosity between participants, rather the groups felt open, honest, and supportive throughout. The value of using focus groups as a method of data collection for an IPA study is further discussed in Chapter 9, where consideration is given to the range of data collection methods (e.g. focus groups, written methods, multiple perspectives etc.) utilised in the studies presented in this thesis.

Although the sample was homogeneous in that all participants were caring for a close relative (adult child, parent, or grandparent), the age range of participants, and the length of time that they

had been caring for did vary quite significantly (though the mean length of years spent caring was 20.6 years). It is also interesting to note that while many studies involving carers seemed to attract predominantly female participants, the gender divide in this study is fairly even (6 female, 5 male participants), and that this was a result of convenience, not purposive, sampling. However, although the group composition was quite diverse, the experience of caring for a person experiencing a mental health problem, having to manage and adapt to changes in their relative's ways of thinking, feeling and behaving, was common to all participants.

5.5.2 How carers understood the experience of caring and the language used to talk about it

Despite attending carers' support groups and responding to the researcher's advertisements, a number of participants said that they did not really think of themselves as 'carers'. They were therefore in a position of loosely identifying with the language of caring, though not really seeing it as being a key feature of their identity. However, there was a sense that in not identifying with the term, participants had missed out on valuable help and support. Caring for a relative when they become unwell was presented as a natural part of the experience of being human, something that we all understand implicitly and which is reflected in our bonds with others. This was often reflected in the participants' use of language like "automatic" and "natural" to explain how they had come to take on caring responsibilities. It is interesting to note that while most of the participants described their role in these terms, only one carer expressed ideas about caring being a deliberate choice. Indeed, this carer was caring for a grandparent and was therefore one generation removed from the experiences of many of the other carers who took part (who were sharing experiences of parent-child relationships). Although it would be inappropriate to speculate on the closeness of these participants' relationships here, it might well be that where relationships are not as immediately close as might be expected in the parent-child dyad, there may be more perceived freedom in terms of choice around caring. Societal expectations about who will provide care when somebody becomes unwell may make it likely that parents and children feel they have certain obligations to one another that grandchildren feel they have a greater degree of choice over.

When it came to describing 'caring', the language used was often quite vague, with talk about things like: having an impact (on the carer's, family's and service-user's life); having input into (the service-user's life, carers' groups); and taking responsibility for things (e.g. finances, household chores, childcare). Many of the things that these carers did were seen as an extension of normal caring relationships (e.g. spending time together, helping around the house, helping out with money), but others were clearly more specific to caring for somebody experiencing mental health difficulties. For example, spending time with the person when they are showing signs of their condition might be extremely challenging, facing situations like being verbally abused, listening to delusions, and witnessing bizarre behaviour. Managing medication and other health-specific interventions can also be a big part of caring. Helping out in this way might involve: learning about medications and their side effects; knowing how to administer medications; and helping to monitor anything from behaviour to blood-work. While many participants helped out relatives financially, they talked about having to take greater responsibility as a result of their relative's condition, for example, taking sole responsibility for their estate; helping to buy things like food and clothing; or contributing towards the provision of formal care. Carers might often be involved in strenuous physical activity over a prolonged period, something participants reflected on as presenting another challenge as they advanced in years. Participants also talked about the mental and emotional energy that they put into caring, and the fact that this can be difficult to manage and sustain over time.

Despite all of the extra responsibilities participants talked about taking on, there seemed to be a general sense that being a carer meant doing what you would normally do for a relative, only doing a bit more. In describing caring in this way, the participants seemed to be normalising their caring role, which produced the effect of minimising the efforts they were making to support their relatives. However, this contrasted with other stories about participants going to extraordinary lengths, and being pushed to their limits, in offering care and support. This contradiction between 'only doing a bit more' and 'going above and beyond' what might be expected of normal close relationships highlighted an ongoing tension between being a concerned relative and being a

'carer'. This conflict may well have implications for the ways in which people who take on caring responsibilities are able to manage their own psychological needs and well-being. As noted in Chapter 2, self-determination theory (Deci & Ryan, 2002) offers one framework for thinking about the ways in which caring might impact on an individual's basic psychological needs and inherent human need for personal growth, by identifying, autonomy (e.g. perceived control of choices about caring); competence (e.g. perceived ability to manage caring within the context of their daily lives); and relatedness (e.g. family roles taking priority over the 'carer' identity). Minimising caring responsibilities may therefore be one way of normalising experiences of caring and mental health difficulties within the context of the carers' lifeworld, and therefore reducing threats to autonomy, competence and relatedness. How carers' psychological needs can be supported to promote well-being and personal growth, when faced with the challenges of caring and mental health difficulties, will be further discussed in Chapter 9.

As well as actually doing things, there was also the sense that carers were in a position of having an increased burden of worry about the person they were supporting. While all parents will worry about their children to some extent, for these carers there was a sense that their relatives were less independent than their peers, and that they would benefit from ongoing help and support for the rest of their lives. For the parental carers, this often raised concerns about what would happen after they had passed away. A number of participants also expressed ideas about nobody caring for their relative as much as they did, and that if they were not around to offer help and support, their relative would be disadvantaged.

So, although there was a sense that the word carer is easy to define and understand, these carers seemed to find that it was something that took a whole range of experiences, often over a prolonged period, to recognise that it applied to them. Even then, it seemed that there was often some discomfort around identifying with the term 'carer'. A number of participants stated that the familial connection took priority over being a 'carer', and that the word carer seemed almost to diminish the primary familial role. There was a sense that this might lead professionals to view

carers as a homogeneous group of people, only there to offer help and support, rather than as individuals who have complex caring relationships with service-users. Clear illustrations of this occurred when Frank talked about his experience of referring to himself as “only” a carer (Group 2), and when Dawn talked about there being “...no mums and dads, brothers and sisters, sons and daughters because we’re all becoming carers.” (Group 2). This seemed to be a cause for concern, with carers wanting professionals to be aware that, for many, being a carer is an extension of a caring role, not the be all and end all of their relationship with their relative.

It is interesting to note that although the term carer was often contested, none of the participants expressed any desire to be rid of it. They acknowledged that although it is a term they often only loosely identify with, it was useful in terms of “opening doors” and accessing support. In their critique of the universal adoption of the term ‘carer’, Molyneaux and colleagues (2011, p. 434) suggest that, “Each caring relationship should be identified according to the relationship from which it arises”, avoiding labelling that might lead to negative consequences for sense of self and damage to the relationship between the ‘carer’ and ‘cared-for’. The participants in this research seemed to have faced negative experiences as a result of either not realising they were carers (missing out on help and support), or as a result of the carer label inspiring prejudice from others (particularly in relation to employment opportunities). In terms of the relationships between the carer and cared-for person, the label seemed to be something that carers were wary of, highlighting that it can create awkwardness and misunderstanding about the nature of their relationships, for example as highlighted in extract illustrating the confusion between Ellie and her daughter, whereby her daughter questioned Ellie’s role as a carer, wanting to see her parents as “mum and dad”, not “carers”.

As outlined by these participants, being a carer is intensely personal, yet at the same time incredibly common, experienced by countless others. It is seemingly so obvious that it does not require explanation, yet at the same time not well understood by outsiders. It may or may not be a choice, and being labelled as such can be both helpful, and a hindrance. It often means finding

empathy and support in the experiences of others, yet can lead to experiences of prejudice and the need to be “secretive” about caring activities. Much of informal caring is also often bound up with formal care, navigating formal care “systems” like health, social care, and benefits. The professionals that make up these systems are also a key feature of the experience of caring with exclusion, rapport, and the timeliness of intervention often having a huge impact on carers' daily lives.

5.5.3 Implications of this research for improving carers' experiences

It would seem that much of what would improve the experience of informal caring is heavily bound up with what is offered by formal care services, and the way in which it is offered. In terms of what is available for carers, a number of participants talked about there being a noticeable change for the better over the years. Although this is promising, Noel (Group 1) and Marie (Group 3) both highlighted their perceptions that there seems to be a certain amount of duplication of services which can be confusing for carers, and wasteful of resources. Participants suggested that services would benefit from being more “joined-up”, placing an emphasis on better communication with other service providers and carers.

Participants noted that one of the ways in which progress had been made in thinking about carers' health and support needs, is through the introduction of carers' assessments. However, concerns were often expressed about the utility of such assessments, with some participants taking quite a cynical view that they were simply a tick-box exercise for services to demonstrate carer involvement. For example, Marie talked about completing a number of carers' assessments and care plans, but that the paperwork was fundamentally useless until she decided to “fight” for the bits she really wanted. The experiences of these carers seemed to suggest that the onus for achieving successful outcomes from carers' assessments lies with the carers themselves. This was perceived to be an added burden for carers who are commonly already stressed and exhausted by the time they come to be assessed. There would therefore seem to be a greater opportunity for

services to monitor and evaluate the ways in which the assessment process is utilised. For these activities to be meaningful to families, services need to communicate clearly, honestly and openly with carers about how they will meet the needs identified, and what should happen if they are unable to meet these needs.

In areas where there seems to be a greater expectation that there will be carers involved in the service-user's daily life (e.g. child and adolescent services involve parents; older adult services involve adult children), participants' experiences seemed to reflect receiving a better service when compared with adult services (which are often geared towards treating the individual). Family awareness training for mental health professionals in such services might therefore be beneficial. Also, disparity in the quality of care offered by professionals was a source of concern for many participants, illustrated by stories about immensely challenging and stressful situations. Again, honest, open communication seemed to be a big part of what carers saw as the solution to many of the problems that are exacerbated by carers being "shut out" of formal healthcare. Participants highlighted training (for professionals and carers), interpersonal skills, and communication as being key issues in developing meaningful collaborative relationships.

These participants' experiences also seemed to suggest that caution should be exercised in terms of using the language associated with informal care. Professionals should be mindful that those people they might identify as carers might feel conflicted about being labelled in this way, identifying with it to different degrees at different times. These people will often have pre-existing familial, or friendship, bonds that are more of a priority to them than being a 'carer' (and may be being threatened), when a relative or friend becomes unwell. It may be that rather than abandoning the term carer, the way we define and value it needs to be reconsidered.

5.5.4 Limitations and ideas for the development of this research

All participants were recruited through attendance at support groups. It is noted that by attending such groups, people might develop certain ways of talking about their experiences in group situations, and that this might have an impact on the research findings. To overcome this potential for the sharing of any one support group's jointly constructed story as much as possible, convenience sampling and constructed groups design were utilised by the researcher. The aim of this was to encourage the carers to talk to others that they were not overly familiar with so that they might spark off new ways of thinking about things and therefore go beyond how they might usually talk with their own support group peers. Participants were encouraged to share their stories, and seemed confident and comfortable in doing so, which might also be a feature of their experience of attending support groups.

A key concern considered by the researcher, and also discussed in Group 3, is how to access the experiences of carers who do not attend carers' support groups. Concerns were expressed about how to explore the experiences of family members who are not in contact with service-users, for example, where service-users have been rejected by families who feel unable to cope with them. It could well be anticipated that family members' experiences in situations like this would be significantly different to those captured by this research. However, how to access and engage with people in these circumstances presents a number of difficulties. For example, it seems reasonable to suppose that they are not likely to identify with the term 'carer', or to attend carers' organisations, or mix with other carers; they are less likely to be identified by health services than those who actively seek to be involved in their relative's care; they may be less likely to need support for the practical aspects of caring (e.g. respite, financial assistance, medical supplies) and so less likely to seek out or be involved with any services that would identify them as carers. However, it may be argued that such people are in even greater need of emotional support and guidance to help them through a difficult situation.

In order to go beyond the experiences of self-identified carers, this research also includes the experiences of carers who have been identified in other ways, for example, by Early Intervention services (see Chapters 6 and 7). Consideration might also be given to trying to recruit people through general practitioners (GPs). Indeed, a number of participants shared experiences of talking to their GPs about their health concerns and caring responsibilities. In cases such as this, GPs might be willing to explore whether their clients would be interesting in taking part in this type of research. However, it is noted that this would be extremely time consuming and not without a number of ethical considerations. Indeed, there might be particular issues concerning the impact of GPs labelling their clients as carers, and how to approach talking about caring where the GP is aware of a caring relationship even if the individual does not recognise it themselves.

Following this chapter, Chapter 6 explores service-users' and carers' experiences of first-episode psychosis. This leads on to an exploration of one family's experiences of mental health difficulties in Chapter 7, and mental health professionals' experiences of identifying and working with families and carers in Chapter 8. Further consideration of how these experiences relate to the wider research project, and the literature on caring more generally, is covered in Chapter 9.

Chapter 6

Exploring the meaning of service-users' and carers' experiences of first-episode psychosis

6.1 Abstract

Data were collected from mental health service-users and informal (unpaid) carers in order to explore the effects of written emotional disclosure on post-traumatic stress disorder (PTSD) symptoms following a recent first episode of psychosis. Data were collected from eight community-based, Early Intervention, psychosis outreach service-users (three male, five female, aged from 18-33 years, mean age 23 years) and eight carers (one male, seven female, aged from late-30s to mid-50s). Seven of the carers were caring for a child, while one was caring for a spouse.

The studies for which the data were originally collected, using quantitative analysis, suggested that the traumatic effects of first-episode psychosis can be reduced for both service-users and carers through the use of written emotional disclosure as an intervention (Bernard, Jackson & Jones, 2006; Barton & Jackson, 2008). The strong experiential component of the data also suggested it had more to offer from a phenomenological perspective and therefore warranted further analysis. This was done using interpretative phenomenological analysis (IPA) in order to further explore the lived experience of first-episode psychosis from both service-users' and carers' perspectives.

Analysis suggested that issues around identity and loss were key concerns for both service-users and carers, particularly in relation to the impact of psychosis on the service-user's personality: who they used to be; and who they could be in the future. There also seemed to be striking similarities between service-users' and carers' concerns with adapting to a change in circumstances and dealing with future uncertainty, with both groups expressing concerns about (and hopes for), the

future. A key difference between the groups centred on a sense of conflict about the potential causes of mental health difficulties. For the most part the service-users did not express their thoughts about why they might have become unwell, whereas the carers tended to focus far more on the possible causes of their relative's condition, often describing concerns about their own role in the development of mental health difficulties.

Although there is a growing body of literature utilising qualitative methods of analysis with written accounts, there are few that specifically make use of IPA. This chapter suggests that participants' written accounts can be analysed successfully by taking an IPA approach, and illustrates some of the potential benefits and constraints associated with taking this approach.

6.2 Introduction

People experiencing psychosis are often in regular contact with an informal carer, a role that often falls on family members or close friends, who offer support and care without being paid to do so (World Health Organisation, 2003; Pinfold & Corry, 2003; see Chapters 2 and 3). There have been many studies exploring psychosis from both service-users' and carers' perspectives and a number that have investigated trauma-symptoms relating to psychosis. It has been estimated that approximately one third of people develop post-traumatic stress disorder (PTSD) following psychosis (Morrison, Frame & Larkin, 2004), and that carers of people experiencing early psychosis are also likely to be affected by trauma symptoms. It would therefore seem pertinent to explore interventions aimed at reducing trauma symptoms in these populations. One such approach is written emotional disclosure as developed by Pennebaker and colleagues (Pennebaker & Beall, 1986). This approach encourages emotional expression through writing about trauma-related thoughts and feelings. This involves emotional processing, exposure and cognitive restructuring. One indirect outcome of asking participants to express themselves in this way is the generation of accounts which may lend themselves to qualitative analysis. Qualitative analysis methods can be applied to a range of data sources. Many studies have utilised written accounts, and

some have analysed written emotional disclosure data (e.g. Theadom *et al.*, 2009; Byrne-Davis *et al.*, 2006; van Zuuren *et al.*, 1999).

More typically, written emotional disclosure is used as an intervention, and its outcomes are measured in terms of variables related to distress and trauma. Bernard and colleagues (2006) utilised this method with 33 participants who had recently experienced a first episode of psychosis and who were in a recovery phase of their condition at the time of their recruitment to the study. They found that participants who wrote about their first episode of psychosis demonstrated reduced PTSD symptoms when compared with participants who wrote about an unrelated topic. The positive change was linked to a reduction in participants' avoidance of reminders and feelings of first-episode psychosis. This research prompted a further study within the same service, which aimed to establish whether the written emotional disclosure method could also alleviate trauma-like symptoms among carers of people with psychosis (Barton & Jackson, 2008). In that study, carers practicing written emotional disclosure were significantly less likely to avoid reminders and feelings associated with their relative's episode. Those who had exhibited trauma-like symptoms also showed reductions in trauma severity. They concluded that written emotional disclosure could be helpful for carers experiencing trauma symptoms following a relative's first episode of psychosis.

These are promising findings with implications for mental health service provision, if they can be replicated on a larger scale. In addition, more can be learned about the relational and familial experience of first-episode psychosis by further utilising the dual-perspective data generated in these two studies. In this chapter, a qualitative exploration of the written accounts of carers and service-users is presented.

As might be expected from a task designed to elicit accounts of stressful events, the written emotional disclosure data from these studies were rich in experiential detail and appeared well-suited to a phenomenological approach to further analysis. The focus of this chapter is on

understanding the meaning of participants' experiences, and interpretative phenomenological analysis (IPA) was adopted to guide further exploration of the data. IPA is an approach expressly developed for the analysis of small numbers of rich, first person data. Its grounding in hermeneutic phenomenology (Smith *et al.*, 2009) – which emphasises the perspectival and relational qualities of human experience – means that it copes well with accounts which explore phenomena from more than one perspective (e.g. Wane *et al.*, 2009; Rostill-Brookes, Larkin, Toms & Churchman, 2011).

While IPA studies have most frequently drawn upon research interviews for their data, IPA researchers have also used focus groups, diaries, and internet forums (Palmer, Larkin, de Visser & Fadden, 2010; Smith, 1999a; 1999b; Telford, 2009). As Smith and colleagues noted, “IPA is best suited to data collection methods that invite participants to offer a rich, detailed, first-person account of their experiences.” (2009, p. 56). Although the data presented in this paper were not specifically collected with this principle in mind, the results do meet these criteria. The principle aim of this chapter is to illuminate the experiences of service-users and carers in early psychosis, with a particular focus on their relational qualities and their interdependence. Reflection on the suitability of using participants' written accounts in IPA research (specifically written emotional disclosure data), will also be presented.

Chapter 6 therefore seeks to address the following research questions:

1. What is it like to directly experience, or to care for a relative who experiences, a first episode of psychosis?
2. Is interpretative phenomenological analysis an appropriate approach for examining written emotional disclosure data?

6.3 Method

6.3.1 Data collection

The data discussed in this paper were originally collected as part of two intervention studies conducted by Mark Bernard and Karen Barton, both clinical psychologists working in the English Midlands, UK. These studies were carried out with service-users and carers to examine the effects of utilising written emotional disclosure as an intervention for post-traumatic stress disorder symptoms (Bernard *et al.*, 2006; Barton & Jackson, 2008). Further details of the service-user and carer participants are provided below, followed by an outline of the IPA process.

Participants took part individually, and were told that the research would involve completing a number of self-report surveys. They were also informed that they would be asked to write for about 15 minutes on three separate occasions about some aspect of their experiences over a period of 4-6 weeks. They were told that they might find some of the writing tasks upsetting.

6.3.2 Participants A): *Service-users' written accounts of first-episode psychosis*

Of the 12 sets of accounts from the intervention condition that were collected from Early Intervention service-users, eight were selected for further analysis here. Of the four that were not selected, one participant withheld their transcript, one was significantly older than the rest of the sample and two only completed two out of the three writing sessions. Therefore, those selected were considered to be a more homogeneous sample of Early Intervention service-users. Of the eight sets of accounts that were selected, three were written by males, five by females. Participants were aged from 18-33 years (mean age 23 years). All participants had recently experienced a first episode of psychosis and were asked to write about the most stressful and upsetting aspects of their condition and treatment (or whatever they had reported on the *Impact of Events Scale-Revised* (IES_R) – e.g. psychosis, paranoia) (Weiss & Marmar, 1997), using a protocol adapted from

Pennebaker and Beall (1986). Bernard and colleagues (2006) stated that to meet ethical criteria all participants were not currently acutely psychotic or suicidal at the time of participating. With regard to the suitability of the data for further analysis, a preliminary content analysis of participant's accounts by Bernard and colleagues highlighted the following:

“The majority of participants wrote about the debilitating and threatening effect of positive symptoms (e.g. voices, delusions, hallucinations, paranoia) and the negative emotions that accompanied these experiences. In addition, many participants wrote about other negative experiences such as being sectioned, the adverse effects of taking prescribed medication, stigma and interpersonal rejection. However, some participants also wrote about positive experiences of contact with mental health services and nearly all expressed a desire for support and understanding.”

(Bernard *et al.*, 2006, p. 410)

The participants were given pseudonyms during the analysis process. The service-user participants are referred to throughout as: Claire, Delia, Kerry, Carole, Sally, Simon, Charlie and Dave.

6.3.3 Participants B): Carers' written accounts of a relative's first episode of psychosis

From the accounts collected in the carers' intervention condition for the original study, eight were selected for further analysis. Of the participants that were not selected, a number wanted to keep their data (thus making it unavailable for further analysis), or withdrew from the original intervention study. Of the eight sets of accounts that were selected, one carer was male, seven were female. All of the carers were aged from their late-30s to mid-50s. Seven of the carers were caring for a child, while one was caring for a spouse. While the homogeneity of the sample in terms of gender and relationship to the cared-for person might seem somewhat compromised (one male/seven females; one spouse/seven parents); the main factor linking their experiences together is that all of the 'cared-for' who formed the focus of the carers' experiences in this group had

recently experienced a first episode of psychosis at the time of writing. All participants were over the age of 18 years, had capacity to understand the nature and purpose of the research, and gave written informed consent to participate. Participants were asked to write about their thoughts and feelings concerning the time that their relative first experienced psychosis. An example of the rich, detailed, first-person accounts that pointed towards using an IPA approach with these data is given below:

“D Day, Judgement Day, Armageddon, the End of the World, the most awful day of my life so far happened on [date]. The day that [my son] was sectioned under the mental health Act. Oh yes, we had had some bad times leading up to this dreadful day, but nothing could have prepared me for the awfulness of seeing my eldest son go mad.”

(Sharon, Parent, Account A)

The participants were given pseudonyms during the analysis process. The carer participants are referred to throughout as: Laura, Becky, Angela, Elsie, Sharon, Paula, Emma and Sid.

6.3.4 Data analysis: utilising interpretative phenomenological analysis with written accounts

All data were transcribed by the researcher (MP) from participants' handwritten accounts. Each participant was given a pseudonym and their accounts were formatted to appear as close to the handwritten account as possible with regard to paragraphs and punctuation. Occasional difficulties making out words in the handwritten accounts meant that a few words were not transcribed, but this was comparable with not being able to hear every word uttered by participants taking part in audio-recorded research interviews. The length of the accounts typically varied from around half a page, to a full page of handwritten text.

Much has been written about how to go about doing IPA (for a more detailed discussion of its use and application see Smith *et al.*, 2009; Larkin & Thompson, (2011); or Willig, 2008). The analysis of these data did not differ significantly from commonly used analytical practices, beginning with a detailed, descriptive coding of the data and becoming increasingly interpretative as the analysis developed.

The analysis was developed on a case-by-case basis. The cases in each sample were then brought together to explore emerging themes and to examine similarities and differences. The initial thematic structure was further refined and developed at this stage. This process was completed for each of the two samples, before a further superordinate review was conducted to bring both analyses together. Bernard and Barton provided further feedback and reflections during this final stage. The analysis was forwarded to Bernard and Barton who both marked the document with comments, including asking for clarification on certain points, or highlighting useful references where they felt it was appropriate (e.g. comments about linking faith and explanatory models of illness). The researcher (MP) then responded to these points and re-circulated the document to check that these matters had been addressed in a satisfactory way. A short extract of worked data is presented in Appendix 8 to illustrate the initial coding stage and development of emergent themes.

6.3.5 Context in which themes are set: stressful experiences

Participants were asked to write about their experiences of first-episode psychosis, with a view to exploring the effects of written emotional disclosure on post-traumatic stress disorder symptoms. It is therefore unsurprising that participants dedicated much of their accounts to the stressful and challenging aspects of early psychosis. Stressful experiences are therefore not a theme in their own right, but more the overarching context in which the themes are located, a function of the way in which the data were collected. For both service-users and carers, experiences seemed to particularly focus on: symptoms and difficult behaviour; medication; hospitalisation; prognosis;

and shame and stigma. As with the extract from Sharon's account (detailed above), the following extracts give a flavour of the ways in which distress was experienced by both service-users and carers:

“My voices say the usual comments every day but on the odd occasion I feel well. Really well they are in the far distance. On the odd occasion that I do feel well, I can't believe that I usually feel so low and down and depressed. When I'm feeling well I promise myself never to feel this way again but within a day two days or three days the most off I go into that sad sad world of mayhem inside my head.”

(Carole, Account C)

“When [my son] first went into hospital it was a relief but also tore at the heart strings. I looked into his face on the day I left him and I know he was terrified. The actual physical act of going into hospital seemed to increase his symptoms tenfold, the stress of something new, and unfamiliar and upsetting surroundings. But we all knew there was no alternative.”

(Angela, Parent, Account A)

In sharing their experiences, participants often drew attention to the broader socio-cultural and economic factors that impacted on their lives. As noted above, with experiences of stress, these things do not constitute themes in their own right, rather they inform the context in which the themes are situated. Within the service-users' and carers' accounts, issues of conflict and concerns about coping; work and financial burden; and safety and security, are often presented as a backdrop to difficult and challenging experiences.

This section will give an outline of the themes that emerged from the data and are divided into two sections: A) service-users'; and B) carers' accounts. These will be further explored in the synthesis and discussion sections.

6.4 Themes

6.4.1 Themes derived from A): service-users' written accounts of first-episode psychosis

The key themes that emerged from the service-users' experiences appeared to be concerned with existential conflicts. These involved questions about perceptions of self, and about connections to others (summarised in Table 6.1).

Table 6.1: Summary of themes derived from service-users' written accounts

What sort of person am I?	<ul style="list-style-type: none"> • 'Old' me versus 'new' me • Connections to: family, friends, strangers and professionals • How does psychosis impact on what sort of person I am?
Who I could have been and who I could be	<ul style="list-style-type: none"> • Who I could have been: stories of loss • Who I could be: planning for the future, recovery, hope, and desires for a better life ahead

6.4.1.1 Service-users' concerns with: What sort of person am I?

'Old' me versus 'new' me

Sources of conflict were present in each of the service-user's accounts in one way or another. A number of participants spent time reflecting on the ways in which their condition had affected the type of person they were. Two participants wrote explicitly about their sense of conflict between their 'old' and 'new' selves. Charlie, a young man, began his first written account by stating, "There was a time when I felt like I had failed in life." (Charlie, Account A), and went on to detail

events that led to a period of depression and suicidal thoughts. He wrote about failing in his studies and losing contact with friends, feeling trapped in a job he didn't like, and using illicit drugs, despite wanting to quit. This led up the statement: "I can't stand myself anymore." (Charlie, Account A). As his written accounts progressed, highlighting the steps taken towards recovery, Charlie reflected on what he used to be like, and acknowledged the negative impact of psychosis on his activity levels and happiness, and how he was getting back to his 'old self':

"Recently I've got control of voices (internal dialogue) I hear, attending a voices group really helped. I'm more active, confident and I feel like my old self. I've quit cannabis for 5-months and I can't see myself going to back to it. I've found a job and I'm pleased with it. I'm still working with the Early Intervention Team and they'll be there until I've fully recovered for 6-months to a year."

(Charlie, Account C)

The other participant, Carole, to explicitly contrast 'old' and 'new' selves, went a step further, identifying an alter-ego, "Katy", and making direct comparisons between "Me" and "Katy" (emphasis added):

"I am always in constant turmoil in my own head and only people that are really close to me understand how I feel. My parents think I'm okay, life is rosy but it's not. I try to discover why I feel like this and to be grateful for the things I have in life and have achieved despite my illness but I don't. *I long for my old head back.* The head that would take pride in myself and go about daily life without looking past the surface of life. I am too deep for my own good. I think and feel and hear dim thoughts and feelings every day. I mask it well though. *I wear nice clothes and do my make-up and hair because I don't want anyone to see 'Katy'.* *Katy is the girl that wakes up in the morning and goes to bed at night but in between is me. Me, is the one with the hair/make-up/clothes. Katy is a sad, despicable, depressed person who hates herself*

and all other people around her. I hate Katy. I can't believe the voices which I try hard not to do they would have me think I am a useless old soldier with no worth and self belief in anything. I hate being me."

(Carole, Account C)

Carole clearly described the turmoil she experienced, trying to make sense of her feelings. She wrote about longing for her "old head" back, referencing the person she used to be before she became unwell. In trying to explain this change, she introduced "Katy", a character she had created to represent the illness-related aspects of herself which she did not like ("sad, despicable, depressed"). While she made a clear distinction between "Me" and "Katy", the complexity of the relationship between these different parts of her identity was highlighted in strong emotional terms: "I hate Katy"; Katy "hates herself and all other people around her"; and "I hate being me". So, although "Katy" was described as a sort of autonomous figure, capable of both inspiring and exuding hatred, the boundaries between "Me" and "Katy" appeared to be blurred by Carole's experiences of conflict between the sort of person she is and how she presents herself to others. While these two participants were very explicit in identifying their 'old' and new' selves, others acknowledged a change in themselves in a less direct, and not always negative, way:

"It's made me a stronger person by what has happened to me."

(Claire, Account C)

Much of Claire's account focused on the difficult and upsetting nature of the paranoid delusions she experienced, and on her efforts to manage these difficult thoughts. By the end of her third account, Claire was beginning to focus on her thoughts for the future, thinking about opportunities for future success. While the difficult experiences had impacted on their perceptions of what sort of people they were (for example, a "failure", "hateful", "stronger", as detailed in the above extracts), the service-users also wrote about their perceptions of their connections to other people. Indeed, many accounts referenced a number of others including, family members, friends,

strangers, and professionals, and offered some reflection on the impact that these people had on their sense of self.

This theme highlights one of the ways in which experiencing a first episode of psychosis had led to some of the service-users questioning their sense of self, specifically identifying 'old' and 'new' selves. This significant change, from one to the other, seemed to be described as changeable, fluctuating along with the course of the service-user's condition. However, although this process can be extremely challenging, it is not necessarily exclusively negative, offering the opportunity for personal growth and optimism about the future.

Connections to others: family, friends, strangers, and professionals

Both of the participants (Charlie and Carole, outlined above) who explicitly identified 'old' and 'new' versions of themselves also made direct references to attempted suicide, highlighting times when they felt particularly vulnerable and were struggling to cope with their view of themselves, or perceptions of how they were perceived by others (emphases added):

"I tried to throw myself off a cliff face. Because I couldn't get through to my family. How distraught they were making me feel. At the time I felt unwanted, rejected, and unloved."

(Carole, Account A)

"A week has passed now and I've been isolated, mainly in my room not talking to family 'cos they're upset that I've left work. Now it's two weeks and my thoughts are getting too complex. I am now not only depressed but I keep thinking of numerous ways to end my life."

(Charlie, Account A)

Both of these participants described feeling isolated and unable to communicate with family members when facing difficulties associated with their condition. Others also chose to write about the way psychosis had impacted upon their relationships with their families. One participant, Delia, wrote about the way she avoided communicating with her family, to protect her family members from witnessing her difficult behaviour:

“Another thing is avoiding the outside world not communicating with other people not talking to my family. There were times when I did not want to see my family at all. I would be locked up inside the house not wanting to see anyone. I thought being alone was the best thing.”

(Delia, Account A)

However, Delia also described how, following a period of respite, she found that talking to her family was helpful for her recovery. Aside from family relationships, a number of participants also reflected on the nature of friendship. Some focused on difficulties they had, while others wrote about the positive aspects of friendships. For those experiencing difficulties, suspicions about friends' motivations towards them, and the idea that people might not be 'real friends' appeared to have an unsettling effect. Descriptions of these experiences seemed to focus on being isolated from something that should be beneficial - the idea that friends should support, help and reassure you in times of distress. In the extract below, Simon made a clear distinction between 'so-called' friends and 'real' friends:

“I felt that so-called friends that I had did not really have my interests at heart and were not real friends. I have been alone for a while and I am prepared to stay alone if I have to.”

(Simon, Account A)

In terms of his identity, Simon seemed to be making a claim about who he feels he has to be, isolated from others and prepared to stay alone, to protect himself against false friends. In a subsequent account he went on to write about the way in which he felt undermined by others as a result of his mental health difficulties, noting that all his friends are also in similar situations:

“It is also strange because people I have told that I suffered from a mental health problem have sometimes used that fact to undermine me and make me feel they were a better person than me. ... I do[n't] have any friends that are outside that mental health service. All the friends I have at the moment have had mental health problems and this hinders me.”

(Simon, Account C)

Another participant, Claire, also wrote about her experience of questioning a friend's behaviour towards her at a time when she was feeling increasingly paranoid and persecuted by others. Claire detailed how she told a friend about the problems she was having, only to be confused by her response:

“I had a friend and I told her all my problems I was having. I confronted her about the graffiti [which was a source of concern for Claire, though no further information was given about its content]. I thought it might have something do to with her. She said maybe it was and she had a grin on her face. I felt upset and confused. To cope with this problem that I had, she then told me to fight these nasty things that were happening to me by not looking at the graffiti. But I couldn't understand why she was giving me advice and it had something to do with her.”

(Claire, Account C)

In contrast to these difficult experiences, other participants related their more positive experiences of friendships. For Kerry, friends, family and faith were important factors in overcoming isolation and maintaining a sense of happiness:

“I like to have my friends and relatives around me. I like it also when friends and family write me letters. I feel that god is in my future. I don't plan too much without asking for my Good lord to guide me. I am quite happy. I have lots of relatives and friends' houses to who I can go to visit.”

(Kerry, Account C)

For another, the kindness of strangers had a significant impact on her life at a time when she faced an almost complete breakdown in communication with her family:

“I stayed with a next door neighbour. Stranger at the time. Frank his name was. He took me in, thank God.”

(Carole, Account A)

Elsewhere in their accounts, participants wrote about the important role played by relationships with health professionals (describing both good and bad relationships), and with services more generally (particularly in relation to medication). They also wrote about their worries in relation to the 'outside world' (the world of people outside of mental health services). A kind of 'existential inquiry' links all of these concerns. Through seeing themselves in relation to others, participants were constantly either asserting their identities, or re-evaluating them.

How does psychosis impact on what sort of person I am?

For the most part the service-users tended not to focus in too great a detail on why they had become unwell, or what the potential causes might be. Instead, as instructed by the research brief,

they focused more on writing about specific experiences that had been difficult for them following the onset of psychosis. Where service-users' references to potential causes of illness did occur, they seemed to be linked to the ways they thought about themselves as people (e.g. Sally: is it okay to be happy?), some of the choices they have made (e.g. Dave: taking illicit drugs), or other life circumstances (e.g. Kerry: financial stress). One participant, Sally, simply wondered why she had been affected when nobody else in her family had been:

“I have also wondered why I have this illness and nobody else in my family has got it.”

(Sally, Account C)

Research in psychosis has often looked for biological explanations, or at the impact of family dynamics, on the onset of illness, so it seems unsurprising that someone affected by psychosis might also consider these factors. This lack of focus on the potential causes of their condition seemed to contrast with the carers' written accounts, as they went into much greater detail about their perceptions of what these might be. This key difference will be explored further in the synthesis section of this chapter.

During adolescence individuals find themselves becoming increasingly autonomous. As part of this process, peer-relationships and potential mentor-figures become increasingly important, and the potential for conflict during this transition can leave people vulnerable to psychosis (Harrop and Trower, 2001). Indeed, one young male participant, Dave, wondered if his sensitive nature, feeling that he was susceptible to being easily influenced by others, had left him vulnerable to mental health difficulties:

“...it's like some of the circumstances and situations I've been in where people or inanimate objects or signs have affected me as I have taken certain things to heart and

that's why they have affected me I think I am a highly sensitive natured person and so there are influences all around."

(Dave, Account A)

Other participants also wrote about their perceptions of the impact of their symptoms and treatment on what kind of people they were, especially in relation to their ability to control their own thoughts, feelings and behaviour. For Sally, the difficulties she faced in trying to differentiate between 'normal' and 'clinical' feelings and behaviours were a primary concern:

"One of biggest problems I have with my illness is the fact of how I should feel, and is how I'm feeling telling me, or showing me, that I am going to become ill again. Sometimes I am really happy, someday it could be because of a reason or simply the fact that I woke up happy, but does this have to mean that I am becoming manic or it if was the opposite way around and I didn't feel like doing anything not even getting out of my bed does it automatically mean I'm depressed."

(Sally, Account B)

Indeed, results of studies conducted with adolescents suggested that some of the symptoms associated with psychosis, particularly those relating to the prodromal period (deterioration preceding psychotic relapse) are far more common in normal populations than might be expected (Harrop & Trower, 2001). They noted that, "...a substantial empirical literature shows that certain characteristics typical of adolescence such as conflicted family relationships, grandiosity, egocentrism, and magical ideation bear a distinct resemblance to the phenomena seen in psychotic disorders." (Harrop & Trower, 2001, p. 241). Sally went on to reflect on the extent to which her condition and medication control how she feels. The extract below highlights a conflict between what she had been told about not letting her condition determine how she feels, and how difficult this was to reconcile with having to take medication:

“I was once told that my illness shouldn't determine how I feel, but how can people say that when what determines how you feel is up to a bottle of medication.”

(Sally, Account B)

In dealing with issues of identity, the service-users focused on the specific things associated with their condition that they felt had changed who they were. At a time that is commonly associated with increased autonomy and individuation, these young people were also having to integrate aspects of their condition into their sense of self, adding a further level of complexity to growing-up and making their own way in the world. However, in thinking about the difficulties and challenges they faced, a number of the service-users also wrote about their concerns about their ability to overcome psychosis and their hopes for a better future. These concerns are encompassed in the theme of ‘Who I could have been, and who I could be’.

6.4.1.2 Service-users' concerns with: Who I could have been, and who I could be

Who I could have been – stories of loss

When writing about the difficulties they had experienced as a result of the onset of psychosis, a number of participants reflected on missed opportunities, which highlighted a sense of loss for what might have been. Simon explicitly wrote about losses associated with education and employment opportunities:

“I lost the chance to do many things because I was diagnosed with psychosis. I tried to join the [armed forces] but was turned down because of my illness. I tried to complete a number of courses but could not because of my situation.”

(Simon, Account A)

Simon also wrote about isolation and the difficulties he had experienced in developing 'real' friendships (outlined earlier in the chapter). So, in addition to the loss of education and employment opportunities, Simon also highlighted a sense of loss within the sphere of personal relationships. For another participant, Kerry, the focus of her loss was also closely linked to her ability to form connections to others, specifically in relation to her desire to have a family of her own:

“Before I took ill I had lots of plans about my future. Now everything seems too dim. One day I would eventually like to emigrate. I had a lot of hopes and plans about getting married and having children. Now though everything I said before seems dim.”

(Kerry, Account C)

The service-users' stories of loss seemed primarily concerned with loss of potential, and what might have been. This might well be a function of their young age range and the fact that they were typically at a stage in their lives where their potential outweighed their life experience in terms of individuating themselves from their parents and striking out on their own, almost, they had more to offer than they had to lose. This 'potential' is something that many of the carers were also concerned with as they considered who their relative could have been if things had been different - this will be further explored in the synthesis section. Further, contrasting with their stories of loss, many of the participants wrote about their hopes for the future, turning away from who they could have been, towards who they could still be.

Who I could be: Planning for the future, recovery, hope, and desires for a better life ahead

As might be anticipated, when asking young people to write about their experiences, their thoughts often turned towards the future. Indeed, it seemed like the service-users were attempting to set their previous difficult experiences in the context of their lives ahead of them. As with their

stories of loss, which often focused on missed opportunities in education and employment, many of the service-users' plans for the future were linked to these things:

“In the future I hope I can to do college without these problems being there. I want to achieve something in my life.”

(Claire, Account C)

“Now I am a little better I want to move on by thinking about my future ahead. I would like to study. I am in two minds I don't know whether to start work or to study. Sometimes I find it hard to think about what I want to do with myself. Being ill has made it difficult for my future.”

(Delia, Account C)

Throughout participants' accounts, stories about opportunities for the future appeared to be closely linked with thoughts of recovery, and the support that will be required from others in order to achieve their goals. A number of participants made reference to their relationships with others, specifically relating to their perceptions of their present identities (as outlined in the previous section concerning the importance of connections to others). The importance of these connections again becomes important in relation to the impact that they will have on their future identity. One young woman, Sally, made an explicit connection between encouragement from teachers and family members, and her academic achievements and progressive recovery:

“My experiences with my illness hasn't stopped me achieving my goal which was to make it to university. I had some pitfalls along the way due to it though... If it wasn't for the teachers and family encouragement my life would have taken a different direction from today. Now that I am at university I am trying to get through the course without any major hiccups and most of all trying to get well enough to come off the medication.”

(Sally, Account C)

This extract describes a struggle between ambition and hope for the future, and trying to manage the symptoms of psychosis, something that was also reflected in other participants' accounts. Carole also wrote about her attempts to remain optimistic in the face of the difficulties she experienced during episodes of psychosis:

“I hope there is a cure for me long term. I must keep fighting this illness, with research, medicine, and knowledge. It is easy to become defeated but I can't let it get to me. I promise my kids to keep fighting and I hope to feel at least as though I am winning more days than I am losing.”

(Carole, Account C)

This optimism for a better life ahead is echoed throughout participants' accounts as they focused on their potential for future achievement and success (emphasis added):

“Overall I do get distressed quite a lot some time but I believe *I will overcome it someday.*”

(Dave, Account C)

In some ways, these participants' stories about who they could have been, and who they could be in the future, reflected the same sorts of concerns that many young people face, whether or not they are affected by mental health difficulties. Concerns about educational development, employment and career prospects, and having a family of one's own, will surely be common to most people throughout their lives, and particularly at times when these things are threatened by difficult circumstances. To summarise the themes derived from the service-users' accounts, there seemed to be an overwhelming concern with the impact of psychosis on identity. These participants were very much concerned with what sort of people they were, who they could have been, and who they could be in the future. Although these things may be common to most adolescents, for these participants, the onset of psychosis had particular consequences for the development of their

identities. The links between psychosis and identity will be further explored in the synthesis section, through the integration of both service-users' and carers' accounts of being affected by first-episode psychosis.

6.4.2 Themes derived from B): carers' written accounts of a relative's first episode of psychosis

The key themes that emerged from the carers' experiences appeared to be overwhelmingly concerned with conflict around perceptions of the identity of the cared-for person, the impact of illness on the wider family, and conflict relating to the potential causes of their relative's condition (summarised in Table 6.2).

Table 6.2: Summary of themes derived from carers' written accounts

<p>Questioning a relative's identity</p>	<ul style="list-style-type: none"> • 'Old' versus 'new' relative – stories of change • Adjusting to loss
<p>Impact of mental health difficulties on family relationships</p>	<ul style="list-style-type: none"> • Changes to family structure (family breakdown) and roles within the family • Sources of support
<p>Conflict concerning the potential causes of psychosis</p>	<ul style="list-style-type: none"> • What caused this to happen? Innate vulnerability, parenting, family difficulties, and spirituality and faith, it can happen to anyone

6.4.2.1 Carers' concerns with: *Questioning a relative's identity*

'Old' versus 'new' relative – stories of change

A key component of this theme is a sense of conflict about the cared-for person's identity as the carers struggled to accept the 'new' version of their relative following their first episode of psychosis. Many of the carers who expressed this most clearly were parents of the cared-for person. A number of these carers wrote about visualising their child in the early stages of childhood:

“No-one really understood what it was like to see my daughter like this images of her as a child passed before my eyes, she now seemed like a different person, I did not recognize her anymore.”

(Emma, Parent, Account B)

Another carer, Sharon, expressed her feelings of conflict over the potential causes (i.e. parenting, family breakdown, an internal cause) of her son's difficult behaviour and change in personality. Sharon's visualisations of her son focused on some of the physical characteristics of his lost youth:

“I let him down, this was my lovely blond haired first born whom I had loved so much. We gave him everything we could but he turned against me.”

(Sharon, Parent, Account A)

A further extract from Sharon highlighted the way she positioned her son as an innocent, infantilising him back to his 'little boy' self:

“...but this underworld of drugs, deceit, scheming, stealing and getting high to the point of oblivion is a world I don't know. I don't understand, I don't like it and my little boy doesn't belong there.”

(Sharon, Parent, Account B)

This sense of having difficulty accepting the 'new' persona of their relative was also reflected in other accounts. For another participant, Angela, whether or not to accept these changes seemed to be a major source of conflict:

“I found it very upsetting watching this thing take hold of him and change his personality. He wasn't the person I knew and loved, although I knew deep inside that person was still there.”

(Angela, Parent, Account B)

“I couldn't really face up to the reality that he had got a serious mental illness, I just wanted my boy back, how he used to be. I am still struggling with this aspect and haven't fully accepted that he won't get better and be the same as he ever was.”

(Angela, Parent, Account B)

In the first extract, Angela wrote about knowing that the 'old' version of her son, the person she knew and loved, was still deep inside him somewhere. Yet in the second extract, she wrote about wanting her son to go back to how he was before the onset of psychosis, struggling to accept that he won't be “the same as he ever was”. This struggle seems to be reminiscent of conceptualisations of loss and grief in psychosis, as parents try to come to terms with significant changes in their children (e.g. Osborne & Coyle, 2002).

There is evidence to suggest that both young people and their parents can have difficulty recognizing the difference between experiencing problems and experiencing mental illness

(Watson, Kelly & Vidalon, 2009). Watson and colleagues found that most families they interviewed acknowledged that their child was having problems, but tended not to define them in mental health terms, preferring instead to speak in behavioural, or situational, terms. This also seemed to be true of these participants. Many of the carers' vividly described the 'positive' symptoms of psychosis (those which are 'added on' to usual thoughts and feelings, for example, challenging behaviour, violence and aggression). However, the negative symptoms of psychosis (those things that are 'taken away', for example, motivation) were also seen to present difficulties:

“[My daughter] is doing marvellously and is getting stronger every day, but sometimes when she goes through a ‘flat’ period at the height of the negative symptoms, I yearn for her to be able to just chat, to make small talk. Because I spend so much of my spare time with her, when she is going through these ‘flat’ periods it does feel lonely. I miss my chatty, quirky, vibrant and intelligent daughter tremendously.”

(Laura, Parent, Account B)

In addition to questioning their relative's 'new' identity, a number of the participants also seemed to experience conflict in relation to their relative's ability (or lack thereof), to make a positive change to their lives and/or get better. Were they unwilling, or unable, to change?:

“Why is he like this? Is this his illness or didn't I bring him up properly? He doesn't care about these things that bother me so much. He doesn't pay his rent and I'm constantly topping up his electric and taking him food supplies. The rest of the time he goes round to the family begging a meal here and there. Is this any way to live?”

(Sharon, Parent, Account B)

“It took them 3 weeks before they sectioned him [under the Mental Health Act] giving him plenty of time to consider what he was doing, to me I was just existing day to day

feeling that there was not going to be action to be taken... he didn't seem to understand what we were going through.”

(Becky, Spouse, Account C)

As an aside to questioning a relative's identity, it is also noted that the carers themselves sometimes struggled with aspects of their own identities. For example, Emma had worked as a mental health professional for a number of years. She shared her experiences of trying to reconcile her professional and personal identities when dealing with her daughter's experiences with psychosis:

“At the time [when her daughter first became ill] I did not find it particularly painful, just bizarre, as I work in the field I became detached and tried to treat her as just another patient this was not possible as she was my daughter and the impact that her illness had on not just my life but her sisters life and our extended family.”

(Emma, Account B)

Emma wrote about trying to take a professional, detached response to her daughter, suggesting a significant change to their relationship. However, she also noted that this was unsustainable, the bond between them being too strong. In writing about this mother-daughter bond, Emma also brought up the fact that her daughter's condition had also impacted on other family members. She was not the only carer to consider wider family relationships, and this will be further discussed as a separate theme.

Adjusting to loss

As previously noted, the carers shared experiences of loss throughout their accounts, with some specifically making reference to a 'new' person who had taken the place of their 'old' relative, something that was also familiar in the service-users' accounts. While this change was usually

described as being for the worse, it should be noted that this was not exclusively the case, as one carer noted:

“In many ways despite the realisation of my daughter having this devastating illness being something that I still find hard to come to terms with, it is becoming, slowly, more of a blessing than a curse.”

(Laura, Parent, Account C)

Here, Laura was framing her experiences in a positive way, focusing on adapting to change while maintaining the closeness of their relationship. Again, as reflected in the service-users' accounts, loss of potential and 'what might have been' seemed to be key concerns. In addition to the loss of certain personality traits, the carers also wondered about potential career opportunities, financial difficulties, dependence, and quality of life issues for their relative.

6.4.2.2 Carers' concerns with: Impact of mental health difficulties on family relationships

Changes to family structure and roles within the family

All of the carers mentioned other family members in their accounts, and highlighted family relationships as a primary concern. The extracts below illustrate some of the carers' experiences of the impact of a first episode of psychosis on the wider family system:

“It affected the whole family, it began to create tension between us and arguments would break out every other day.”

(Angela, Parent, Account B)

“When things like this happen to a loved one it usually tears the family apart and it is never the same.”

(Elsie, Parent, Account C)

Family breakdown was also a central feature of some carers' experiences. Sharon expressed her worries about whether her divorce from her son's father contributed to his condition. She also went on to describe a further breakdown of a new relationship, following the onset of her son's difficulties:

“At this time [during a period of increased aggression and drug use in her son] I had also met my current partner who was witness to all that occurred. It was this situation which caused us to split up for two months – he said he could not stand to see the lives of my youngest children ruined due to [my son's] behaviour. Remember, at this time, everyone assumed [my son] was unruly and ill-behaved – the diagnosis of mental illness had not been made.”

(Sharon, Parent, Account C)

Here, Sharon explicitly identified her son's difficulties as a source of tension in her relationship, and as presenting challenges for her other children. She also went on to write about having to take the difficult step of having her son forcibly evicted from the family home, a step she took, she explained, to protect her younger children and herself. While this is a somewhat severe example of family tensions, other carers also expressed more positive experiences. For example, for Laura, having her daughter at home was a pleasant, but unanticipated consequence of her becoming unwell:

“She is a home-loving girl, and although I can't pretend that I wouldn't love her to be out, socialising and uniting with people her own age, on the other hand I make the most of every minute that she wants to spend with me. At an age when most mums are having to come to terms with their daughters spreading their wings, mine has come back to the rest.”

(Laura, Parent, Account C)

As Harrop and Trower noted, "...a major theme of the adolescent literature is that adolescents need to emerge from under the parents as a person in their own right." (2001, p. 243). A number of these carers described relationships where their child was still dependent on them in a number of areas that they might have been expected to have outgrown had they not become unwell (for example, continuing to live in the family home, help with routine daily tasks - encouraging personal hygiene, household chores; financial assistance). Linking in with some of the carers' visualisations of their children as their young, child-like selves, this increased level of dependence led some participants to present an infantilised view of their relatives:

"I feel like just at the time he should be becoming more independent in all aspects, suddenly he is dependent again and almost childlike in some ways."

(Angela, Parent, Account C)

In contrast, for others, there was a sudden, often difficult, break in a primarily dependent relationship. For example, through enforced separation, with the cared-for person having to leave the family home:

"I had to have James forcibly evicted by the police from his family home. I threw him out into the world but I didn't know he was ill."

(Sharon, Parent, Account A)

As previously noted, Sharon faced the difficult decision to take these steps to protect herself and her younger children. This extract highlights her struggle with trying to understand what was bad behaviour and what was mental health difficulties, and how to respond as home-life became increasingly difficult. Trying to balance the provision of support offered, with encouragement for independence, was presented as difficult by a number of the carers. Paula asked, "Will support turn into a recipe for dependency?" (Paula, Parent, Account B). She went on to recall a situation where she became financially and emotionally drained as a result of taking on responsibility for her

relative's personal and professional development. Indeed, a number of the carers wrote about seeking support from others to help manage challenging situations, this is further explored below.

Sources of support

The experiences detailed above highlight some of the ways in which changes to the family structure, and roles within the family, can be difficult to cope with. They also illustrate the potential for conflict between psychosis as a would-be cause of difficulties for families, and difficulties within families as a possible causal factor for mental health difficulties. Although acknowledging times when things have been difficult for their families, a number of carers also wrote about them as a source of strength and support. Angela wrote about her son's condition affecting the whole family, often prompting tension and arguments between family members. However, her experiences also identified family support as integral to coping:

“I think we are coping pretty well, I have lots of supporting family and plenty of people to talk to, which is what you need at the time.”

(Angela, Parent, Account C)

The help Laura received from her own mother when her daughter (Hannah) was unwell was described as being invaluable to her being able to maintain some semblance of her normal daily life. However, she too experienced difficulties with family and friends' perceptions of her daughter's condition:

“One thing I find frustrating is the lack of understanding close friends and family have of the illness. We have only told close friends and family and they have been very sympathetic; however they still have expectations of Hannah which result from a lack of understanding. For example, as I'm out at work all day and Hannah is at home, my mum expects Hannah to have the house clean and tidy and dinner on the table when I

get home. I have tried to explain about the negative symptoms of psychosis, but my mum still has problems with perceptions of Hannah being 'lazy'."

(Laura, Parent, Account B)

These carers' experiences highlight the potential for additional conflict and complex relationships to emerge in families affected by first-episode psychosis. There is an increasing awareness of the positive impact that involving carers and families in mental healthcare can have, for both the person who is unwell, and the carers and family members themselves (Pilling *et al.*, 2002; Pitschel-Walz *et al.*, 2002; Perlick *et al.*, 2006). The implications for greater involvement of carers and families in mental health care provision will therefore be further considered in the discussion section.

6.4.2.3 Carers' concerns with: Conflict concerning the potential causes of psychosis

What caused this to happen?

Another key focus of the carers' accounts seemed to be conflict concerning the possible causes of their relative's condition. There appeared to be three key areas of concern here that were closely interlinked: parenting, upbringing and family breakdown; spirituality and faith; and the idea that mental health difficulties can happen to anyone. For a number of the parent-carers, parenting skill and upbringing were a major cause of concern regarding the onset of psychosis and maintenance of difficult behaviour:

"I started questioning my skills as a mother what did I do wrong? What didn't I do right?"

(Emma, Parent, Account B)

Although Emma clearly identified questioning her own role in her daughter's condition, she also expressed conflicting ideas, attributing her daughter's life choices as another potential causal factor:

“At times I felt so angry with my daughter as I was sure her marriage had contributed to her psychosis, I had warned her not to marry... and I felt she did not have enough life experience to deal with this man, it was too much too soon, she should have listened to me, her first proper experience of a relationship resulted in her suffering with psychosis, it seemed so unfair.”

(Emma, Parent, Account B)

Another parent-carer, Sharon, highlighted her personal struggle, focusing on her own parenting skills and family breakdown as potential contributing factors to her son's experience of psychosis. However, she also contradicted these beliefs by stating that her son's behaviour was definitely not the result of external influences:

“Everyone who meets him for the first time believes they can change him, almost as if he just needs some encouragement and guidance. Can't they see I tried this for years – this is not the answer, there is something inside him – he is ill – it's nothing to do with his background. Even if I did not have his younger brother and sister and could live alone with him and give him 100% of my time and support, it wouldn't change the way he is.”

(Sharon, Parent, Account B)

Throughout Sharon's accounts, this sense of conflict about the causes of psychosis was highlighted as she seemed to consider all the possible options, even though her beliefs were contradictory at times. For another parent-carer, concerns about not spending enough time with his son when he was younger (attributed to family breakdown through divorce), were a key issue:

“I found it difficult to talk to some people as they don't really understand, they call it mental illness but I know it as SPIRITS that get inside and through certain things or ways and manifest in certain kind of behaviour. I felt guilty at time because I didn't spend time with him when he was younger because of the divorce, I felt angry as I could have educated him on the spiritual side of life.”

(Sid, Parent, Account C)

Here, Sid described feelings of having let his son down with regard to spiritual guidance. He wondered if things had been different, whether his son's mental health difficulties might have been either reduced or completely avoided. As highlighted in the extracts above, Sid's experiences also link in with explanatory models of illness, people's beliefs about the nature, cause, severity of the problem, how it might progress, and what the treatment preferences might be (Kleinman, 1980). As seeking explanations for the causes of mental health difficulties seemed to be a key feature of the carers experiences, this will be further explored in the synthesis section.

While not of concern to all the carers, issues of spirituality were a key concern for some. As with Sid's accounts, Paula also identified family separation as a potential cause of her relative's mental health difficulties. She went on to emphasise her perception that her relative's 'spiritual life' was adversely affected as a result of this separation:

“When I consider his early life, I feel he lost a sense of direction and focus. At an early age he was removed from his family and culture, to live in a part of the country where every experience was unfamiliar, the lifestyle, the community, the food, the people, the school, the attitude etc. I feel that in later life when he had returned to base and background, he grappled for grounding, but it was too late. Feeling a sense of loss... his spiritual life in tatters he began an inner search but without answers.”

(Paula, Parent, Account B)

Paula also went on to write about the state of conflict in which her relative found himself in relation to being part of a family later in life, wanting to join in, but finding it difficult to do so. She also drew attention to the fact that their upbringing and lifestyles differ, and as such, were a further source of conflict, leading to trust and communication difficulties.

For other carers, the theme of conflict around the possible causal factors of mental health difficulties seemed less pertinent. In sharing their experiences of being affected by a relative's first episode of psychosis, they instead chose to focus on the condition as it presented itself, and what the prognosis might be. There was no direction from the researchers to discuss this specific aspect of the condition, simply to focus on what was distressing. It is therefore difficult to know whether these carers were of the opinion that mental health difficulties are just one of those things that can happen to anybody, or whether they had simply chosen not to share their thoughts about this at the time of writing.

6.5 Synthesis of service-users' and carers' experiences

As previously noted, these data were collected with a view to exploring the impact of taking part in a reflective writing task on the stressful effects of experiencing a first episode of psychosis for both service-users and carers. Participants were prompted to recount distressing experiences linked to this time, but were essentially free to write about whatever was most important to them at the time of completing the task. Consequently, their accounts were much concerned with distressing and challenging experiences, forming the backdrop against which the themes are set. While a wide range of experiences were shared, issues relating to conflict, coping, work and financial burden, and safety and security, seemed to recur throughout participants' accounts.

This chapter has identified a number of themes that capture the things that were important in the experience of first-episode psychosis for these service-users and carers. It is striking that, although they differed in terms of the specifics of each group, there were a number of interesting

convergences. For these service-users and carers, themes of identity and loss, adapting to the future, and concerns about the causes of psychosis seemed to be particularly pertinent.

Identity and loss

Particularly striking across both the service-users' and carers' accounts were concerns with identity and loss. They reflected on the loss of the 'old' self and the development of 'new' identities that had developed following a first episode of psychosis. A number of service-users wrote about how they had changed as a result of being affected by psychosis, and also the impact of this on their connections to others. Service-users' relationships with the self, mental health services, family and friends were often presented as sources of conflict: a potential source of difficulties and isolation; while also being a potential source of strength and support. Communication also seemed to be a key factor relating to difficulties with others. Accounts of difficult relationships with mental health services, family and friends often featured stories about isolation, not being able to talk to family members, or doubting the motivations of others.

A number of carers also seemed to relate to this idea of 'old' and 'new' version of their relative, indicating a significant change in the person they thought they knew so well. This seemed particularly salient for some of the parent-carers who chose to illustrate this change by describing their adult children as they were as a child, eliciting a sense of lost childhood innocence. A number of carers also expressed concerns about lost opportunities, and the potential adverse consequences of these losses on their relative's aspirations:

"I am concerned that he might use this valuable time of his life unwisely and so miss opportunities for development, for his career, education, personal life, become someone without focus and end up relying on the help of the state."

(Paula, Parent, Account A)

“I did fear that I would lose her to the obscurity of homelessness and that my darling daughter would become another statistic in the mental health register.”

(Laura, Parent, Account A)

The service-users who explicitly made a distinction between ‘old’ and ‘new’ versions of the self seemed to be striving to get the ‘old’ self back. Others also described a sense of deterioration when writing about how the experience of first-episode psychosis had impacted on them, using language associated with failure, anxiety and isolation to describe their experiences. A number of the carers also seemed to show a preference for the ‘old’ identity of their relative, and expressed concerns about accepting the changes as permanent, hoping that the ‘old’ persona would return.

However, not all participants’ stories about identity and loss focused exclusively on the negative aspects of changes in these areas. A number of service-users and carers also recorded some of the benefits they perceived to have emerged from their experiences. Claire noted that her experiences had made her “stronger” (Account C), while Laura, a parent, wrote that she was beginning to view her daughter’s difficulties as “more of a blessing than a curse” (Account C). Adapting to significant changes to identity, and loss, were also closely linked with experiences of adjusting one’s perceptions of how the future will be, and dealing with uncertainty.

Adapting to a change in circumstances and an uncertain future

Again, there were striking similarities between service-users’ and carers’ accounts of adapting to change and facing an uncertain future. These things were also linked to identity and loss, with both groups reflecting on ‘what might have been’ and ‘what could be’ (as noted above).

For the service-users, concerns about the future seemed to be a key feature of their accounts. This might well be expected from participants in this age range (18-33 years, mean age 23 years), where individuals face the transition from being dependent on their parents to becoming increasingly

autonomous, moving towards making decisions about education, career, and relationships, for themselves. All but one of the participants made some reference to thinking about the future, though this was often juxtaposed with stories about lost opportunities (particularly in relation to education and employment). In looking to the future, a number of participants wrote about wanting to achieve goals in these areas, and their hopes for recovery. For a number of the service-users, recovery and potential future success seemed to be closely linked with relationships with other people, as they looked to others to for guidance and support (again, a common feature of young people developing autonomy and seeking to form relationships of their own). The service-users wrote about things like wanting to achieve goals, have a better life, and overcome their difficulties and seemed generally quite hopeful about their future prospects. This might well be a feature of youthful optimism, but is also likely to be linked with contact with Early Intervention services which aim to support recovery and foster hope in their young client-group.

As noted above, a number of the carers expressed concerns about their relative's lost potential and the difficulties this may present for their future. However, they also expressed a sense that things were not all bad, and that they had sometimes benefitted from their experiences. For example, Laura, a parent, wrote about making the most of spending time with her daughter, taking the opportunity to strengthen their relationship. However, overall the carers presented mixed experiences of the impact of first-episode psychosis on family relationships. Tension, arguments, and family breakdown were contrasted with enjoying each others' company and seeking support and comfort from each other to get through difficult times.

Conflict concerning the potential causes of psychosis

It is interesting to note that there was a marked difference between the service-users' and carers' accounts when it came to reflecting on the potential causes of psychosis. As previously noted, only two service-users made specific reference to this: Sally wondered why she had been affected when nobody else in her family had; while Dave wondered if his sensitive nature had left him vulnerable

to psychosis. The service-users focused more on how they thought their condition had affected them as a person, and their ability to manage their symptoms and recover.

In contrast, for these participants, it would seem that caring for a relative experiencing psychosis was more closely linked with conflict over its potential causes. A number of the carers seemed to experience a deep inner-conflict between: guilt and self-blame that they might have done something to cause their relative's condition; and the idea that there is an innate vulnerability and it would have happened no matter what. Considering seven of the eight carers in this study were a parent of the person they cared for, this finding is consistent with the wider literature that parents often experience feelings of guilt when a child is affected by psychosis (Karp & Tanarugsachock, 2000). These concerns about blame for illness may also reflect previous psychological theories about causes for psychosis. For example, in the 1960s and 1970s it was suggested that parents had a significant role in children's subsequent development of mental illness (e.g. Laing & Esterson, 1964). Although our understanding of mental health difficulties has developed over the years, it may well be that these types of ideas about parental blame are still an available discourse that parents draw on when trying to make sense of their children's mental health difficulties.

Aside from the potential causes of illness, and linked to adapting to uncertainty, a sense of conflict was also evident in some of the carers' thoughts about the changes in their relative's personality and behaviour: was the cared-for person unwilling, or unable, to change or get better?

“When [my son] first developed psychosis I didn't really know what was happening, none of us did. His symptoms were confusing and we weren't sure whether it was just him being awkward or whether he was really ill.”

(Angela, Parent, Account B)

The difference between a person being unwilling, or unable, to change their unattractive personality traits and behaviour (for example, being 'awkward'), may well affect the ways in which carers feel able, and willing, to respond to their relative. This struggle between trying to understand whether challenging situations are the result of deliberate choices, a difficult transition to adulthood, being unwell and not well able to manage thoughts and behaviours, or a combination of all these things and more, might well have serious implications for familial relationships. In Karp and Tanarugsachock's (2000) paper exploring mental illness, caregiving and emotion management, they identified carers' experiences of uncertainty and confusion, going on to describe a sense of 'emotional anomie'. The authors also stated that the suggestion of 'mental illness' leads family members to feel obliged to treat their relative with "...the same love, understanding, sympathy, and compassion owed to any acutely ill family member." (Karp & Tanarugsachock, 2000, p. 12). However, if the 'illness' itself is in question, it could well be anticipated that this could lead to difficulties for carers and family members in coming to accept and manage significant changes to family life.

6.6 Discussion

In exploring the ways in which service-users and carers try to make sense of their experiences of first-episode psychosis, it is hoped that the themes identified in this research will be able to assist clinical understanding and the implications for interventions offered to service-users and their families. However, it is noted that while some striking similarities were identified for both groups, these may not be shared by all families. Indeed, it should be noted that this sample of service users and carers was a small subset of all those who were in contact with Early Intervention services at the time the research was conducted. Those who withdrew their data, or withdrew from the research, may well have had significantly different experiences to those presented in the present study.

6.6.1 Implications for greater involvement of families and carers in mental health care provision

The themes derived from these participants' experiences suggest that efforts to help service-users and family members adjust to the changes they face, following a first episode of psychosis, in the following areas may be particularly valued: encouraging social support for people; psycho-education for service-users; family; and extended family; ensuring service-users are listened-to and involved in their recovery; and supporting educational/vocational roles. The experiences outlined in this research also suggest that although experiences of first-episode psychosis are typically extremely difficult and challenging, participants also seek to frame their experiences in a positive way where possible. Therefore, seeking to draw on hope, rather than concentrating exclusively on difficulties, may be a good way to encourage engagement with services. Exploring how the service-user and family members characterise what is happening when a relative experiences a first episode of psychosis could also be important. For example, how do they respond to ideas about, and the language associated with, 'illness' and diagnoses?; Are these things helpful, or more of a hindrance? None of these participants specifically focused on these things in this research, but a few did write about difficulties associated with understanding what was 'illness' or 'clinical' thoughts and behaviour, and what was 'normal'.

The accounts analysed in this study highlight some of the ways in which first-episode psychosis can impact upon family relationships. Consistent with the wider literature on caring for a relative with psychosis, a number of these carers wrote about strained relationships: tension, arguments, family breakdown (e.g. Marsh *et al.*, 1996). Indeed, family support seemed to be an important factor in aiding coping for both these service-users and carers. However, previous research also suggested that many carers feel that they are invisible, silent partners in care, and that they are under-valued by mental health services (Sin *et al.*, 2005; Pinfold & Corry, 2003). Only one carer, Elsie (a parent), explicitly wrote that mental health services could look at the ways in which they work with families. However, in conjunction with the other service-users' and carers' stories, this

would seem to indicate that greater family and carer involvement is considered to be valuable in helping them cope with mental health difficulties. Indeed, the findings of this research seem to support the NICE guidelines for Schizophrenia recommendations (NICE, 2010), based on service-users' and carers' experiences of care. Of particular relevance are those focusing on: optimism; working in partnership with carers; service level interventions; and employment, education and occupational activities. Also, family interventions should be offered where service-users live with, or are in close contact with, their family (NICE, 2009).

6.6.2 Reflections on participants' engagement with the written method of data collection

Generally, participants appeared to focus on the content of what they were writing rather than the task of writing as a way of collecting data. The majority of participants therefore made no direct reference to taking part in a written emotional disclosure task. Indeed, many wrote about their experiences much as you would expect them to have told them to an interviewer. In the service-users' accounts, two participants made a direct, albeit brief, reference to their engagement with the written task they had been set:

“First and foremost I would like to write about when I felt I was mishandled by the mental health services.”

(Simon, Account A)

“Firstly I'm not 100% percent better so bear with me.”

(Dave, Account A)

Both of these participants began the first of their three accounts in this way, but made no subsequent reference to the task in their writing. In the carers' group, only one participant, Sharon, made references to the act of writing about her experiences. However, in contrast to the service-

users who did this, Sharon made explicit references to her engagement with the task throughout two of her three accounts:

“Just writing this paragraph has me crying because I’m there again, sitting in the room at the [clinic].”

(Sharon, Parent, Account A)

“My crying has eased, my writing is returning to a more consistent neatness.”

(Sharon, Parent, Account A)

“I suppose I’m writing this because I want you all to believe this and not blame me.”

(Sharon, Parent, Account C)

In two of these extracts, Sharon appeared to be making an appeal to the reader to consider the content of her accounts in the context of challenging situations. She went on to stress her need to be believed, and not blamed for her son’s illness, as if seeking reassurance. This seemed to also link in with Dave’s account, asking the reader to bear with him while he constructed his story (as noted above). The effect of this seemed to emphasise that sharing these experiences was difficult for these participants, and what was being shared might have led the reader to make negative judgements about them. They therefore seemed to be appealing for the reader’s understanding and empathy, attempting to protect themselves from the potentially negative perceptions of others.

Again, much as you might expect in an interview situation, some of the participants posed questions throughout their accounts (illustrated by the following extracts):

“Is this his illness or didn’t I bring him up properly?”

(Sharon, Parent, Account B)

“I started questioning my skills as a mother what did I do wrong? What didn't I do right?”

(Emma, Parent, Account B)

“How will it affect our lives?”

(Angela, Parent, Account C)

However, in contrast to a typical interview situation, the participants were obviously aware that there would be no immediate response. The questions posed in these accounts may well have a variety of purposes, for example: a) To illustrate the questions they have asked themselves in difficult times, or that they are currently attempting to resolve (to highlight an element of soul searching); b) To make attempts to defend their own, or their relative's, behaviour, or choices they have made; c) To elicit a response, albeit at a later stage, from a professional (participants were all aware that their accounts would be read by a clinical psychologist). In contrast, it is interesting to note that the service-users did not include questions in their accounts.

This use of questions seemed to reflect the greater focus for carers on reflections about the potential causes of psychosis. While not exclusively the case, many of the questions were posed by parent-carers, wondering about their impact on the course of their child's condition. That only the carers put questions down in writing in this way, might also be linked to the fact that while the service-users would have had opportunities to talk with mental health professionals about their experiences, this would likely not have been the case for the carers. Therefore, attempts to seek reassurance, or seek answers to difficult situations might well be more pronounced with this group.

6.6.3 *Potential benefits and limitations of using written emotional disclosure with interpretative phenomenological approaches*

As previously noted, the use of IPA with non-standard data collection methods, including written accounts, is an area of increasing interest to researchers (Smith *et al.*, 2009, p. 204). It would therefore seem worthwhile to note some of the potential benefits and limitations of this approach that have developed from the analysis of these data (see Table 6.3).

Table 6.3: Potential benefits and limitations of using written emotional disclosure with IPA methodology

Benefits	Limitations
<ul style="list-style-type: none"> • Analysis can be carried out in much the same way as with interview data collection methods • Potential for experiential content to be obtained much as it might be from an interview • Participants might have more time to formulate their thoughts, to think about and include experiential details • May be easier to arrange data collection and less time consuming for the researcher • Transcription is usually quicker than from interview data (if necessary at all) • Possibilities for a range of data collection methods, for example, responses to different questions set at different time periods, diary extracts, email, blogs and internet forums 	<ul style="list-style-type: none"> • A certain level of literacy is required for participants to be able to provide rich experiential accounts • Researcher is unable to clarify anything that doesn't make sense with participants during the time of disclosure (spelling and grammar may be an issue for some participants) • Important to set the right question early on as there is less opportunity to clarify or change it (as might happen during an interview) • Exploring use of language, for example, might participants use different forms of expression/turns of phrase when speaking compared to engaging in written accounts? • Limited guidance in the literature about how to set up an IPA study using written emotional disclosure or other written data collection methods as the primary method of data collection

There are therefore a number of benefits offered and limitations to be overcome that might be presented in taking this type of approach to data collection in an IPA study. How these have affected the analysis in this study will be further explored below. It would seem that taking an IPA approach to the analysis of these data worked well, despite the fact that they were originally collected for another purpose (to explore the effects of written emotional disclosure on psychosis-related and post-traumatic stress disorder symptoms). However, it is noted that there were some differences in the exact way data were collected, for example: some participants met with the researcher (KB) and did the writing in the researcher's presence; others met the researcher but preferred to complete the writing in private; while others preferred to correspond by post. These differences did not seem to produce any noticeable between-participants differences in the data collected. All seemed to have a good understanding of what was required and tended to produce accounts of a similar length, rich in experiential detail.

In any research project, consideration must be given to the suitability of the data collection method for the participants that will be recruited. Taking part in a task that requires handwritten, or typed accounts, might present challenges for some participants (for example, if there are difficulties with literacy, motor-skills, sight etc.). Some of these difficulties may be easily overcome through the use of voice-to-text software packages. However, data collected in this way might then be considered more akin to recorded interview data, than written accounts. So, although the use of written accounts is not without its challenges, in this case it would seem that taking an IPA approach to participants' written emotional disclosure has been successful. This research suggests that there is potential for the utilisation of this combination of methods to help develop our understanding of the lived experience of caring and mental health difficulties. The value of taking a non-standard approach such as this to data collection for an IPA study is further discussed in Chapter 9, where consideration is given to the range of data collection methods (e.g. focus groups, written methods, multiple perspectives etc.) utilised in the studies presented in this thesis.

Following this chapter, Chapter 7, explores a family's experiences of being affected by mental health difficulties. This leads on to an examination of mental health professionals' experiences of identifying and working with families and carers in Chapter 8. Further consideration of how these service-users' and carers' experiences relate to the wider research project, and the literature on caring more generally, is covered in Chapter 9.

Chapter 7

Exploring the meaning of a family's experiences of being affected by mental health difficulties

7.1 Abstract

The aim of this chapter is to explore the ways in which a family understands and makes sense of its experiences of mental health difficulties, focusing particularly on the impact on family relationships and understanding of the language of care. Data were collected from four members of a family who were identified through Early Intervention services operating in the English Midlands, UK. Individual interviews were conducted with each family member using a set of prompts to elicit experiences of being affected by mental health difficulties. Family members provided rich, detailed accounts of their experiences, sharing their personal take on family life.

This study employed an interpretative phenomenological approach (IPA) and the results are presented as individual family member case studies. Family members shared their understanding of mental health difficulties, talking about the impact on family life over the years. Although difficulties and challenges were presented, there was also a sense of learning and development. Family members talked about the knowledge and skills they have picked up, as well as opportunities that have arisen, and personal developments in softer skills, such as, empathy and compassion. From a family perspective, concerns seemed to focus on making sense of: what happened to Luke when he became unwell; how mental health difficulties had impacted on roles and relationships within the family system (e.g. choice, detachment, role-reversal and replacement); differences between the impact of chronic and acute mental health difficulties; and sources of support outside the family. The family context, and implications for improving families' experiences of mental health difficulties, are also discussed.

7.2 Introduction

This chapter explores the ways in which a family affected by mental health difficulties has come to understand, and make meaning from, its experiences. As highlighted in the literature review (Chapter 3), various studies have explored a range of caring roles (e.g. parents, cohabitants/spouses) from a phenomenological perspective (e.g. Champlin, 2009; Pejler, 2001; Tranvåg & Kristoffersen, 2008). However, there would seem to be less research that focuses specifically on exploring family members' perspectives from members of the same family. This research therefore employs a case study approach to a single family's experiences through different member's perspectives.

A number of papers suggest that grief and loss might be a key feature of caring experiences (Osborne & Coyle, 2002; Tranvåg & Kristoffersen, 2008; Champlin, 2009). Carers might have to deal with feelings that their relative has been taken away from them, replaced by a different, post-morbid version of the person they knew. As noted in the previous chapter (exploring service-users' and carers' experiences of a recent first episode of psychosis), mental health difficulties can have a significant impact on sense of self for both service-users and carers. Participants in both groups reported struggling to come to terms with the 'old' and 'new' selves of the person experiencing mental health difficulties. Aside from loss and grief, Chapter 5 (carers' experiences of caring and mental health difficulties) also identified themes associated with: the impact of labelling; choice in caring; identifying others and seeking support in others' experiences; the links between informal and formal care; and concerns about the future. This chapter therefore seeks to explore whether these issues also have resonance for one family system that has been affected by mental health difficulties across two generations.

Chapter 7 therefore seeks to address the following research questions:

1. What is the daily lived experience of being part of a family where a family member experiences mental health difficulties?
2. In what ways have family relationships been affected by mental health difficulties?
3. How is the language associated with informal caregiving understood by family members?

7.3 Method

7.3.1 Participants

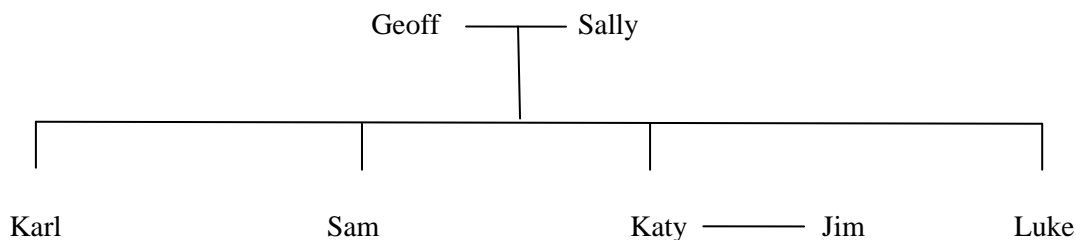
The researcher approached Early Intervention services across the English Midlands, UK, to help identify families that might be interested in taking part in this research. Mental health professionals were asked to approach families that they were already working with, supplying details of this research (see Appendix 9, participant information sheet), facilitating contact between families and the researcher (MP). The recruitment criteria for this study were that at least three members of a family (including the Early Intervention service-user, who must have capacity to give informed consent to participate) would volunteer to take part in order to gather a range of family member experiences. Where there were more than three members of a family who might be eligible to participate (over the age of 18 years), all those who were interested in the research were told that participation was voluntary. While it was anticipated that up to five families might take part in this study, only one family were identified within the time frame of this research project. When the family expressed an interest in taking part, the researcher contacted them and arranged a visit to talk about the research project in more detail. The family were told that if any of their members expressed any concerns about taking part that it would not be appropriate for any of them to take part as the focus of this research was on family experiences. Family members were informed that they should not share anything that they did not want to, and that they were free to withdraw their data (individually, or as a family) for up to two weeks following participation. The

family were encouraged to discuss areas of their experiences that they might like to share, or would rather not share, together before taking part. The family were then given two weeks to discuss this research and their possible participation and were asked to contact the researcher following this period if they would like to proceed. Of the six family members that were approached, four volunteered to take part. The other two were aware of their relatives' participation but did not want to take part themselves (they did not give specific reasons for declining at the time). A brief summary of demographic information is provided in Table 7.1, and an illustration of the main relationships discussed by family members is presented in Figure 7.1. Further details are not provided to protect anonymity.

Table 7.1: Overview of family members' demographic details

Family member	Age range (years)	Ethnic background	Contact with mental health services
Geoff	65+	White British	
Sally	55-65	White British	Long-term contact with adult mental health services
Katy	26-35	White British	
Luke	26-35	White British	Currently in contact with Early Intervention services

Figure 7.1: Basic family tree to illustrate the main family relationships discussed during family member interviews



7.3.2 Data collection

Individual, semi-structured, interviews were conducted with each family member who wanted to take part. Of the six family members that were approached, four took part. Where family members decided not to participate, they were aware of the research project, and did not express any concerns about other family members taking part. Each interview was conducted by the researcher (MP) at a time and location that was convenient to individual family members. Each interview lasted for approximately one hour.

The researcher used a prompt sheet (see Figures 7.2 and 7.3) to keep each interview on track, though family members were encouraged to express the things that were important, and meaningful, to them. Each interview was audio-recorded and transcribed verbatim for analysis. All participants were given pseudonyms during the transcription process.

Figure 7.2: Prompt sheet for family members with a relative in contact with Early Intervention services

Interview prompts for individual family members/carers:

NB. The below are prompts only. The Chief Investigator will rephrase/prompt for more detail as appropriate during each individual interview.

1. Can you tell me a bit about the nature of ... [service-user's] difficulties?
2. Can you tell me a bit about how you started to become involved with services? When do you think services started to think of you/treat you as a carer? (Which team members did/do you have contact with?; How often do you see them?; What type of information do you share with them etc.).
3. Can you tell me a bit about the way in which you care for/support ... [service-user]? Has this changed from when they first became unwell?
4. Has your relationship with ... [service-user] changed at all since they became unwell/how has it changed? Do you feel closer to/more isolated from ... [service-user]?
5. Do you think that your relationship with ... [service-user] would be different if they were not unwell? If yes, how so?

6. Have your relationships with other family members changed since ... [service-user] became unwell/how have they changed? Do you feel closer to/more isolated from other family members?
7. Has family life in relation to family/household activities changed at all since ... [service-user] became unwell? (e.g. family get-togethers, chores, more/less arguments). If yes, how so?
8. What changes in ... [service-user's] life do you think would make the biggest difference to the family? What would have to happen to make these changes occur? (e.g. family communication; contact with services).
9. Can you tell me a bit about what you think you have learnt as a family that has been directly affected by mental illness? (e.g. resilience, coping strategies, awareness of mental illness, family communication etc.).

Figure 7.3: Prompt sheet for family member in contact with Early Intervention services

Interview prompts for individual service-users:

NB. The below are prompts only. The Chief Investigator will rephrase/prompt for more detail as appropriate during each individual interview.

1. Can you tell me a bit about the nature of your difficulties?
2. Can you tell me a bit about how you started to become involved with services? (Which team members did/do you have contact with?; How often do you see them? etc.).
3. Can you tell me a bit about the way in which your family members care for/support you? Has this changed from when you first became unwell?
4. Do you think that your relationship with your family members/friends would be different if you were not unwell? If yes, how so?
5. Have your relationships with other family members changed since you became unwell/how have they changed? Do you feel closer to/more isolated from other family members?
6. Has family life in relation to family/household activities changed at all since you became unwell? (e.g. family get-togethers, chores, more/less arguments). If yes, how so?
7. What changes in your life do you think would make the biggest difference to the family? What would have to happen to make these changes occur? (e.g. family communication; contact with services).
8. Can you tell me a bit about what you think you have learnt as a family that has been directly affected by mental illness? (e.g. resilience, coping strategies, awareness of mental illness, family communication etc.).

7.3.3 Data analysis

Data were analysed using interpretative phenomenological analysis (Smith, 1996; 2004). Each interview was first analysed to explore what was meaningful to each individual family member. The transcripts were read through several times before the initial noting stage took place. The data were then explored and notations made focusing on descriptive, linguistic and conceptual comments. Data were then clustered into emergent themes in preparation for exploring the connections across accounts. These analyses were then integrated in order to consider what was meaningful to the family and the context in which individual accounts were situated. A short extract of worked data is presented in Appendix 10 to illustrate the integration of data regarding emergent themes as part of the data analysis process.

Ethical approval for this study was granted by the [REDACTED]. All participants were given written information about the study and discussed what would be involved in participation with the researcher prior to taking part. All participants were aged over 18 years, had capacity to understand the nature and purpose of this research, and gave written informed consent to participate.

7.3.4 Context in which themes are set: overview of the family system and key relationships

The researcher was put in touch with the family through the Early Intervention team's contact with Luke. Luke had been given a diagnosis of bipolar disorder (a condition affecting moods and characterised by episodes of depression and mania) and had been in contact with Early Intervention services for about two-and-a-half years. His mother, Sally, had been living with a long-term diagnosis of bipolar disorder herself. Sally was married to Geoff, and the couple had four children, two of whom, Luke and Katy, took part in this research. Geoff and Sally lived together in the family home, while Luke and Katy each had their own homes. However, since becoming unwell, Luke had tended to spend more time at his parents' home.

The key features of each family member's accounts of their experiences are presented below. They are presented in the order in which the interviews took place. Each family member was aware of this order, and at times made reference to the researcher having spoken to, or, going on to speak to, other family members. The overall familial context is further considered in the synthesis and discussion sections.

7.4 Themes

7.4.1 Family member: Geoff

Geoff was over 65 years old, married, and had four children. He lived with his wife, Sally, and their adult children lived independently. Sally was diagnosed with bipolar disorder before they were married. Around two-and-a-half years ago, their son, Luke, was diagnosed with bipolar disorder following a serious episode. Geoff attempted to relate his experiences as they happened, providing the details of Sally and Luke's experiences with mental health difficulties in a fairly chronological order. He was mindful that this was his account of how things had appeared to him, and that other family members might have different views about things to his own.

Being a carer: impact on family relationships and gradual detachment from the role

Geoff did not really talk about himself as a carer. When asked when he first came across the term he talked about when he was working. He stated that he felt he had to give up work to care for Sally and that ideas about supporting carers seemed to be in their infancy around this time. He went on to say that things seem to have developed in terms of thinking about carers over the years. In thinking about caring, Geoff linked his experiences in this area with Sally being unwell over many years, rather than Luke's more recent experiences.

Geoff talked about the impact Sally's difficulties have had on their relationship, particularly in relation to giving up work and the consequences of this for the dynamics of their relationship, saying, "I had to claim dependence on my wife, so the roles had to be reversed to get any income". Here, Geoff highlighted quite a fundamental shift in the nature of their relationship. Some of the things that had been quite central to his identity in the relationship (working and providing an income), changed drastically, a change that Geoff described as quite frustrating.

Over the years this caring role seemed to be something that Geoff had gradually detached from as Sally had developed ways of managing and coping with her difficulties. He talked about the importance of them both having their own space, acknowledging that they both have different ways of dealing with things, "...she's very, very, um, regimented, and I'm just the opposite so, and that's led to difficulties in the past because her expectations being different to mine". Geoff seemed to have come to the conclusion that their situation was relatively stable and manageable now, compared to experiences they have had in the past, and that to some extent he could stop worrying. He went on to reflect on the impact of the type of person he is on the way he has been able to cope:

"I think, well, I'm, I'm fairly stable I think, so, if I wasn't, If I was more unstable it might have destabilised me a lot more I think... erm, it, it depends who the people are doesn't it... and what they're given."

This was also linked with other comments Geoff made about hearing other carers' and families' experiences, setting his own experiences in a wider context, "Yeah, and some, some, some had been horrific and really, ours has been sort of mild compared with theirs [other carers'] I think... there are some tragedies aren't there?"

In terms of caring for Luke, Geoff made no specific reference to himself as a carer, instead talking more generally about the types of things parents would normally do, like, keeping an eye on the

children to make sure they are all right. Geoff talked about Sally tending to offer Luke support with the things he needs, and went on to express concerns about what would happen when he and Sally were no longer around to offer support in the future, "...he'll need a supporter." However, although Geoff was not specific about who might take on this role, he did also make reference to his belief that a stable romantic relationship might be beneficial to Luke.

Impact of mental health difficulties on family relationships

Throughout Geoff's interview he made references to the impact of mental health difficulties on family relationships. As noted above, Geoff highlighted a significant change in his and Sally's relationship when he gave up work in order to take on a caring role for her. However, the relationship between Geoff and Sally was not the only family relationship to have been impacted by mental health difficulties.

Geoff noted that he had occasion to, "...worry about the effect it has on the kids when they're very young" when they experience the sorts of bizarre behaviour that might be exhibited by somebody experiencing bipolar disorder. However, Geoff did not dwell on this or go on to speculate about what it might have been like for them. When asked what he thought things might have been like for Luke's siblings since Luke became unwell, Geoff replied, "...I'd like to know, I don't really know", and went on to say how all of the children had reacted differently to their various experiences over the years. This response seemed to highlight Geoff's desire for other family members to be involved in this research so that they could provide their own accounts which they may not have previously talked about together, something he went on to summarise later in the interview, "Well, I, we see things, we're sure to see things from a different angle aren't we... because we're standing in different places. And we're standing at different ages as well you know."

In terms of supporting Sally when she was unwell, Geoff acknowledged that Sally was often, "...dependent very much on her mother to look after her when things have gone wrong." He noted that he sometimes found Sally to be very protective of the children and that this, and similarities with the approach of Sally's own mother, could sometimes come across as controlling. However, Geoff noted that things have moved on a lot over the years and he seemed to respect Sally's abilities to be able to assess herself with regard to her health needs, "...I also think it's beginning to get the, ability to stand outside herself and look at herself when it's not always easy for a mentally ill patient to do that."

Understanding mental health difficulties: Learning as a family

At one point Geoff talked about his ideas concerning the prevalence of mental health difficulties, "...I'm sure mental illness has increased since, I don't know, maybe I'm not, maybe I'm wrong, but, in, since the old days... or maybe it just wasn't picked up on." Geoff seemed to highlight the wider context of mental health difficulties in society and, to an extent, normalise his own family's experiences within this. Towards the end of the interview, Geoff reflected on what the family have learned through their experiences, highlighting their perceived strengths and weaknesses:

"Yeah, yeah, we feel that we have [learnt a lot over the years] mmm. We feel we've got insight, the, the psychological area I think we could, pick up on, I think that's our weak suit, rather than the psychiatric area."

Geoff made a clear distinction between psychology and psychiatry, not explicitly defining these terms, but rather using them to sum up his story so far. Indeed, Geoff's focus had been more on psychiatric diagnoses and management through medication, than more psychological approaches to mental health, for example, things like talking therapies, relapse planning, and support with education and training, that had been experienced more recently through Early Intervention services.

Geoff also shared his perceptions of mental health issues through his own experiences, saying, "It seems that triggers set things off, but, but it's latent, but I do think that modern, that modern life isn't conducive to good mental health, I think there's too many stressors." In talking about latency, Geoff was suggesting that there may be some sort of genetic predisposition to mental health difficulties, which might lie dormant but which can be set off by triggers. But he also went on to say that this was not something that had really occurred to him when the children were younger:

"I never, I didn't, I never gave it a thought, until it happens you, no we weren't apprehensive in advance, I wasn't anyway, I don't know whether my wife was, were probably on a guilt trip when it happened, I think, I think she was, feeling guilty for passing on genes or something... you can't help it can you?"

For Geoff, understanding of mental health issues was also bound up with spirituality and faith. He and his family identified as Christians and were involved in Church activities. Geoff talked about his faith being a source of support, but also acknowledged that there can sometimes be conflict between faith and mental health issues. He talked about Sally's difficulties being framed by others as a sort of faulty faith, "...and she had sort of experiences with churches that sort of, um, suggested that she could be healed by faith or whatever, and if she wasn't healed there was something wrong with her faith." However, there was a clear sense that this was not a universal experience with all churches, and that his faith had generally been a comfort to him.

As noted above, Geoff attributed much of his ability to cope to being a stable person and the fact that Sally had been able to manage her own condition increasingly well over the years. Their experiences of dealing with Sally's difficulties together meant that they had learned things that prepared them to identify Luke's difficulties when he became unwell. Geoff talked about the time they realised Luke was becoming unwell:

“Yeah, because we were ready for it but it was a bit of a shock to see it appearing, but we recognised it straight away... whereas if we hadn't had my wife's illness first, I think, I don't think we'd have been so prepared... and we had a little bit of an idea how the system worked, a slight, slight amount... I think it's been much more supportive lately.”

7.4.2 Family member: Sally

Sally was aged between 55 and 65 years old, married, and had four children. She lived with her husband, Geoff, and their adult children lived independently. Sally was diagnosed with bipolar disorder before she and Geoff were married. Around two-and-a-half years ago, their son, Luke, was diagnosed with bipolar disorder following a serious episode. Sally began her account by revealing that she was a trained psychiatric nurse, and that she became unwell many years ago during her time as a student. Sally highlighted the fact that this meant that her immediate family have only known her since she had been unwell.

Support and caring

Sally talked about her relationship with her parents and the help and support they had offered her over the years. Sally revealed that her parents were shocked when she first became unwell, and took a long time to come to terms with recurring episodes of bipolar disorder. However, once they had come to accept the situation they were very good to her, often having her to stay at their house when she did not feel well enough to manage on a daily basis. Sally also credited this response from her parents as keeping her out of hospital, giving her a bit of time and space to have a break. Sally went on to give a bit more detail about her relationship with her mother, saying, “I could always pick up the phone at any time and she'd always listen to me.” She then went on to talk about her own mother's concerns about how Sally would get on when she was no longer around to support her, saying, “...she wondered what I'd be like, you know, when she, she died... I, I just got

to the point where I felt, you know, able to cope without her.” Sally reflected on the consequences of this for the relationship she has with her daughter, going on to say how she had “replaced” her mother in some ways as the person she can pick up the phone and talk with.

With regard to her relationship with Geoff and his transition into the carer role, Sally said:

“I don't think Geoff wanted to be my carer, he didn't really want to be in that role... I said to Geoff, he was prepared to give up work... but I think he didn't mind leaving the work he was in, he didn't really want to be pinned down and I think once he got onto, erm, a pension and that, he, he just doesn't think of himself as a carer for me any more... and he doesn't want, you know, he doesn't really want to be tied up in any way... but then I've got such wonderful children that it doesn't really matter a great deal, but erm, no it's, he was, I would say he was more sympathetic when, in my earlier years, you know, but I think he's got tired of it really.”

Here, Sally's account complemented Geoff's, of sharing his experiences of giving up work to care for her. In both accounts there was a sense that Geoff wasn't keen to take on the caring role but that it was necessary and agreed on without too much conflict at the time. Sally's account also highlighted Geoff's sense of detachment from the role as the years have progressed, with Geoff not wanting to be “tied up” with caring responsibilities, leaving them both free to enjoy their personal space now that Sally's situation was more stable and the children were able to offer support.

In terms of seeing herself as a carer for Luke when he became unwell, Sally talked about drawing on all her experiences as a mother, nurse and service-user to describe the support she was able to offer. Sally talked about being a caring person, but noted that there are aspects of her condition that can make it difficult to do the things she would like to be able to do for others, “I've always been a caring person when I'm, when I'm as well as I can be, so from that angle it's erm, something that fits quite comfortably, but it's just my illness rejects that side.” This conflict about

wanting to be supportive, but finding it difficult, was also repeated a little later, "...so being a carer, yes, well the days that I feel able to do what I'm expected I really enjoy it, and I feel um, it's a valuable contribution to him [Luke] but I'm not consistent." When asked about where these expectations about caring came from, Sally went on to say that they came from her, based on her knowledge and experience as both a nurse and a parent, blurring the lines between these roles.

In thinking about how the language around caring might have been formalised in the support that she offered to Luke, Sally went on to say, "I don't think the word [carer] was used a great deal, it was more a, sort of, implication, you know, you just felt that that's what you were and that's what you must do and get on with it." This was suggestive of caring being a natural progression for a parent when a child becomes unwell, whereby they simply continue to do what they have always done to ensure their child is supported.

Impact of mental health difficulties on family relationships

In addition to the sort of help and support that family members have offered Sally, the impact of mental health difficulties on other family relationships was also considered. A central feature of Sally's experience focused on her relationships with her children. Sally talked about how she started to become unwell during her time as a student and that she was not able to work for long (as a nurse) before having to give up work. Sally went on to talk about leaving work when she was expecting her eldest child:

"I happily left work for good, I mean I knew that I wasn't really fit to work, and I certainly didn't want to work when I had the children, and so in that way it affected it, and I can remember thinking when I was nursing the babies, you know I loved the babies [at work], and I was thinking, the only way I can ever, sort of, replace my career is to have my own children."

Sally talked about how she and Geoff both wanted a large family. However, Sally acknowledged that it wasn't always easy to manage her condition with her parental role, "...but little did I know how many times I'd have to give them up, you know, when I went into hospital." Sally also talked about how her condition impacted her decisions about having her own family, "...then I knew if I kept on having children, I probably wouldn't have my life with them at all, you know, I'd probably be in hospital more than I was with them... and it just wouldn't be right." Sally went on to say that she had wanted to be able to look after the children better than she had, and to have been more stable for them. But she also noted that she felt she had done the best she could under the circumstances.

In terms of supporting the children, Sally talked about how she had helped them all, in different ways, when they needed it. However, she noted that Luke had seemed to need a bit more input since experiencing a serious episode of bipolar disorder himself. Luke had been spending more time at the family home, since becoming unwell, and Sally tended to offer support with things like doing household chores, and monitoring signs of health and well-being (such as, eating, sleeping, stress, and taking medication). Sally had noticed that Luke being unwell had also impacted on other family members to some extent, but that, "I don't think it's affected it [family life] too detrimentally really." Sally talked about her daughter, Katy, being "protective" over Luke, highlighting that, "she's wanted to help him a lot and when I'm poorly she always rings him up and asks if he's had his [medication] and things like that, you know." Indeed, Sally commented that it is nice to have Luke's company about the house and that doing things for him (like, cooking his meals) makes her feel, "...you've done something worthwhile afterwards."

Thinking about the time when Luke became unwell, both Geoff and Sally mentioned that he came to the family home just before the episode that led to him spend some time in hospital. Sally went on to say how the whole family were concerned about Luke, anxious about his well-being. Sally expressed that she felt some concern that Luke might blame her in some way, "...you know, for having him, or, for, not wanting to be the same as me." but went on to say that there were no

difficulties between them, "...he wasn't a bit antagonistic to me... and I think he probably finds it fairly helpful that I can identify with his symptoms." She also went on to talk about the ways in which she tried to make sure Luke was staying well:

"I must say, he probably resents me at times because I'm very, erm, routine, structured person, and 'oh, have you had your [medication]', you know, checking up and 'have you slept?', and, you know, I can't stop myself, as well as being his mum I'm a trained nurse and sort of wanting to, um, make sure everything's as good as it can be."

Here, Sally talked about her concerns from two perspectives that are quite central to her identity, being a mother, and being a trained nurse. Later in the interview she also responded to caring for Luke from another key perspective, that of someone who has experienced bipolar disorder themselves:

"...to tell you the truth, I think my experience of the illness is more valuable than my training in terms of relating to people, you know, I mean, I was a very, quite compassionate when I was a nurse, but I'm more so now having experienced it."

Sally talked about how the family's experiences meant that they were able to recognise that Luke was heading into difficulties following a significant relationship breakdown, and went on to say, "...it was wild, you know, and of course everybody knew then he was headed for an illness." She talked about how Luke came to understand what had been happening to him following this serious episode, recounting something he said during the time he spent in hospital:

"And I think the morning after this happened, he said to the nurse, 'I wonder if my family will still want to know me? So obviously in his mind we were still quite

important to him... he seemed to want to be, involve us all in it... so I would say we still had that, er, connection.”

The experience of Luke starting to become unwell and wanting to be close to his family seems indicative of the close knit structure described throughout the interview. The idea that Luke felt his family might not want to know him was presented as difficult for him, but not something that any other family members would have considered. Sally talked about Luke coming out of hospital to stay at the family home for a while, highlighting the change that had occurred during his episode of illness, “I mean, he wasn’t fully well, but he was, you could relate to him as Luke, the Luke we’d known, and um, so, then he probably had another couple of little dips but not so extreme.” Here, Luke’s very identity, the Luke that is ‘known’ to the family was described as being threatened by his experience of bipolar disorder. Sally stated that while Luke was still much the same as he always was (e.g. active, loving, humorous and easy going), there was a marked difference in his personality when he was unwell, though there did not seem to have been any lasting detrimental effects.

Understanding mental health difficulties

As noted above, Sally had a lot of experience, both professionally and personally, in the field of mental health. Thinking about Luke’s recent diagnosis made Sally think back to when she herself became unwell, “...he [Luke] was astounded, as I was when I was first given the diagnosis, although I’d worked with patients, never recognised it in myself.” Sally also talked about how perceptions of situations can change when one becomes unwell, going on to say, “I mean, I’ve been like that myself, not recognising the, it all seems um, fantastic, you know, you seem to be in like a film somehow.” Sally was clearly identifying with some of the things that Luke described happened to him when he was unwell. She also went on to talk about how she feels her experiences might have been helpful to Luke:

“I think I was probably able to reassure him, from the angle of having it myself, perhaps more convincingly than someone who was just an outsider, you know, an onlooker, and you know, I mean I knew that these things always improve, you always get better.”

Throughout the interview Sally talked about the importance of routines and sleep in managing her condition. Being vigilant about these things was a way of making “...the most of a life for yourself.” In addition to these things, and good medication management (something that she felt confident about with her training and experiences over the years), faith was also important to Sally. She talked about how her faith had been a support to her but that it wasn't without difficulties at times:

“Well, it helps to know that whatever happens to me is under God's control and it will work out for my good ultimately, but I have to admit that in the acute suffering it's often very difficult to be aware that you've got any faith, erm, I'd be telling lies if I was to say all the way through I'd got faith that helped me because, I, I still believe that God is there but, and somehow it will work out, but erm, there are very dark days where you can't see the future.”

7.4.3 Family member: Katy

Katy was aged between 26-35 years and was Geoff and Sally's daughter. She lived with her husband, Jim. Sally was diagnosed with bipolar disorder before Katy was born, and had experienced episodes throughout Katy's lifetime. Around two-and-a-half years ago, Katy's brother, Luke, was diagnosed with bipolar disorder following a serious episode which led to him spend time in hospital.

Impact of mental health difficulties on sense of self and carer identity

Throughout her account Katy made reference to how her experiences of others' mental health difficulties, particularly in relation to her mother's condition, have impacted on her as a person. She talked about how it must be difficult having to cope with experiencing bipolar disorder, and that she didn't feel she would cope with it very well herself. Katy said that her mother had told her that with experiences of bipolar disorder, mania is actually the best bit, but she acknowledged that this isn't the case from the perspective of those seeing a close relative exhibit bizarre behaviour, "...seeing it, it might be at the time for the person, but the people are having to cope with the person doing strange [Laughs] things, it's quite, it's quite embarrassing." Katy talked about the impact of going through some of the things she went through as a child:

"...and in one sense I kind of feel that maybe it's shaped me into the person, you know, that I am, and that, that I guess I feel if I did meet a child with a, with a parent with bipolar, I guess I would feel quite passionate towards them, and almost, you know, want to help them, and I guess if you haven't had those experiences then, then, I guess they're not going to relate to you, you know, as much as somebody that has."

Katy's sense of feeling quite protective and nurturing towards children who have had similar experiences to herself seemed, at least in some ways, bound up with a perceived lack of support for children whose parents experience mental health issues. Katy talked about wanting more support for children like herself:

"I kind of wished, as a child, that I'd had more support, maybe just from understanding really that, the illness, from being a child, I don't think there's enough books on, on mental illness, for children to understand... so I didn't even have a book really, all I had was my mum's experience."

Katy went on to talk about how some days she would be affected quite detrimentally by what was happening at home, but that she was quiet and wouldn't have felt able to go up to a teacher and say that she was struggling. However, Katy also appreciated that for those who have not experienced mental health difficulties, it can be difficult to understand what such a situation might be like:

“I think some people, a lot of people, don't really understand it unless they've experienced it, or, a member of a family or a friend, I don't think they really understand it, so, so, to a teacher maybe it didn't really click as to what I would have to cope with.”

Katy expressed a sense of conflict in identifying with the term carer. With regard to Luke's condition, Katy related to him in the role of a concerned sister rather than as a carer. However, in her relationship with her mother (Sally), Katy talked about sometimes feeling like a carer. In response to being asked about whether anybody had ever referred to her as a carer, Katy said, “I guess as a child I didn't see myself as a carer although I probably was.” Katy talked about it being more likely that her father was supposed to take on this role but that this was not something that always came easy, and she understood why he would sometimes seem to detach from the role. Katy went on to talk about the role in which she found herself at the time of the interview:

“I sometimes, I still kind of think, am I really, am I really a carer, because I kind of feel that I don't live with my mum anymore, and is it right to call myself a carer when I only help so often, I don't know.”

Here, Katy was commenting on proximity to the other needing support being an issue in feeling like a carer. This sense of confusion over whether to identify as a carer or not also related to Katy's place in the family, and relationship with the person needing support:

“I went to one carers meeting... and I almost keep doubting as to whether I should be going, as to whether I'm really a carer because all the other carers are like, mums of children, and I'm like a daughter of a mother.”

Katy talked about attending a carers' support group, but only attending once, not sure if she really fit in with the other carers (who all appeared to be mothers of the cared-for person). The value of support groups for this family will be further discussed in the synthesis section. In terms of thinking about Luke and Sally's support needs, Katy made a comparison between their situations. Katy talked about having done more for her mother than for her brother, and the fact that Sally was able to help Luke manage his condition:

“I guess I've helped my mum more than I've helped Luke because my mum's got, um, chronic, I think it's chronic, called chronic mental illness, and I don't think that Luke has because he, he's only really had one really, really bad episode, and when my mum or he notices him going a little bit high, he'll um, well he'll up, up his dose... um so, most of the time he seems to, to cope quite well, and manage it quite well, and he does get depressed sometimes but, not as low as he got that, that time, so from that angle I kind of don't really worry about him as much as I worried about my mum as a child.”

Impact of mental health difficulties on family relationships

Katy talked about being shocked when her brother was diagnosed with bipolar disorder:

“...it was quite shocking for me because, because it wasn't until he was [in his thirties], my experience was with my mum that, she, she, hers started a lot earlier, so I assumed that all of us would be okay and that nobody in the family would have anything, so, from that angle it was a big shock, and I'd always assumed it would be

me, rather than Luke, because he was so outgoing and didn't seem to, erm, I didn't think he fitted into that."

Here, Katy outlined some of her perceptions about mental illness, highlighting some of the protective factors she felt might have prevented difficulties from taking hold.

Katy talked about what happened when Luke started to become unwell and the factors that led him to spend time in hospital. She went on to say that her mother was probably the first person to notice, and that she herself was in a state of confusion about what was happening during the early stages. Katy remembered going to visit Luke and seeing a significant difference in him, that he had lost weight, was being affected by medication, that his usual humorous disposition was not evident, and that he seemed helpless and vulnerable. Katy went on to talk about how he turned to her, saying, "...you're the only one that understands me." and that:

"...he would only let me go and get him water, he wouldn't have water from the staff, or any other member of the family to start with because he thought it was poisoned and he believed that I would, he trusted me enough to go and get him some water, at, at that time, so I kind of felt that I was help, helping him."

These experiences illustrated a strong bond of trust and friendship between Katy and Luke. Katy said that she felt that she and her siblings had good, close relationships. She acknowledged that, at times, she had felt closer to some than others, but that this seemed to be a natural function of growing-up and had not been particularly affected by mental health difficulties. In terms of supporting Luke since he spent time in hospital, Katy acknowledged that it tended to be their mother that helped him on a daily basis, doing the sorts of things she used to do for him when he was younger, before he left home:

“...my mum, um, she's kind of, reminds him, has he taken his medication every day, and erm, because now he, he spends some of the time at my mum's house and some of the time in [at his own house] so, she kind of, it's almost like he's back at home when he is at home and she used to do quite a lot for him, when he was at home, like his washing and everything [Laughs] and his meals, which she still does, so, I guess, but I think she enjoys it [Laughs].”

As noted above, throughout her interview Katy reflected on how her mother's experiences with bipolar disorder affected her childhood and the impact that they have had on the sort of person she has become. Katy was clear to point out that mental illness is not something you have control over so there is no point in being bitter about some of the difficulties she faced in childhood:

“I don't think, I don't blame my mum and think, why did you have to have this stupid illness [Laughs]... you know, she didn't ask to have bipolar did she, um, and she, tried to cope the best that she could and I guess I've learned an awful lot from having to cope with it.”

She also talked about some of the ways in which she was able to support her mother, offering something that other family members could not:

“I do feel that, I, when my mum's been ill, and almost, hospital, you know, almost needing to go into hospital which she hasn't, it's been because I've, I've gone round and I've, erm, calmed her down and, because nobody else in my family can do that, they just wind her up and they get annoyed which doesn't help, but I guess me being calm and quiet and, I guess all she wants is somebody to listen to her, has, I guess, saved her from going into hospital a few times.”

Katy went on to say that being the only family member who can relate to her mother in this particular way can be quite a great responsibility on her, and although she wasn't explicit about it at this point in the interview, there was a sense that this level of responsibility could sometimes be difficult to cope with.

In terms of seeking support for herself, Katy talked about a range of sources that might be helpful to her. Katy acknowledged that at times, seeking support from other family members could seem to present more challenges:

“I don't really feel that I can talk to my dad, er, because I almost feel like I'm gossiping behind my mum's back, er, and, I guess I don't really feel I can talk to my brothers, erm, I guess, so the closest person would be [my husband] Jim, and after a, a while he kind of gets a bit fed up and, you know, with it all.”

Katy also talked about the benefits of being able to talk to a health professional, someone outside the family, who could offer a confidential, safe, space for talking about her feelings.

Understanding mental health difficulties

As noted above, Katy talked about mental health difficulties not being something you choose to have and also about her understanding that there was often a genetic component, with mental illness running in families. Katy mentioned that, when she was younger, she often did not tell her friends that her mother was experiencing mental health difficulties, and tended to be vague, saying that she just wasn't very well, noting that people tended to assume that there was a physical problem instead. Katy mentioned that she had experienced depression herself and believed that there can be a lot of misunderstanding and stigma directed towards mental health difficulties:

“I guess the thing is that a lot of, a lot, in, in what, what I kind of feel that, is that, um, with mental illness, because, because it's not, it's not something physical, even though it does affect you physically, you kind of almost, when you have depression, you kind of don't feel valid that you're having time off work, in one sense, even though you've got every right to have time off work... but I almost thought that people with depression, oh, just, just get over it or do something fun, and you'll be okay [Laughs].”

Katy went on to say she felt her own experiences had made her more sympathetic and compassionate towards people that experience mental health difficulties. Katy said that part of the problem with people not understanding and accepting mental health difficulties might lie in the fact that such difficulties can be difficult to see, contrasting physical and mental health difficulties to explain her point:

“...it brings out a different kind of reaction I guess, to if you'd broken your leg, or if you'd got something physically wrong with you but, people accept that, most of the time that, people have got something physically wrong with them and they can't do things, but because you can walk around and you look fairly okay, yeah, I guess, they don't, they can't tell by talking to you can they?”

7.4.4 Family member: Luke

Luke was aged between 26-35 years and was Geoff and Sally's son. He had his own home which he shared with his wife before they separated. Luke divided his time between his own home and his parents' house. Sally was diagnosed with bipolar disorder before Luke was born, and had experienced episodes throughout his lifetime. Around two-and-a-half years ago he was diagnosed with bipolar disorder following a serious episode. He had been in contact with local Early Intervention services since this time.

Impact of mental health difficulties on sense of self

Luke began by talking about a serious episode he experienced that led him to spend time in hospital and receive a diagnosis of bipolar disorder. Luke talked about how he was confused during this period, not really knowing what was going on, finding it difficult to be rational:

“...it was just real fluctuation of mood, real quickly, and, like, anger, to happy, you know, it was just crazy... I had loads of different thoughts as well in my head at the same time, like, stuff that, if I think about it now it's not particularly rational because I had too many different thoughts, and they were too, you know, to be the truth you couldn't have one thought of this and another thought of that because it just ain't on, but at the time it seemed very real and, you know, like it was really happening.”

Luke talked about being scared by the situation he found himself in, and used words like, “weird”, “mad” and “crazy” to describe his experiences. At the end of the interview he reflected on how he felt about the situation now that some time had passed, saying:

“I'm a bit embarrassed about some of the stuff I did when I was high but that's, such is, you know, it could have been worse, I mean, I look at it and I think, well it could have been worse.”

In response to being asked about if he feels he has changed much as a person, Luke responded by saying:

“Oh big time, I think like, it was like going through Hell with the depression, unbelievable, I've never, never, ever felt like that, the anxiety and all that stuff that's horrible, I can't tell you, you know, it is really really hard, it's one of the hardest things to get through, erm, the highs, the high was, it was again, it was like one of

them mad experiences like in your mind, you think, wow, you know, did that really happen.”

Luke talked about learning about the power of the human mind, and used words like “amazing”, “unbelievable” and “incredible” to describe his experiences. When Luke talked about his experiences, he seemed keen to pick up on areas where he felt he had grown and developed as a person. He outlined opportunities he has been able to take advantage of, such as, attending college to develop a new career path:

“I think it’s done me a lot of good, in the long-run I think, you know, I would never have had an opportunity like this if I wasn’t ill, and um, you know, I just, I don’t know, I think it, I think things have worked out for the best really and you know, I’m glad, I’m glad that, things happened even though it was hard at the time, it was horrible, it was really bad going through the illness but there’s a lot of benefits to going through the illness really there’s been a lot of good stuff come out of it, you know, more support, I probably needed support before really... so, yeah, just nice to have a bit of, erm, you know, care, bit of people round and stuff.”

Luke talked about the importance of managing his sleep and routines in order to stay well. He also talked about the impact of stress on his condition and trying to avoid triggers that might lead him into difficulties. Luke seemed to have a certain sense of conflict about work in this regard. He was keen to work and make a contribution to society, but he also recognised that the type of stress he has faced at work in the past could be detrimental to his health if he were to go back into the workplace too soon:

“I think I’m getting better, obviously I’m still on the sick [claiming benefits as a result of not being able to work due to illness], I sometimes feel guilty for being on the sick, like I should be out there working and doing something, but, I, I don’t know what, and

then obviously I've got this college course anyway so, in a way the college course is keeping me safe for a while because, you know what I mean, at least it looks like I'm doing something, well I'm doing, I am doing something, and I'm doing it well, but, you know, it's just, one of them things, sometimes you just, I don't like, I don't like to think that I'm playing the system, I don't, I don't think I am because the CPNs [Community Psychiatric Nurses] always say, "Oh no, you're not", but I feel like I, you know, that I could give more than I do, you know what I mean, I feel there's more but I just don't know how to input into society really, at the moment, I don't want to get to a, step ahead, you know what I mean, to like go too fast for what I'm ready to go."

Luke's focus, having only experienced one major episode of bipolar disorder, was therefore on keeping well, learning from his experiences, and channelling his energies into something he enjoyed doing, and that would also allow him to contribute to society.

Impact of mental health difficulties on family relationships

Luke talked about spending more time at his family home since becoming unwell. He talked about a relationship breakdown that he believed acted as a trigger, amongst other things, for his psychological difficulties. Following the relationship breakdown, Luke found himself feeling a bit isolated living by himself in a different locality to his family. However, although Luke spent more time back at his family home, he was also keen to maintain his independence by keeping his own home, splitting his time between the two locations. In response to thinking about the terminology around caring being applied to his family members and their relationships, Luke said, "Yeah, I suppose they're, my mum and dad are my carers, but, although I don't really, it's weird because it just happens naturally I suppose don't it, it's like, you know [Chuckles]."

When asked about whether Luke thought his mother also experiencing bipolar disorder had had an impact on his own journey with the condition, he talked about how she was quick to recognise the signs:

“Yeah, she was clued up, looking back now she knew what the score was, she said it from the beginning, well, from, she thinks she knew about half-a-week or a week before it happened, she was quite clued up even though I thought, I didn't believe her.”

Luke's assertion that he did not believe his mother was also reflected in Sally's account, and they both talked about how it took a while for Luke to realise he was having psychological difficulties and accept a psychiatric diagnosis. Luke also went on to highlight the unexpected nature of becoming unwell in this way at his age, something that Katy also made reference to in her interview. Luke said:

“I just, you get up to that certain age and you think well nothing's ever happened before this and you didn't expect, you know, it was unexpected, you know what I mean, you don't think it's going to, you're going to have a problem, but I still, obviously at the moment because, because I had that breakdown, I mean, it's only ever happened, like, that once, like, bad, you know what I mean.”

Both Luke and Katy stressed the acute nature of Luke's condition, and expressed hope and a certain confidence that Luke would be able to manage his condition (through things like avoiding stress, managing sleep and medication) and avoid future episodes.

Luke talked about appreciating his family caring for him when he was unwell, and reflected on the impact of their intervention on his stay in hospital:

“I, obviously I appreciate them looking after me, you know, because at the time I really needed them, you know what I mean, I couldn't have, I often worry that, like, if they hadn't have come and got me out of there I don't know how long I'd have been in there for, that's the honest truth, because if they'd have kept on giving me the drugs, would I, I often wonder whether I'd have got better, erm, or whether I'd have just been stuck in there, and they'd have always been saying, “No, you're not well enough to go home now”, you know, because that's what it was like for some of them.”

Luke also noted that he felt that family relationships have become stronger since he became unwell:

“I feel that the relationship's grown stronger between everybody as a, as a result of what's happened, erm, well like, I feel like, that they're closer to me now, and they're all like, care more, if you know what I mean, there's almost like, an element, they're looking out for me a bit more, do you know what I mean so, yeah, it's good, so, so good things do come out of bad things sometimes.”

Luke seemed keen to frame his experiences in a positive way, focusing on the good things that have come from the difficulties and challenges.

Understanding mental health difficulties

As previously noted, Luke talked about the impact of experiencing a serious episode of bipolar disorder on his sense of self, using words like “weird”, “crazy” and “mad”, going on to conceptualise his experiences as the time when, “I lost my mind.” Although Luke said this with humour, he also talked seriously about recovery, saying “I didn't think I'd ever get my mind back, it was a feeling of not, you know, I don't know if I'll ever get my mind back.”, highlighting serious

concerns for his sense of self. For Luke, gaining an insight into the power of the mind was a feature of going through difficult experiences:

“...it’s just amazing, because your mind’s so powerful, when you’re thinking things and believing it you almost can do, you know, do anything really, it’s just phenomenal [Laughs] you know, you don’t realise, I didn’t, you know, I think it really opened my mind up to how powerful the human mind really is, you know, it’s unbelievable, absolutely incredible, but then when it’s out of control, you lose it, you can’t, and you can’t get it back, it’s a scary place.”

Luke also stressed the importance of clear, honest communication when people experience psychological difficulties. Throughout his interview Luke talked about how his feelings of paranoia and confusion, combined with rapid changes in mood, led to a number of difficulties in relating to others, particularly when he became angry and stressed. Luke talked about how the police approached him in an aggressive manner, which only served to escalate his own aggressive behaviour. Luke also felt that the police didn’t bother to try and explain things to him, as they didn’t believe he would understand them, saying:

“...so even if they don’t think I understand what they’re saying, they should tell me anyway because it’s only right, I think it’s only fair, and you do hear, it doesn’t matter, even if you don’t believe what they’re saying, or you don’t agree with it, if they’re telling you that that’s the truth and this is what they’re doing, then, in your mind it’s always going to be there and eventually it’s going to help you get through it quicker because you’re going to know where you are, once you start to believe people and trust them, you know what I mean, and start to realise that what they’re saying is the truth, so I think it’s very important to, to tell people even if you don’t accept the, even if they don’t accept at the time, I think it’s important to be telling and speaking

about what's going to happen about this, that and the other, I think that's very important."

Luke went on to talk about acting out of insecurity, and being concerned about perceived threats, when he was unwell, and the ways in which this can exacerbate aggression. He therefore advocated "gentle words" rather than a forceful approach to dealing with crisis situations.

The themes identified in the individual family member accounts will now be further discussed in relation to the wider family context.

7.5 Synthesis of family members' experiences

7.5.1 Making sense of what happened to Luke when he became unwell

All of the family members interviewed offered an outline of what happened when Luke became unwell from their own personal perspective. They described the difficult circumstances that led to Luke being hospitalised and diagnosed with bipolar disorder, highlighting the main events chronologically, as well as their personal responses to these events. The family's experiences seemed to be divided between shock and surprise that Luke should have become unwell in this way; and a feeling that they had seen it coming, and were somewhat prepared for it (though Sally was considered to be the one who first noticed the subtle signs). The family's experiences of Luke becoming unwell were therefore inextricably linked with Sally's own experiences with bipolar disorder over the years. In many ways, the family's experiences of Sally being unwell had shaped their understanding of bipolar disorder, and psychological difficulties more broadly, so that they felt better able to identify Luke's difficulties and support him through the challenges it posed.

Luke and Katy both made references to being surprised at the onset of his difficulties, both thinking that he had gotten to a stage in his life where he would not be affected by bipolar disorder.

They both linked this to Luke's age at the time he experienced his first episode (having passed through his twenties), and the fact that he was outgoing and confident, and therefore did not seem a likely candidate for psychological difficulties. These expectations seemed, in part, to be based on their experiences of Sally becoming unwell at a young age, and the idea that bipolar disorder was most likely to develop within an individual's late-teen/early-adult years. The possibility of a genetic vulnerability to mental health difficulties was also mentioned by family members. However, this was presented as only one potential 'trigger' for mental health difficulties, and life-circumstances were thought to perhaps have had a greater influence on Luke's condition.

All of the family members made references to things like "triggers", "routine" and "sleep" as being important factors in managing bipolar disorder and staying well. As might be expected of being part of a family where a close relative has experienced a long-term condition, the family were aware of, and used the language associated with psychiatric diagnosis freely, having integrated it into their ways of talking about their circumstances (e.g. terms relating to diagnosis, medication, and mental health services). All of the family members presented accounts of learning about psychological difficulties, and how to manage the challenges associated with this, through their combined family experiences, as well as through their interactions with mental health services. Although they all talked about going to a series of meetings organised by Luke's Early Intervention team (describing them as useful), the family tended to focus more on learning through their experiences, rather than through more formalised channels, such as, contact with mental health services or support groups.

So, although there was an element of surprise that Luke had become unwell early on, this family were quite quickly able to normalise their experiences within the wider context of a system that already had experience of successfully managing bipolar disorder (in relation to Sally's long-term diagnosis). As presented in Chapter 6 (service-users' and carers' experiences of first-episode psychosis), participants wrote about the traumatic effects of first-episode psychosis, and a number of the carers (all close family members of service-users) wrote about the sometimes catastrophic

impact of mental health difficulties on family life. In contrast, for this family, the potentially traumatic aspects of Luke's first-episode of bipolar disorder seemed to be tempered by their knowledge and experience of bipolar disorder as something that can be well-managed (or in some cases, even overcome) with the right support.

7.5.2 Making sense of the ways in which roles and relationships have been impacted by mental health difficulties: choice, detachment, role-reversal and replacement

In recounting their experiences over the years, the family members made references to the ways in which their roles within the family had changed and developed as a result of mental health difficulties. Key features of these changes seemed to focus on choice, detachment, role-reversal and replacement. In thinking about caring and psychological difficulties, choice was presented as an issue in terms of taking on the carer role. Sally talked about how she felt that Geoff did not want to take on the role of her 'carer', and both she and Geoff identified his reluctance to take on this role, and gradual detachment from it over the years. The carer role was seen to have changed the dynamic of their relationship by upsetting its former balance, making Geoff increasingly dependent on Sally. Geoff noted that in leaving work to care for Sally (and therefore becoming financially dependent on her), "...the roles had to be reversed." This was described as a source of frustration by Geoff, who went from being a working husband and father, to a husband and father who was dependent on his (mentally unwell) wife. Geoff's gradual detachment from the role over the years seemed to be a way of him regaining a greater sense of equality within his and Sally's relationship, attempting to increase his autonomy in managing his own time and responsibilities (as Sally's condition had become more stable, and the need for support had therefore decreased).

In addition to thinking about the dynamics of their relationship, Sally also talked about the impact of her condition on her and Geoff's desires to have their own family. Sally described coming to the realisation that she would have to give up work, and that having a family of her own had helped in some sense to "replace" her career when she was no longer able to work. Having their own

family was therefore presented as something that was immensely important to the development of Sally and Geoff's life together. Sally talked about being close to her own parents, often turning to them for support with managing her condition with her own immediate family responsibilities. Katy recounted how her grandparents would often also look after her and her siblings if her mother was unwell, further suggesting a close-knit, supportive family group. Sally talked about being reassured by the knowledge that her mother was always at the end of the phone if she ever needed to talk. Since her parents passed away, Sally reflected on how Katy had almost "replaced" her mother, particularly in relation to just being at the end of the phone if she felt the need to talk. In addition to Katy being presented in a 'replacement' role, Katy also reflected on being reminded by her father that, at times, she had looked after Sally in a way that somewhat reversed the parent-child relationship (offering personal care). Again, as first described by Geoff (about his relationship with Sally – "the roles had to be reversed"), this highlighted another relationship in which role-reversal was a feature.

Katy also admitted that she found herself taking on responsibilities that others were not able to adopt. For example, Katy talked about being the only member of the family that was able to calm her mother down when she was unwell, or, being the one that Luke trusted implicitly when he was in hospital. Katy reflected on how her personality traits of being a calm, quiet person, meant that she was the person that family members often turned to in difficult times. She also reflected on how her early experiences had shaped her as a person, and how her subsequent experiences had given her a better understanding of mental health difficulties and enabled her to be more insightful and compassionate to those affected by such difficulties.

The family members all talked about being part of a close-knit, loving and supportive family. A range of familial roles were represented by participants (e.g. spouse, parent, child, sibling) and these were presented as the primary roles through which care (for, and about, each other) was provided. Sally clearly identified herself in a range of roles (e.g. daughter, wife, mother, nurse), explicitly demonstrating that the giving and receiving of care was a central feature of all of these

positions. In terms of general parenting, Sally talked about how she and Geoff had helped all the children in different ways over the years. In thinking more specifically about supporting Luke since his experience of bipolar disorder, Sally talked about offering care from the perspective of someone who is a mother, has experienced of bipolar herself, and was a trained nurse. However, in caring for Luke, she stated that the care offered was a natural extension of being a parent ('it's just what you do'), though the boundaries of what might be considered 'normal' parental care, and what goes beyond this, became somewhat blurred by Sally's other roles. However, she credited her experiences in these roles with enabling her to be more compassionate than someone who had not gone through these things, therefore valuing what she had learned from the challenges and difficulties, drawing on them all for the overall benefit of the family. Luke also noted that although he recognised his parents could be thought of as his 'carers', it was strange to think of them in this way because caring for each other "just happens naturally" within their family. Indeed, throughout his interview, Luke did not offer reflections on his parents and family members as 'carers' until specifically prompted to do so by the researcher. Even then, Luke did not appear to find this language particularly meaningful, rather he focused on the ways in which they supported him, by doing things that they would have typically done for each other (e.g. making meals, doing laundry, spending time together) before he became unwell (though noting that their input had been somewhat greater in helping support his recovery). The fact that Luke had only experienced one serious episode meant that Luke and his family talked about him as 'having been unwell', rather than someone who 'was unwell' and therefore he was not seen as being 'cared for' within the family at the time of this research.

So, the family's accounts explored a range of transitions and changes to their established roles over the years. A key feature of these changes related to the specific challenges posed by mental health difficulties and taking on caring responsibilities for another family member in need. It seemed that these changes typically did not involve decision making processes, rather they were perceived as automatic responses to the needs of beloved family members. Where the carer label was considered, it was often presented as having little meaning for family members, not really resonant

with their experiences of caring for each other. For example, Katy talked about acknowledging that Geoff was Sally's carer, but also being aware that at times she felt she was better able to respond to her mother's difficulties than he was. Caring for each other, particularly in relation to experiences of psychological difficulties, was therefore presented as dependent on a range of roles and relationships that were flexible and adaptable over time, not just on who might be identified as 'a carer' by those outside the family.

7.5.3 Impact of mental health difficulties on sense of self: experiences of chronic and acute conditions

In thinking about how experiencing mental health difficulties had impacted on Sally and Luke's sense of self, Sally talked about becoming unwell at a young age, and the fact that her family have never known her as 'normal'. The fact that Sally's condition had been so long-term seemed to produce the effect that none of the family members, including herself, speculated on what her life, or family life, might have been like had she not become unwell. Family members made reference to Sally developing insight into her condition and ways of managing it to reduce the severity of her experiences of mania and depression. Sally was therefore positioned by the family as someone living with a chronic, but stable and well-managed condition. In contrast, Luke had only experienced one serious episode of bipolar disorder, and consequently was positioned by the family as someone who had experienced acute psychological difficulties, and who had excellent prospects for maintaining well-being in the future. However, while the family might not have noticed a great overall change in Luke, he personally acknowledged that experiencing bipolar disorder had changed him, "...big time.", giving him an insight into the power of the mind, and that there had been good and bad things to come out of his experiences.

Unlike the experiences of the service-users and carers presented in Chapter 6 (relating to first-episode psychosis), this family did not express a sense of loss or grief for the person Luke was before he experienced bipolar disorder. Family members' accounts of their experiences of seeing

Luke when he was acutely unwell suggested that there was a marked difference in his character. However, Sally noted that soon after his episode, the family were able to relate to Luke as, "...the Luke we'd known." Katy echoed this when she said of the time Luke became unwell:

"...it felt like a lot had changed, but after he got over, over the episode, and um, then it, it, life seemed to be fairly normal again, um, and, and now it, it doesn't really feel like a lot's changed, but it does feel like he's got a slight personality change, in the sense that he's not as confident as he was and he, and he lost a lot of friends and he was very, very outgoing, which he still is but not to the same, extent that he was."

The family's experiences were suggestive of a temporary loss of 'Luke' associated with his symptoms of, and treatment for bipolar disorder. However, this loss was negated as the 'old' Luke recovered and returned to the family.

So, while Sally's chronic condition was presented as having had significantly impacted on the family system's growth and development over the years, Luke's acute experiences seemed to have had less of an impact, being quickly normalised by the family, so that they could overcome the potentially traumatic features of his experience and focus on maintaining recovery and well-being. In terms of specific caregiving, family members talked about the ways in which they helped and supported each other as a close-knit family system. The family also acknowledged that mental health services had been helpful in supporting their efforts. Indeed, the Early Intervention team were presented as a key feature of Luke being supported to manage his own condition and stay well within the community, and therefore also continue to benefit from ongoing family support.

7.5.4 Sources of support outside the family system

In addition focusing on the impact of mental health difficulties on family relationships, family members also spent some time reflecting on people and organisations outside of the family that had

been involved as a result of Luke's, and Sally's, experiences of bipolar disorder over the years. The Early Intervention service, psychiatric inpatient services, the police, and support groups were all mentioned as things that have both helped, and hindered the family's ability to cope at times.

Early Intervention services

Luke talked about having regular contact with several members of the Early Intervention team. Although he didn't get off to a great start with all of the team members, he talked about how they had gone on to build a relationship over the time they had worked together:

“[The Community Psychiatric Nurse] was only trying to help, you know, I mean obviously I've got a good relationship with [the CPN] now but at the time I felt, like, a bit, you know what I mean, you don't always know who they are though do you, you're not sure, about who anybody is”

He talked about the help he has received in a range of areas, including starting a college course, getting help to manage his finances while he is training, and covering things like early warning signs relating to potential relapse situations. As noted above, Luke was very proactive about managing things like sleep, routines, and stress, mindful of doing what he can to stay well and achieve the things he would like to accomplish in the future.

In terms of Luke's contact with the Early Intervention service, the type and level of care they provided was seen by the family as being very good, vigilant and helpful in supporting Luke to manage his condition and avoid future crises. Sally said that the whole family felt included in Luke's formal care, “...there's always been explanations, about what's happening, what they expect, communication with all of us and it's very helpful.”

Other formalised psychiatric care

Both Luke and Sally talked about their experiences of psychiatric inpatient care, both preferring to receive support within the community. Geoff was not convinced that putting people together when they were unwell was the best thing to do. In experiences relating to both Sally and Luke, Geoff made references to, "...a lot of the patients went high together." and the idea that, "when you look at somebody, you, you, you tend to absorb that and reflect it back again." This is something that Luke echoed in describing his experiences of inpatient care, as he said, "...I don't think it does anybody any good because you're looking round and everybody, near on as paranoid as you, and it's flipping worrying, you know, it only takes one to spark the others off in a way." Geoff acknowledged that it might be necessary to put people with similar conditions together from an economic perspective, but that it doesn't really do people much good. Geoff therefore advocated the importance of having outdoor space available where people can relax in a less stressful environment, "...like, hear the birds singing and see the flowers growing and stuff." The family perspective therefore seemed to appreciate that while psychiatric inpatient care is perhaps necessary in extreme crisis situations, family support, and care in the community is preferable wherever possible.

The police

All of the family members mentioned the police being involved the time Luke first became unwell. Luke's experience was that they seemed overly aggressive and did not communicate clearly what was happening to him. He and Geoff both expressed concerns about police treatment of those experiencing mental health difficulties. Geoff acknowledged that it can be difficult when a person with no previous history of mental health difficulties becomes involved in a situation that requires police intervention. However, Luke and Geoff both identified mental health as an area where the police could benefit from training, as Geoff said, "I think the police need training in mental illness really, so they can spot it, and they, they're very insensitive and brutal a lot of the time." Luke's

experiences echoed Geoff's feelings, and he talked about being sensitive to the reasons behind behavioural displays of paranoia and aggression:

“I think they should try and do something in the police force, to recognise illness and deal with it better, and um, you know, I think, they don't realise that when you're ill you're ever so paranoid so anything that they do, it just, you know, if they're going to be aggressive, that's completely the wrong way to handle anything.”

Support groups

Sally and Luke both mentioned a support group for people experiencing bipolar disorder, Sally was a regular attendee, while Luke had only been once. Sally talked about the group being a source of mutual support, a place where experiences can be shared, and tips for managing the condition exchanged. Luke seemed more sceptical about the support group, and although he said it was interesting to hear other people's experiences, he wondered how useful it could be when people were in different states. These different views about the value of support groups seemed to be a reflection of Sally's more chronic condition, in comparison with Luke's single acute episode.

Experiences of carers' support groups were also explored, again with mixed feelings presented. Geoff talked about it being interesting to hear about other families' experiences, and said that he hoped their family's input was helpful to others. Katy also talked about it being interesting to hear carers' experiences of how they coped when a relative became unwell, and noted that she derived comfort from knowing she wasn't the only person going through these sorts of situations. However, she also reported experiencing some discomfort with support groups. In talking to some of the other carers, some of their responses to the experiences she shared left her feeling unsure and upset. Katy also expressed an inner-conflict over whether or not to identify as a carer, and so questioned whether her membership of such groups was appropriate. The local carers' group was also said to meet at an inconvenient time, which also made it difficult to attend. However, a

series of carers' meetings, organised by Luke's Early Intervention team were described by Katy and Sally as being valuable. So, it would seem that while support groups have offered something of interest to family members, they were not a major source of support for most.

7.6 Discussion

7.6.1 Implications of this research for improving families' experiences of mental health difficulties

The Early Intervention service was generally seen as very helpful in supporting Luke's recovery. The variety of professionals available and the input that they offered was seen as very beneficial to the whole family. Geoff and Sally talked about being involved in Luke's formal care by the Early Intervention team, but they also expressed that Luke wanted them to be involved in his life, and was happy to share information with them about his condition and steps towards recovery. Geoff and Sally did not therefore have a great deal of contact with team members, but this was described as their choice. Overall, the family described the Early Intervention team as "impressive" and Sally commented on how professionals communicated in a way that was helpful to the family as a whole.

While experiences of mental health services in general, and Early Intervention services in particular, were described in positive terms, there were still some areas where family members felt further training and awareness-raising could be beneficial. The family expressed concerns about Luke's treatment by the police. Both Luke and Geoff suggested that the police acted more aggressively than was necessary, and that training in mental health issues should be routinely offered. Geoff acknowledged that it can be difficult in cases where there is no prior history of psychological difficulties, but there was a sense that this should not be used as an excuse to brutalise vulnerable people.

The family expressed a sense of learning through experience. Both Sally and Katy talked about being more understanding and compassionate having experienced mental health difficulties (albeit in different ways) themselves. Luke talked about having a greater insight into the power of the mind, and was more mindful than he used to be about taking steps to protect his health and well-being. Geoff also highlighted the family perspective, what they have learned together, of having a greater insight into the psychiatric area (e.g. diagnosis, medication, psychiatric care options), though suggested that they could still learn more about the psychological side (e.g. talking therapies, relapse planning, maintaining well-being) of mental health.

In terms of support groups it would seem that they certainly have something to offer to service-users and carers, though they can also present difficulties for those who might benefit from their services. In some cases, confusion around whether to attend or not was closely bound up with the very nature of the group. For example, Katy wondered whether she was really a carer, sometimes feeling that she was, at other times, that she was not. This impacted on her decision-making abilities to identify with, and attend groups from which she might derive support. Care should be taken by these groups in terms of the ways in which they advertise themselves, being aware of the impact the 'carer' label might have on people who feel uncertain about how to classify their roles and responsibilities. Attention should also be paid to ensuring support groups are offered at different times of day to enable people to attend outside of normal working hours.

A sense of confusion around the language of caring was also explicitly expressed by Sally and Luke. Sally talked about her role being bound up in that of mother, a trained nurse, and someone who experiences bipolar disorder and in caring for Luke she is just doing what she has always done. Luke also acknowledged that his parents could probably be considered 'carers', but did not really identify with the term in any meaningful way. In terms of Sally and Geoff's relationship, Sally noted that she believed Geoff did not want to be her carer, and they both talked about how he had gradually detached from this role as the years have passed and Sally's condition has become

more stable. It would therefore seem that for this family, the term 'carer' is not particularly well used, or considered especially meaningful, or useful, in their daily lives.

7.6.2 Reflections on family members' participation in the research

All of the family members commented on their participation at some point in their individual interviews. The researcher began each interview by going over the aims of the research (to find out about family members' experiences since Luke became unwell) and stressing that they were free to talk about what was important to them (though participants were reminded that they should not share anything they thought other family members would not want to share themselves about their experiences, and that they had been encouraged to discuss these things together before participating in this research). The researcher informed participants that there was a list of prompts that might be called upon to help guide the conversation. A couple of times Geoff asked the researcher for a prompt to move the discussion on. Sally also told the researcher to let her know if she was not answering the questions in the way the researcher expected. Katy and Luke also both highlighted points in the conversation where they felt they hadn't answered the prompt in the way the researcher would have wanted them to, though the researcher reminded them that there were no right or wrong answers. Though, it is worth noting that the participants seemed at ease, often laughing and joking with the researcher, taking the opportunity to talk about the things that were meaningful to them.

The family members who participated in this research all expressed a willingness to take part voluntarily and were aware of the others who were also taking part, and the order in which the interviews would be taking place. As the interviews got underway, it became apparent that although the research began by asking about the family's experiences since Luke first became unwell, the family made sense of these experiences in the wider context of the impact of Sally's condition on family life. In the first interview, Geoff referred to it being beneficial to this research to have a variety of family member perspectives on what things have been like since Luke became

unwell. In the second interview, Sally started to talk about what things might have been like for Katy but acknowledged that this was something Katy might want to talk about for herself. Katy and Luke also made reference to certain things, going on to say that other family members had probably already mentioned them. Family members tended to focus on their own experiences, sharing their stories of what things had been like for them, and seemed to value the multi-perspectival design of this research. However, it is worth noting that family members might have felt that certain aspects of the family's experience might have already been covered and this might have led to them withholding things they might otherwise have shared. To overcome this as much as possible, the researcher emphasised that the purpose of this research was to explore the family's experience through detailed personal accounts, encouraging participants to share what was meaningful to them while being sensitive to other family members. Indeed, family members' accounts tended to focus on the experiences of those taking part in this research, with other family members being mentioned only briefly.

The value of using a multi-perspectival approach with members of the same family as a method of data collection for an IPA study is further discussed in Chapter 9, where consideration is given to the range of data collection methods (e.g. focus groups, written methods, multiple perspectives etc.) utilised in the studies presented in this thesis.

7.6.3 Limitations and ideas for the development of this research

It was anticipated that between three and five families would participate in this part of the research. Early Intervention services across the English Midlands, UK, were approached by the researcher who talked through the study with teams, encouraging professionals to help identify families that might be interested in sharing their experiences. It was also hoped that there would be a follow-up element to the interview procedure, with the researcher going back to interview family members between 6- and 9-months after the first interviews. In light of difficulties in finding several

interested families to take part within the allotted time scale of the project, the decision was taken to turn this study into a case-study without a follow-up.

It could be argued that such a case study design is perfectly in keeping with IPA studies and lends itself well to in-depth idiographic analysis of a small number of participant accounts. Rather than being seen as a limitation, this change to the design should therefore be seen as a key strength of the study, allowing time and space to be given to one family's set of experiences. One limitation of this research might relate to anonymity, as presenting only one family's experiences, and the details that make their experiences unique to them, may make it easier to identify them. Care has therefore been taken to try and attend to as much of the detail of participants' accounts as possible, while being mindful of maintaining their anonymity. It is also noted that one of the reasons for liaising with Early Intervention services was to try to identify families who were perhaps 'newer' to caring and mental health difficulties. However, this family had an extensive history and range of experiences with both of these things. While this family's experiences might therefore be quite different to those who had not previously experienced mental health difficulties (e.g. as with the participants' experiences presented in Chapter 6 – first-episode psychosis), that is not to say that their experiences are any less valid or interesting to research in this area.

In terms of developing this research, it would be interesting to continue with the original intentions of this project, recruiting other families, to explore their experiences in the way outlined above. By gathering a range of family case studies, further integration of the data could lead to a broader picture of families' experiences when a relative becomes unwell and is referred to Early Intervention services. While any individual family's experiences will be unique to them, in sharing and integrating such accounts, it is hoped something new may be learned about how to improve the experience of mental health difficulties for families.

So far this research has explored the literature, and rationale for taking an interpretative phenomenological approach to exploring, caring and mental health difficulties (Chapters 2-4),

moving on to explore a range of carers' and service-users' experiences of mental health difficulties (Chapters 5 and 6). This chapter has presented a family's experiences of being affected by mental health difficulties, highlighting a sense of mutual support and learning, and a lack of identification with the language of informal care. The next chapter will go on to explore mental health professionals' experiences of caring, mental health difficulties and the language associated with informal care.

Chapter 8

Exploring the meaning of mental health professionals' experiences of working with carers of people experiencing mental health difficulties, and the language of care

8.1 Abstract

The aim of this chapter is to explore how mental health professionals working in Early Intervention services understand the language of informal caring and the ways in which they identify and work with the carers and families of their service-users. Data were collected from a total of 18 Early Intervention (for young people, typically aged 14 to 35, experiencing serious mental illness) and Early Detection (for young people with a high risk of developing serious mental illness) service professionals, over three focus groups. Each group was facilitated by the researcher (MP) who used a semi-structured set of prompts to explore professionals' perspectives on caring, though participants were encouraged to lead the discussions themselves wherever possible. Participants provided rich, detailed accounts of working in Early Intervention and Early Detection services, drawing on their personal and professional experiences of caring.

This study employed an interpretative phenomenological analysis approach and was mindful of the issues that are often associated with the analysis of focus group data (Palmer, Larkin, de Visser & Fadden, 2010). Analysis identified four themes in the data: 'Caring' is doing more than is normal within close relationships; "I'm not a carer, I'm a wife": labelling and personal identity; The impact of the carer label on family relationships; and the Development of relationships with carers and families. Overall, participants, while offering some differences of opinion and specific personal experiences, tended to offer similar accounts of how caring was understood. Discussions seemed to particularly focus on how caring involves doing more than would normally be expected within close relationships, and the idea of the carers' own life being different as a result of their

caring responsibilities. Conflict arose concerning the impact of labelling carers, with participants considering both the positive and negative consequences of identifying and labelling people in this way. Many of the discussions also focused on relationships, specifically the impact of caring on service-user - carer relationships, and the development of relationships between professionals and service-users, carers and family members. Overall, the participants presented an understanding of caring that seemed better defined by experience than circumstances. For example, not all parents are necessarily carers, but carers will most likely be doing more than the norm in their familial role. They will also likely be feeling a sense of burden from their activities, and not be able to go about their own lives in the way that they used to, or would like to. The implications of these findings for mental health services are also considered.

8.2 Introduction

The number of carers in the UK population looks set to increase in the coming years, and the economic and social benefits of informal carers is being increasingly recognised (Buckner & Yeandle, 2007). As previously noted, much of the research on caring and mental health difficulties focuses on burden, distress, relapse rates and resilience (Chapters 2 and 3). While mental health services and carers' organisations offer broad definitions of what a carer is, there is still little research on the experience of how carers themselves come to identify with the term, or how professionals experience identifying, and working with families and carers.

As the literature on caring develops, some researchers have attempted to explore the lived experience of caring, employing qualitative methods to capture rich, detailed accounts of caring that might be used to facilitate the development of family-sensitive services. Where much of the previous research in this area has focused on carers' perspectives, this research aims to explore the meaning of caring through a variety of perspectives, namely those of service-users, carers and mental health professionals. In employing a multi-perspectival design, it is hoped that a more cohesive account of how caring is understood might be presented.

Further rationale for this study stems from the National Institute for Clinical Excellence's recommendation that: research into methods of identifying the individuals who would most benefit from family interventions and methods of promoting the effective implementation if such interventions should be undertaken (NICE, 2006). In order to investigate the ways in which professionals come to identify, and engage with carers, this study will focus on mental health professionals working in Early Intervention/Detection services. These services, unlike many others, have a specific remit to engage and work with the carers and family members of their service-users. In terms of offering a different perspective on caring, it was felt that these professionals would be well situated in terms of working with carers who were maybe only just beginning to see themselves in this way (in contrast with the carer participants in Chapter 5, who had typically been caring for many years).

Chapter 8 therefore seeks to address the following research questions:

1. What is the experience of engaging and working with carers and family members like?
2. How is the language associated with informal caring understood by mental health professionals?
3. How do informal carers come to be identified as such?

8.3 Method

8.3.1 Participants

Data were collected from Early Intervention service, and Early Detection and Intervention Team (ED:IT), staff members from NHS Trusts providing services across the English Midlands, UK. Posters were put up around team bases advertising this research, and information sheets were provided to those who were interested in taking part (see Appendix 11 – advertisement poster; and

Appendix 12 – participant information sheet). A total of 18 participants took part in three focus groups (details summarised in Table 8.1).

Table 8.1: Overview of mental health professionals' demographic details

Gender	Age range (years)	Ethnic background	Length of time spent working in services	Number of participants in each focus group
13 x Female	3 x 18-25	13 x White British	Range: 0.25-40 years	Group One: 4
5 x Male	5 x 26-35	1 x White Irish	Mean: 11.8 years	Group Two: 6
	6 x 36-45	1 x Black - British		Group Three: 8
	3 x 46-55	1 x Asian - Indian		
	1 x 56-65	1 x Asian - Bangladeshi		
		1 x Other (not specified)		

As a function of advertising this research to all Early Intervention/Detection team members, the convenience sampling method of recruitment attracted a wide variety of participants, particularly in terms of job roles and length of time spent working in services. The job roles of the participants included: team manager; care-co-ordinator; community psychiatric nurse; student mental health nurse; occupational therapist; occupational therapy student; assistant psychologist; community support worker; support, time and recovery worker; vocational worker; research co-ordinator; and research associate. As some of these job roles are senior positions, to give further details on the number of people in each job role, or the exact composition of each focus group might be detrimental to protecting participants' anonymity. It is also worth noting that the size of the groups did vary, however, each group consisted of participants of a range of ages, years of experience, and each had at least one male participant. This study sought to include a wide range of experiences, from those just starting out in a career working in mental health, to those who had many years of experience. The aims of the study were to explore how team members go about identifying and working with families and carers and how they understand the language associated with informal care. As all participants were expected to involve families and carers in their daily work (albeit in

different ways), it was hoped that involving a variety of professional roles, from trainees to team managers, would give a more holistic view of how Early Intervention/Detection teams go about their work and promoting their family-sensitive ethos. An outline of the focus group composition, and consideration of the positions adopted by participants, is further discussed below and in the discussion section.

8.3.2 Data collection

Focus groups were set up to elicit mental health professionals' opinions and experiences of what it means to be an informal carer for somebody experiencing mental health difficulties. Each group was facilitated by the researcher (MP) who recruited three convenience samples of professionals from two Early Intervention/Early Detection services. The researcher used a prompt sheet (see Figure 8.1 below) to start the discussions and keep the groups focused on the topic of caring, though participants were encouraged to express what was meaningful to them. The prompts were developed by the researcher following previous research with carers that indicated there were often difficulties in identifying with the language of care (Palmer, 2007). The researcher therefore considered what these carers had said, and what was available in the literature to develop prompts for professionals. Each group lasted for an hour and was held at a location that was familiar to participants. The discussions were audio-recorded and transcribed verbatim for analysis. All participants were given pseudonyms during the transcription process.

8.3.3 Data analysis

Data were analysed using interpretative phenomenological analysis (IPA). A protocol for using IPA with focus group data was used (Palmer, Larkin, de Visser & Fadden, 2010; see Appendix 6); which itself was developed from Smith's work on IPA (Smith, 1996; 2004). Each transcript was first analysed to explore what was particularly meaningful to participants in each group, and how participants were interacting with each other, and with the topic under investigation. These

analyses were then integrated to present a picture of the meaning of caring across the groups, considering key similarities and differences, and the wider context in which this meaning has developed. A short extract of worked data is presented in Appendix 13 to illustrate some of the steps in the data analysis process.

Figure 8.1: Prompt sheet for focus groups with mental health professionals

Focus group prompts for mental health professionals:

NB. The below are prompts only. The Chief Investigator will rephrase/prompt for more detail as appropriate during each individual interview.

1. What do you think of when you hear the term 'carer'?
2. What do you think is meant by the term 'carer'? Do you think it is appropriate? What alternatives might be used?
3. How often do you come across this term in your work/where do you notice this term being used? (e.g. literature, policy documents, colleagues, family members?).
4. Have you ever received training specifically dealing with working with carers/families? If yes, prompt for more details. If no, do you think this would be beneficial? What would you like the training to cover?
5. Is it usual for you to have contact with carers? In what capacity?
6. Is there an expectation that you will work with carers in your service/team? Do you offer any type of family intervention?
7. What do you think are some of the benefits/disadvantages associated with involving carers in mental health care for carers/for staff/services?
8. How do you usually first come into contact with carers?
9. What sorts of things do you discuss with carers about taking on a caring role for somebody who is unwell?
10. How do carers respond when you use this term/introduce this concept of 'caring'? (e.g. Is it new to them?; Are they unsure? Is there some recognition/understanding?; Relief, anger, fear, acceptance?)
11. What other services/support is available for carers in the area you work in (Carers Assessments, financial support, support groups etc.)? How do you let carers know about these services/this support?

Ethical approval for this study was granted by the [REDACTED]

[REDACTED] All participants were given written information about the study and discussed what would be involved in participation with the researcher prior to taking part. All participants were aged over 18 years, had capacity to understand the nature and purpose of this research, and gave written informed consent to participate.

8.3.4 Outline of focus group composition

In order to set the group discussions in context, consideration should be given to the positions adopted by participants within their groups. A brief outline of each group is therefore presented while being mindful of protecting participants' anonymity.

Group 1 (four participants: Liz, Nigel, Alan & Anna)

Liz and Nigel had both recently moved to the ED:IT team following a number of years working in an Early Intervention service. Alan and Anna both worked in an Early Intervention service. Alan was new to his role as a vocational worker following a career change. Anna was an assistant psychologist and was fairly new to the role. Liz and Nigel did most of the talking, sharing their substantial experience of working in mental health services for a number of years, taking turns and encouraging other to share information where appropriate to the conversation. Liz talked about having a reputation with other staff members as being someone who is good at engaging with service-users, carers and families. In doing so, she seemed to be positioning herself as someone who had something to say about the topic under investigation. Indeed, she was the only participant who talked about this research explicitly stating that, "...it's the first time I've seen one done for a long time on carers." Liz went on to say that the research being conducted in mental health, that she was aware of, seemed to focus on medication and relapse, not carers, and that she was glad that this research was being done. Alan and Anna occasionally contributed, seemingly content to defer to their more experienced colleagues.

Group 2 (six participants: Adele, Diane, Sue, Liam, Ian & Kate)

All of the group members seemed to be confident in sharing their experiences within the group setting. They all knew each other quite well and had all worked together for a while, though were not all members of the same team. Adele was very vocal, and more than happy to start the conversation following prompts from the researcher, offering examples from her caseload, as well as from her personal life, to further steer the discussion in the way that she wanted it to go. She talked about “getting on her soapbox”, “moaning” and “going off on a tangent” at various points, apologising to the group for this, but at the same time remaining keen to make her point. The group seemed happy for her to continue in this way throughout the discussion, adding their own opinions and experiences where appropriate. Adele said at the beginning that she probably would not be able to stay for the whole session due to a prior engagement. Her desire to say her piece, jumping straight in, might therefore have also been a function of her feeling she had a more limited time to do this than the other participants (the group lasted for roughly one hour and Adele left after approximately 40 minutes). In contrast to Adele, while still confident, the other members of the group tended to say less at any one time, and were more similar to each other in terms of the length of time they spoke for, and the experiences they shared.

Group 3 (eight participants: Nadia, Rachel, Karen, Emma, Leah, Mark, Celia & Shirley)

The group seemed to spend a reasonable amount of time focusing on what they do as a team, perhaps a function of all group members being part of the same team (unlike Group 1 which had elements of this but with only two experienced team members; and Group 2 which was composed of members from different teams). As might be expected when including the team manager, this participant seemed confident in speaking on behalf of the team at certain points, talking about the things that “we” do. This is not to say that the group presented a single, united viewpoint on everything. In fact, at times, members of the group presented certain views, and others then entered the discussion and gave ‘on the other hand’ responses. There seemed to be the sense that, rather than attempting to establish who was right or wrong, the point in doing this was more about

covering a broad range of experience and expertise, i.e. it can be both like this, and like that. The fact that this seemed to happen more in this group than the others might also be due to this group being larger than either of the others, therefore there were more experiences to draw on.

8.3.5 Context in which themes are set: Early Intervention services

All participants worked within Early Intervention/Detection services in the English Midlands, UK. They typically worked with young people who had recently experienced, or were at risk of experiencing, serious mental illness. Consequently, many participants' experiences of carers were linked with parenting and parent-child relationships. In addition to exploring professionals' perceptions of the meaning of caring, participants presented a picture of what they do on a daily basis in terms of working with service-users, and their families and carers. They talked about the impact of involving families and carers on their work, and considered this involvement in terms of the expectations of their services, thinking not only about what services can do, but also sometimes what they cannot do.

Carers' assessments were mentioned in all three focus groups, though they were presented in a different light by each. For Group 1, carers' assessments were primarily regarded as an engagement tool. Liz talked a lot about using the assessment process to engage with carers and build relationships, and went on to say that assessments were only as good as the people doing them in terms of them being useful in meeting carers' needs. Liz and Nigel both acknowledged that carers' assessments can present difficulties in terms of implementing identified support needs. They suggested that developing links with other professionals and organisations, knowing who to turn to for support, and where to signpost carers to, was something that you learn by doing. The participants in Group 2 talked about carers' assessments being helpful in identifying carers. In line with Liz's comments (Group 1), a number of participants also talked about using the assessment process as a way of engaging with family members, developing a rapport with them through information sharing. For the participants in Group 3, carers' assessments seemed to be more

closely linked with statutory responsibilities. However, the idea that meeting carers' needs goes beyond any one team, knowing what the pathways are, and where to signpost people to, was again highlighted as important if carers' needs are to be met.

8.4 Themes

An outline of the themes derived from the mental health professionals' focus group data is presented below (Table 8.2). Four key themes were identified during data analysis in relation to exploring the meaning of caring: 'Caring' is doing more than is normal within close relationships; "I'm not a carer, I'm a wife": labelling and personal identity; The impact of the carer label on family relationships; and the Development of relationships with carers and families. These themes are further discussed below.

Table 8.2: Summary of themes derived from mental health professionals' focus groups

Theme	Key components of theme
'Caring' is doing more than is normal within close relationships	<ul style="list-style-type: none"> • Activities: input, support and burden • Social norms and lifespan issues
"I'm not a carer, I'm a wife": labelling and personal identity	<ul style="list-style-type: none"> • Impact on carers' identity • Impact on service-users' identity
The impact of the carer label on family relationships	<ul style="list-style-type: none"> • Carer – service-user, or parent – child? • Information sharing – carers can be put in a difficult position
Development of relationships with carers and families	<ul style="list-style-type: none"> • Ability to engage with people - creativity and artistry • Expectations of what the service can and cannot do - boundaries and balance • Supporting caring networks beyond services

8.4.1 'Caring' is doing more than is normal within close relationships

All of the groups typically started by thinking about who might be a carer based on their experiences of working with service-users and the other people that were involved in their lives. Parents, siblings, partners, grandparents, aunts and uncles, and children, all featured heavily in participants' initial thoughts about who might typically be found in the carer role. However, a number of participants were also keen to mention that these types of close, family relationships weren't always indicative of who a carer might be. Ideas were expressed about not having to live with the person you care for, not assuming those in close family roles will always be carers, and that carers might also be friends or neighbours. The participants in Group 3 summarised the idea of taking a broad view when it comes to identifying carers:

Nadia It could be whoever's providing the support but whoever, whoever is around them that feels burdened as well, they might not necessarily be *doing* a great deal but their levels of burden are taken into account

[Pause]

Celia I think anybody who, erm, anybody in the person's life who actually sort of, provides external motivational forces really, and that's, it can be, a partner, a best friend, erm, a mum, a dad, a grandparent, a sister, a brother, a child even...

[Murmur of agreement from the group]

Celia ...so it's quite

F Yeah

Nadia So, I guess we probably think outside the box a little bit in terms of, you know, that traditional, there's one carer involved...

F Mmm

Nadia ...and, you know, we do incorporate the, sort of, whole family unit don't we?

Celia And we also, sort of, we don't just look at it from the perspective of the family that the client is living with at that particular moment in time, we'll see things like reconstituted families, and we'll also see ex-partners and children, all those relationships as well and how, because they'll still have an impact on that so, it's more than just, 'I live with my mum and dad' and that's it...

F Yeah

Celia ...'And my sister', it's a lot bigger than that as well.

(Group 3)

Nadia mentioned thinking beyond perceptions of, "...that traditional, there's one carer involved" (Group 3). In doing so, she was describing her perception of a societal assumption, that people who are unwell will commonly have one carer. In questioning this, the team highlighted their position of not being traditional, rather they are innovative, and open to both seeing, and doing, things differently. This position would seem to be indicative of the Early Intervention model of service provision, identifying mental health difficulties early, and working intensively to support recovery, often involving families and carers in this process. Here, in common with the other groups, the participants in Group 3 presented the idea that they are inclusive, working with a range

of people who are important to the service-user at any given time. It is worth noting here that although the possibility of carers being friends or neighbours was considered, all of the relationships that these participants focus on, and share experiences of, are close family relationships, i.e. those which would have been formed, and involved familial care, *before* the service-user became unwell. This context seemed to reinforce the idea that caring for somebody experiencing mental health difficulties is something that happens in addition to the care that was already being offered. The one exception to this is when Adele talked about a client for whom professionals had taken over the family role:

Adele ...erm, but I do have, again we have a couple, a few people who live in supported housing but I don't think of the support staff as their carers with it, at all, and funnily enough in any of the mental health projects, but... I have a girl who lives in a [Organisation] place, and I really do think that the staff there are her carers, they really look after her like she's, well she is, she's a young girl who's had a crap family, and they've taken on that family role for her and, I do feel like they are her carers but funnily enough, I don't in any of the mental health projects, weird that, isn't it?

(Group 2)

Here, Adele contradicted her own view that support staff are not carers. She used an example from her caseload, seeming to want to make the point that carers can be from outside the family, though this is understood to be unusual. Adele commented on the nature of family, that professionals had taken on the "family role" for a vulnerable young woman because her own family had let her down. This further reinforces the idea that it is close, family relationships, that typically lead to taking on further caring responsibilities. However, where this does not happen, these relationships can be developed in other ways (further consideration is given to relationships as a separate theme). In any case, the links to pre-existing close relationships suggest that caring is something

that tends to develop naturally, i.e. 'it just happens' without much thought being given to the process, or how this process might be recognised:

Emma ... it's not always a choice to become a carer, it's, it just happens.

(Group 3)

Rachel They don't always perceive themselves as carers do they?

(Group 3)

Not surprisingly, thoughts about what a carer *is* were tied up with attempts to define what a carer *does*. As Nadia noted (above), carers might well be providing support, but then there might also be others who are not *doing* a great deal, but feel burdened by their responsibilities (Group 3). However, for the most part, the participants went on to focus on the things that carers *do* that identify them as such, perhaps in part, because these things are more easily recognised and described by carers and those outside the family. Ideas about input and individuals going 'above and beyond' what is normal in close relationships were reflected in the discussions of all three groups (emphasis added):

Liz ...the work you have to put into that person, *it is more than what you would do...for a normal child.*

(Group 1)

Adele I think, *something you wouldn't do for somebody of that age in a normal situation* and that impacts on your life.

(Group 2)

Rachel So, *things you might not normally have to do for an adult person*, really, that they would often do themselves.

(Group 3)

Participants did not typically attempt to define what 'normal' meant in these cases, highlighting a sort of implicit cultural assumption that this is self-evident. Being in close relationships with others, and the give and take that comes with this, is something we all have experience of, therefore the 'norms' of these relationships required no further explanation. However, although this was accepted to some extent, some participants also expressed contrasting views about variance in these social norms across localities and cultures. Ideas about families all having their own individual culture were also noted, with participants suggesting that the potential for differences should be taken into account by services, with professionals being mindful that there is never a one-size-fits-all approach to care. This seemed to point to a conflict between: ideas about caring being something so natural and common to human experience that there is a 'normal' amount and type of care that is offered in all close relationships; and ideas about what is normal for one family might not be for another. As previously noted, parent-child caring relationships seemed to be particularly well represented in these participants' experiences, perhaps a reflection of the young client group typically seen by Early Intervention and Early Detection services. Indeed, several participants made distinctions between *parenting* and *caring*, to illustrate their perceptions that there is something about caring that transcends normal family relationships:

Nigel ...I think in, with Early Intervention, they seem to take a, almost a blanket view that everybody who is looking after somebody with mental health problems is a carer, but, but with ED:IT, because we're dealing with people who, haven't got a mental health diagnosis, diagnosis of illness, they're showing signs of maybe developing a mental health illness in the future, we wouldn't necessarily consider, say parents, as being a carer, they, they may be, you know, they may provide care, but is it care as a 'carer' or care as a 'parent'?

(Group 1)

Nigel was also telling the group about what he saw as the expectations of the Early Intervention service, that everybody who has contact with service-users is a carer in some way. However, the Early Detection team take a more cautious approach to labelling, typically working outside of the diagnostic labels that also often lead to family members being labelled as carers (the impact of labelling carers is further considered as a subsequent theme). Liz went on to give an example of a service-user's mother who was interested in accessing carers' allowance:

Liz Well, because her friends get money, for people who are less, she says, not even as bad, or unwell as her daughter, she feels that she's entitled to this money somehow, and that she is a carer, and that her child wouldn't survive without her, and you think, well, she would actually, and there's *parenting* and caring, that's a bit different.

(Group 2)

Liz used this example to highlight the way in which carers can use this position to catastrophise their child's condition, and to reinforce that caring goes beyond the sort of parental care that most children need to survive and develop on their own. From Liz's point of view, this was problematic because, in her role as a professional, she was working to normalise the experience of mental health difficulties and promote recovery. Adele (Group 2) also reflected on typical parent-child relationships. She too considered the potential impact of labelling carers:

Adele I think, our, in our lot, the person who's most involved in that person's care usually pipes up pretty quick, and I tend to ask, as I don't really use the word carer because I think that it sort of, medicalises something that nine-tines-out-of-ten is what a normal mum would do for a normal son, and I think to keep calling something caring, there is that divide isn't there?

(Group 2)

Here Adele specifically made reference to 'medicalising' normal behaviour, something that was also a feature of other focus group discussions. Celia talked about the age group of their clients and trying to balance, "...what is illness and what's being a stroppy teenager?" (Group 3). Nigel also talked about working with a mother who was worried about her son's behaviour, which he attributed to "teenage angst" (Group 1). Adele talked about working with mothers who do their teenage/young-adult sons' laundry, and being aware of some carers who she felt just do, "...what my mum would do for me and I'm in my thirties and I'm not, I don't have a mental illness" (Group 2). This further emphasised what Adele saw as normal, typical family behaviour, not warranting special attention. So, in addition to what a carer *does*, what a carer *is* also seemed to be closely bound up with what a carer *is not*, with participants starting to try and categorise who is *really* caring.

Conflict around identifying 'carers', as opposed to simply concerned relatives, seemed to be particularly salient for the participants in Group 2, though is echoed by those in Group 1, e.g. the idea that not all parents are carers, and that *parenting* is a bit different to *caring*. While much of the focus was on parent-child caring relationships, the only other relationship that was discussed in any detail was romantic couple relationships (i.e. service-user - spouse/partner). Therefore, concerns about dealing with different relationship dynamics were expressed. Adele talked about the types of carers she worked with in relation to her caseload (working with young people), comparing her perceptions about working with parents, to working with couples:

Adele Yeah, I think I'm the same, that the majority are mums and dads, usually mums in our case, and I've had the, I think in fact we've only had a couple of patients where, the girlfriend, never been a boyfriend for some reason, it's always the girl, I don't know why, it might be because I tend to look after lads, erm, the, the girlfriends seem to be involved, it seems to be quite different, and that, it seems to be more, as part of their relationship, erm, some, somebody said, "Ah, sometimes I feel almost more like a couples

therapist”, and oh my God, I’m not!, I certainly did yesterday while, when we’re looking, when it’s mums and dads, it feels like it’s more education and more support, what is okay and what isn’t okay, and maybe that’s because I have a lot of naughty boys?

(Group 2)

So, although Adele identified the majority of carers she works with as parents, she also referenced partners. In particular, she identified female partners, setting this further in the context of mainly having young-male service-users on her caseload. Celia (Group 3) also acknowledged that a lot of the experiences she had shared with the group were about parental carers, and she deferred to others’ experiences of working with people where the relationship dynamics might be different. Rachel picked up on this thread, offering her experience of working with couples:

Celia ...and I don’t have many couples, maybe one or two, and I’ve not actually come up with any problems so far...

Rachel Mmm

Celia ...so I can’t really speak about what it’s like when you’re talking about a married couple or people who live together, it’s, they’re different, dynamically

F Yeah

Rachel Mmm, mmm, similar kind of thing, you know, he’s likely to want to talk about her, she’s not going to want to hear him talking about her, yet she’ll be listening, it’s very difficult

Leah Yeah

Rachel Mmm, she might accuse you of being his friend

Celia Sounds awful [Laughs]

[...]

Rachel That has happened

Leah Oh dear

Rachel Well, because you're *his* worker, aren't you?

(Group3)

This extract highlights the nature of relationships between professionals and the people they work with, for example, a carer finding the professional - service-user relationship invasive; or viewing the professional as the service-user's 'friend', there to support the service-user over the carer, or to take their side (further consideration is given to professionals' relationships with families and cares as a separate theme).

So, although there may be differences in caring relationship dynamics, there is still something about taking on a caring role that means going 'above and beyond' what would typically be expected in any given set of circumstances. Following her concerns about the 'medicalisation' of normal family behaviour, Adele went on to further reflect on establishing what the social 'norms' were for those people on her caseload, to help her identify who is a concerned relative, and who is a 'proper' carer:

Adele ...that the social norm in [my locality] is for a lad to sit on his back- sit on his backside, while his mum or his then wife cooks, cleans, washes, does his dishes, makes sure he goes to his doctors, while I don't think that's the social norm, everywhere, and I worry that, again, this, "I'm the carer, I'm the carer", is it, and then the next question will be, "How much DLA [Disability Living Allowance] and how much money can I get for being a carer? Because I'm going to jack my job in", sometimes, call me cynical, but I worry that it takes away the impact of the people who really are caring for their children... and it's always the ones who won't claim for carers' allowance because they say it's their job, but actually, they're not working because they're running round after their children.

(Group 2)

Adele acknowledged that this was a somewhat cynical viewpoint, but she seemed to want to make the point that identifying carers should be about acknowledging a need for support, rather than just being about who service-users are close to. She further reinforced this point a few minutes later, talking about carers' allowance forms, and the notional idea that carers are supposed to provide thirty-five hours of care per week, so that theoretically the time spent caring prevents carers from being able to work:

Adele ...and I'm pretty damn sure that a lot of people who would identify themselves as carers, are probably doing, not a lot more than, a, a regular mum or dad would do, but then I think there's quite a few, carers who wouldn't identify themselves as carers who are really trying, working, the [person] I was talking about who used to work so hard looking after these two, I don't know how they coped, I really don't.

(Group 2)

Adele had deliberately chosen examples where she picked out people who were, “not doing more than a regular mum or dad would do” or who seemed to be using the label to seek financial gain. She acknowledged that using these examples made it sound like she has, “...got a really horrible bunch of people, and I really don't” (Group 2). Rather, Adele seemed to want the group to know that she was selectively picking out the cases that illustrated the point she wanted to make. Throughout the discussion she returned to the idea that labelling carers reinforces the sick/carer roles within families and that this can be unhelpful and unnecessary, inhibiting people's ability to recover and move on with their lives. The idea that not all people who might identify themselves as carers would be perceived as carers by services, was echoed by Liz who talked about her experience with a service-user's mother:

Liz ...I have [many] years of, with one client, and funnily enough I'd never offered her a carers' assessment, [Pause], no, because I don't think she, a carer, what she does is, yes, she'll phone, but it's all about her, so you know, if he was caring for the child it would be different, and doing the things that she would, but it's not, it's never usually, an input from her, or what would you be getting, who would you be getting support for, the mum, or the child, or, is she saying, “I'm a carer because I'm needed”, but you look and you think, you know, you break it down, and she probably, she wouldn't meet, many of the definitions of an actual carer.

(Group 1)

Here, Liz talked about this person not meeting the “definitions of an actual carer”, talking as though there was a set of clear criteria against which professionals could assess individuals. However, the group discussions in this study highlighted just how difficult it was to define what a carer might be. Where definitions do exist, they are vague and could almost apply to anybody and the group discussions seemed to support these definitions (broad and inclusive), while the participants' experiences also seemed to suggest that it is possible to identify and make distinctions

between those who are 'really' caring and those who are just doing what might be expected in a close relationship. Like Adele talking about the established norms for those on her caseload, the participants in Group 3 also tried to establish what the 'normal' expectations of relationships might be. These expectations may well be related to issues of caring for people across their lifespan. For example, Nadia talked about there being certain areas of mental health where it seems more acceptable to be a carer:

Nadia And I think there's areas, perhaps in mental health where it's, more acceptable to be a carer, and to go to carers' event and things like looking after the elderly, dementia and that, it's kind of an accepted role isn't it, someone becomes old and they become demented and, whereas if someone's 17 and develops strange symptoms.

(Group 3)

Nadia picked up on the idea that there are times in our lives when the expectations that we will need care are greater than others. So, it seems more 'normal', or socially acceptable, to care for an elderly relative with dementia, than a teenager with psychosis. There was a clear sense across the groups that carers do something that is 'above and beyond' a normal close relationship, but that not all people who care and are in close relationships with somebody who is unwell are carers.

Less common throughout the groups was the consideration of the personal qualities that carers might possess, the main focus being on primary familial relationships (e.g. parent, partner, sibling), and what they do (e.g. personal support, financial support, medication management). While some participants did talk about examples of caring in their personal lives, only one identified as having personal experience of caring. When the facilitator prompted Group 3 to talk about what they think about when they hear the word carer, Rachel began the conversation with:

Rachel I suppose what springs to mind is exhausted, because they often are, and I've been a carer, and I was.

(Group 3)

Here, Rachel drew on her personal experience, which she briefly returned to later in the discussion. She did not go into the particulars of her own caring role, but this opening comment sparked a discussion about the potential support needs of carers. Also thinking about the personal characteristics of carers, Diane (Group 2) said:

Diane Somebody nurturing and had got that, yeah nurturing side to them I suppose.

(Group 2)

In attempting to define what a carer is, the groups talked about who might be most likely to be identified in this way, though the focus was really on what carers were doing, and how they felt about what they were doing. Ultimately, the consensus seemed to be that a carer could be anyone, but was most likely to be someone who had some sort of pre-existing close relationship with the cared-for person, and who was doing more than would normally be expected for that type of relationship. There seemed to be a sense that these norms *can* be defined, but generally are not, as they are common to the experience of human relationships - though there might be some cultural variations between family systems. The participants presented an understanding that carers were bound by a set of common experiences and that these could be explored to identify who might be thought of as a carer. For example, who is going 'above and beyond' what is expected of them?; Who feels burdened or stressed by their caring activities?; Who is exhausted from carrying out caring activities? Exploring the answers to these types of questions seemed to be a key feature of the ways in which participants identified carers, rather than simply looking at the service-users' circumstances and picking out their nearest and dearest. There seemed to be an expectation that carers would have their own support needs, and that they were deserving of help and support from outside the family. Professionals were encouraged to identify and work with families and carers by

the services that employed them, and this way of working seemed to be well-established and successful, with the benefits being recognised across all the focus groups. However, working within services that have finite resources can lead professionals to attempt to identify those in greatest need, having to draw distinctions between those who are 'caring', and those who are 'really caring'.

8.4.2 *"I'm not a carer, I'm a wife": labelling and personal identity*

The act of labelling people as carers prompted discussions about the impact this has on both carers and service-users. As previously noted, one participant, Rachel, identified herself as a carer. Aside from telling the group that she found the role exhausting, she went on to say:

Rachel I hated being labelled a carer, I have to say, I used to say, "I'm not a carer, I'm a wife".

(Group 3)

Rachel went on to say that being called a carer made her "feel old" (Group 3), while Celia suggested that it seemed a bit "clinical" (Group 3). Nadia attempted to summarise why a person might not want to be called a carer, suggesting that other roles take precedence over the carer identity:

Nadia And I guess you don't want, you know, if you're a mother or a father, brother or sister, you don't, you don't want to be called a carer, because you're a mother aren't you, or a wife or a, whatever, you don't want your primary role to be called a carer.

(Group 3)

The idea that labels become negative developed as the group went on to talk about the impact of labelling in general. Nadia went on to say that this made it difficult to know what to call people who support somebody else, while Celia agreed that whatever word you chose, it would become negative in time. However, in spite of this, the idea that carers need to be identified in some way pervaded:

Nadia But that, that role, wife, doesn't portray what you're doing...

Rachel No, no

Nadia ...because you're having to do above and beyond what a, sort of, wife, should be doing

Rachel Mmm, mmm, and different things

Nadia Yeah, yeah

Celia The equality changes

Nadia It's a different role

Rachel Yes, that's right, yes

Nadia So, that is a hard one.

(Group 3)

As explored in the previous theme, the idea that carers are going 'above and beyond' what would be expected of someone in a close relationship, and that this should be recognised, seemed to be

key here. Nadia talked about needing some way of identifying that there had been a fundamental shift in a person's role, that in essence, it is "different". The difficulty seemed to be the way in which the label 'carer' seemed to subsume all other roles, that being a spouse, parent, sibling, was somehow diminished by the carer role. In using the group example of a spousal relationship where a wife was caring for her husband, Celia brought up the idea that "the equality changes". This indicated a significant change in the relationship dynamic, from something that is equal, to something that is unbalanced, and perhaps unfair. So, there seemed to be a sense that caring can dramatically change relationships, and where this happens, this needs to be acknowledged and attended to in a way that is sensitive to the carer and cared-for person. While it is important to value the efforts that the carer is making, simply labelling people as carers is not always useful, and in some cases can feel quite negative, especially where it is seen to diminish the primary relational role.

The impact of labelling was a concern for participants across the focus groups. The idea that labelling carers necessarily leads to the labelling of the 'cared-for' was a source of apprehension for participants, who felt that this could be particularly unhelpful for their young client group. In thinking about his work in Early Intervention and Early Detection teams, Nigel talked about how he might be working with people who have not been given a psychiatric diagnosis, but who may be at risk of developing mental health difficulties:

Nigel Yes, yeah, because I had one client ring, not client, had a client's mum ring me and she complained to me that she hadn't been offered a carers' assessment, and from her point of view perhaps she was justified in feeling that he needed a carers' assessment, we were just desperate not to have her son go down the route, "Oh, I've got a mental illness, all my behaviour I can attribute to mental illness"...

Liz Mmm

F Yeah

Nigel ...a lot of his behaviour was to do with teenage angst, and existential crisis, whatever, and I wanted, was trying to get that across to him, you know, "You're not mentally ill, you're not at risk of developing mental illness", and we were very confident that he never would develop a mental illness, but then you've got his mum on the other hand, who's very distressed by his behaviour...

F Yeah

Nigel ...so clearly she feels that she needs support, and, and I can see her point of view, but to, for me then to go, "Okay, yes, you, we'll give you a carers' assessment"...

Liz Yeah

Nigel ...that would send a message to her son, "Yes, I'm ill"...

Liz Yeah

Nigel ..."My mum, to the point that my mum needs support to look after me".

(Group 1)

So, although Nigel could understand the mother's concerns, appreciate she was distressed and felt in need of support for herself, he was also deeply concerned about the impact of labelling her as a carer. In doing so, he felt it would be detrimental to her son's sense of self, picking him out as

someone who was so unwell that his mother needed support to help care for him. In addition to trying to stop service-users becoming trapped in a 'sick role', some participants also expressed concerns about carers and families falling into sick/caring roles:

Adele ...but I just seem to have had a spate at the moment where I'm quite shocked how, how as soon as somebody's, that sometimes it's not necessarily the patients' falling into the sick role, it's the patients' families who have fallen into this sick/caring role which, well, I don't know, it just seems a bit weird to me.

(Group 2)

Adele was clearly uneasy with the idea of how quickly some families seemed to take on the caring role, taking that identity for themselves, and consequently reinforcing the service-user's condition and identifying them as someone who needed to be cared for. However, consideration was also given to the potential benefits of identifying carers and encouraging them to recognise themselves in this way:

Celia I don't know, from the new chaps that I've got, I've got, it's been, sort of saying to them, "You do realise that, you are actually, a carer, I know you're doing this because you love this person, and I know you want the best for them, at the end of the day, because you're actually doing this for somebody who is ill, and is recognised as being ill, and has a team of people, you, you actually have certain rights, under that", and sometimes you have to give them that little bit of education, that there is rights, involved in that, in that role that they have.

(Group 3)

When prompted to think about how carers reacted to being referred to in this way, the consensus from Group 1 (presented by Nigel and Liz) was that they had found carers to see it in a positive light. Nigel talked about carers mostly feeling “validated” and that their input had been recognised. In contrast to this, Adele in Group 2, talked about the label being “insulting” and “belittling”. However, when the facilitator asked Adele if carers had used these terms, Adele talked about being careful not to use the word carer with the people she worked with. Her reaction to the label therefore seemed to be linked to her perceptions about what carers think, rather than what carers themselves had actually said. Sue went on to talk about how it would be strange to refer to people as carers when you were working with families, that you would be more likely to refer to people by their names because you would have built up a relationship with them. The participants in Group 3 offered the perspective that while some might be quite settled in the caring role, not wanting it to end, others do not want the label. The overall picture seemed to be that for some carers, the label is useful, helping them to feel valued and gain access to resources, while for others it might be perceived as unhelpful and insulting.

8.4.3 The impact of the carer label on family relationships

In addition to exploring the meaning of caring through thinking about going ‘above and beyond’ what is normal in close relationships, and the impact that labelling can have on family members’ sense of self, participants also explored the impact of caring on family relationships. As noted as part of the previous theme, using the label ‘carer’ can impact upon both carers’ and service-users’ sense of self, reinforcing caring- and sick-roles within the family. The focus of this theme goes on to explore the impact on carer - service-user relationships. Celia gave an example of service-users rejecting the label, focusing instead on what might be considered the more primary role:

Celia ...sometimes our clients, a couple of mine have said it, about their parents and them being carers, it’s like, “I don’t want a carer, I want a mum, stop

doing this, I just want you to be my mum”, so it’s sometimes the clients themselves actually going, “Can you just be my parent please?”

(Group 3)

Here, Celia clearly identified the way in which the carer label can displace the more immediate role of the primary relationship (i.e. parent), and that this can be unsatisfactory for service-users who feel a greater attachment to familial labels. For some, it might be that thinking of their relatives as carers makes them feel that they have lost something of the relationship they previously enjoyed. Indeed, Celia went on to highlight a potential consequence of this shift in roles:

Celia ...and I think sometimes when, when, when, especially parents become carers, they sort of lose the ability to have fun, with that person as a person.

(Group 3).

Here, Celia was linking caring responsibilities to not being able to have fun with the cared-for person. She also talked about her efforts to normalise what is happening within the families, emphasising that the young people she worked with wanted parents, not carers, or “babysitters”. Celia’s comment about “babysitters” was linked to carers, and used to reinforce the carer role as one that can infantilise the cared-for person, turning them into a helpless, vulnerable being that is unable to get along without intensive support. Celia also drew a distinction between physical health and mental health difficulties, to highlight how differently people experiencing mental health difficulties are treated by society. Leah went on to share a story about a carer she worked with who felt that she had lost her son because he had changed so dramatically since the onset of his condition. In this case, the change was temporary and he soon went back to his normal self. However, this story prompted Celia to explore the nature of parent-child relationships over time, and the ways in which mental health difficulties can complicate the transition through adolescence:

Celia That's interesting because I had a very similar conversation with one of my clients' mums, erm, first teenager, unfortunately developed psychosis... and er, she's going, "I want to know what the diagnosis is", and it's like, "This is a first-episode psychosis", she's like, "Yeah but that, is that schizophrenia, is he going to be like this forever, he wasn't like this before", and I'm like, "So how was he before?", she went, "Well, he was really close to me", and I went, "That was [a few] years ago, he's [late teenage], he's got friends, he's at college, he's moved out of home, he's not going to be this little lad any more", and it, it's like saying, look, some people just mature into personalities, that, maybe you might not like them, you might not like them, you'll love them, but you might not like them, and isn't that normal adolescent behaviour?

(Group 3)

Here, Celia presented the idea that as adolescents mature they might grow apart from their parents, and that parents might not always like who their children become. Also, these developments may, or may not have anything to do with mental health difficulties, and trying to navigate this transition can be difficult for parents who might be looking for explanations for challenging situations.

There also seemed to be the potential for conflict in carer - service-user relationships when it came to information sharing. Nigel told the group about a service-user he worked with who did not want his mother to share information about him with services:

Nigel ...we were trying to assess him, assess him but we couldn't get information from his mum because he would basically tell his mum, "You can't tell them anything about me", you'd go and speak to his mum, "I'm not talking, I'm not saying anything", so it's almost like she was held to ransom by her own son.

(Group 1)

Nigel talked about the service-user's seemingly threatening behaviour towards his mother, attempting to control her actions to get his own way. This example of a service-user exercising control over a carer in relation to information sharing was also echoed by Sue (Group 2):

Sue There's a couple of cases as well that we've got where the clients use their carer to kind of, back up their side of the story, like if they don't want to engage in services, they kind of almost, say, bullied their kind of mum, or say, you know, "You better tell the doctor that I'm okay", and you can kind of see them in the face that they're going, "Oh yeah, yeah, no he's okay", and you know, we've had people that, they've had tribunals and things, and they've got their mum to say, you know, "He's fine, he's okay", just so he can get off his section, but actually, everybody else knows he's not, and the family probably knows he's not, but it's, you know, the easy way out isn't it, just to agree with them and, let them get on with it.

(Group 2)

Both of these stories highlighted the potential for control issues between service-users and carers to be expressed, particularly in relation to information sharing with professionals. This can therefore have implications for relationships between carers and professionals, if carers feel inhibited from communicating with them.

The professionals were prompted to talk about how they dealt with confidentiality issues where carers wanted to share information with services, but where service-users had not wanted this to happen. Participants talked about considering carers' own needs, and how to manage these within a service that has intervened primarily to help the service-user. Participants noted the importance of maintaining confidentiality, being aware of the boundaries for each service-user and family system, and being open to how these might change over time. These issues seemed to link in with the ways in which professionals come to engage with service-users and their families, building

relationships that encourage, and facilitate, open communication and the development of supportive networks.

8.4.4 Development of relationships with carers and families

A key feature of relationships between professionals and service-users and their families seemed to be linked with professionals' ability to engage and build relationships with people, primarily the idea that this is a natural ability, not something you can teach. Liz talked about the importance of building up relationships, being sensitive and getting to know people gradually:

Liz Yeah, personally, I go on, what I do, I, when I meet someone again, that sort of thing is about you and how you engage with people, because everyone is different, so building up that relationship, you can't go in to do an assessment on someone and start asking them all these questions, they don't know you, [Chuckles] because they're going to think, "Oh, who are you?" So again, it's a natural thing, you either know how to deal with people or you don't, and I think that comes from, not even your nurse training, I think that is a part of you, that you can engage with people, or you can't.

(Group 1)

Nigel talked about his nurse training only covering a small proportion of what he felt he did in his job, and this idea about learning by doing was echoed by Liz and Anna. Celia also talked about the importance of being creative and adaptive, not something that can necessarily be taught, when working with service-users and their families:

Celia ...I think it's, when it comes down to it, that, that, everybody who deals with families, and, and, young people, or people, whatever, who are experiencing mental health problems, when you're dealing with that, it comes down to

pure artistry, that balance is not, it's not something you can teach in a classroom, you can, you can equip people with a toolbox, but you can't teach that, that is, that is something that you develop, your own way of dealing with it.

(Group 3)

Another key feature of the relationship between carers and professionals seemed to focus on expectations about what the service can and cannot offer service-users and carers. There seemed to be a huge potential for conflict in this area. Indeed, this is one of the issues that Adele 'got on her soapbox' about, as she talked about times when she has been "screamed at" for not doing what service-users and carers wanted despite not really being in a position to offer it (Group 2). Liz also talked about being "sacked" by clients (Group 1). However, aside from the difficulties and challenges, the benefits that can be achieved by involving carers and families in mental health service provision, seemed to be a key factor in all of the group discussions. Liz (Group 1) talked about building "trust" and "genuine respect" in her relationships with families. Nigel also talked about feeling his job would be more difficult without carer involvement in services, and went on to say:

Nigel ...if you're in regular contact and got a good relationship with the carer, they're a very good barometer of their son or daughter's mental health.

(Group 1)

Here, Nigel used a metaphor to describe the way in which carers are able to track and report on their relative's mental health. Nigel talked about how this helps in terms of professionals making contact with service-users, helping manage medication, and avoiding crises and relapses. He acknowledged that involving families can initially seem like more work, but overall it saved time and other resources. In the discussion in Group 3, participants seemed to be particularly concerned with managing the balance and boundaries of offering support to carers. The group discussed the

importance of not over-supporting carers so that they become dependent on the service, and unable to cope with the slightest thing by themselves. Avoiding dependence on services was also an important issue for the participants in Group 2. Therefore, one of the functions of developing good relationships with families was to facilitate discussions about what would happen when the service-user was discharged from Early Intervention services:

Sue I think it helps the long term outcome for the client as well, like while they're with us they might, you know, have a really supportive case worker, but then as soon as we discharge them then they have only got their family so if the family's not, like aren't involved, and kind of understanding what's going on, then, you know, they're not going to stay well, stay, you know, they need someone else that's going to be there all the time rather than...

F Yeah

Sue ...our kind of three years

Liam But within that three years you're building a framework for somebody aren't you...

Ian Yeah

Liam ...you're building the other networks that are outside of our service, if the family are providing the role, then you know, it's all the other stuff that's going on

Diane Sometimes, I think you just get those clients as well, who, the clients won't engage with the service at all, and...

Ian You need the carers

Diane ...you're really just liaising literally through the family, and that's so important, because you've got all this stuff going on, and yet, just through, maintaining contact with the carers, making sure they're okay, so you can sort of go in if crisis occurs, and just give the carers the support that way, because I can think of a couple of cases where, yeah, clients won't engage, but they're still engaging with the carers just to be on the safe side.

(Group 2)

An important function of professional-carer relationships was to help develop frameworks and networks that would support service-users and their families in the wider world, beyond mental health services. The participants also discussed the importance of having a supportive team around to enable them to be effective in their professional roles. Liam talked about "support structures" and "supervision" being in place, as well as the importance of team members being able to "share experience" in learning how best to approach the involvement of families and carers in services (Group 2). The participants in Group 3 also referred to working with a carer consultant, and specialist carers' workers, which were felt to provide an extra source of expertise and experience that they could draw on for the benefit of their service-users, families, and their own professional development. However, in addition to other team members being seen as sources of support, some relationships could be more fraught as Mark explained:

Mark I will say this, I have found myself embroiled in, sort of like, torn apart between, between the carer and the psychiatrist, erm , the dissatisfaction, you know, what the psychiatrist is doing, what treatment that he or she is carrying out, and you're sort of like, you are in the middle of that, and you've got the carer saying, this, this, that and the other, and you've got, er, the psychiatrist, you know, you've got the two of them, at each other, and

you're in between that, and you're trying to get an even balance, and it's just getting frustrating [Chuckles].

(Group 3)

Here, Mark shared his experience of an unsatisfactory professional-carer relationship (between another professional, in this case a psychiatrist, and a carer) going on to impact his professional relationship with the same carer. Mark admitted to feeling in the middle of a difficult situation, being able to see both sides, and feeling a responsibility to come to a resolution that suited both parties. Throughout the group discussions, relationships between professionals and carers were described as supportive and mutually beneficial; as well as being difficult and frustrating at times. While professionals strove to build relationships with carers and families, describing the benefits of carer involvement, boundaries and balance also remained key issues. Overall, there was a sense across the focus groups that carer involvement was "invaluable" (Group 3). While it can be challenging, time consuming, and a lot of personal effort, ultimately investing in developing relationships with carers and families was found to be rewarding and beneficial to professionals, service-users and their families.

Also, it is worth noting that while many of the focus group discussions focused on family relationships and professional-family relationships, some thought was also given to the impact of carers supporting other carers. Carers' support groups were mentioned as sources of comfort and information in all the focus groups. There seemed to be a general perception that carers might be more comfortable talking to others in similar situations to themselves, than engaging with groups like multi-disciplinary teams of professionals. Such support groups were therefore thought to provide opportunities to chat with others, raising awareness that others are going through similar situations, and that they're not alone. In addition to providing opportunities to share experiences, Adele also viewed such groups as a good way for professionals to intervene, to offer things like psychoeducation, and signposting to other services that might be useful for carers. At one point

she talked about maybe renaming the carers' group to make it more accessible, something that is picked up again by Kate later in the discussion:

Kate ...a few of ours will say, sort of, the main carer, will they want to come to the group, and they're, "Oh they might not but will my sister, or would somebody else be able to come?" So sort of, it would be better to sort of give it a broader label because they just see one person, and normally they say, "Well my mum can't come but can my sister or could my girlfriend or brother, or whatever", so, you could be excluding people calling them carers as well.

(Group 2)

The idea of labelling carers' groups in this way links in with the idea that not all people who take on caring responsibilities would identify themselves as carers, and so think to access a carers' group that might be helpful to them. The idea that carers' support groups should be inclusive to all those who feel they would like to attend also links into participants' ideas about the need to support caring networks outside of mental health services. Though these groups may also be accessed by professionals to offer interventions that might be useful (e.g. psychoeducation). However, it may well be important not to over-professionalise the support group environment, focusing instead on creating a safe space in which carers and family members can share their experiences.

8.5 Discussion

This section will offer some reflections on the nature of the focus groups, and the use of this data collection method with an IPA approach to data analysis. The value of using focus groups is further discussed in Chapter 9, where consideration is given to the range of data collection methods utilised in the studies presented in this thesis. The themes will then be further discussed, and the implications and limitations of this study considered.

8.5.1 Reflections on mental health professionals' participation in research focus groups

All of the participants communicated a genuine interest in this research, and engaged with the researcher to explore their understanding of caring, and the impact it had on the service-users and families they worked with. As previously noted, some participants were more vocal than others, particularly those who had spent a greater length of time working in mental health services. All three of the groups seemed to have one person who was happy to take the lead (Group 1: Liz, Group 2: Adele, and Group 3: Nadia), all of whom were in quite senior positions in terms of job role, and years of experience, compared with other group members. It is noted that the other group members appeared to be satisfied with this, though it is also acknowledged that some group members, particularly those who were less experienced, might have felt uncomfortable speaking up in the company of more senior colleagues. Convenience sampling meant that the groups varied in size (4, 6 and 8 participants respectively), though this did not appear to have a detrimental effect on either the length of the discussion, or the range and depth of topics covered.

All three of the groups generated discussions that lasted for approximately one hour, each starting with the researcher prompting the group with, "What do you think of when you hear the word 'carer'?" Following the initial prompt the researcher encouraged participants to take an active part in leading the discussions, utilising active listening techniques (eye contact, nodding, smiling, making encouraging sounds) throughout to encourage participation. At times the researcher asked for clarification of something that had been said, or attempted to move the group on through the use of another prompt if they seemed to have come to the natural conclusion of the previous prompt. The prompts outlined (see Figure 8.1) were used only if necessary (i.e. to keep the groups on topic), and the order, or specific language used was amended to suit the discussion thread of each group. In line with the ground-rules discussed by the researcher and each group at the beginning of each session, all participants were respectful of one another, gave others the opportunity to participate, did not interrupt each other, or offer criticism of others' responses. Indeed, while there was a lot of consensus on a number of issues, there were times when

participants offered conflicting opinions and experiences. This did not lead to animosity or conflict within the groups, rather a sense that different people have different experiences, and that it would be a good thing for the researcher to be aware of this variety. While many of the experiences shared by participants seemed to already be known to other members of the group, there were times when they indicated that they were learning something new from what others were saying. There seemed to be a general sense that the participants had enjoyed taking part in the focus groups, and that they felt this research was worthwhile and relevant to themselves, and their services.

The way in which the groups were conducted seemed to fit with the way in which an IPA study would hope to collect rich experiential data required for a successful analysis (i.e. the researcher using semi-structured prompts, encouraging participants to lead the discussion). Analysis was carried out using the protocol developed by Palmer and colleagues (2010) and the researcher was mindful of the factors set out in helping to consider whether the data were suitable for this type of analysis (including: the generation of data that clearly suggest a phenomenological analysis; exploration of positionality; consideration of organisations and systems; exploration of participants' stories and language; a degree of homogeneity within and between groups). Data were explored as participants' accounts of their experiences of working within Early Intervention and Early Detection services. The researcher has not attempted to present a clear and accurate definition of caring that might be recognised by all Early Intervention staff, rather has explored these professionals' attempts to understand, and make sense of, caring within the context of their daily lives. It is hoped that this will be of interest to mental health services more generally, and will make a relevant contribution to the literature on family-sensitive mental health services.

8.5.2 Towards a more psychological definition of caring

In exploring definitions of what a carer is, Carers UK, a carers' charity, states, "carers provide unpaid care and support to ill, frail or disabled friends or family members" (Carers UK, 2011).

The Princess Royal Trust for Carers (also a charitable organisation), offers a similar, but more detailed definition:

A carer is someone of any age who provides unpaid support to family or friends who could not manage without this help. This could be caring for a relative, partner or friend who is ill, frail, disabled or has mental health or substance misuse problems.

Anyone can become a carer; carers come from all walks of life, all cultures and can be of any age. Many feel they are doing what anyone else would in the same situation; looking after their mother, son, or best friend and just getting on with it.

Carers don't choose to become carers: it just happens and they have to get on with it; if they did not do it, who would and what would happen to the person they care for?

(Princess Royal Trust for Carers, 2011)

These definitions offer a general picture of carers as those who offer help and support to those who need it and who are not paid for doing so. The Princess Royal Trust for Carers' definition states that anyone can be a carer, but points to pre-existing close relationships (family and friends) as perhaps being most likely. The idea of 'social norms' and 'doing what is expected' appears, highlighting parent-child and friendship relationships as examples of the circumstances in which a person might offer help and support in difficult times. This definition states that carers do not choose this role, further emphasizing a lack of choice, and questions who else would care, and what would happen to people who need help and support if informal carers did not take on these responsibilities.

It is worth noting that the definitions above are not limited to carers of people experiencing mental health difficulties, rather they aim to try and capture a general sense of caring. However, although this research was carried out with mental health professionals, the themes that were derived from

the data, although pointing to a more psychological definition of caring, are not necessarily only applicable to mental health carers. Indeed, it would be interesting to explore perceptions in other areas of healthcare where professionals are encouraged to work with their service-users' carers and families.

The participants in this research seemed to broadly agree with these definitions, but went further, pointing towards a more detailed, psychological definition of caring. Indeed, although the language and terminology of caring was often used as a short hand by professionals, it seemed that they were not always comfortable using it directly with family members and those who were close to the service-users they worked with. Also, in dealing with issues of assessing risk for future mental health difficulties, normalising existing difficulties, and promoting recovery, the participants talked about being wary of labels, seeming to take a more formulation-driven approach to exploring individual family circumstances.

When prompted to think about what a carer might be, the participants tended to begin by thinking about the sorts of people that might take on this role, focusing on close-familial relationships, such as, parent, spouse or partner, child and so on. Throughout the group discussions there seemed to be a sense that everybody knows what a carer is, and that it is something that can be easily defined. However, as the discussions progressed, none of the participants attempted to offer a clear definition of what a carer is. Rather, they talked about the general ways in which they come to identify carers based on a range of criteria including: the expectations of the services they worked within; statutory requirements (e.g. offering carers' assessments); those who are doing more than would normally be expected within close relationships; those who experience burden or distress as a result of their caring role; and those who are unable to go about their own daily lives in the way that they could before they took on a caring role.

The theme of 'doing more than is normal within close relationships' points to things like level of input (e.g. physical, psychological, financial), perceived burden, and expectations concerning

social norms. The fact that participants did not attempt to explicitly define what was considered 'normal' within relationships seemed partly to do with the idea that we all have a general sense of what is normal based on our own experiences, and those of our peers; and also that what is normal for one family might not be normal for another. This therefore seems to indicate that efforts should be made by professionals to establish family norms for the family systems they work with at different points in time (e.g. what were relationships like before the service-user experienced mental health difficulties, before they came into contact with services, what have they been like since that time etc.). This could help professionals to identify where people are going 'above and beyond' their normal level of caring, and where they might need help and support to continue with these activities, and look after their own health and well-being.

The theme of 'labelling and identity' suggests that it is not always helpful or desirable to label carers, but at the same time recognises that there needs to be some way of identifying and valuing the efforts that people are making in offering help and support to those who need it. The impact of labelling on identity was discussed in relation to carers and service-users, and consideration was given to the way in which labelling may reinforce sick- and carer-roles within families which might otherwise be avoided. There seemed to be a sense across the groups that the carer label can be both helpful (validating efforts and opening up opportunities for support), and a hindrance (it could be viewed negatively, perhaps even seen as insulting). Participants' discussions about this issue drew on experiences of things that carers had told them directly, but also on their own ideas about how the service-users and carers they worked with might understand this language. This might be due, in part, to the fact that although professionals might identify people as carers (both informally in terms of information sharing, and more formally in terms of offering carers' assessments, carers' allowance, carers' breaks, and so on), they do not generally use the term when working with carers and family members.

So, there seemed to be a sense that professionals might offer carers' support to people without necessarily directly exploring what caring means to them. Participants talked about working with

service-users' families to build up a picture of who is taking on caring responsibilities, identifying who is 'doing more than is normal within close relationships', even though the carers themselves might not have realised they were doing anything that would warrant any extra help and support for themselves. However, there were cases where being directive with the language was helpful. As Celia noted, saying to carers, "You do realise that you are actually a carer?" can be a way of raising awareness of carers' rights and the services that are available to them (Group 3).

The impact of caring and mental health difficulties on family relationships was considered. The participants talked about the importance of acknowledging the primary familial roles and relationships, and the idea that loss might play a part in adapting to a situation where a relative needs to be cared for. On the one hand, concerns were expressed about the loss of the service-users' identity, as carers struggled to accept a new version of their relative. On the other hand, there was thought to be the potential for service-users to feel that they were losing their relatives (e.g. a child losing a parent) to the role of carer.

This links in with the idea of 'going above and beyond' in terms of the care and support offered, but there was also the sense that these types of relationships would change over time, over the course of individuals' lifespan, but this could be further complicated by mental health difficulties and the typically young client group that are involved with Early Intervention services. The professionals also drew on information sharing as a potential area for complication in relationships between service-users and their families. Nigel (Group 1) and Sue (Group 2) both offered examples of service-users attempting to manipulate close family members into doing what they wanted (i.e. not sharing information, or giving misleading information to services). This therefore had implications for the ways in which professionals developed and maintained relationships with service-users and their families.

All three of the groups also spent a significant amount of time talking about identifying and engaging with service-users and their carers and families. A number of participants talked about

the informal ways in which they go about engaging and building relationships with people, emphasising natural skill, creativity and artistry. The value of informal communication, such as, simply having a chat with carers, catching up on how things have been, was described as important for a number of participants. Liz (Group 1) talked about the importance of easing into relationships with people, taking the time to get to know each other, and putting people at ease, not just jumping straight into some of the most personal aspects of their lives. The relationships that professionals were able to build with service-users, their carers and families, also seemed to be closely bound up with the expectations of the service. The participants talked about the importance of meeting the expectations the service has of them, but that this can sometimes be at odds with the expectations that service-users and carers have about what they are there to do. Indeed, Adele (Group 2) talked about being “screamed at”, Liz and Nigel (Group 1) talked about being “sacked”, while Celia (Group 3) talked about “balance and boundaries”, doing what you can with the resources available.

8.5.3 Implications of this research for mental health services

All participants presented the view that engaging and working with carers and families is beneficial. Consideration was given to some of the potential difficulties (e.g. it can create extra work in the short-term, it can be very time consuming, there can be difficulties associated with confidentiality and information sharing), though these were seen as a small price to pay for the benefits that can be achieved. The participants presented a view that carers are going ‘above and beyond’ what might be normally expected of them, and that their contributions should be acknowledged and valued. How best to go about recognising and valuing carers led to discussions about labelling: thought to offer recognition and validation, but with the potential costs of being experienced as insulting by some, and detrimental to recovery, reinforcing sick and carer roles which could be difficult to move on from. Participants acknowledged that they might identify people as carers, and offer help and support in relation to this, but this was not always something that would always be explicitly discussed. It was felt by some that the language associated with

caring could conflict with acknowledging family relationships, and could be seen as a barrier to forming good working relationships. So, for some, it could be beneficial to have such discussions, while for others it could be detrimental, and therefore care should be taken to judge each individual situation.

It would seem that in terms of identifying and engaging with carers, there are clear expectations from services, and statutory responsibilities that must be met. However, in practice how best to go about meeting these expectations can be less clear, and may well lead to professionals feeling that they are doing more than they are required to do, or in some cases, should be doing. Participants generally talked about taking a very open approach to identifying carers, for example, acknowledging anyone who is offering unpaid care to the service-user as a potential carer, which seems to be in line with definitions offered by carers' organisations. However, discussions about caring led to ideas about 'doing more than would normally be expected within close relationships'. This was therefore also linked to identifying differences between say, parenting and caring, which meant being a carer was not necessarily the same as being a concerned relative or friend. There seemed to be an underlying conflict for professionals, tasked with supporting people's well-being and wanting to be as inclusive as possible, but also having to operate within finite resources. This inevitably led to participants sometimes making comparisons between the carers they worked with, making distinctions between those who seemingly did more than others, and perhaps those who were therefore more deserving of certain resources at any given time. This can put professionals in a difficult position and may have implications for the ways in which they manage service-users', carers' and families' expectations of the service, as well as their ability to form meaningful relationships with the people they work with.

While forming relationships with service-users and their families was seen as a key feature of their work, the importance of supportive networks was also considered in terms of how professionals worked with other professionals to develop an understanding of caring, and strategies to meet carers' support needs. Liz (Group 1) talked about the importance of the informal professional

networks she had built up over the years in helping her to meet the needs of her service-users and their families. Nigel also acknowledged the importance of drawing on others' experience and expertise, and turning to other team members for advice and support when needed. A number of participants talked about training, and there was a sense that while training has a part to play in preparing professionals to go about their jobs; working with people, and adapting to their individual needs and circumstances is how you really learn. Therefore, the most valuable learning and training opportunities came from sharing experiences with others. Indeed, formal training was often questioned, with participants feeling that the real test of their skills came in demonstrating one's ability to engage with people creatively, flexibly and sensitively to foster strong working relationships.

8.5.4 Limitations and ideas for the development of this research

The convenience method of sampling enabled the researcher to recruit the amount of participants required for each group at a time and place that was convenient to staff members, helping them to feel at ease with each other, and their surroundings. However, although the variety of professional backgrounds and length of time spent working in services covered a reasonable range, not all professional groups were represented (for example, no psychiatrists or clinical psychologists took part). It should be noted that the research was advertised to all multi-disciplinary team members, and no professional groups were deliberately excluded, rather a convenience sample of who was available at the time of each focus group was recruited. It might therefore be interesting to hear from those professionals who were not represented, both in terms of their opinions and experiences, and their positions within the focus group situation. Indeed, it might also be interesting to explore whether groups of people from the same professional background or role (e.g. all community psychiatric nurses, care co-ordinators or team managers) would express significant similarities or differences in the way they understand informal caring and the language used to talk about it. In approaching data collection this way, it might be possible to learn more about the ways in which job roles impact on the way in which professionals view caring and their

approach to involving carers and families in healthcare. In the same sense, it might be interesting to compare Early Intervention service staff with those from other services (e.g. adult mental health services, psychiatric inpatient care, Assertive Outreach teams).

So far this research has explored the literature on caring and mental health difficulties, and the case for taking an interpretative phenomenological approach to the study of these things (Chapters 2-4). It has also presented a range of service-users', carers', and a family's experiences of caring and mental health difficulties (Chapters 5-7). This chapter has presented mental health professionals' experience of caring and mental health difficulties, and the language of caring. The following chapter will go on to further discuss the issues raised throughout these chapters, and the research questions it set out to answer.

Chapter 9

Synthesis of service-users', carers', family members', and mental health professionals' experiences of caring and mental health difficulties

9.1 Abstract

As outlined at the beginning of this thesis, the overall aim of this research is to provide a greater experiential base from which to better understand the implications of taking on a caring role for somebody experiencing mental health difficulties. As highlighted in the literature review, while much is known about caring and mental health difficulties from a broad range of theoretical perspectives, less is known about the lived experience of caring as described by service-users, carers, family members, and mental health professionals, in their own words. This research therefore aims to add to this developing literature, specifically by investigating multiple perspectives on caring and mental health difficulties, and focusing on issues around identity and family relationships, and the ways in which mental health services respond to these things.

This chapter therefore offers a synthesis and discussion of the previous chapters, and reflections on the methodological approach and research process. The implications of this research for mental health services, limitations, and possible directions for its development are also considered.

9.2 Introduction

An overview and review of the literature on caring and mental health difficulties were presented in Chapters 2 and 3. The overview began by broadly outlining what is known about caring for a person experiencing mental health difficulties, and moved towards a review exploring the lived experience of caring, typically from carer and service-user perspectives. An apparent gap in the

literature for exploring caring and mental health difficulties from a wider range of perspectives was identified. Therefore, in addition to further exploring these perspectives (i.e. carers – Chapter 5; service-users and carers – Chapter 6), this research also presents a family’s experiences (Chapter 7), and mental health professionals’ experiences (Chapter 8) of caring and mental health difficulties. The overview (Chapter 2) also highlighted the case for further exploring how service-users, carers, family members and mental health professionals understand and identify with the language associated with informal caring. Indeed, this research has highlighted that issues of language and labelling can cause conflict for those who use this language, and that it might not be well understood by, or meaningful to, those who could most benefit from identifying with it (for example, in terms of improving their ability to access support and resources).

This research has presented a range of shared and distinct concerns about the ways in which caring and mental health difficulties were understood by participants. Overall, concerns with managing threats to familial relationships in order to meet one’s basic psychological needs for relatedness were presented as a key feature of the experience of caring. While many studies identified in Chapters 2 and 3 focused on caring in relation to burden, stress and relapse, this research has highlighted, in greater depth, the importance of relatedness in caring relationships (i.e. feeling connected to others, to caring for, and being cared for by those others, and having a sense of belongingness, both with other individuals and within one’s community). Informal caring relationships were typically presented as a natural extension of pre-existing familial relationships, though these relationships were often significantly altered as their dynamics were challenged by experiences of mental health difficulties (i.e. by the cared-for person requiring a greater level of input in relation to their increased support needs, challenging behaviour, impaired ability to communicate etc.). Caring relationships also had consequences for the wider networks in which service-users and their family systems were situated, with caring and mental health difficulties potentially impacting on social mobility (e.g. opportunities for developing friendship networks and employment). Indeed, there was a sense that caring and psychological difficulties were poorly

understood by those who had not experienced these things, which all too often led to experiences of stigma and discrimination.

Before moving on to further explore how this research has addressed these issues in greater depth, it is worth reconsidering the primary research questions (identified in Chapter 4) here:

1. What are the perspectives of service-users, carers, family members and mental health professionals on the experience of being (directly or indirectly) affected by mental health difficulties, recovery, and caregiving and how do they relate to one another?
2. How is taking on an informal caring role for a family member understood to affect family relationships?
3. How do informal carers come to be identified as such?

While these primary research questions reflect the overall aims of this research, they were not posed directly to participants. In order to address these overall questions, a broader range of questions were used to prompt participants to talk about their experiences of caring and mental health difficulties (see Figures 5.1; 7.2; 7.3; and 8.1), in order to make full use of the multi-perspectival design.

Therefore a synthesis of the findings presented in Chapters 5-8 is offered below, to explore how the individual chapters contribute to the ways in which these things were understood by participants. The striking features of the themes outlined in Chapters 5-8 can be broadly divided into how participants attempted to make sense of caring and mental health difficulties (and the ways in which these things have impacted on their lifeworlds), and how the language of caring and impact of labelling were understood. Of course, there was some overlap between these things, but this division offers one way of highlighting some of the key features of these data.

A summary of the overall focus, number and perspective of participants, and key themes is presented in Table 9.1. These findings will also be discussed in terms of the wider context of the literature outlined in Chapters 2-4 in the synthesis of multiple perspectives section. Reflections on the implications for mental health services, the research process, limitations, and thoughts on how this research might be developed, are also considered in the discussion section.

Table 9.1: Summary of focus, participants, and key themes presented in each chapter

Chapter	Key themes derived from the data
<p>Chapter 5</p> <p>Carers' experiences of caring for somebody experiencing mental health difficulties, and the language of care</p> <p>Participants: 11 carers (3 focus groups)</p>	<p>Being an informal carer...</p> <ul style="list-style-type: none"> • is a useful label? • is a choice? • can mean identifying other carers and finding support in others' experiences • means taking on responsibilities that blur the lines with formal care • means having to deal with (unprofessional conduct) • can present difficulties for the future <p>Being a carer is intensely personal, yet at the same time incredibly common, experienced by countless others. It is seemingly so obvious that it does not require explanation, yet at the same time is not well understood by others. It may or may not be a choice, and being labelled as such can be both helpful, and a hindrance.</p> <p style="text-align: right;">Continued...</p>

Chapter	Key themes derived from the data
<p>Chapter 6</p> <p>Service-users' and carers' experiences of first-episode psychosis</p> <p>Participants: 8 service-users 8 carers</p>	<p>Service-users' accounts:</p> <ul style="list-style-type: none"> • What sort of person am I? • Who I could have been, and who I could be <p>Carers' accounts:</p> <ul style="list-style-type: none"> • Questioning a relative's identity • Impact of mental health difficulties on family relationships • Conflict concerning potential causes of psychosis <p>Synthesis:</p> <ul style="list-style-type: none"> • Identity and loss • Adapting to a change in circumstances and an uncertain future • Conflict concerning potential causes of psychosis <p>These themes capture things that were important to service-users and carers following a recent first episode of psychosis. It is striking that, although they differed in terms of the specifics of each group, there were a number of interesting convergences. For these service-users and carers, themes of identity and loss, adapting to an uncertain future, and concerns about the potential causes of psychosis seemed to be particularly pertinent.</p>
<p>Chapter 7</p> <p>A family's experiences of being affected by mental health difficulties</p> <p>Participants: 4 family members</p>	<p>Concerns with:</p> <ul style="list-style-type: none"> • Making sense of what happened to Luke when he became unwell • Roles: choice, detachment, reversal and replacement • Impact of mental health difficulties on sense of self: experiences of chronic and acute conditions • Sources of support outside the family <p>Family members shared their understanding of mental health difficulties, and talked about their impact on family life over the years. Although difficulties and challenges were presented, there was also a sense of learning and development.</p> <p style="text-align: right;">Continued...</p>

Chapter	Key themes derived from the data
<p>Chapter 8</p> <p>Mental health professionals' experiences of working with carers of people experiencing mental health difficulties, and the language of care</p> <p>Participants: 18 professionals (3 focus groups)</p>	<p>Concerns with :</p> <ul style="list-style-type: none"> • 'Caring' is doing more than is normal within caring relationships • "I'm not a carer, I'm a wife": labelling and personal identity • The impact of the carer label on family relationships • Development of relationships with carers and families <p>Findings suggested that mental health professionals sometimes faced conflict between being open and inclusive, and having to manage finite resources. Overall, participants presented an understanding of caring that seemed better defined by experiences than circumstances.</p>

9.3 Synthesis of multiple perspectives on caring and mental health difficulties

9.3.1 Making sense of caring within the context of mental health difficulties, family relationships and identity

This section explores the ways in which the experiences presented in this thesis address the first two overall research questions, namely how participants made sense of caring within the context of mental health difficulties, family relationships and identity issues. The ways in which the language of caring and the impact of labelling were understood, while closely linked with these things, relate more to the third overall research question, and as such are further explored in the following section.

The phenomenological literature on caring and mental health difficulties appeared to focus on the process of accepting and adjusting to significant, often challenging, changes to daily life. As highlighted in the literature review (Chapter 3), the uncertainty and unpredictability that often accompanies psychological difficulties can contribute to perceived carer stress and burden, and this change in circumstances often requires coping strategies to be developed. Loss and grief also appeared to be strikingly common features, as carers shared experiences of their relatives becoming unrecognisable to their former selves. While a number of papers highlighted issues around service-users' identity being questioned (e.g. Champlin, 2009; Osborne & Coyle, 2002), fewer examined how this impacts on family relationships, and how carers' personal identity might also be affected. This research therefore took a multi-perspectival approach to exploring how service-users, carers, family members, and mental health professionals attempted to make sense of caring and mental health difficulties.

Making sense of what carers do: Doing more than is 'normal' in close relationships

As noted in the Chapter 2, conceptualisations of 'care' are many and varied. Even when specifically applied to long-term physical or mental health, or disability, or problems relating to old-age, it is still something that is open to a range of possible interpretations and responses. In sharing their experiences of caring and mental health difficulties, participants (aside from the service-users in Chapter 6) reflected heavily on the things that they did (physically and mentally) for relatives experiencing mental health difficulties. Features of caring were often described in terms of: worrying about the cared-for person; spending more time with the cared-for person; medication management and physical health support; increased involvement in household matters; and increased financial responsibilities.

There seemed to be a prevailing sense that caring means 'doing more than you normally would' for a relative. However, while this is clearly open to interpretation, and will depend on each family's own culture and norms, there was also a sense that some people are carers, while others are not. It

is interesting to note that a number of the carers and professionals picked up on this issue. For the carers, it seemed to be a matter of status and value. So, for those who were doing a great deal to help another in need, there was a consensus that they should be recognised as having an ‘extra’ role that should be acknowledged (for example, via a label like ‘carer’), as going beyond simply being a concerned parent, spouse, or sibling etc. However, for professionals, while considering carers’ visibility and the ways in which their efforts were valued, this issue seemed to be linked more closely with resource issues. As gatekeepers to resources, it was clear that there was therefore a responsibility on them to allocate resources to those who were in greatest need, i.e. those who are ‘really’ caring.

Making sense of the ways in which family relationships are affected by caring and mental health difficulties

All of the experiences presented in this research reflected caring relationships between family members (e.g. parent, child, sibling, spouse etc.), rather than other types of caring experiences (e.g. friend or neighbour). As such, the systemic paradigm, focusing on interpersonal relationships, presents one framework for exploring individual experiences in relational terms, and may therefore be a useful lens through which to view the experiences presented in this thesis. Indeed, as Vetere and Dallos stated, “...individual distress can no longer be seen only as the product of an individual’s psychology, but rather as a complex iterative process that is understood in terms of relational dynamics at many levels of contextual understanding.” (2003, p.7). So, in exploring caring and mental health difficulties, the multi-perspectival design of this research, and the further relationships that these perspectives tap into, are presented with a view to exploring how these experiences can be improved for service-users, families, and professionals.

In ‘An introduction to family therapy’ Dallos and Draper (2000) outlined how the nature and definitions of ‘family’ have changed over the years, citing ever-changing differences in characteristics like marriage, divorce, single-parent families, homosexual families, and

expectations about greater sharing of working-life and domestic roles. The authors also drew attention to conceptualisations of the ‘family life cycle’ which can be used to chart the major changes or transitions in family life, such as, births, children growing up and leaving home, and bereavements. Dallos and Draper noted that, “...families need to continually adapt and adjust to deal with these tasks, but particularly at these key transitional points. Each family is seen as developing ways of dealing with the tasks facing them.” (2000, p. 8). The family system is therefore a product of the tasks it faces, the choices it makes in response to these, the outcomes of these choices, and the beliefs it holds. As previously noted, experiences of caring and mental health difficulties often result in significant changes to family life, and so are worth approaching from a systemic perspective.

In this research, a key feature of many participants’ experiences was the way in which family relationships had been affected by caring and mental health difficulties. In a number of cases, a perceived significant change in the cared-for person’s identity was a key concern. In Chapter 6, a major focus of these experiences centred on loss, with both service-users and carers identifying ‘old’ and ‘new’ selves and having to adapt to significant changes in family circumstances. A number of these carers also reflected on some of the negative consequences for families, for example, “tension”, “arguments”, and relationships being “torn apart”. However, experiences were not presented as exclusively difficult, with some participants describing improvements in family relationships, with family members being brought closer together by their experiences. Also, although difficulties and challenges for family systems were acknowledged, their potential as sources of support was also highlighted.

The family members in Chapter 7 offered an insight into family life where two family members had been diagnosed with bipolar disorder. Sally talked about how becoming unwell in her youth had a considerable impact on her career choices, as well as on decisions about having a family of her own. Sally, and her husband, Geoff, both talked about the dynamics of their relationship being fundamentally changed by experiences of caring and mental health difficulties. Sally, Geoff, and

their daughter, Katy, all gave examples of experiences of what they referred to as role 'reversal' or 'replacement' which highlighted some of the ways in which family members had taken on roles and responsibilities that they might not have otherwise have done had they not been affected by mental health difficulties. In thinking about family relationships and patterns of communication, it is also interesting to note that Sally, Luke, and Katy all made references to experiencing mental health difficulties, and that they felt their experiences had made them more understanding and compassionate towards people experiencing such difficulties. While Luke admitted that his experiences had had a big impact on him personally, the family experience was that Luke had had a single acute episode of bipolar disorder and there was a hope that, with support, he would be able to manage his condition and avoid future difficulties. In sharing their stories, this family highlighted the ways in which their experiences of Sally's chronic experiences of bipolar disorder had given them ways of understanding mental health difficulties that had been helpful to them in identifying what was happening to Luke when he started to become unwell, and supporting him to manage his daily life to reduce the risk of relapse. The impact of Luke's serious episode of bipolar disorder had therefore been normalised within the family which seemed to have played an important part in reducing stress and tension in family communication, which can become a common feature of family-relating when a relative becomes unwell.

Indeed, in contrast with this family's experiences, those presented by the service-users and carers in Chapter 6 (relating to first-episode psychosis) were described, for the most part, as stressful and immensely challenging. The participants in this study were selected because they were at risk for experiencing trauma symptoms as a result of either having experienced (service-users), or being in close contact with a relative who had experienced (carers), a recent first episode of psychosis (Bernard *et al.*, 2006; Barton & Jackson, 2008). For these participants, the experience of first-episode psychosis was typically described as novel to the family, whereby they had no previous experiences of being affected by mental health difficulties. It is noted that one participant (a carer) wrote about working in mental health services, though despite having developed specialised knowledge and skills to deal with mental health difficulties in the workplace, facing such

challenges within the context of family life was presented as being something entirely different, and difficult to cope with. A number of other participants also noted differences between taking a professional approach to caring responsibilities, and having to manage these within the context of complex family relationships (presented in Chapter 5 - carers who attended support groups). For example, Dawn gave an example of her daughter (a mental health professional) and mother (experiencing mental health difficulties) arguing with each other, and that she had intervened by saying, "I hope you don't talk to your clients like that!." Dawn went on to say that her daughter noted that the situation was "different" and the rest of the group agreed that "it's hard when it's personal." So, managing mental health difficulties within the context of family relationships was presented as challenging, even for those who had trained to work in the field of mental health, because the close, stable relationships that they had enjoyed before the onset of mental health difficulties were being threatened. However, the family's experiences presented in Chapter 7 demonstrated how a family system can come to develop an understanding of caring and mental health difficulties, building resilience into their understanding and ways of relating, to minimise the potential negative effects of future difficulties. For example, Sally reported that when she first became unwell her mother and father were shocked and took a while to adapt to the impact of her condition on family life. Sally went on to say that, over time, they did adjust to the change in circumstances, and supported her as she went on to have her own family. Sally's own nuclear family therefore developed around her experiences of bipolar disorder, as she said herself, her family had never known her as "normal". The family therefore developed an understanding of caring and mental health difficulties in the context of them always being part of family life, finding ways to meet the challenges presented, and increase stability over the years. When Luke then became unwell, unexpectedly, family members reported being initially shocked, but demonstrated that they were quickly able to normalise the situation and support Luke in his recovery, drawing on the psychological resources they had built up over the years.

A number of the mental health professionals also made references to family relationships (Chapter 8). Celia shared her experience of working with a mother whom she thought found it difficult to

distinguish between ‘normal’ adolescent behaviour and development, and the symptoms of psychosis. Similarly, in their written emotional disclosure accounts (Chapter 6), a number of carers also expressed concerns about what is just a relative being “awkward”, or “lazy”, for example, and what is the result of mental health difficulties. Trying to make sense of these things was presented as challenging, as family members struggled to accept changes in their relatives that, at times, had left them feeling somewhat shocked or disappointed. Celia also offered her perceptions, through working with families affected by mental health difficulties, that when parents become carers they lose the ability to have fun with their child. In sharing this example, Celia seemed to be reinforcing the carer role as something that is often characterised by responsibility, burden and distress, those things that impede one’s ability to have fun. The consequences for happy, harmonious relationships might therefore be called into question, as relationships become increasingly sombre and roles become progressively more formalised into carer, and cared-for.

Some participants attempted to make a distinction between familial roles and being a carer, and this divide seemed to link back to the idea of ‘going above and beyond’ what is normal in close relationships. As previously noted, many of the caring relationships described in this research reflected parents caring for children experiencing mental health difficulties. Consequently, the relationship between parenting and caring seemed to be particularly well represented. For example, in one of the professionals’ focus groups, Liz talked about there being “*parenting* and caring, that’s a bit different.” (Chapter 8). However, for the parent-carers themselves, parenting was seen as the priority, with any and all care offered to a child being an extension of the parenting role. As Dan said, “...because, parent, in my mind is, you know, takes priority over carer... it’s your prime duty to look after your children.” (Chapter 5). However, this was not exclusive to parent-child relationships. Indeed, other carers (covering a range of family relationships) also made reference to love, duty, reciprocity and social expectations to explain how they came to take on caring responsibilities.

As noted in the Chapter 2, self-determination theory offers one framework for thinking about self-development through experience (Deci & Ryan, 2002). This theoretical framework provides a way of thinking about individuals' personal growth by meeting innate psychological needs for autonomy, competence and relatedness. As examined throughout this thesis, caring and mental health difficulties offer opportunities for all of these areas to be challenged and/or developed. But in particular, this research points to opportunities for thinking about how the relatedness within family systems is challenged by psychological difficulties when a member becomes unwell, and how families can be supported to manage these changes while minimising tension and distress. Also, as noted above, language associated with informal care can impact on family members' sense of self, and the ways in which they view how their relationships are being affected by mental health difficulties and caring. While issues of language and labelling are further considered in the next section, it is worth noting here that these things will have practical implications for mental health policy and practice in terms of best practice for involving carers and families in mental health services.

Making sense of how people become carers, or come to identify as carers?

Many of the participants (particularly those identified in Chapters 5 - carers; 7 - family members; and 8 – mental health professionals), noted that trying to make distinctions between caring and being 'a carer' can be confusing and lead to fundamental aspects of identity being called into question. A number of participants talked about themselves as concerned relatives, prioritising the family relationship over being a carer. Many of the carers made references to caring being a natural extension of their relationships, i.e. 'it's just what you do for the people you care about', though also described situations where they had gone to extraordinary efforts in supporting their relatives. Picking up on this, the mental health professionals focused on 'doing more than is normal in close relationships' as a factor in identifying carers. Though it was acknowledged that this 'doing more' could be both physical (e.g. helping out with medication, household chores etc.), and/or mental (e.g. worry, distress, burden etc.).

Only one participant (Anne, Chapter 5) specifically talked about making a deliberate choice to take on caring responsibilities. Anne explained that everybody has the ability to make a choice whether or not to care, acknowledging that, although it might sound cold, any individual could walk away from another if they really wanted to. Anne further explained that her choice to care for her grandmother was linked to her family situation and issues of framing personal autonomy, stating that making a choice to care can stop one becoming resentful of the situation. The other members of Anne's focus group, Dawn and Frank, agreed that Anne had a point about making a choice to care, but they tended to focus on the seeming lack of available, or attractive, choices about taking on caring responsibilities for their relatives. In trying to establish whether carers have a choice or not, Dawn related an example of a mother she knew who cared for her two children with physical disabilities. Dawn used this example to illustrate her perception that this person did not have a choice. In contrast, Anne was adamant that this mother did have a choice in whether or not to care. In their exchange, Anne very much took the existentialist perspective that individuals are always free to make choices, and that this freedom cannot be escaped, even in overwhelming circumstances (i.e. when faced with two children with serious health needs). Dawn, however, displayed what Sartre conceptualised as 'bad faith', in describing a situation in which a mother is unable to transcend her situation and denies her essential freedom to choose whether or not to take on caring responsibilities (Sartre, 1943). Dawn and Frank both cited love, duty, reciprocity, and societal expectations as all playing a part in impacting on an individual's ability to make decisions about caring borne from close relationships. However, while Dawn and Frank both seemed to be opposed to Anne's point of view, they also accepted that there was a fundamental truth to it, despite sharing personal experiences of feeling that they didn't really have a choice about caring. As noted in Chapter 5, the fact that Anne was the grandchild of the cared-for person (and therefore one generation removed compared with Dawn and Frank who were both a child of the person they cared for) may also have had implications for her feeling able to make a choice about caring.

While participants' experiences of caring and mental health difficulties and family relationships highlighted the importance of these relationships for meeting basic psychological needs for

relatedness, their experiences of choice, or perceived lack thereof, highlighted issues around their basic needs for autonomy. As noted in Chapter 8, the Princess Royal Trust for Carers' definition of what a carer is states that, "Carers don't choose to become carers: it just happens and they have to get on with it." (2011). In positioning carers as individuals who do not have a choice, there may well be consequences for them feeling put upon, burdened and unable to escape their circumstances. However, in thinking about how the position of caring is framed, i.e. in framing it as a choice, carers might be able to regain a sense of personal autonomy which could help to limit the bitterness and resentment that Anne identified in Chapter 5.

A number of participants talked about being identified as carers by health professionals, or other carers; and in turn also identifying others as carers themselves. For example, Marie highlighted a conversation with a friend that led her to her say, "...you're a carer like I am a carer." (Chapter 5). Indeed, many of the carers' experiences seemed to be linked to being identified by others, or at least coming to realise they could be seen in this way, after gathering information from health services, and then starting to talk to others about their caring responsibilities. Two participants (Theresa, Chapter 5; and Sally, Chapter 7) highlighted their nursing backgrounds as a feature of identifying as carers, expressing their ideas about going into a vocation where one is typically seen as a carer (albeit in a more formalised sense). Both of these participants linked their vocational choices to their preparedness for taking on an informal caring role, drawing attention to aspects of their character (e.g. nurturing, empathetic) that they felt meant they were well-suited to the role both professionally, and personally. In any case, however carers come to be identified as such, there still seems to be a divide between being *identified* as a carer, and *feeling* like a carer. This section has outlined some of the ways in which people come to take on caring responsibilities, and be identified as carers. The impact of this language and labelling, and the consequences for the integration of caring experiences with sense of self, are further considered below.

9.3.2 How the language of caring, and the impact of labelling, were understood by participants

As previously noted, there is evidence to suggest that although the term ‘carer’ has developed in a well-intentioned way, it often fails those who might adopt it, and the people they care for (Molyneaux *et al.*, 2011). While other research has explored carers’ and healthcare services’ adoption of this term, there has been less that has explored it from a multi-perspectival, phenomenological research design. One of the principle aims of this research was to address how informal carers came to be identified as such. While the previous section explored how individuals who had taken on caring responsibilities made sense of caring and the impact it had on their lifeworlds, this section will now focus on the language and labelling that is associated with informal care.

Making sense of being labelled as a carer

The participants’ experiences presented in this thesis suggested that being identified and labelled as ‘a carer’ was considered to be both helpful, and a hindrance, at times. On the one hand, it was seen to open up access to valuable services and resources; while on the other, it was perceived as patronising, and threatening the relatedness of ‘carer’-‘cared-for’ relationships, and the potential for integration into wider social networks. So, it would therefore seem that there is a balance to be struck between being recognised and valued; and being marginalised and diminished. A prime example of this was when Frank talked about referring to himself as ‘just’ a carer, indicating a sense that he had begun to internalise a diminished role when describing himself to others. In his case, this was picked up on and challenged by a campaigner for carers’ issues, which caused Frank to review how he used the label, turning it into something that he could be proud of as an acknowledgement of his efforts to support his father. Participants’ experiences suggested that the carer label can be perceived as a barrier within relationships (between family members, and between families and professionals), and come to be internalised in a way that diminishes individuals’ sense of self. However, as Frank’s experience demonstrated, reframing the term in a

more positive way can have positive consequences, such as, feeling that one's efforts are valued and should be rewarded.

Carers and mental health professionals made references to the impact of labelling on 'carer' and 'sick' roles that may be reinforced within families which was seen as being detrimental to all. Indeed, there was a sense that labelling individuals in this way could lead to misunderstandings about the risk of developing mental health difficulties; could have a catastrophising effect on families with regard to prognosis and options for recovery; and could lead to the adoption of sick/carer 'lifestyle' choices that could also impede recovery and families' ability to build resilience and move on from difficult situations. There seemed to be a sense that labelling service-users and carers could threaten individuals' autonomy by forcing roles upon them that they might not have otherwise chosen for themselves. In Chapter 8, Nigel and Liz, mental health professionals working for the Early Detection and Intervention Team, identified the importance of avoiding labelling their service-users, and by extension, carers and family members. They highlighted addressing issues of risk for mental health difficulties, and avoiding labels, as key features of their work. Other professionals also talked about being aware of identifying family members as carers, but, for the most part, not explicitly using this term with them directly, preferring instead to focus on developing relationships with them, supporting the (typically pre-existing) close relationships between service-users and their relatives. This highlighted one of the ways in which professionals sought to support the familial relationships that were important in service-users and carers being able to maintain a sense of relatedness that was more meaningful to them than conceptualisations of their relationships as 'carer' and 'cared-for'. Indeed, in the family's experiences presented in Chapter 7, Luke noted that although his mother and father could be thought of as carers, it was "weird" to use the word carer to describe "mum and dad" when they were just doing what they had always done (i.e. care for their children). The label was therefore seen as not particularly meaningful in the context of what they did for each other. Also, as the family system had developed its own extensive resources and resilience through its experiences of

caring and mental health difficulties over the years, the label was not seen as particularly useful in terms of accessing further help and support.

Relatedness, feeling connected to others, to caring for and being cared for by others, was necessarily a key feature of the caring relationships explored in this research. Again, experiences of these things being both threatened, and supported, were common throughout participants' accounts. Familial relationships typically offer opportunities for mutual care and belonging. However, when the dynamic of family relationships is affected by mental health difficulties, these opportunities may be reduced if a relative suddenly requires increased help and support and is unable to offer these things to others in return. Mental health difficulties might also have significant implications for people's sense of 'belonging'. For example, a number of the service-users wrote about isolation and having difficulties in communicating with family and friends (Chapter 6). A number of carers and family members also picked up on social isolation, both in terms of their own, and their relative's, ability to develop and maintain relationships within, and outside of the family (Chapters 5 and 7).

As previously noted, many participants came to take on caring responsibilities, and be identified as carers, without really identifying with this term. Indeed, many of the carers shared stories of having been caring for a number of years before they realised, or were told by others, that they could be thought of as carers. Even when this recognition did occur, it was not always easy, or desirable, to accept the label. However, there was also a sense that not identifying with the label could have negative consequences for carers, as Dan said, "Haven't we all lost out, the people in this room, because we didn't think of ourselves as carers?" (Chapter 5). Here, Dan was talking specifically about being visible to services and organisations that could offer help and support to families affected by mental health difficulties, and this example further reinforces the need for professionals and services to be aware of the impact of labelling, and how they can overcome some of the difficulties associated with identifying with this language.

While some research is critical of the universal adoption of the term ‘carer’ (Molyneaux *et al.*, 2011), the findings of this research would seem to suggest that while the language associated with informal care can be confusing and uncomfortable for those who take on caring responsibilities, there is value in having a term available to capture the extra efforts that individuals and families are making in supporting relatives experiencing mental health difficulties. The findings of this research suggest that relationships that were formed before the cared-for person became unwell should be recognised, valued, and supported to overcome the challenges that might be faced when affected by mental health difficulties. The implications of language and labelling for mental health service provision are further considered in the discussion section.

9.3.3 Reflections on utilising an interpretative phenomenological approach to explore the meaning of caring from multiple perspectives

Data were collected by way of focus groups (Chapter 5 – carers, and Chapter 8 - mental health professionals), written emotional disclosure (Chapter 6 - service-users and carers), and individual interviews (Chapter 7 - members of one family).

Focus groups

A total of 11 carers were recruited to three focus groups (one group of five, and two groups of three participants). While 18 mental health professionals were recruited to three focus groups (four, six and eight participants respectively). In terms of recruiting carers and mental health professionals, employing a convenience sampling approach allowed for a wide range of experiences to be gathered. Indeed, the recruitment criteria for these groups were kept deliberately broad so as to be as inclusive as possible. However, this approach did have an impact on the homogeneity of the samples. In the carers’ groups, there was a fairly even gender divide (six females, five males), though participants’ ages varied considerably, as did the length of time spent in the caring role. Caring experiences were related to close relatives (adult children, parents and

grandparents), and the sample was predominantly White British in terms of ethnic background. In the professionals' groups, the gender divide was less even (thirteen females, five males), and again, age ranges varied considerably. The length of time spent working in mental health services also highlighted significant differences (from trainees to those approaching retirement). Again, this sample was also predominantly White British in terms of ethnic background. A range of professional backgrounds were represented, though it is noted that those with more years of experience working in mental health services seemed more forthcoming in sharing their experiences. However, these differences did not seem to significantly impact on the experiences shared. A number of the carers and professionals did make references to cultural issues, but these participants were not always from ethnic minority backgrounds themselves. Overall, it seemed that these differences added something to the range and depth of the experiences shared, rather than complicated the findings presented in this research.

One of the attractions of taking part in a focus group might have been the opportunity to share experiences in a group setting (with the opportunity to share as much, or as little as one feels comfortable with). There is therefore less individual pressure to contribute than in one-to-one interview situations. While the more experienced professionals seemed to contribute more to their group discussions than those less experienced than themselves, this was less pronounced in the carers' groups. However, it is noted, that in some cases, a small number of participants took on a sort of spokesperson role (either for carers or professionals). The purpose of this seemed not to seek to dominate the discussion, but rather to consolidate opinion and present a stronger message. Indeed, all participants engaged well with each other, and the researcher, to explore their experiences of caring and mental health difficulties.

In terms of using focus groups with IPA, the research was planned and analysed according to the guiding principles of this methodology (Smith, 1996; 2004). A protocol developed for taking an IPA approach to focus group data was employed to guide the analytical process (Palmer, Larkin, de Visser and Fadden, 2010). This protocol was itself developed from research exploring

experiences of caring and mental health difficulties. This protocol offered a framework for thinking about how to manage some of the complexities of focus group data that are specific to this method of data collection (e.g. group dynamics, positionality, roles and relationships, language etc.) as well as managing IPA's idiographic commitments. Indeed, where this research has presented focus group data, a range of individual participant stories, as well as dialogue between participants have been provided to illustrate both individual and group concerns. While the groups provided a forum for carers to talk about their experiences, it is noted that they tended to share individual experiences, rather than attempting to co-construct a shared meaning of caring. It may therefore be argued that the focus groups were not used to their full potential in terms of what they were able to offer. For a fuller discussion of participant interaction in focus groups see work conducted by Duggleby (2005) and Morgan (1997).

Written emotional disclosure

Written emotional disclosure data from 16 participants (eight service-users, eight carers) were analysed to explore experiences of first-episode psychosis. This multi-perspectival approach is in keeping with the overall research project, presenting a range of experiences that were set in the context of stressful circumstances. The service-users were more equally divided by gender (five females, three males) than the carers, and were typically young adults (mean age 23 years). The carers had a more significant gender bias (seven female, one male), were typically the parents of a service-user (seven parents, one spouse), and were aged from their late-thirties to early-fifties. As noted with the focus groups, these differences in the sample did not seem to have a significant impact on the experiences shared. Indeed, as participants drew on their individual backgrounds to help make sense of their experiences, it seemed that the novelty and challenging context of being so closely affected by first-episode psychosis provided a sufficiently homogeneous sample. As written accounts have typically been less well used in IPA studies, Chapter 6 reflected on some of the methodological issues of combining these approaches.

In thinking about developments in IPA research, Smith and colleagues suggested that they would like to see whether methods can be developed to prompt participants to “...provide a different level of recall – a ‘re-imagining’ or ‘reliving’ or focusing of their experiences – [which] will lead to a strand of IPA work which gets even more ‘experience close’.” (Smith *et al.*, 2009, p. 204). Although the written emotional disclosure task that was used to collect the data presented in Chapter 6 was not set up with this specific aim in mind, it does seem to have elicited these types of accounts. Indeed, some participants, for example, Sharon, explicitly wrote about having an emotional reaction to the task at the time of writing, reliving her experience of seeing her son being hospitalised:

“Just writing this paragraph has me crying because I’m there again, sitting in the room at the [clinic].”

(Sharon, Parent, Account A)

It is noted that this approach was being explored as an intervention, its outcomes measured against variables related to distress and trauma, and was therefore well-suited to examining experiences of first-episode psychosis. However, it would be interesting to explore how this approach might work with other types of distressing or challenging experiences, going beyond first-episode psychosis.

Individual interviews

Individual interviews were employed to collect data from four members of the same family (presented in Chapter 7). The decision was taken to employ individual interviews, rather than a family-group focus group, to give individual family members a greater opportunity to share their personal experiences and perspective on family life. Before the interviews took place, the researcher had a number of telephone conversations and met with family members to talk about this research. Family members were also encouraged to discuss the research project together before coming to a decision about whether or not to take part. The researcher then visited family

members at their place of residence to conduct interviews, as this was considered the most convenient option for family members, as well as being familiar and comfortable. All interviews lasted for about one hour and ended at a point where they seemed to come to a natural conclusion.

Although it was originally intended to recruit between three and five families, difficulties with recruitment meant that this was not possible within the time scale of the project. However, that is not to say that the data collected are in some way lacking or unable to make a significant contribution to the literature on understanding the lived experience of caring and mental health difficulties. On the contrary, this family's experiences offer a valuable insight into what can happen within a family system when a relative experiences mental health difficulties. Chapter 7 therefore presents an in-depth, multi-perspectival account of one family's experiences. An interesting feature of this family's experiences, which was not described by other participants, is a multi-perspectival understanding of different generations of the same family being affected by mental health difficulties. Sally had been unwell for a number of years, while her son, Luke, had experienced only one serious episode. This family was therefore concerned with experiences of caring and psychological difficulties that had occurred over a number of years, seeing changes across areas, such as, family relationships, approaches to caring, understanding of mental health difficulties, and developments in mental health services. For this family, although difficulties and challenges were presented, they were often framed in the context of opportunities for learning and development. The family's accounts explored a range of changes to established roles and relationships over a number of years, as family members worked towards greater stability in family life, and resilience in being able to manage future challenges. While help and support outside the family was valued, the primary focus was on developing as a family system, being mindful of caring as a feature of relatedness, and therefore a way of expressing love, care, and belongingness.

Much has been written about IPA and individual interviews, which are typically considered to be the best method for collecting the rich, detailed, first person data required for an IPA study (see Smith *et al.*, 2009). All family members engaged well with the researcher, and valued the

individual interview method as a way of gathering different perspectives on the family's circumstances. Data were analysed using IPA as outlined by Smith (1996; 2004) which worked well with these data, first exploring individual accounts, before integrating them to examine the broader family experience.

Multi-perspectival design

In reflecting on the future developments of IPA research, Smith and colleagues (2009) highlighted that systemic and multi-perspective design, longitudinal studies, and single case studies are already becoming increasingly popular. They also commented on the increasing use of focus groups/small-group interviews to collect data, and their hopes to see developments in the use of diaries and written accounts. This research has therefore sought to contribute, not only to the literature on caring and mental health difficulties, but also to thinking about ways of using IPA methodology to explore the lived experience of these things.

The rationale for approaching the study of caring and mental health difficulties from a qualitative perspective in general, and a phenomenological perspective in particular, was outlined in Chapters 3 and 4. The case for exploring these things from multiple perspectives was also highlighted, as was the utilisation of different data collection methods to gain access to populations that can be difficult to engage in research studies. Smith and colleagues (2009) reported that typically IPA studies recruit small, homogenous samples, where each participant contributes once, though they acknowledge that it is possible to be more adventurous with study design. They went on to state that employing a multi-perspective design can be a way of developing "...a more detailed and multifaceted account of that phenomenon." (Smith *et al.*, 2009, p. 52), citing examples such as Clare (2002) - exploring coping with the onset of Alzheimer's disease, and Larkin and Griffiths (2004) - investigating risk from the perspectives of Ecstasy-users and bungee-jumpers.

Overall, this thesis presents multiple perspectives that have been gathered in a number of different ways, and by prompting participants to think about these things in different ways. However, the studies that are the subject of Chapters 6 and 7 also employed a further level of multi-perspectival design, with participants (service-users and carers; and individual family members respectively) sharing their experiences of the same phenomenon by the same methods. In exploring how service-users, carers, family members, and mental health professionals talked about caring and mental health difficulties in their own words, this research presents their experiences of these things, and their impact on family relationships, and personal identity.

9.4 Discussion

9.4.1 Implications of this research for mental health care design and delivery

As highlighted in the literature, and noted by a number of the participants in this research, caring often seems to be characterised by a lack of choice, and is presented as something that just happens to individuals who suddenly (or perhaps, so gradually that they do not realise it is happening), find themselves taking on caring responsibilities when a relative becomes unwell. While only one participant in this research actively advocated for always having a choice to care, the majority of the participants focused on love, devotion, duty, reciprocity and societal expectations when talking about their experiences of caring. Indeed, these things may be seen as factors that impede decision making about caring, in that they reduce the availability of attractive choices for individuals who are faced with caring responsibilities. So, it would appear that caring and mental health difficulties can present significant threats to individuals' ability to perceive themselves as the origin of their own behaviour. Individuals facing caring responsibilities may well find themselves in a position that is not of their own choosing, but that they are not necessarily choosing to reject either. In exploring how individuals perceive their autonomy in taking on a caring role, mental health professionals can work with them to ensure caring is framed as a positive choice, as opposed to an

enforced situation that is beyond their control, thereby reducing the potential for bitterness and resentment, and promoting personal development and growth.

Meeting basic psychological needs for competence, was also described as challenging by a number of participants. The uncertainty and unpredictability of mental health difficulties often presented challenges for the carers feeling effective in their own interactions with their environment. A number of the carers talked about learning through experience, trial and error, and at times wishing that they had done things differently. However, a number of carers also talked about acknowledging their developing expertise in their particular circumstances, often sharing stories displaying highly specialised knowledge and mastery of new skills. So, although competence may be threatened by experiences of caring and mental health difficulties, there are also areas where it can be developed to provide a sense of achievement.

As noted in the synthesis section, supporting and valuing family relationships was seen as immensely important by the participants in this research. The family-sensitive ethos of Early Intervention services was appreciated by those who had experiences where they had been involved. Indeed, there was a sense that family-awareness, considering service-users in their wider context, should be a central feature of services, embedded in the formal care offered. There is therefore a case to be made for mental health services adopting the family-sensitive model of Early Intervention services more widely. Another key feature of having good experiences with professionals and services focused on communication issues, with clear, open, honest, information sharing being described as important by service-users, carers, family members and professionals alike. Communication was identified as a key tool in supporting relationships between service-users, their families, and services, so that all were given the opportunity to share their experiences and reduce feelings of burden and distress. Part of this centred on greater transparency about what services were able, and also unable, to offer service-users and their families, and also considering boundaries and balance in supporting families to maintain a sense of independence, and be able to disengage with services at an appropriate time.

The language associated with informal care should also be seen as an opportunity for professionals to engage with service-users and their families. While the participants in this research reported welcoming being included by services, they also expressed conflict and confusion around the language that was often used to describe their caring responsibilities within familial relationships. The findings of this research suggest that issues of language and labelling should always be explored with each family, and used as a way of engaging and valuing their efforts in the face of immensely challenging circumstances. However, there was a sense that primary familial relationships should always take priority over caring relationships, with the label being used as an additional way of valuing efforts, not as a way of diminishing pre-existing close relationships. Indeed, it seemed that one of the most beneficial things that services could offer to families was to support the complex network of relationships that exist within families, and their broader social context.

9.4.2 Reflections on researcher reflexivity and learning

Qualitative research requires the researcher to reflect on the perceptions and presuppositions that they bring to the research process, and impact they might have on its findings and outcomes. It is therefore worthwhile reflecting on my personal involvement in this research. My interest in caring and mental health difficulties stems, in part, from working with the Meriden Programme, a family intervention training programme based in the West Midlands region, UK. I have previously used IPA to explore carers' experiences which led to work with data from carers' support groups and the development of a protocol for using IPA with focus groups (Palmer *et al.*, 2010). While my experiences will have had an impact upon the analysis of the data presented in this thesis, it is worth noting that care was taken to ground the data in participants' own language. While it is not possible to include large amounts of raw transcript data in this thesis, examples of the process of data analysis have been included in the appendices to give a feel for the way in which themes were developed (see Appendices 7, 8, 10 & 13). The researcher was also supervised by an experienced qualitative researcher (Dr Michael Larkin) who, although not immersed in the raw data or

transcripts, offered valuable feedback on the development of the themes presented. Areas that required clarification for those not as familiar with the entire body of the data were identified and links to the literature on caring and mental health difficulties were discussed.

The convenience sampling approach to recruitment for the focus groups presented in this thesis (Chapter 5 – carers; Chapter 8 – mental health professionals) seems to have worked well. However, despite advertising this research widely across support groups throughout the English Midlands, UK, it was extremely time consuming to set up the groups, and fewer participants were attracted than was originally anticipated. In liaising with Early Intervention services, there were also difficulties in identifying interested families as potential participants. In part, these difficulties seemed to be associated with the researcher's position as a postgraduate researcher working outside of mental health services. Consideration of these issues in supervision highlighted the importance of having 'champions' within services who would also have a stake in this research, and therefore be further motivated to encourage recruitment.

Regular research supervision has been invaluable in completing this research. The transition from typically working on smaller-scale projects, or working on projects as part of a larger research-team, to taking responsibility for this research, certainly benefited from the guidance and input of an experienced research supervisor (Dr Michael Larkin). In addition to supervision, regular research meetings with other qualitative researchers also provided opportunities for thinking about the broader context in which this project is located, as well as much-valued peer-support. I have also been involved in a number of workshops and attended conferences to develop my research skills and awareness of current research beyond the scope of my own project.

In undertaking IPA research, the researcher makes a commitment to represent participants' experiences in way that is fair and transparent, attending to idiographic detail while maintaining anonymity. In recruiting individuals that had experiences of caring and mental health difficulties, many participants shared their personal accounts of exceptionally challenging, distressing and

sensitive circumstances. Care was therefore taken to set up focus groups and interviews that provided a safe environment for participants to share their stories. Participants acknowledged that some of the experiences shared were upsetting, especially when they talked about going through difficult emotions, such as, being in shock, being embarrassed, screaming and shouting, crying, and fighting. It is noted that none of the participants became personally distressed during the data collection process (with the exception of Sharon, detailed above who took part in the written emotional disclosure task, and where the data were not directly collected by myself). However, for me personally being so close to accounts that were themselves so 'experientially close' to stressful and challenging situations was, at times, difficult, and supervision was also valuable here, offering the opportunity to talk through the issues associated with this.

9.4.3 Limitations of this research

As the literature focusing on caring and mental health difficulties from a phenomenological perspective (presented in Chapter 3) was considered in the context of Yardley's (2000) criteria for assessing the quality of qualitative work (see Appendix 2), this research should also be considered in terms of its sensitivity to context; commitment and rigour; transparency and coherence; and impact and importance. With regard to sensitivity to context, the literature on caring and mental health difficulties was examined in Chapters 2 and 3, and the rationale for taking an interpretative phenomenological approach to the study of caring and mental health difficulties was presented in Chapter 4. After identifying a gap in the literature, this research has taken a multi-perspectival approach to understanding the meaning of caring, and the consequences of these things for informal carers. In attempting to make sense of participants' experiences, this research has presented an account of caring and mental health difficulties that is grounded in how participants described their experiences in their own words, offering data extracts throughout.

This research examined the experiences of a relatively small number of participants, though this is in keeping with previous published IPA research (Smith *et al.*, 2009). In the planning stages of this

research, it was anticipated that there would be a greater range of experiences included, particularly from carers (looking more specifically at the benefits and burdens of caring), and families where a family member is in contact with Early Intervention services (see Chapter 7). Difficulties in recruiting carers and families meant that the decision was taken to reduce the number of participants sought, and to focus on the data that is presented in this thesis. While this has worked well in terms of addressing the overall aims of this research, it has led to a reduced number of experiences being presented.

In terms of commitment and rigour, this thesis has presented the broad inclusion criteria for this research and participants' demographic details, while being mindful of protecting anonymity. While convenience sampling may have affected demographic homogeneity, the homogeneity of experience was considered to be the primary concern, and the experiences presented allowed for a detailed analysis to be carried out. One of the main difficulties with this research project centred on recruitment issues. As noted in Chapter 4, service-users, carers and mental health professionals can all be difficult populations to access and engage in research. This research was interested in exploring the lived experience of caring; how the language of caring was understood; and how people came to be identified as carers. In advertising research, the researcher was aware that appealing for participants by using the language of care would only serve to attract those who were familiar with the language and identified with it to some extent. To access the first set of carers' experiences presented in this thesis (Chapter 5), the researcher advertised through support groups which led to focus groups where all participants attended carers' support groups, and typically had a number of years experience of caring. In order to gather a broader range of caring experiences, Chapter 6 explored the written accounts of service-users and carers relating to first-episode psychosis. These participants were therefore typically newer to experiences of caring and mental health difficulties, and so were able to offer different perspectives. The inclusion of a family group identified by an Early Intervention service (Chapter 7) also offered a different range of perspectives on caring and mental health difficulties. Again, it was anticipated that working with Early Intervention team members to identify families that wanted to take part would lead to

participants who were not overly experienced with caring and psychological difficulties. However, the family that took part had a range of experiences of caring and bipolar disorder, some going back for many years.

Again, in the planning stages of this research, it was hoped that the voices of younger family members and carers (under the age of 18 years) would also be included in this research. However, ethical approval was only granted to interview adults (over the age of 18 years). While the [REDACTED] [REDACTED] agreed that seeking to include young people's experiences would be worthwhile and valuable to this research, the practicalities of meeting the committee's conditions to do this proved impossible with the resources available to this project.

In terms of transparency and coherence, details were provided of the prompts used with participants to elicit their experiences. The analytic framework employed (interpretative phenomenological analysis) was outlined and referenced (i.e. Smith, 1996; 2004), and the rationale was presented for using different data collection methods (i.e. focus groups; written emotional disclosure; and individual interviews), in each chapter. Examples of the analytic process, through extracts of worked data, were referenced and presented in the appendices, illustrating the stages of data coding, ways of managing focus group data, and the integration of cases to form a coherent account of the data. With regard to the impact and importance of this research, it is hoped that it will be of interest to mental health service-users, carers, family members and professionals. The implications for the mental health services have been discussed with a view to improving the experience of caring and mental health difficulties for all those affected by these things.

It is acknowledged that the experiences of these service-users, carers, family members, and mental health professionals cannot be said to represent a complete understanding of the daily lived experience of caring for a person experiencing mental health difficulties. However, it is hoped that by presenting these multiple perspectives, this research is able to contribute something worthwhile to how informal care and the language associated with it is understood.

9.4.4 Ideas for the development of this research

As previously noted, trying to recruit carers for this type of research can pose difficulties in terms of how to identify, access and engage with individuals who take on caring responsibilities for people experiencing mental health difficulties. While carers' support groups can be a good place to start, and provide an interesting set of perspectives on caring (see Chapter 5), the context of support groups can lead to the research being impacted by features of those individuals that have led them to attend support groups, and so may share certain types of experiences. So, while support groups might provide a certain level of homogeneity to the research sample (while at the same time making it possible to attract a wide variety of caring experiences), it might also deny access to different sorts of caring experiences. This was a concern expressed by some of the participants (carers attending support groups - Chapter 5), who gave examples of different situations to their own, for example, families that break apart when a member becomes unwell. One of the ways in which this research sought to address this issue was to link with mental health services to identify carers (i.e. Early Intervention services - Chapters 6 and 7). One of the reasons for liaising with Early Intervention services was to increase the opportunities for engaging carers who were newer to the caring role, and therefore maybe had a different perspective on caring than individuals who had been managing caring responsibilities for a number of years. While this worked particularly well in Chapter 6, exploring service-users' and carers' experiences of first-episode psychosis, it worked less well in Chapter 7, as the family who took part had many years of experience between them of caring and mental health difficulties. While this family's experiences were both interesting and valuable to this research, there is therefore still further scope to explore families' experiences where family members have less experience with caring and mental health difficulties. Recruiting such families, could provide a greater insight into how families react when a member becomes unwell, with a view to further exploring what can be done to improve the experience of mental health difficulties for families. As noted in Chapter 5, participants also often discussed their concerns (for themselves and the people they cared for) with their general

practitioners. This might therefore be another way of identifying carers who are less established in the carer role.

This research has identified that the experience of language and labelling can be an important part of how caring and mental health difficulties are understood. While other studies have explored how the language of care is utilised by services and carers (Molyneaux *et al.*, 2011; O'Connor, 2007; Heaton, 1999), there has been less work carried out on the lived experience of what it feels like to be called a carer. In exploring this from the perspectives of service-users, carers, family members and professionals, this research has sought to increase awareness of how the language is experienced by those who use it. However, there is still scope to develop this work, particularly in terms of the interface between professional, service-user and carer/family member communication.

While this research focused on the experiences of those who had close first-hand experiences of caring and mental health difficulties, the findings highlighted that participants often seemed concerned about how wider society viewed these things. Participants described concerns about discrimination and stigma in relation to mental health issues and caring. Indeed, it was felt that mental health difficulties were often poorly understood by those who had not experienced them (or cared for someone who had experienced them), and that caring was often seen as akin to 'doing nothing', or unemployment. It would therefore be interesting to explore outsiders' perspectives on caring and psychological difficulties, and to look at ways in which awareness of the value of caring could be raised. As highlighted in this research, the number of carers is set to rise in the coming years, and choices about caring can be controversial, involving intense conflict and turmoil for those taking on caring responsibilities. How caring is perceived by wider society, and how carers are able to integrate their responsibilities into their pre-existing identities and relationships within this society, will therefore only become increasingly important in the coming years.

9.4.5 Summary

While much is known about caring and mental health difficulties from a broad range of theoretical perspectives, less is known about the lived experience of caring for a relative experiencing mental health difficulties. This thesis therefore adds to the developing literature in this area by taking a phenomenological approach to understanding the meaning of caring as described by service-users, carers, family members, and mental health professionals, in their own words. For these participants, the language of caring was presented as problematic. On the one hand, it was helpful, linked to being valued, visible, and opening up access to help and support; while on the other, it was seen as threatening to the primary relational qualities of the pre-existing close relationships that had led to taking on caring responsibilities in the first place. In terms of the implications for mental health service design and delivery, a family-sensitive ethos involving open communication and information sharing was seen as essential in developing meaningful relationships between service-users, their families, and professionals, to the benefit of all concerned. Supporting familial relationships in a way that goes beyond simple characterisations of ‘carer’ and ‘cared-for’, focusing on the essential relatedness of the family system, and helping families to develop their own resources and resilience, was also seen as a key way in which mental health services could support the service-users and families they work with.

References

2001 Census (2001). 29 April, Count me in. England Household Form. London: Office for National Statistics. In L. Buckner & S. Yeandle (2007), *Valuing Carers – calculating the value of unpaid care* (p. 2). London: Carers UK.

American Psychiatric Association (1994). *Diagnostic and statistical manual of mental disorders: DSM-IV-TR (4th Edition)*. Washington DC: American Psychiatric Association.

Baltes, P.B. & Baltes, M.M. (1990). Psychological perspectives on successful ageing: The model of selective optimization with compensation. In P.B. Baltes & M.M. Baltes (Eds.), *Successful ageing: Perspectives from the behavioural sciences* (pp. 1-34). Cambridge: Cambridge University Press.

Barbato, A. & D'Avanzo, B. (2000). Family interventions in schizophrenia and related disorders: A critical review of clinical trials. *Acta Psychiatrica Scandinavica*, 102, 81-97.

Barker, C., Pistrang, N. & Elliott, R. (Eds.) (2002). *Research methods in clinical psychology: An introduction for students and practitioners (2nd Edition)*. Chichester: John Wiley & Sons.

Barton, K. & Jackson, C. (2008). Reducing symptoms of trauma among carers of people with psychosis: pilot study examining the impact of writing about caregiving experiences. *Australian & New Zealand Journal of Psychiatry*, 42, 8, 693-701.

Benner, P. (1985). Quality of life: A phenomenological perspective on explanation, prediction and understanding in nursing science. *Advances in Nursing Science*, 8, 1, 1-14.

Benner, P. (1994). The tradition and skill of interpretative phenomenology in studying health, illness, and caring practices. In P. Benner (Ed.), *Interpretative phenomenology: embodiment, caring and ethics in health and illness* (pp. 99-127). Thousand Oaks, CA: Sage.

Benner, P., Tanner, C.A. & Chesla, C.A. (1996). *Expertise in nursing practice: caring, clinical judgement, and ethics*. New York: Springer.

Bentall, R. (2003). *Madness explained: Psychosis and human nature*. London: Penguin Books Ltd.

Bernard, M., Jackson, C. & Jones, C. (2006). Written emotional disclosure following first-episode psychosis: Effects on symptoms of post-traumatic stress disorder. *British Journal of Clinical Psychology*, 45, 403-415.

Bolas, H., van Wersch, A. & Flynn, D. (2007). The well-being of young people who care for a dependent relative: An interpretative phenomenological analysis. *Psychology & Health*, 22, 7, 829-850.

Boyle, M. (1990). *Schizophrenia: A scientific delusion?* London: Routledge.

Buckner, L. & Yeandle, S. (2007). *Valuing Carers – Calculating the value of unpaid care*. London: Carers UK.

Byrne-Davis, L.M.T., Wetherell, M.A., Dieppe, P., Weinman, J., Byron, M., Donovan, J., Horne, R., Brookes, S. & Vedhara, K. (2006). Emotional disclosure in rheumatoid arthritis: Participants' views on mechanisms. *Psychology & Health*, 21, 5, 667-682.

- Campbell, A.S. (2004). How was it for you? Families' experiences of receiving Behavioural Family Therapy. *Journal of Psychiatric and Mental Health Nursing*, 11, 261-267.
- Caqueo-Urizar, A. & Gutiérrez-Maldonado, J. (2006). Burden of care in families of patients with schizophrenia. *Quality of Life Research*, 15, 719-724.
- Carers UK (2011). *Who are carers?* <http://www.carersuk.org/Aboutus/Whoarecarers> (accessed 23/03/2011).
- Chaffey, L. & Fossey, E. (2004). Caring and daily life: Occupational experiences of women living with sons diagnosed with schizophrenia. *Australian Occupational Therapy Journal*, 51, 199-207.
- Champlin, B.E. (2009). Being there for another with a serious mental illness. *Qualitative Health Research*, 19, 11, 1525-1535.
- Chang, K.H. & Horrocks, S. (2006). Lived experiences of family caregivers of mentally ill relatives. *Journal of Advanced Nursing*, 53, 4, 435-443.
- Charmaz, K. (1991). *Good days, bad days: The self in chronic illness and time*. New Jersey: Rutgers University Press.
- Charmaz, K. (2003). Grounded Theory. In J.A. Smith (Ed.), *Qualitative psychology: a practical guide to research methods* (pp. 81-110). London: Sage.
- Cohen, M.Z., Kahn, R.H. & Steeves, R.H. (2000). How to analyze the data. In M.Z. Cohen, R.H. Kahn & R.H. Steeves (Eds.), *Hermeneutic Phenomenological Research. A Practical Guide for Nurse Researchers* (pp. 71-84). Thousand Oaks, CA: Sage.

Colaizzi, P.F. (1978). Psychological research as the phenomenologist views it. In R.S. Valle & M. King (Eds.), *Existential-phenomenological Alternatives for Psychology* (pp. 48-71). New York: Oxford University Press.

Cuipers, P. (1999). The effects of family interventions on relatives' burden: A meta-analysis. *Journal of Mental Health*, 8, 3, 275-285.

Czuchta, D.M. & McCay, E. (2001). Help-seeking for parents of individuals experiencing a first episode of schizophrenia. *Archives of Psychiatric Nursing*, 15, 4, 159-170.

Dahlberg, K., Drew, & Nystrom, M. (2001). *Reflective life-world research*. Lund, Sweden: Studentlitteratur.

Dallos, R. & Draper, R. (2000). *An introduction to family therapy, systemic theory and practice*. Buckingham: Open University Press.

Deci, E.L. & Ryan, R.M. (2002). Overview of Self-Determination Theory: An Organismic Dialectical Perspective. In E.L. Deci & R.M. Ryan (Eds.), *Handbook of Self-Determination Research* (pp. 3-33). New York: University of Rochester Press.

Department of Health (1995). *Carers (Recognition and Services) Act 1995*. London: HMSO.

Department of Health (1999). *National Service Framework for Mental Health. Modern standards and service models*. London: Department of Health.

Department of Health (2003). *Developing services for carers and families of people with mental illness*. London: Department of Health.

Diekelmann, N.L. (1992). Learning-as-testing: a Heideggerian hermeneutical analysis of the lived experiences of students and teachers in nursing. *Advances in Nursing Science*, 14, 3, 72-83.

Diekelmann, N.L., Allen, D. & Tanner, C. (1989). *The NLN criteria for appraisal of Baccalaureate programs: A critical hermeneutic analysis*. New York, National League for Nursing.

Downs-George, R. & Cobb-Howell, C. (1996). Clients with schizophrenia and their caregivers' perceptions of frequent psychiatric rehospitalizations. *Issues in Mental Health Nursing*, 17, 573-588.

Duggleby, W. (2005). What about focus group interaction data? *Qualitative Health Research*, 15, 832-840.

Dwyer, F.W. & Miller, M.K. (1990). Differences in caregiving network by area of residence: Implications for primary caregiver stress and burden. *Family Relations*, 39, 27-37.

Effraimsson, E., Höglund, I. & Sandman, P. (2001). 'The everlasting trial of strength and patience': transitions in home care nursing as narrated by patients and family members. *Journal of Clinical Nursing*, 10, 813-819.

Evenson, E., Rhodes, J., Feigenbaum, J. & Solly, A. (2008). The experiences of fathers with psychosis. *Journal of Mental Health*, 17, 6, 629-642.

Fadden, G., Bebbington, P. & Kuipers, L. (1987). The burden of care: The impact of functional psychiatric illness on the patient's family. *British Journal of Psychiatry*, 150, 285-292.

Fadden, G., Shooter, M. & Holsgrove, G. (2005). Involving carers and service users in the training of psychiatrists. *Psychiatric Bulletin*, 29, 270-274.

Fine, M. (2004). Renewing the social vision of care. *Australian Journal of Social Issues*, 39, 3, 217-232.

Galovski, T. & Lyons, J.A. (2004). Psychological sequelae of combat violence: A review of the impact of PTSD on the veteran's family and possible interventions. *Aggression and Violent Behaviour*, 9, 5, 477-501.

Giorgi, A. (1970). *Psychology as a human science*. New York: Harper and Row.

Giorgi, A. & Giorgi, B. (2003). Phenomenology. In J.A. Smith (Ed.), *Qualitative psychology: A practical guide to research methods* (pp. 25-50). London: Sage.

Glaser, B.G. & Strauss, A.L. (1967). *The discovery of grounded theory*. Chicago: Aldine.

Good, B. (1994). The narrative representation of illness. In B. Good (Ed.), *Medicine, Relationality, and Experience: An anthropological perspective* (pp. 135-165). New York: Cambridge University Press.

Graham, J.E. & Bassett, R. (2006). Reciprocal relations: The recognition and co-construction of caring with Alzheimer's disease. *Journal of Aging Studies*, 20, 335-349.

Harris, T.J.R., Pistrang, N. & Barker, C. (2006). Couples' experiences of the support process in depression: A phenomenological analysis. *Psychology and Psychotherapy: Theory, Research and Practice*, 79, 1-21.

- Harrop, C. & Trower, P. (2001). Why does schizophrenia develop at late adolescence? *Clinical Psychology Review*, 21, 2, 241-266.
- Heaton, J. (1999). The gaze and visibility of the carer: a Foucauldian analysis of the discourse of informal care. *Sociology of Health & Illness*, 21, 759-777.
- Heidegger, M. (1927, reprinted 1962). *Being and Time* (J. Macquarie & E. Robinson trans.). Oxford: Blackwell.
- Heiker, D. (2007). Story sharing: Restoring the reciprocity of caring in long-term care. *Journal of Psychosocial Nursing and Mental Health Services*, 45, 7, 20-24.
- Henderson, J. (2001). 'He's not my carer – he's my husband': personal and policy constructions of care in mental health. *Journal of Social Work Practice*, 15, 2, 149-159.
- Highet, N.J., McNair, B.G., Davenport, T.A. & Hickie, I.B. (2004). "How much more can we lose?": carer and family perspectives on living with a person with depression. *Medical Journal of Australia*, 181, 7, 6-9.
- Hirst, M. (2005). Carer distress: A prospective, population-based study. *Social Science & Medicine*, 61, 697-708.
- Hodgins, H.S. & Knee, C.R. (2002). The Integrating Self and Conscious Experience. In E.L. Deci and R.M. Ryan (Eds.), *Handbook of Self-Determination Research* (pp. 87-100). New York: University of Rochester Press.
- Howard, P.B. (1994). Lifelong maternal caregiving for children with schizophrenia. *Archives of Psychiatric Nursing*, 8, 107-114.

- Howard, P.B. (1998). The experience of fathers of adult children with schizophrenia. *Issues in Mental Health Nursing, 19*, 399-413.
- Hsiao, F-H., Klimidis, S., Minas, H. & Tan, E-S. (2006). Cultural attribution of mental health suffering in Chinese societies: the views of Chinese patients with mental illness and their caregivers. *Journal of Clinical Nursing, 15*, 998-1006.
- Huang, X.-Y., Hung, B.-J., Sun, F.K., Lin, J.-D. & Chen, C.-C. (2009). The experience of carers in Taiwanese culture who have a long-term schizophrenia in their families: A phenomenological study. *Journal of Psychiatric and Mental Health Nursing, 16*, 874-883.
- Huang, X.-Y., Sun, F.-K., Yen, W.-J. & Fu, C.-M. (2008). The coping experiences of carers who live with someone who has schizophrenia. *Journal of Clinical Nursing, 17*, 817-826.
- Huke, K. & Slade, P. (2006). An exploratory investigation of the experiences of partners living with people who have bulimia nervosa. *European Eating Disorders Review, 14*, 436-447.
- Jeon, Y.-H. & Madjar, I. (1998). Caring for a family member with chronic mental illness. *Qualitative Health Research, 8*, 5, 694-706.
- Jones, K. (2004). Mission drift in qualitative research, or moving toward a systematic review of qualitative studies, moving back to a more systematic narrative review. *The Qualitative Report, 9*, 1, 95-112.
- Jones, K. (2006). Informal care as relationship: the case of the Magnificent Seven. *Journal of Psychiatric and Mental Health Nursing, 13*, 214-220.

- Joyce, J., Leese, M., Kuipers, E., Szmukler, G., Harris, T. & Staples, E. (2003), Evaluating a model of caregiving for people with psychosis. *Social Psychiatry and Psychiatric Epidemiology*, 38, 189-195.
- Karp, D.A. & Tanarugsachock, V. (2000). Mental illness, caregiving, and emotion management. *Qualitative Health Research*, 10, 1, 6-25.
- Kelly, T.B. (2007). *Supported to Care? Carers' views of services*. Glasgow: Glasgow Caledonian University.
- Kleinman, A. (1980). *Patients and healers in the context of culture: An exploration of the borderland between anthropology, medicine and psychiatry*. Berkley, CA: University of California Press.
- Laing, R.D. & Esterson, A. (1964). *Sanity, madness and the family*. London: Penguin Books.
- Langdridge, D. (2007). *Phenomenological Psychology: Theory, Research and Method*. Harlow: Pearson.
- Larkin, M. & Thompson, A. (2011). Interpretative Phenomenological Analysis. In D. Harper & A. Thompson (Eds.) *Qualitative research methods in mental health and psychotherapy: An introduction for students and practitioners (pp. 101-116)*. Oxford: Wiley.
- Leonard, V. (1989). A Heideggerian phenomenologic perspective on the concept of the person. *Advances in Nursing Science*, 11, 4, 40-55.
- Lincoln, T.S. & Guba, E.G. (1985). *Naturalistic enquiry*. Newbury Park, CA: Sage.

Lindseth, A. & Norberg, A. (2004). A phenomenological hermeneutical method for researching lived experience. *Scandinavian Journal of Caring Sciences*, 18, 145-53.

Lobban, F. & Barrowclough, C. (Eds.) (2009). *A casebook of family interventions for psychosis*. Padstow: John Wiley & Sons.

Magliano, L., Fadden, G., Madianos, M., Caldas de Almeida, J.M., Held, T., Guarneri, M., Marasco, C., Tosini, P. & Maj, M. (1998). Burden on the families of patients with schizophrenia: results of the BIOMED I study. *Social Psychiatry and Psychiatric Epidemiology*, 33, 405-412.

Magliano, L., Fiorillo, A., De Rosa, C., Malangone, C. & Maj, M. (2005). Family burden in long-term diseases: a comparative study in schizophrenia vs. physical disorders. *Social Science and Medicine*, 61, 313-322.

Magliano, L., Guarneri, M., Marasco, C., Tosini, P., Morosini, P. & Maj, M. (1996). A new questionnaire assessing coping strategies in relatives of patients with schizophrenia: development and factor analysis. *Acta Psychiatrica Scandinavica*, 94, 224-228.

Marsh, D.T., Leffley, H.P., Evans-Rhodes, D., Ansell, V.I., Doerzbacher, B.M., LaBarbera, L. & Paluzzi, J.E. (1996). The family experience of mental illness: Evidence for resilience. *Psychiatric Rehabilitation Journal*, 20, 2, 3-12.

Maslow, A. (1954). *Motivation and Personality*. New York: Harper.

Maurin, J. & Boyd, C. (1990). Burden of mental illness on the family: A critical review. *Archives of Psychiatric Nursing*, 4, 2, 99-107.

Mayeroff, M. (1971). *On Caring*. New York: Harper & Row.

- Maykut, P. & Morehouse, R. (1994). *Beginning qualitative research: A philosophic and practical guide*. London: Falmer Press.
- McKie, L., Bowlby, S. & Gregory, S. (2001). Gender, caring and employment in Britain. *Journal of Social Policy*, 30, 2, 233-238.
- Miller, F. (1996). Grief therapy for relatives of persons with serious mental illness. *Psychiatric Services*, 47, 633-637.
- Molm, L.D. & Cook, K.S. (1995). Social exchange and exchange networks. In K.S. Cook, G.A. Fine & J.S. House (Eds.), *Sociological perspectives on social psychology* (pp. 209-235). Needham Heights, MA: Allyn and Bacon.
- Molyneaux, V., Butchard, S., Simpson, J. & Murray, C. (2011). Reconsidering the term 'carer': a critique of the universal adoption of the term 'carer'. *Ageing and Society*, 31, 422-437.
- Morgan, D.L. (1997). *Focus groups as qualitative research* (2nd Edition). Thousand Oaks, CA: Sage.
- Morosini, P., Roncone, R., Veltro, F., Palomba, U. & Casacchia, M. (1991). Routine assessment tool in psychiatry: A case of questionnaire of family attitudes and burden. *Italian Journal of Psychiatry and Behavioural Sciences*, 1, 1, 95-101.
- Morrison, A.P., Frame, L. & Larkin, W. (2004). Relationships between trauma and psychosis: A review and integration. *British Journal of Clinical Psychology*, 42, 331-352.
- Murray, M. & Chamberlain, K. (1999). Health psychology and qualitative research. In M. Murray & K. Chamberlain (Eds.), *Qualitative Health Psychology: Theories and Methods*. Wiltshire: Sage.

NHS Choices (2011 Website). *NHS Choices: Your health, your choices*. www.nhs.uk (accessed 12/11/2011).

NICE (2006). *Schizophrenia: Full national clinical guideline on core interventions in primary and secondary care*. London: Gaskell and the British Psychological Society.

NICE (2009). *Understanding NICE guidance: Information for people who use NHS services. Schizophrenia*. London: National Institute for Health and Clinical Excellence.

NICE (2010). *Schizophrenia: The NICE guideline on core interventions in the treatment and management of schizophrenia in adults in primary and secondary care. Updated Edition*. London: The British Psychological Society and The Royal College of Psychiatrists.

O'Connor, D.L. (2007). Self-identifying as a caregiver: Exploring the positioning process. *Journal of Aging Studies*, 21, 165-174.

Osborne, J. & Coyle, A. (2002). Can parental responses to adult children with schizophrenia be conceptualized in terms of loss and grief? A case study analysis. *Counselling Psychology Quarterly*, 15, 4, 307-323.

Oyebode, J. (2003). Assessment of carers' psychological needs. *Advances in Psychiatric Treatment*, 9, 45-53.

Oxford English Dictionary (2011). *Definition of Care*. <http://oxforddictionaries.com/definition/care?rskey=5vAnjH&result=1> (accessed 8 July 2011).

Palmer, M. (2007). *An exploration of carers' experiences and perceptions of mental health services available within the West Midlands region, UK*. MRes: University of Birmingham.

- Palmer, M., Larkin, M., de Visser, R. & Fadden, G. (2010). Developing an interpretative phenomenological approach to focus group data. *Qualitative Research in Psychology*, 7, 99-121.
- Parker, I. (2004). Criteria for qualitative research in psychology. *Qualitative Research in Psychology*, 1, 95-106.
- Pejlert, A. (2001). Being a parent of an adult son or daughter with severe mental illness receiving professional care: parents' narratives. *Health and Social Care in the Community*, 9, 4, 194-204.
- Pennebaker, J.W. & Beall, S.K. (1986). Confronting a traumatic event: Toward an understanding of inhibition and disease. *Journal of Abnormal Psychology*, 95, 274-281.
- Penny, E., Newton, E. & Larkin, M. (2009). Whispering on the water: British Pakistani Families' experiences of support from an Early Intervention Service for First-Episode Psychosis. *Journal of Cross-Cultural Psychology*, 40, 969-987.
- Perlick, D.A., Rosenheck, R.A., Kaczynski, R., Swartz, M.S., Cañive, J.M. & Lieberman, J.A. (2006). Components and correlates of family burden in schizophrenia. *Psychiatric Services*, 57, 8, 1117-1125.
- Phinney, A. & Chesla, C.A. (2003). The lived body in dementia. *Journal of Aging Studies*, 17, 283-299.
- Pickens, J. (1998). Formal and informal care of people with psychiatric disorders: Historical perspectives and current trends. *Journal of Psychosocial Nursing and Mental Health Services*, 36, 1, 37-43.

Pilling, S., Bebbington, P., Kuipers, E., Garety, P., Geddes, J., Orbach, G. & Morgan, C. (2002). Psychological treatments in schizophrenia: I. Meta-analysis of family intervention and cognitive behaviour therapy. *Psychological Medicine*, 32, 763-782.

Pinfold, V. & Corry, P. (2003). *Who Cares? The experience of mental health carers accessing services and information*. Surrey: Rethink.

Pitschel-Walz, G., Leucht, S., Bäuml, J., Kissling, W. & Engel, R.R. (2002). The effect of family interventions on relapse and rehospitalization in schizophrenia – a meta-analysis. *Schizophrenia Bulletin*, 27, 1, 73-92.

Player, J. & Leggatt, M. (1999). Carers: Their needs, rights and contributions. In Deaking Human Services Australia (Ed.), *Learning together: Education and training partnerships in mental health. Final report (pp. 28-32)*. Canberra: Commonwealth Department of Health and Aged Care.

Porter, S. (2000). Qualitative analysis. In D. Cormark (Ed.), *The Research Process in Nursing (4th Edition)*. Oxford: Blackwell Science.

Princess Royal Trust for Carers (2000). *Key findings on mental health research*. London: Princess Royal Trust for Carers.

Princess Royal Trust for Carers (2011). *What is a carer. Definition of a carer*. <http://www.carers.org/what-carer> (accessed 23/03/2011).

Reid, C., Moss, S. & Hyman, G. (2005). Caregiver reciprocity: The effect of reciprocity, carer self-esteem and motivation on the experience of caregiver burden. *Australian Journal of Psychology*, 57, 3, 186-196.

- Reine, G., Lancon, C., Simeoni, M.C., Duplan, S. & Auquier, P. (2003). Caregiver burden in relatives of persons with schizophrenia: an overview of measure instruments. *Encephale-Revue de Psychiatrie Clinique, Biologique et Therapeutique*, 29, 2, 137-147.
- Ricoeur, P. (1976). *Interpretation theory. Discourse and the surplus of meaning*. Fort Worth, Texas: Christian University Press.
- Rosenthal, G. (1993). Reconstruction of life stories: principles of selection in generating stories for narrative biographical interviews. In R. Josselson & A. Lieblich (Eds.), *The Narrative Study of Lives (pp. 59-91)*. London: Sage.
- Rostill-Brookes, H., Larkin, M., Toms, A. & Churchman, C. (2011). A shared experience of fragmentation: Making sense of foster placement breakdown. *Clinical Child Psychology and Psychiatry*, 16, 103-127.
- Ruggeri, M., Leese, M., Thornicroft, G., Bisoffi, G. & Tansella, M. (2000). Definition and prevalence of severe and persistent mental illness. *British Journal of Psychiatry*, 177, 149-155.
- Sanseeha, L., Chontawan, R., Sethabouppha, H., Disayavanish, C. & Turale, S. (2009). Illness perspectives of Thais diagnosed with schizophrenia. *Nursing and Health Sciences*, 11, 306-311.
- Sartre, J.-P. (1943, reprinted 1993). *Being and Nothingness: An Essay on Phenomenological Ontology*. London: Routledge.
- Sethabouppha, H. & Kane, C. (2005). Caring for the seriously mentally ill in Thailand: Buddhist family caregiving. *Archives of Psychiatric Nursing*, 19, 2, 44-57.

Sherblom, S., Shipps, T. & Sherblom, J. (1993). Justice, care and integrated concerns in the ethical decision making of nurses. *Qualitative Health Research*, 3, 442-464.

Shooter, M. (2004). *Extract from Mike Shooter's 'Partners in Care' campaign launch speech published on the Royal College of Psychiatrists' website.*
<http://www.rcpsych.ac.uk/campaigns/partnersincare/launch.aspx> (accessed 17/01/2011).

Sin, J., Moone, N. & Wellman, N. (2005). Developing services for the carers of young adults with early onset psychosis – listening to their experiences and needs. *Journal of Psychiatric and Mental Health Nursing*, 12, 589-597.

Singleton, N., Maung, N.A., Cowie, A., Sparks, J., Bumpstead, R. & Meltzer, H. (2002). *Mental health of carers.* Office for National Statistics on behalf of the Department of Health. London: HMSO.

Slade, M., Pinfold, V., Rapaport, J., Bellringer, S., Banerjee, S., Kuipers, E. & Huxley, P. (2007). Best practice when service users do not consent to sharing information with carers. *British Journal of Psychiatry*, 190, 148-155.

Slade, M., Powell, R. & Strathdee, G. (1996). Current approaches to identifying the severely mentally ill. *Social Psychiatry and Psychiatric Epidemiology*, 32, 177-184.

Smith, J.A. (1996). Beyond the divide between cognition and discourse: Using interpretative phenomenological analysis in health psychology. *Psychology & Health*, 11, 261-271.

Smith, J.A. (1999a). Identity development during the transition to motherhood: An interpretative phenomenological analysis. *Journal of Reproductive and Infant Psychology*, 17, 281-300.

Smith, J.A. (1999b). Towards a relational self: Social engagement during pregnancy and psychological preparation for motherhood. *British Journal of Social Psychology*, 38, 409-426.

Smith, J.A. (2004). Reflecting on the development of interpretative phenomenological analysis and its contribution to qualitative research in psychology. *Qualitative Research in Psychology*, 1, 39-54.

Smith, J.A., Flowers, P. & Larkin, M. (2009). *Interpretive phenomenological analysis: Theory, method and research*. London: Sage.

Smith, J.A., Flowers, P. & Osborn, M. (1997). Interpretative phenomenological analysis and the psychology of health and illness. In L. Yardley (Ed.), *Material discourses of health and illness* (pp. 68-91). London: Routledge.

Smith, J.A., Jarman, M. & Osborn, M. (1999). Doing interpretative phenomenological analysis. In M. Murray & K. Chamberlain (Eds.), *Qualitative health psychology: theories and methods*. London: Sage.

Smith, J.A. & Osborn, M. (2003). Interpretative phenomenological analysis. In J.A. Smith (Ed.), *Qualitative psychology: A practical guide to research methods*. London: Sage.

Spiegelberg, H. (1976). On some human uses of phenomenology. In F.J. Smith (Ed.), *Phenomenology in perspective* (pp. 16-31). The Hague: Martinus Nijhoff.

Szmukler, G.I. & Bloch, S. (1997). Family involvement in the care of people with psychoses. *British Journal of Psychiatry*, 171, 401-405.

Telford, E. (2009). *IPA and the Internet* (presentation given at the Annual Interpretative Phenomenological Analysis Conference, Queen's University Belfast, 3 September 2009).

Tesch, R. (1990). *Qualitative research. Analysis types and software tools*. Basingstoke: Falmer Press.

Theadom, A., Smith, H., Horne, R., Bowkill, R., Apfelbacher, C.J. & Frew, A.J. (2009). Participant experiences of a written emotional disclosure intervention in asthma. *Stress and Health, 26*, 45-50.

Thiede-Call, K., Finch, M.A., Huck., S.M. & Kane, R.A. (1999). Caregiver burden from a social exchange perspective: Caring for older people after hospital discharge. *Journal of Marriage and the Family, 61*, 3, 688-699.

Tranvåg, O. & Kristoffersen, K. (2008). Experience of being the spouse co-habitant of a person with bipolar affective disorder: a cumulative process over time. *Scandinavian Journal of Caring Science, 22*, 5-18.

Trevarthen, C. (2002). Making sense of infants making sense. *Intellectica, 1*, 34, 161-188.

Tuck, I. (1995). Qualitative designs. In L.A. Talbot (Ed.), *Principles and practice of nursing research*. St Louis: Mosby.

Tuck, I., du Mont, P., Evans, G. & Shupe, J. (1997). The experience of caring for an adult child with schizophrenia. *Archives of Psychiatric Nursing, 11*, 3, 118-125.

Van Manen, M. (1990). *Researching lived experience: Human science for an action sensitive pedagogy*. New York: State University of New York Press.

van Zuuren, F.J., Schoutrop, M.J.A., Lange, A., Louis, C.M. & Slegers, J.E.M. (1999). Effective and ineffective ways of writing about traumatic experiences: A qualitative study. *Psychotherapy Research, 9*, 3, 363-380.

Vetere, A. & Dallos, R. (2003). *Working systemically with families: Formulation, Intervention and Evaluation*. London: Karnac.

Walmsley, J. (1993). Contradictions in caring: Reciprocity and interdependence. *Disability and Society, 8*, 2, 129-141.

Walters, A.J. (1995). A Heideggerian hermeneutic study of the practice of critical care nurses. *Journal of Advanced Nursing, 21*, 492-497.

Wane, J., Larkin, M., Earl-Gray, M. & Smith, H. (2009). Understanding the impact of an Assertive Outreach Team on couples caring for adult children with psychosis. *Journal of Family Therapy, 31*, 284-309.

Watson, A.C., Kelly, B.L. & Vidalon, T.M. (2009). Examining the meaning attached to mental illness and mental health services among justice system-involved youth and their parents. *Qualitative Health Research, 19*, 8, 1087-1099.

Weiss, D.S. & Marmar, C.R. (1997). *The impact of events scale – revised*. In J.P. Wilson & T.M. Keane (Eds.), *Assessing psychological trauma and PTSD* (pp. 399-411). New York: Guildford Press.

Wilkinson, C. & McAndrew, S. (2008). ‘I’m not an outsider, I’m his mother!’ A phenomenological enquiry into carer experiences of exclusion from acute psychiatric settings. *International Journal of Mental Health Nursing, 17*, 392-401.

References

Willig, C. (2008). *Introducing qualitative research in psychology (2nd Edition)*. Maidenhead: Open University Press.

World Health Organisation (2003). *Investing in mental health*. Geneva: World Health Organisation.

Yardley, L. (2000). Dilemmas in qualitative health research. *Psychology & Health*, 15, 215-228.

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Appendix 1

Links to Chapter 3: Literature review: Exploring the meaning of the caring experience

Summary of phenomenological papers exploring mental health difficulties and caring identified within the literature review.

Article and Author	Sample	Method of data collection	Method of data analysis	Key themes identified	Key findings	Particularly relevant to this research?
The well-being of young people who care for a dependent relative: An interpretative phenomenological analysis (Bolas, van Wersch & Flynn, 2007)	N = 5	Individual interviews	Interpretative phenomenological analysis	<ul style="list-style-type: none"> • What caring means • Isolation and distancing from others • Integrating caring 	Participants struggled to make sense of caring, finding it relentless, overwhelming and frustrating. They experienced stigma, which led to secrecy, withdrawal and social isolation. They sought to integrate caring into their identity.	Excluded from further discussion: focus on mental and physical illness
How was it for you? Families' experiences of receiving Behavioural Family Therapy (Campbell, 2004)	N = 27 (participants are members of 10 family groups)	Family group interviews	Constant comparative method (Maykut & Morehouse, 1994)	<ul style="list-style-type: none"> • Engagement with BFT • Therapist qualities • The practice of BFT • Perceived gains attributable to BFT • Empowerment of users and carers 	Families reported being satisfied with the intervention. They reported reduced levels of stress within the family, reduced carer burden, enhanced communication skills and a positive sense of empowerment. They attributed these changes to receiving BFT.	Excluded from further discussion: focus on experience of intervention

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Article and Author	Sample	Method of data collection	Method of data analysis	Key themes identified	Key findings	Particularly relevant to this research?
Caring and daily life: Occupational experiences of women living with sons diagnosed with schizophrenia (Chaffey & Fossey, 2004)	N = 6	Individual interviews	Thematic analysis (Lincoln & Guba, 1985; Tesch, 1990)	<ul style="list-style-type: none"> • It's a whole new thing • The need to provide support • The situation just evolved • 'Much of our life is focused on him' • 'Don't get too optimistic' 	The themes illustrate how the women's life trajectories and occupations were altered to incorporate caring. The pursuit of their interests is important to sustain satisfying lives.	Included for further discussion
Being there for another with a serious mental illness (Champlin, 2009)	N = 12	Individual interviews	Descriptive phenomenological approach (Dahlberg, Drew & Nystrom, 2001)	<ul style="list-style-type: none"> • Accepting the changed other and grieving the loss of who the other once was • Taking action in challenging circumstances • Recognizing the ongoing, never-ending and sometimes unpredictable nature of the experience • Feeling isolated • Having ambiguity of the heart • Experiencing the tension of waiting • Knowing the other well • Caring for the other 	Describing the relationship between the mentally unwell person and the non-professional caretaker in his or her life. Implications for helping professionals understand and support people who are in this experience from a more caring paradigm.	Included for further discussion

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Article and Author	Sample	Method of data collection	Method of data analysis	Key themes identified	Key findings	Particularly relevant to this research?
Lived experiences of family caregivers of mentally ill relatives (Chang & Horrocks, 2006)	N = 19	Individual interviews	Thematic analysis (Heidegger, 1962; Diekelmann <i>et al.</i> , 1989; Diekelmann, 1992; Walters, 1995) QSR Nvivo (1.3) software for qualitative analysis was also used to help store, sort, retrieve and code data	<ul style="list-style-type: none"> Managing the day-to-day care Enduring the caregiving process Surviving the caregiving process 	Mental health nurses need to help Chinese family caregivers to cope with the stresses and stigma of their relative's mental illnesses through psychosocial education or family intervention and to provide culturally congruent care. The public should be educated through health promotion and education.	Excluded from further discussion: focus on cultural perspectives (Chinese)
Help-seeking for parents of individuals experiencing a first episode of schizophrenia (Czuchta & McCay, 2001)	N = 20 completed questionnaires Subset of N = 5 described their help-seeking experience	Questionnaires Individual interviews	Thematic analysis and analysis of exemplars (Benner, 1985; Leonard, 1989)	<ul style="list-style-type: none"> Evolving change: What does it mean? Continuous help-seeking The help-seeking experience: Impact on parents 	Developing an understanding of parents' experience of help-seeking in response to their child's first episode of schizophrenia.	Included for further discussion

Continued...

Article and Author	Sample	Method of data collection	Method of data analysis	Key themes identified	Key findings	Particularly relevant to this research?
<p>Clients with schizophrenia and their caregivers' perceptions of frequent psychiatric rehospitalizations</p> <p>(Downs-George & Cobb-Howell, 1996)</p>	N = 10	Individual interviews	<p>Constant comparative method</p> <p>(Lincoln & Guba, 1985)</p>	<ul style="list-style-type: none"> • An event providing a safe place • An event providing stabilization of medication • An event producing renewal of hope • An event producing frustration • An event producing a lack of individual control 	Attempts to achieve an understanding of the lived experience of frequent rehospitalizations on both service-users and carers. Findings can be used to develop a more comprehensive model of care for intervention with service-users and caregivers.	Excluded from further discussion: focus on frequent rehospitalisation
<p>'The everlasting trial of strength and patience': transitions in home care nursing as narrated by patients and family members</p> <p>(Efrainsson, Höglund & Sandman, 2001)</p>	N = 12	Individual interviews	<p>Phenomenological-hermeneutic method</p> <p>(Ricoeur, 1976)</p>	<ul style="list-style-type: none"> • Taking on the challenge • The new life • Beyond the horizon 	The findings reveal where natural caring was changed into patient-caregiver relations. Changes in life situations were interpreted as long lasting and trying transitions.	Excluded from further discussion: focus on experience of transition to home care nursing
<p>The experiences of fathers with psychosis</p> <p>(Evenson, Rhodes, Feigenbaum & Solly, 2008)</p>	N = 10	Individual interviews	Interpretative phenomenological analysis	<ul style="list-style-type: none"> • Psychosis undermines the father-child relationship and the work of parenting • Pre-fatherhood aspirations • Fears for the children • Impact of fatherhood 	Treatment and care programmes need to be sensitive to the effects of fatherhood on psychosis and the effects of a father's psychosis on the mental health of his family.	Excluded from further discussion: focus on fathers with psychosis

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Article and Author	Sample	Method of data collection	Method of data analysis	Key themes identified	Key findings	Particularly relevant to this research?
<p>Couples' experiences of the support process in depression: A phenomenological analysis</p> <p>(Harris, Pistrang & Barker, 2006)</p>	<p>N = 18</p>	<p>Couples interviews (key participant and their partner)</p>	<p>Interpretative phenomenological analysis</p>	<ul style="list-style-type: none"> • Couples experience of depression: • Bafflement • 'Battling through' – coping with a family emergency • Coping with the 'long, grey periods' • Starting to 'swim again' – the recovery phase • The threat of relapse • The healing process: • 'Stumbling along' • 'Walking on eggshells' • Communication in depression – a 'Catch 22' • Working together • Managing one's feelings as a helper 	<p>Couples accounts of the support process were characterized by a pervasive sense of bewilderment and struggle. The findings highlight the importance of including partners in psychological interventions for depression.</p>	<p>Included for further discussion</p>

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Article and Author	Sample	Method of data collection	Method of data analysis	Key themes identified	Key findings	Particularly relevant to this research?
<p>“How much more can we lose?”: carer and family perspectives on living with a person with depression</p> <p>(Hight, McNair, Davenport & Hickie, 2004)</p>	N = 37	Structured focus groups	Thematic analysis (employing QSR NUD*IST software package for qualitative data)	<ul style="list-style-type: none"> • Direct impacts of depression on carers • Impact of depression on intimate relationships • Lack of broader social support • Lack of respect or engagement by healthcare providers • Importance of support groups/agencies 	The experiences of carers and families of people with depression highlight the need for more extensive community education about depression and more productive collaboration with the healthcare system.	Included for further discussion
<p>The experiences of fathers of adult children with schizophrenia</p> <p>(Howard, 1998)</p>	N = 12	Individual interviews	Constant-comparative method	<ul style="list-style-type: none"> • Crisis • Learning, coping and acceptance • Involvement in care • Unresolved issues • Severity of the event 	Offers a description of the lived experience of fathers of adult children with schizophrenia by exploring the extent they engaged in caregiving. Implications for practice include immediate assessment of fathers, supportive listening and brief therapy.	Included for further discussion

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Article and Author	Sample	Method of data collection	Method of data analysis	Key themes identified	Key findings	Particularly relevant to this research?
<p>Cultural attribution of mental health suffering in Chinese societies: the views of Chinese patients with mental illness and their caregivers</p> <p>(Hsiao, Klimidis, Minas & Tan, 2006)</p>	N = 56	Individual interviews	<p>Narrative analysis</p> <p>Influenced by reading response theory (Good, 1994)</p>	<ul style="list-style-type: none"> • Plots, themes and contrasting or complementary perspectives • Includes issues around failure or gender roles, family conflicts, self-blame, guilt and shame, impact on identity 	<p>Chinese people's well-being is significantly determined by a harmonious relationship with others - social and cultural context. Psychotherapy focusing on an individual's growth and autonomy may ignore the value of maintaining interpersonal harmony.</p>	Excluded from further discussion: focus on cultural perspectives (Chinese)
<p>The experiences of carers in Taiwanese culture who have long-term schizophrenia in their families: a phenomenological study</p> <p>(Huang, Hung, Sun, Lin & Chen, 2009)</p>	N = 10	Individual interviews	<p>Narrative analysis</p> <p>(Colaizzi's seven steps method, 1978)</p>	<ul style="list-style-type: none"> • Burdens of caring • Emotional burdens • Strategies of coping 	<p>Carers in families with long-term schizophrenia in Taiwanese culture are experiencing several burdens. Cultural factors are identified.</p>	Excluded from further discussion: focus on cultural perspectives (Taiwanese)
<p>The coping experiences of carers who live with someone who has schizophrenia</p> <p>(Huang, Sun, Yen & Fu, 2008)</p>	N = 10	Individual interviews	<p>Narrative analysis</p> <p>(Colaizzi's seven steps method, 1978)</p>	<ul style="list-style-type: none"> • Psychological coping mechanisms • Social coping strategies 	<p>The importance of understanding the coping experiences of carers where a family member has schizophrenia</p>	Excluded for further discussion: focus on cultural perspectives

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Article and Author	Sample	Method of data collection	Method of data analysis	Key themes identified	Key findings	Particularly relevant to this research?
An exploratory investigation of the experiences of partners living with people who have bulimia nervosa (Huke & Slade, 2006)	N = 8	Individual interviews	Interpretative phenomenological analysis	<ul style="list-style-type: none"> • Living with the secrecy and deception • Struggling to understand and find reasons • Discovering your powerlessness • ‘It’s like growing to live with it’ • Experiencing strengths and strains in the relationships 	Living with someone with bulimia presents many challenges to partners. It is suggested partners could be offered opportunities to access support and their perspectives could be a useful resource for therapeutic interventions.	Excluded for further discussion: focus on eating disorder
Caring for a family member with chronic mental illness (Jeon & Madjar, 1998)	N = 14	Individual interviews	Hermeneutic-phenomenological method (Van Manen,1990)	<ul style="list-style-type: none"> • Temporality and family caring: Taking each day as it comes • Relationality and family caring: looking at the world through the other’s window 	Aims to depict the lived world of caring for a family member with chronic mental illness. This world of caring is defined subjectively by a strong sense of responsibility.	Included for further discussion
Informal care as relationship: the case of the Magnificent Seven (Jones, 2006)	N = 2	Individual Narrative Interpretive Method interviews	Interpretive phenomenology (Rosenthal, 1993)	<ul style="list-style-type: none"> • Interconnected lives: Polly’s and Carl’s stories • Analyses of the lived life and told stories – Polly and Carl 	This family defines disability as a status that they share in common: disability demonstrates relationships and keeps the family together but discourages mobility.	Excluded from further discussion: focus on mental and physical illness

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Article and Author	Sample	Method of data collection	Method of data analysis	Key themes identified	Key findings	Particularly relevant to this research?
<p>Can parental responses to adult children with schizophrenia be conceptualized in terms of loss and grief? A case study analysis</p> <p>(Osborne & Coyle, 2002)</p>	<p>N = 4</p>	<p>Individual interviews</p>	<p>Interpretative phenomenological analysis</p>	<p>Case studies presented including themes around: Uncertainty prior to diagnosis, interpreting illness in terms of loss, emotional reactions, coping with loss, resisting diagnosis, continuity of the person, coping with the condition, aspirations for the future, and coping with negative feelings</p>	<p>Exploring parental responses to adult children with schizophrenia in relation to loss and grief, centred around loss of the pre-morbid version of their child. Implications for counselling psychology are considered, particularly with regard to providing facilitative environments for parents to explore their concerns about their child's condition.</p>	<p>Included for further discussion</p>

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Article and Author	Sample	Method of data collection	Method of data analysis	Key themes identified	Key findings	Particularly relevant to this research?
<p>Being a parent of an adult son or daughter with severe mental illness receiving professional care (Pejlert, 2001)</p>	<p>N = 10</p>	<p>Individual interviews</p>	<p>Phenomenological-hermeneutic approach (Ricoeur, 1976)</p>	<ul style="list-style-type: none"> • Living with anguish, sorrow and constant worry • Living with guilt and shame • Being in a relationship with nurses/care: comfort and hardships • Coming to terms with difficulties 	<p>The narratives disclosed a cultural conflict between the family system and the care system. This was interpreted as a threat to the parental role, but experiences of comfort and confidence in care were also experienced. Experiences of stigma were related to the labelling of illness. Persistence in caring and hope were interpreted as coming to terms with difficulties. Mental health professionals need to be aware of their own attitudes and treatment of families.</p>	<p>Included for further discussion</p>

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Article and Author	Sample	Method of data collection	Method of data analysis	Key themes identified	Key findings	Particularly relevant to this research?
Whispering on the water. British Pakistani families' experiences of support from and Early Intervention Service for first-episode psychosis (Penny, Newton & Larkin, 2009)	N = 11 (participants are members of 6 family groups)		Interpretative phenomenological analysis	<ul style="list-style-type: none"> • A story of loss • A social problem • Divergent points on the path to change 	Themes identified reflect on the impact on participants' lives, their understandings of the problems and possible solutions and their use of a range of cultural resources. Importance of engaging with British Pakistani families' interpretations of psychosis for successful relationships with services	Excluded from further discussion: focus on cultural perspectives (British Pakistani)
The lived body in dementia (Phinney & Chesla, 2003)	N = 18	Individual interviews	Interpretive phenomenological analysis (Benner, 1994; Benner <i>et al.</i> , 1996)	<ul style="list-style-type: none"> • Being slow • The case of using equipment • The case of conversation • Being lost • Lost in the world of space • Lost in the world of equipment • Lost in the world of activity • Being a blank • Forgetfulness • The body as silent 	These finding challenge the problematic mind-body dualism that pervades the current understanding of dementia. Attempts to open the possibility for developing a vocabulary of care that takes a more complete account of the lived experience of dementia.	Excluded from further discussion: focus on dementia

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Article and Author	Sample	Method of data collection	Method of data analysis	Key themes identified	Key findings	Particularly relevant to this research?
<p>Illness perspectives of Thais diagnosed with schizophrenia</p> <p>(Sanseeha, Chontawan, Sethabouppha, Disayavanish & Turale, 2009)</p>	N = 30	Individual interviews	<p>Hermeneutic-phenomenological analysis</p> <p>(Cohen <i>et al.</i>, 2000)</p>	<ul style="list-style-type: none"> • Perceptions of mental illness • Perceptions of the causes of illness • Perceptions of discrimination • Attempting to live with schizophrenia 	<p>The findings include strong underlying cultural and spiritual beliefs and attitudes unique to Thai participants. Understanding the perceptions of participants might help healthcare providers to be more sensitive to those living with schizophrenia in Thailand and elsewhere.</p>	<p>Excluded from further discussion: focus on cultural perspectives (Thais)</p>
<p>Caring for the seriously mentally ill in Thailand: Buddhist family caregiving</p> <p>(Sethabouppha & Kane, 2005)</p>	N = 15	Individual interviews	<p>Phenomenological qualitative analysis</p> <p>(including a 'multi-step analysis' as described by Cohen <i>et al.</i>, 2000)</p>	<ul style="list-style-type: none"> • Caregiving is Buddhist belief • Caregiving is management • Caregiving is acceptance • Caregiving is suffering 	<p>Although the suffering from the problems posed by mental illness permeated their lives, these caregivers were able to maintain compassion, management and acceptance in caregiving to their relatives.</p>	<p>Excluded from further discussion: focus on cultural perspectives (Thai Buddhists)</p>

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Article and Author	Sample	Method of data collection	Method of data analysis	Key themes identified	Key findings	Particularly relevant to this research?
Developing services for the carers of young adults with early-onset psychosis – listening to their experiences and needs (Sin, Moone & Wellman, 2005)	N = 11	Individual interviews	Responsive reader method (Sherblom <i>et al.</i> , 1993; Porter, 2000)	<ul style="list-style-type: none"> • Living together • Caring extensively and intensively • Knowing and caring • The search for normalizing activities • Support in caring • Adjusting to the caring role 	All carers were providing a comprehensive range of practical, emotional and financial support for their relative, including initiating and sustaining engagement between them and local mental health services.	Included for further discussion
Experience of being a spouse/cohabitant of a person with bipolar affective disorder: a cumulative process over time (Trånvag & Kristoffersen, 2008)	N = 8	Individual interviews	Phenomenological-hermeneutic method (Lindseth & Norberg, 2004)	<ul style="list-style-type: none"> • Fear • Accusations • Self-doubt and doubt about one's judgement • Care and information Vs being overlooked by health personnel • Stigmatization and loss of social network • Uncertainty, powerlessness and hope • Loneliness • Anger and despair • The persistent threat • Own health problems • Grief over loss • Dawning acceptance • Reconciliation • New hope 	A theoretical understanding using Gestalt therapy theory suggests that burdensome experience can be seen as an inner-imbalance in the spouse/cohabitant if meaning cannot be found in their experiences. Insight and meaning can protect them from burdensome experiences and nurses can empower them through care, health-promotion, education and guidance.	Included for further discussion

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Article and Author	Sample	Method of data collection	Method of data analysis	Key themes identified	Key findings	Particularly relevant to this research?
<p>The experience of caring for an adult child with schizophrenia</p> <p>(Tuck, du Mont, Evans & Shupe, 1997)</p>	<p>N = 9</p>	<p>Individual interviews</p>	<p>Phenomenological methodology</p> <p>(Giorgi, 1970; Spiegelberg, 1976; Colaizzi, 1978; Tuck,1995)</p>	<ul style="list-style-type: none"> • The temporal life world • Struggling to frame events as normal • Seeking help • Transformation of the loved child • Living with constantly changing levels of hope • Endless caring • Gathering personal meaning • Preserving identity • Knowing 	<p>Findings suggest the diagnosis of schizophrenia in a child is experienced by the parent as a destructive force that interrupts and radically transforms the normative family life trajectory. The experience is characterized as grief-filled, involving the loss of the imagined, idealized child and a transformation of the physically present child into a needy stranger. Dissatisfaction with initial mental health evaluations suggests a change to current practices could be beneficial.</p>	<p>Included for further discussion</p>

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Article and Author	Sample	Method of data collection	Method of data analysis	Key themes identified	Key findings	Particularly relevant to this research?
Understanding the impact of an Assertive Outreach Team on couples caring for adult children with psychosis (Wane, Larkin, Earl-Gray & Smith, 2009)	N = 6 (three couples)	Individual interviews	Interpretative phenomenological analysis (Smith, 1996)	Inclusion: <ul style="list-style-type: none"> • Relief • Feeling valued as a carer; having access to the team • Receiving family-focused interventions • Improving family relationships Ambiguity: <ul style="list-style-type: none"> • Insecure relationships with team members • Lack of appropriately targeted information and support • Worries about contacting the team • Making a better life; fear for the future 	Carers had felt painfully excluded from their parental roles – both by their children and by services. Different needs and concerns were expressed not only between, but also within couples. Changing roles and relationships in families were related to what families wanted from services. Engagement with systemic ways of working – may have benefits to the development of Assertive Outreach services.	Excluded from further discussion: focus on mental health service model
'I'm not an outsider, I'm his mother!' A phenomenological enquiry into carer experiences of exclusion from acute psychiatric settings (Wilkinson & McAndrew, 2008)	N = 4	Individual interviews	Hermeneutic-phenomenological approach (Van Manen, 1990)	<ul style="list-style-type: none"> • Powerlessness • Feeling isolated • A need to be recognized and valued • A desire for partnership 	Findings reflect carers' views in other studies, identifying a desire to work in partnership with health-care professionals but often feeling excluded at a clinical level. Consideration of improving carer involvement.	Excluded from further discussion: focus on mental health service model

Appendix 2

Links to Chapter 3: Literature Review: Exploring the meaning of the caring experience

Summary of phenomenological papers specifically exploring the lived experience of caring for somebody experiencing mental health difficulties identified within the literature review considered in terms of Yardley's (2000) principles for assessing the quality of qualitative research.

Article and Author	Sensitivity to context e.g. appropriateness of method; awareness of existing literature; compelling and convincing; participant extracts	Commitment and rigour e.g. commitment through sensitivity to context; appropriateness of sample; completeness of analysis	Transparency and coherence e.g. clarity of research process stages; inclusion of interview schedule (or sample); details of interviews; analytic process outlined; coherent story	Impact and importance e.g. does it tell us something interesting, important or useful?
Caring and daily life: Occupational experiences of women living with sons diagnosed with schizophrenia (Chaffey & Fossey, 2004)	Thematic analysis – rationale given for choosing a qualitative approach, particularly lived experience. Good evaluation of relevant literature and how this research contributes to the field.	Broad details of inclusion criteria given. Demographic details of participants included. Homogeneity – mothers of sons diagnosed with schizophrenia. Use of field journal to enhance analysis noted. Themes briefly outlined and quotes used throughout.	Details of interview schedule referenced and process given. Analytical framework broadly outlined and referenced. Coherent set of themes and relevant discussion. Implications and limitations considered.	Noted as being particularly relevant to occupational therapy research. Contributes to argument for effective partnership working between families and mental health professionals.
Being there for another with a serious mental illness (Champlin, 2009)	Descriptive phenomenological approach – rationale given for choosing a phenomenological approach. Brief evaluation of the extant literature and gap for this study highlighted.	Broad details of recruitment process given. Inclusion criteria and demographic details given. Homogeneity – clear breakdown given of fathers, mothers, spouses and close friends. Themes outlined and relevant lengthy quotes used throughout.	Interview schedule not provided. Analytical framework briefly outlined and referenced. Coherent set of themes discussed in relation to relevant theoretical frameworks. Limitations and implications considered.	Aims to explore the idea of 'being there' in the caring relationship, stressing the carer perspective. Relevant to community intended for.

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Article and Author	Sensitivity to context	Commitment and rigour	Transparency and coherence	Impact and importance
<p>Help-seeking for parents of individuals experiencing a first episode of schizophrenia</p> <p>(Czuchta & McCay, 2001)</p>	<p>Thematic analysis – no clear rationale given. A small subset of a prior quantitative study population recruited for qualitative component – greater focus on quantitative component.</p> <p>Evaluation of relevant literature and purpose of study given.</p>	<p>Recruitment criteria and overall sample demographic details provided but no specific details on those who also took part in the qualitative component (n = 5 of 20 participants in total).</p> <p>Homogeneity – parents of individuals experiencing first episode psychosis. Use of field notes and observations noted. Themes briefly outlined, all refer to examples from the data but not all employ direct quotes.</p>	<p>Interview schedule not provided. Analytical framework very briefly outlined and referenced.</p> <p>Some discussion of what both the qualitative and quantitative findings suggest.</p> <p>Brief mention of limitations and implications. Does not seem particularly strong in detailing the rationale for or analysis of qualitative work.</p>	<p>Aims to understand experiences of parental help-seeking through triangulated methods.</p> <p>Relevant to community intended for but focus seems to be more on the quantitative than qualitative components of this study.</p>
<p>Couples' experiences of the support process in depression: A phenomenological analysis</p> <p>(Harris, Pistrang & Barker, 2006)</p>	<p>Interpretative phenomenological analysis – rationale given. Relevant literature reviewed and gap for this research identified with clear clinical implications in mind from the start.</p>	<p>Recruitment process and inclusion criteria are clearly stated. Demographic details given. Homogeneity – couples (where one person experiences depression) covering a varied range of length of relationship.</p> <p>Themes are clearly divided into two domains – a clear and coherent story is presented.</p>	<p>Areas covered by the interview schedule outlined. Details of the interview process given. Analytical framework outlined and referenced and 'credibility' is discussed. Limitations. Implications and directions for future research are discussed.</p>	<p>Full discussion of the themes identified in the context of the literature. Relevant to the community intended for.</p> <p>Highlights the importance of including partners in psychological interventions for depression.</p>

Continued...

Article and Author	Sensitivity to context	Commitment and rigour	Transparency and coherence	Impact and importance
<p>“How much more can we lose?”: carer and family perspectives on living with a person with depression</p> <p>(Hightet, McNair, Davenport & Hickie, 2004)</p>	<p>Thematic analysis utilising the QSR NU*DIST computer software package – no clear rationale given for choosing this method though it is relevant for the topic under investigation.</p> <p>Brief consideration of the literature and purpose for the research stated.</p>	<p>Inclusion criteria are given and demographic details provided. Average details are given for the composition of the focus groups that were held. Homogeneity – carers, partners and family members caring for a person experiencing unipolar depression. Themes are coherent but briefly presented and use of quotes is limited to short bullet points of one sentence with only a couple of longer extracts.</p>	<p>The ‘six stem questions’ that were asked of each focus group are presented. Brief details of the focus group process are given. Reference is made to the software used to analyse the data but theoretical underpinnings are not explored.</p>	<p>Discussion is brief but does make links with relevant literature. Implications for medical education are discussed. Relevant to the community intended for, particularly in terms of highlighting family perspectives and encouraging further reading.</p>
<p>The experiences of fathers of adult children with schizophrenia</p> <p>(Howard, 1997)</p>	<p>Constant comparative method – appropriate but no clear rationale given by the author. Consideration of relevant literature but perhaps more could have been made of the position of this study.</p>	<p>Inclusion criteria are stated and demographic details given for both the fathers (interviewees) and their children with schizophrenia (cared for). Homogeneity – fathers of a child 18 years or older with a diagnosis of schizophrenia. Themes are coherent but quotations are not clearly set out throughout, often appearing as short sentences embedded within the text.</p>	<p>The development of an interview guide is described and sample questions given. The interview procedure is outlined. The data analysis process is outlined but no reference is made to its theoretical underpinnings.</p>	<p>The experience of fathers is linked to that of mothers in similar situations. Relevant to the intended community, particularly concerning interventions aimed at helping fathers.</p> <p style="text-align: right;">Continued...</p>

Article and Author	Sensitivity to context	Commitment and rigour	Transparency and coherence	Impact and importance
<p>Caring for a family member with chronic mental illness</p> <p>(Jeon & Madjar, 1998)</p>	<p>Hermeneutic-phenomenological method – rationale and reference given. Literature review presented as introduction and background to the present study. Rationale given in context of previous work.</p>	<p>Recruitment and demographic details given. Homogeneity – family carers caring for a relative with chronic mental illness over a range of time periods. Overarching interrelated themes are identified and tell a coherent story and quotes are used throughout.</p>	<p>Interview schedule not provided but it is noted that a preliminary analysis of initial interviews was used to generate issues for clarification and further questions in follow-up interviews. The analytical framework used is briefly outlined and referenced. No real discussion of the limitations of this work.</p>	<p>Links to relationships with professionals and clinical practice are drawn. Relevant to intended community, adding to the literature aimed at directing nursing practice.</p>
<p>Can parental responses to adult children with schizophrenia be conceptualized in terms of loss and grief? A case study analysis</p> <p>(Osborne & Coyle, 2002)</p>	<p>Interpretative phenomenological analysis – rationale and reference given. Relevant literature reviewed and the aims of the present study clearly stated.</p>	<p>Recruitment details are given and demographic details are given with each case study. Homogeneity – parents of people who had been diagnosed with schizophrenia. Each case study is explored for individual themes in the context of loss.</p>	<p>Interview schedule not provided but it is noted that it was designed explore responses to the condition and whether they experienced it in terms of loss. Interview procedure noted. The analytical framework used is described, discussed and referenced. Limitations, theoretical implications and implications for counselling psychology practice are discussed.</p>	<p>Particularly relevant to counselling psychology but interest extends beyond this to other mental health fields.</p>

Continued...

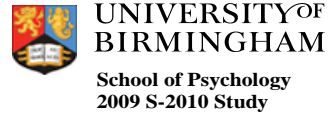
Article and Author	Sensitivity to context	Commitment and rigour	Transparency and coherence	Impact and importance
<p>Being a parent of an adult son or daughter with severe mental illness receiving professional care</p> <p>(Pejlert, 2001)</p>	<p>Phenomenological-hermeneutic approach – brief rationale and references given. Relevant literature reviewed with the ‘meaning of mental illness’ identified as an area covered by few studies.</p>	<p>Recruitment criteria and demographic details given. Homogeneity – parents of an adult child living in a group dwelling. Themes are clearly presented, coherent but with quotes embedded in the text – a table is also used to show how meaning units were used to generate themes.</p>	<p>Interview schedule not given – is noted that parents were asked to narrate their relationship with their child. Interview procedure details are briefly noted. The analytical framework is referenced and the reader is taken through ‘naive reading’, ‘first, second and third structural analyses’ before being presented with the themes. Critical considerations of the study are considered.</p>	<p>Relevant to the intended population, encouraging better relationships between families and professionals.</p>
<p>Developing services for the carers of young adults with early-onset psychosis – listening to their experiences and needs</p> <p>(Sin, Moone & Wellman, 2005)</p>	<p>Phenomenological approach – although the approach is briefly outlined and referenced, there seems to be no real rationale provided though it seems appropriate for the topic under investigation.</p>	<p>Recruitment criteria are outlined. Demographic details are provided for both carers (interviewees) and the ‘cared for’ service-users. Homogeneity – carers (parents) of young adults with early onset psychosis. Themes are clearly presented and coherent, using extended quotes throughout.</p>	<p>Interview schedule not given – it is noted that the interviews aimed to explore carers’ opinions about what they felt would best sustain them in their caring role. The analytical framework is briefly outlined and referenced. Limitations and implications for clinical practice are considered.</p>	<p>It is noted that the themes generated are similar to a number of previous studies on the experiences of carers. Relevant to the intended population, highlighting practical needs of families that services should seek to address.</p> <p style="text-align: right;">Continued...</p>

Article and Author	Sensitivity to context	Commitment and rigour	Transparency and coherence	Impact and importance
<p>Experience of being a spouse/cohabitant of a person with bipolar affective disorder: a cumulative process over time</p> <p>(Trånvag & Kristoffersen, 2008))</p>	<p>Phenomenological-hermeneutic approach - method and relevance outlined and referenced.</p>	<p>Recruitment criteria and detailed demographic information given. Homogeneity – spouses/cohabitees of a person with bipolar disorder. A number of short, concise themes, briefly outlined and illustrated with an extended quote. These themes are organised into a cumulative process model.</p>	<p>Main question in the interview guide given. The analytical framework is clearly outlined in relation to the research design. Methodological considerations are discussed. Limitations and implications for practice and further research are discussed.</p>	<p>Particularly relevant to nursing, but also relevant to other mental health fields.</p>
<p>The experience of caring for an adult child with schizophrenia</p> <p>(Tuck, du Mont, Evans & Shupe, 1997)</p>	<p>Phenomenological methodology – specific authors are referenced as guiding the study.</p>	<p>Sampling method and recruitment criteria are outlined. Demographic details are given. Homogeneity – carers of an adult child with schizophrenia. Themes present a coherent story and are illustrated with extended quotes.</p>	<p>The key interview question is given and the fact that additional probes were used noted. The analytical framework is detailed as a set of 12-steps and the process of analysis is briefly outlined. Implications for practice and future research are considered. No real discussion of the limitations of this work.</p>	<p>Relevant to the intended community, particularly with regard to community-based family-centred mental health care.</p>

Appendix 3

Links to Chapter 5: Carers' experiences of caring and mental health difficulties – Participant advertisement poster.

This poster was sent out to carers' support groups across the English Midlands, UK, to advertise this research to potential participants. For distribution, the poster was printed full-size A4, on white paper.



- Do you care for somebody experiencing mental illness?
- Would you be interested in taking part in a research study?
- Would you like to talk about your experiences of supporting and caring for somebody with mental illness?
- Would you like to participate in a small group discussion with other carers?



I am looking for five carers to take part in a small group discussion about the experience of caring for somebody who is mentally unwell.

Discussion group to be held on[Date/time] at[Location]

There is no obligation to take part if you change your mind after contacting me. If you are unable to attend on this date but are still interested in taking part in this research please contact me as I will be running other groups.

If you would like to know more about this study please contact the researcher



Please take a tear-off slip below:

Four identical tear-off slips are shown, each containing the following text and a bar chart:

Research Study: Exploring the meaning of caring
Would you like to take part in a focus group to talk about your experience of caring for somebody who is mentally unwell?

Appendix 4

Links to Chapter 5: Carers' experiences of caring and mental health difficulties – Participant advertisement leaflet.

This leaflet was sent out to carers' support groups across the English Midlands, UK, to advertise this research to potential participants. For distribution, the leaflet was, double-side printed on coloured paper, full A4 size (landscape presentation), and presented as a tri-fold information leaflet.

Side 1:

- Do you care for somebody experiencing mental illness?

- Would you be interested in taking part in a research study?

- Would you like to talk about your experiences of supporting and caring for somebody with mental illness?

- Would you like to participate in a small group discussion with other carers?

Discussion groups to be held on:

[Insert Date & Time]
or
[Insert Date & Time]
or
[Insert Date & Time]
or
[Insert Date & Time]
at the
University of Birmingham
You only need attend one group.

If you are unable to attend on these dates but are still interested in taking part in this project please contact me as I will be running other groups.

There is no obligation to take part if you change your mind after contacting me.

Appendix 4


Contact details:

Michelle Palmer
Doctoral Researcher

[Redacted]
[Redacted]
[Redacted]
[Redacted]
[Redacted]
[Redacted]


This project is being supervised by:

Dr. Michael Larkin
Senior Lecturer

[Redacted]
[Redacted]
[Redacted]
[Redacted]
[Redacted]

INFORMATION LEAFLET

**Research Project:
Exploring the
meaning of
caring**

Researcher: Michelle Palmer



I am looking for five carers to take part in a small group discussion about the experience of supporting and caring for somebody who is mentally unwell

Research Study 2009



Links to Chapter 5: Carers' experiences of caring and mental health difficulties – Participant advertisement leaflet.

This leaflet was sent out to carers' support groups across the English Midlands, UK, to advertise this research to potential participants. For distribution, the leaflet was, double-side printed on coloured paper, full A4 size (landscape presentation), and presented as a tri-fold information leaflet.

Side 2:

Research Project: Exploring the meaning of caring

What is the project about?

The aim of this research is to explore the experience of caring for somebody who is mentally unwell. The purpose of this research is to support the development of mental health services which are better able to support service users, their families and friends.

Who can take part?

I am looking for people who support and care for people with severe and enduring mental illness, particularly, depression, bi-polar disorder or psychosis, on an informal basis — that is, you are not employed to support the person you care for. The person you care for might be a family member or a friend.

What will I have to do?

You will be invited to attend a small group discussion with three or four other carers who, like yourself, have responded to this leaflet. The group will be informal and will involve me asking you about your experiences of caring for somebody who is affected by mental illness.

I am interested to hear about when you first came across the word 'carer' in relation to yourself and the impact this has had on your daily life. The group discussion will take about 60-minutes.

What will happen to the information?

The group discussion will be recorded and then what was said will be written down. I will not use anybody's real name in the written copy to protect your identity. The audio-recordings and the written copies will be kept secure and destroyed once the study has ended.

The discussion will be studied with the aim of learning about carers' experiences of caring for and supporting people with mental illness. The results will be reported in a thesis, presented to the University of Birmingham, and in a professional journal. The results will also be made available to everyone who takes part in the project.

Will the things I say be kept private?

When I write about the discussion all names will be changed (yours and anybody you talk about). The written copy of the discussion will be looked at by me and relevant research staff at the University of Birmingham to make sure that what I present is a fair and reasonable account of what was said. I am also required to share the content of our discussion if I am concerned that you or anybody else may be at risk of harm.

Direct quotes of things you have said may be used in the write-up but these will not identify anybody who took part.

What happens if I do not want to take part?

You do not have to take part if you do not want to. If you choose to take part and change your mind before or during taking part in the discussion, you are free to say that you no longer want to take part. You do not have to give a reason for withdrawing from the project.

You will also have the opportunity to withdraw either all of your comments, or specific comments, from further study up to two-weeks after the discussion has taken place. Any data you withdraw will be destroyed.

Expenses and payments

Arrangements are in place for you to receive reimbursement for any travel expenses incurred by participating in this research.

What if I have any questions?

At any time during the research you can contact the researcher—Michelle Palmer

What happens next if I choose to take part?

If you would like to take part in this project, or would like further information, please contact Michelle Palmer. Contact details are provided on the back of this leaflet.

Who is the researcher?

My name is Michelle Palmer and I am a doctoral researcher at the University of Birmingham. I have clearance from the Criminal Records Bureau to work with children and vulnerable adults. This research is being carried out in collaboration with Dr Michael Larkin, Senior Lecturer at the University. This research has been approved by the [redacted]

[redacted] This research is funded by the Economic and Social Research Council.

Thank you for taking the time to read through this leaflet

Appendix 5

Links to Chapter 5: Carers' experiences of caring and mental health difficulties – Participant information sheet.

This participant information sheet was sent out to those who expressed an interest in taking part in this research. For distribution, the information sheet was printed full-size A4, double-side printed on white paper.

UNIVERSITY OF
BIRMINGHAM
School of Psychology

PARTICIPANT INFORMATION SHEET

Title of Project: Exploring the meaning of caring
Researcher: Michelle Palmer

I would like to invite you to take part in a research study. Before you decide you need to understand why this research is being done and what it would involve for you. Please take the time to read through the following information carefully. Talk to others about the study if you wish. If there is anything that is not clear, or if you would like more information please contact me, Michelle Palmer (see details below), and I will be happy to discuss the research with you. Take time to decide whether or not you wish to take part.

- **What is the purpose of this research?**

The aim of this research is to explore how carers of people experiencing mental health difficulties respond to taking on a caring role. The purpose of this research is to support the development of mental health services which are better able to support service-users, their families and friends. I will also be inviting a number of families and other carers affected by mental illness to participate in this research.

- **Why have I been invited to take part?**

You have been invited to take part because you are in a caring role for a person affected by mental illness. It is up to you if you want to take part. It is hoped that nine other carers will also take part in this research study. All participants in this research will be recruited, as you were, via advertisement posters. This information sheet is for you to keep and I will discuss the study with you in detail before you make your decision.

- **What would be involved?**

If you agree to take part we will then arrange to have a research interview. The interview will be quite informal and will involve me asking you to tell me about your experience of caring for somebody affected by mental illness. I am interested to hear about the impact that taking on a caring role has had on your daily life. The interview will be held at a time and in a location that you are happy with (most likely: your own home or the University of Birmingham) and will last for approximately 60 minutes.

When we meet for the research interview I will ask you to fill in a consent form to say that you agree to participate in this research. I will also ask you to complete a brief questionnaire to record some basic details such as: your relationship to the person you care for (e.g. parent, sibling, friend etc.), and length of time spent in a caring role. This is so that I can present a general picture of who took part in the research when it is written-up. This information will not be used to identify any individual.

- **What will happen to the information?**

With your permission, I will audio-record our discussion. After the interview I will make a detailed written copy of what was said (a transcript) which will be used when analysing all the data collected for this study. I will then write a report which will be assessed as part of my PhD. I would be happy to send you a research summary of the findings if you would like to receive this. Access to the entire research project may be arranged through the University of Birmingham. I also hope to write articles for scientific journals and to give presentations to carers groups and mental health professionals to raise awareness of this research.

[Please turn over]

- **Will the things we say be kept private?**

When I create the transcript, I will change your names and the names of anybody else that you mention. The transcripts will be looked at by myself and relevant research staff at the University of Birmingham to ensure that the analysis is a fair and reasonable representation of the data. Direct quotes may be used in the write-up or publication of results but these will not identify any carers as participants in this research. The original recordings will be kept in a secure place at the University of Birmingham. These will be destroyed once the study has ended. All information collected will adhere to ethical and legal practice and all information about you will be handled in confidence.

- **What will happen if I do not want to carry on with the study?**

If you do agree to take part you will be free to withdraw at any time prior-to or during the research interview, without giving a reason. Once the research interview has taken place you will have a further two-week period for reflection. After this time, I will contact you again and you will be given the opportunity to withdraw either all or part of your interview data. Again, at this stage you can withdraw your data without giving a reason. Any data that you withdraw will not be used in the analysis or write-up of this research and will be destroyed immediately.

- **Expenses and payments**

Arrangements are in place for you to receive reimbursement for any travel expenses incurred by participating in this research (e.g. travel to interview). Should you choose to withdraw from the study you will still be reimbursed for any travel expenses incurred.

- **Who is the researcher?**

My name is Michelle Palmer and I am a doctoral researcher at the University of Birmingham. I have clearance from the Criminal Records Bureau to work with children and vulnerable adults. This research is being carried out in collaboration with Dr Michael Larkin, a senior lecturer at the University. All research at the University is looked at by independent group of people, called a Research Ethics Committee to protect your safety, rights, wellbeing and dignity. This study has been reviewed and given favourable opinion by the [REDACTED]. My research is funded by the Economic and Social Research Council.

Thank you for taking the time to consider this research study. If you think you might be interested in taking part please contact me to discuss the research in more detail. We can discuss the study over the telephone and I am happy to arrange a personal visit if you feel this would be beneficial. You can contact me at any time on: Tel: [REDACTED] or Email: [REDACTED]

Appendix 6

Links to Chapters 5 and 8: Protocol for using interpretative phenomenological analysis with focus group data. For further explanation of its development see full article (Palmer, Larkin, de Visser & Fadden, 2010).

<p>1. Experiential Claims a. Pick out experiential claims and concerns as they appear in the transcript. b. Summarise these, and sort into emergent patterns.</p> <p>2. Positionality a. Explore the role played by facilitators, keeping track of questions, permissions, encouragements, redirections etc. (What is their perspective, stance, position?) b. Explore the function of statements made by respondents. (What is their perspective, stance?)</p> <p>3. Roles & Relationships a. Examine references to other people: What roles and relationships are described? What sorts of meanings and expectations are attributed to these relationships? b. What are understood to be the consequences of these?</p> <p>4. Organisations & Systems a. Examine references to organisations and systems: How are they described? What sorts of meanings and expectations are attributed to these? b. What are understood to be the consequences of these?</p> <p>5. Stories Examine the stories told by participants: look at the structure; genre; imagery and tone. What does each story achieve? How do participants support or impede each other to share their experiences? What temporal referents exist?</p>	<p>6. Language Throughout stages 1-5, monitor language use, paying particular attention to use of metaphor, euphemism, idiom etc. Consider: a. Patterns Repetition, jargon, stand-out words and phrases, turn-taking, prompting – are these identified in individuals or the whole group? b. Context Impact on language used; descriptions of feelings/emotive language; jargon and explanation of technical terms; impact of facilitator c. Function How/why is certain language being used? (e.g. to emphasise/ back-up a point, to shock, to provoke dis/agreement, to amuse/lighten the tone?)</p>
<p>7. Adaptation of Emergent Themes Return to the emergent themes from step 1b. and adapt them according to the work done subsequently. Answering the following questions will help:</p> <ol style="list-style-type: none"> What experiences are being shared? What are individuals doing by sharing their experiences? How are they making those things meaningful to one another? What are they doing as a group? What are the consensus issues? Where is there conflict? How is this being managed/resolved? 	
<p>8. Integration of Multiple Cases Where more than one focus group has taken place integrate work done with each to build up an overall analysis of the topic under investigation. Data should be checked to ensure sufficient homogeneity between focus groups to allow for successful integration. To draw the analysis to completion:</p> <ol style="list-style-type: none"> Pick out commonalities and stand-out differences between groups drawing out superordinate themes. Frequently revisit the transcripts to check themes in relation to original claims made to help ensure accuracy. Consider the analysis in the wider context of existing relevant theories, models and explanations. 	

Appendix 7

Links to Chapter 5: Carers' experiences of caring and mental health difficulties – Extract illustrating data analysis.

This extract shows part of the transcript from one of the carers' focus groups (Group 1). It provides a brief snapshot of the initial coding process for the first stages of data analysis using interpretative phenomenological analysis.

Participant	Example of participant data from transcript	Initial coding
Theresa	Well for me it was very easy because I took up nursing in any case, so, you're a carer, once you do that, but I was just saying to this gentleman that the difficulty you have in getting it across to people that they are carers, is if you've got, say an elderly person who needs a certain amount of attention, the next door neighbour's handy and helpful and friendly, comes across, then one day I turn round to someone and said, 'you're a carer', she says, 'no I'm not'. I said, 'yes you are my love, you go in the morning, you see that she's got her tea, you see her during the day, give her a hand when she's having a bath and sort of make sure...'	Identifying carers – easy. Links to professional/vocational role – nursing. Old age – support needs. Neighbours. Handy, helpful, friendly = caring. Identifying others. Potential for dispute/conflict.
F	Yeah	<i>Carer – if not that, then what?</i>
Theresa	'That's not being a carer' [in the tone of other woman speaking], so, okay, what is being a carer?	Somebody who assists – <i>inclusive</i>
Edward	Somebody who assists in any way shape or form, you know	Potential for <u>dispute/conflict</u>
Theresa	It doesn't come across like that to some people	[Edward in agreement with Theresa]
Edward	No, no	Caring for a son - "had to". Unexpected. Confusion, no idea.
Nick	We had to care for a son who had started first year at university and [early on] he just arrived home one weekend and he was clearly very ill, erm, psychotic illness, and we didn't understand it at first, we'd no idea...	[Theresa in agreement with Nick]
Theresa	No	"Obviously bemused", confusion. Journey of learning.
Nick	...but he landed on us at home, we were obviously bemused by it all and bewildered, and we started on the long train, this was about twenty-five years ago, he's [much older] now, erm, on the long train of learning about medication, you know, what he should do, shouldn't do, you know, the benefits system, the whole thing of caring...	

Appendix 8

Links to Chapter 6: Service-users' and carers' experiences of first-episode psychosis – Extract illustrating data analysis.

This extract shows part of the transcript from one of the carer participants' written emotional disclosure data. It provides a brief snapshot of the initial coding process and development of emergent themes derived from the data using interpretative phenomenological analysis.

Emergent themes	Example of participant data from written emotional disclosure account	Initial coding
<p>Changes to family relationships (“we’d had some bad times leading up to this”).</p> <p>[Engagement with data collection method].</p> <p>Concerns with changes to family relationships – betrayal, disappointment, had loved.</p> <p>Visualisations of the ‘old’ innocent child contrasted with the ‘new’ dark, aggressive son.</p>	<p>D Day, Judgement Day, Armageddon, the End of the World, the most awful day of my life, so far, happened on [date]. The day that [my son] was sectioned under the mental health Act. Oh yes, we had had some bad times leading up to this dreadful day, but nothing could have prepared me for the awfulness of seeing my eldest son go mad.</p> <p>Just writing this paragraph has me crying because I’m there again, sitting in the room at the [clinic] with my [family members], a nurse and [my son]. I can see him now – he thought he was a vampire. He was totally uninhibited... But do you know what I remembered the most – he had been evicted from his hostel and was stressed about where he would live and when the nurse told him she would find him somewhere, he asked if there would be a plant on the windowsill. All the time we all knew he was going to be sent to a secure unit with all his freedom and possessions removed. We betrayed him. I let him down, this was my lovely blond haired first born whom I had loved so much. We gave him everything we could but he turned against me... He brought darkness, depravity and drugs into our home and became aggressive to me and his [siblings].</p> <p>[Data have been edited to protect anonymity]</p>	<p>“The <i>most</i> awful day of my life <i>so far</i>” – expectation that things could get worse? Extremely emotional.</p> <p>Build up over time, leading up to this. Nothing could have prepared me for the awfulness Witnessing ‘madness’ – characterisation of psychological distress. [Emotional reaction to the writing task] – getting ‘experience close’, reliving the awfulness. Visualisation of the scene.</p> <p>Remembrance of something seemingly insignificant in the scheme of things [son’s concerns about having a pot plant]. Idea that ‘we knew something he didn’t’. Positioning the family as having a greater understanding of the enormity of the situation. Betrayal and let down – contrasted with love and visions of her son as an innocent child. Darkness, depravity and aggression [not the norm]</p>

Appendix 9

Links to Chapter 7: A family's experiences of being affected by mental health difficulties – Participant information sheet.

This participant information sheet was sent out to families that expressed an interest in taking part in this research. For distribution, the information sheet was printed full-size A4, and printed on white paper.

PARTICIPANT INFORMATION SHEET

UNIVERSITY OF
BIRMINGHAM

School of Psychology

Title of Project: Exploring the meaning of caring

Researcher: Michelle Palmer

I would like to invite your family to take part in a research study. Before you decide, it is important for you to understand why this research is being done and what it would involve for you all. Please take the time to read through the following information carefully and to discuss it as a family. A separate information sheet is available for younger family members to read. Talk to others about the study if you wish. Take time to decide whether or not you wish to take part.

- **What is the purpose of this research?**

The aim of this research is to explore how families respond when a family member is affected by mental illness. The purpose of this research is to encourage the development of mental health services which are better able to support service-users, their families and friends.

- **Why has our family been invited to take part?**

You have been invited to take part because a member of your family has been directly affected by mental illness. Your family has been identified through your contact with mental health services. I am hoping to carry out this research with at least three members of your family (including the person who experiences mental illness). It is up to you as a family if you want to take part. Participation should be voluntary for all family members. It is hoped that four other families will also take part in this study. This information sheet is for you to keep and I will discuss the study with you in detail before you make your decision.

- **What would be involved?**

Individual research interviews between each family member and myself. All interviews will be quite informal. I will ask you to tell me about your experience of being part of a family where a member experiences mental illness. This will include questions like: how did you become involved with mental health services?; and how has family life changed? Each interview will be held at a time and place that you are happy with (e.g. your own home, the University of Birmingham, or a local NHS site).

Each interview will last for approximately 60 minutes. It is hoped that each family member will take part in two interviews in total. The second interview will be held 6-to-9-months after the first. Between the interviews your family will be asked to keep an informal diary of key events (e.g. birthdays, important family events, relapse etc.) in a notebook. The purpose of having two interviews and keeping a diary is to help me try to build up a detailed picture of how families respond and adapt to being affected by mental illness and how this changes over time and in relation to events in family life.

When we meet for the research interview I will ask you to fill in a consent form to say that you agree to participate in this research. I will also ask you to complete a brief questionnaire to record some basic

details such as: your role in the family, gender and age range. This is so that I can present a general picture of who took part in the research when it is written-up. This information will not be used to identify any individual or family.

- **What will happen to the information?**

With your permission, I will audio-record our discussions. After each interview I will make a detailed written copy each interview (a transcript) which will be used when analysing all the data collected for this study. I will then write a report which will be assessed as part of my PhD. I would be happy to send you a research summary of the findings if you would like to receive this. Access to the entire research project may be arranged through the University of Birmingham. I also hope to write articles for scientific journals and to give presentations to raise awareness of this research.

- **Will the things we say be kept private?**

When I create the transcript, I will change your names and the names of anybody else that you mention. The transcripts will be looked at by myself and relevant research staff at the University of Birmingham to ensure that the analysis is a fair and reasonable representation of the data. Direct quotes may be used in the write-up or publication of results but these will not identify any family members as participants in this research. The original recordings will be kept in a secure place at the University of Birmingham. These will be destroyed once the study has ended.

All information collected will adhere to ethical and legal practice and all information about you will be handled in confidence. However, parts of the data may be made available to the NHS team responsible for your, or your family member's care. This will only happen if any previously undisclosed issues of risk to you, or your family member's safety should be disclosed.

- **What will happen if any of us do not want to carry on with the study?**

If you do agree to take part you will be free to withdraw at any time before or during the research interviews, without giving a reason. This would not affect the standard of care that you or your family member receives. Once each research interview has taken place you will have a two-week period for reflection. After this time, I will contact you again and you will be given the opportunity to withdraw either all or part of your interview data. Again, at this stage you can withdraw your data without giving a reason. Any data that you withdraw will not be used in the analysis or write-up of this research and will be destroyed immediately.

- **Expenses and payments**

Arrangements are in place for you to receive reimbursement for any travel expenses incurred by participating in this research (e.g. travel to interviews). Should you choose to withdraw from the study you will still be reimbursed for any travel expenses incurred.

- **Who is the researcher?**

My name is Michelle Palmer and I am a doctoral researcher at the University of Birmingham. I have clearance from the Criminal Records Bureau to work with children and vulnerable adults. This research is being carried out in collaboration with Dr Michael Larkin, a senior lecturer at the University. All research in the NHS is looked at by independent group of people, called a Research Ethics Committee to protect your safety, rights, wellbeing and dignity. This study has been reviewed and given favourable opinion by [REDACTED]. My research is funded by the Economic and Social Research Council.

Thank you for taking the time to consider this research study. If you think you might be interested in taking part please contact me to discuss the research in more detail. We can discuss the study over the telephone and I am happy to arrange a personal visit if you feel this would be beneficial. You can contact me at any time on: Tel: [redacted] or Email: [redacted]

• **What happens next?**

Please fill in the tear-off slip below indicating whether or not at least three members of your family would like to take part.

If I have not heard from you within two weeks, I will ask [key worker mentioned in invite letter] to give you a call to check that you have received the information. Please do not feel under any pressure to take part, this will simply be a courtesy call to make sure you have received the information and been given the opportunity to take part.

Dear [name] family

I would be grateful if you could respond to this invite letter and information sheet in one of two ways:

1) Complete the tear-off slip below and return to me in the envelope provided

OR

2) Email me stating whether or not you would like to take part in this research (you can copy the wording from the tear-off slip below): [redacted]

It would help me if you could respond within two weeks of receiving this letter. If you are unsure about whether you want to take part, or completing this form, please contact me, or’s [service-user’s name] key worker [key worker’s name] for further assistance.

Yours sincerely

Michelle Palmer

.....Detach along this line

[Family name]

Please tick one statement below which best describes how your family feels about taking part in this research. Please return the slip in the envelope provided. Thank you.

Our family is interested in taking part in this research. Please contact us again to discuss the research and make arrangements for us to take part.

Our family is unsure about taking part in this research and would like more time to think about it. Please contact us again to discuss the research in more detail.

Our family is not interested in taking part in this research. Please do not contact us again.

Appendix 10

Links to Chapter 7: A family's experiences of being affected by mental health difficulties – Extract illustrating data analysis.

This extract illustrates the development of an emergent theme through the integration of participants' accounts. The ways in which caring and mental health difficulties have impacted on relationships within the family system are further explored within the wider context of the overall body of data.

Participant	Example of participant data from transcripts	Emergent theme
Geoff (L35-41)	...we used to do things, when we started we had a common purse and we used to go shopping together and quite... one of the things I had to do, um, I was employed and I, she said she, I felt I had to give up my job to look after her, and I, I missed out on early retirement because I was about a year too soon, um, and I had to claim, dependence on my wife, so the roles had to be reversed to get any income, so I claimed as her dependant...	Roles: reversal and replacement Geoff explicitly identified a fundamental change (role reversal) in his relationship with Sally (his wife) when he felt he had to give up his job to care for her.
Sally (L1011-1015)	...I happily left work for good, I mean I knew that I wasn't really fit to work, and I certainly didn't want to work when I had children, and so in that way it affected it, and I can remember thinking when I was nursing the babies, you know I loved the babies on [Ward], and I was thinking, the only way I can ever, sort of, replace my career is to have my own children...	Sally explicitly identified thinking about replacing her career (when she became too unwell to work) with having a family of her own.
Sally (L1138-1139)	Erm, and of course my daughter, she's really replaced my mum because I can pick up the phone and talk to my daughter or she'll come round and...	Sally explicitly identified Katy (her daughter) replacing her own mother (who has passed away) in terms of being able to pick up the phone and talk.
Katy (L819-820)	Er, well my dad said that I once had to bath my mum, which I don't remember, but if I did it would have been really embarrassing for me...	Katy talked about being reminded of a situation that described the roles between her and her mother (Sally) being reversed with the young Katy taking on a sort of parenting role for her own mother (the consequences of which were described as embarrassing).

Appendix 11

Links to Chapter 8: Mental health professionals' experiences of caring and mental health difficulties – Participant advertisement poster.

This poster was sent out to Early Intervention teams across the English Midlands, UK, to advertise this research to potential participants. For distribution, the poster was printed full-size A4, on white paper.



UNIVERSITY OF
BIRMINGHAM
School of Psychology
2009-2010 Study

Would you be interested in taking part in a research study?

Would you like to participate in a small group discussion with other mental health practitioners?

What is a carer?

How do you know who cares for your clients away from services?

How do you involve carers and families in the care you provide to your clients?

I am looking to recruit five mental health practitioners (from a range of teams) to take part in a small group discussion about how services identify and work with carers and families.


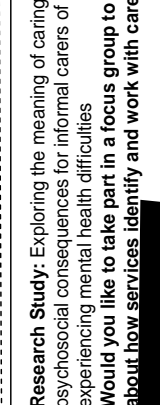
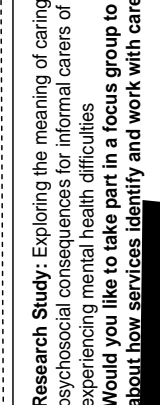
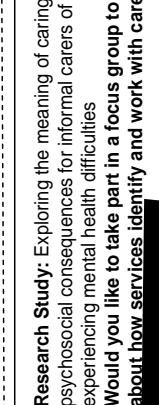
Focus group to be held on[Date] at[Location]

**Exploring the meaning of caring:
Psychosocial consequences for informal carers of people experiencing mental health difficulties**

If you would like to know more about this study please contact the researcher

Tel. [REDACTED]

[REDACTED], Edgbaston, Birmingham, B15 2TT

<p>Research Study: Exploring the meaning of caring: psychosocial consequences for informal carers of people experiencing mental health difficulties Would you like to take part in a focus group to talk about how services identify and work with carers?</p> 	<p>Research Study: Exploring the meaning of caring: psychosocial consequences for informal carers of people experiencing mental health difficulties Would you like to take part in a focus group to talk about how services identify and work with carers?</p> 	<p>Research Study: Exploring the meaning of caring: psychosocial consequences for informal carers of people experiencing mental health difficulties Would you like to take part in a focus group to talk about how services identify and work with carers?</p> 	<p>Research Study: Exploring the meaning of caring: psychosocial consequences for informal carers of people experiencing mental health difficulties Would you like to take part in a focus group to talk about how services identify and work with carers?</p> 
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Appendix 12

Links to Chapter 8: Mental health professionals' experiences of caring and mental health difficulties – Participant information sheet.

This participant information sheet was sent out to those who expressed an interest in taking part in this research. For distribution, the information sheet was printed full-size A4, and printed on white paper.

UNIVERSITY OF
BIRMINGHAM

School of Psychology

PARTICIPANT INFORMATION SHEET

Title of Project: Exploring the meaning of caring: psychosocial consequences for informal carers of people experiencing mental health difficulties

Researcher: Michelle Palmer

I would like to invite you to take part in a research study. Before you decide you need to understand why this research is being done and what it would involve for you. Please take the time to read through the following information carefully. Talk to others about the study if you wish. Take time to decide whether or not you wish to take part.

- **Who is the researcher?**

My name is Michelle Palmer and I am a doctoral researcher at the University of Birmingham. I have clearance from the Criminal Records Bureau to work with children and vulnerable adults. This research is being carried out in collaboration with Dr Michael Larkin, a senior lecturer at the University. All research in the NHS is looked at by independent group of people, called a Research Ethics Committee to protect your safety, rights, wellbeing and dignity. This study has been reviewed and given favourable opinion by [REDACTED]. My research is funded by the Economic and Social Research Council.

Thank you for taking the time to consider this research study. If you think you might be interested in taking part please contact me to discuss the research in more detail. We can discuss the study over the telephone and I am happy to arrange a personal visit if you feel this would be beneficial. You can contact me at any time on: Tel: [REDACTED] or Email: [REDACTED]

- **What is the purpose of this research?**

The aim of this research is to explore how mental health practitioners identify informal carers and how they perceive the role that they play in the lives of people experiencing mental illness. The purpose of this research is to support the development of mental health services which are better able to support service-users, their families and friends.

- **Why have I been invited to take part?**

You have been invited to take part because you are a mental health practitioner who is likely to be in contact with the carers and family members/friends of your clients. It is up to you if you want to take part. It is hoped that four other staff members will also take part in this research. This information sheet is for you to keep and I will discuss the study with you in detail before you make your decision.

- **What would be involved?**

You will be invited to attend a focus group with other staff members. The focus group will be quite informal and will involve me asking the group to tell me about their experience of working with carers and their perceptions of the language used by services in relation to carers. This will include questions like: is 'carer' an appropriate term?; and have you had any training in working with carers and families? The focus group will be held on[date] at[location] and will last for approximately 60 minutes.

When we meet for the focus group I will ask each of you to fill in a consent form to say that you agree to participate in this research. I will also ask you all to complete a brief questionnaire to record some basic details such as: your job role, length of time working in services, gender and age range. This is so that I can present a general picture of who took part in the research when it is written-up. This information will not be used to identify any individual.

- **What will happen to the information?**

With your permission, I will audio-record the discussion. After the focus group I will make a detailed written copy of it (a transcript) which will be used when analysing all the data collected for this study. I will then write a report which will be assessed as part of my PhD. I would be happy to send you a research summary of the findings if you would like to receive this. Access to the entire research project may be arranged through the University of Birmingham. I also hope to write articles for scientific journals and to give presentations to raise awareness of this research.

- **Will the things I say be kept private?**

When I create the transcript, I will change your name and the names of anybody else that you mention. The transcripts will be looked at by myself and relevant research staff at the University of Birmingham to ensure that the analysis is a fair and reasonable representation of the data. Direct quotes may be used in the write-up or publication of results but these will not identify you as a participant in this research. The original recording will be kept in a secure place at the University of Birmingham. This will be destroyed once the study has ended. All information collected will adhere to ethical and legal practice and all information about you will be handled in confidence.

- **What will happen if I do not want to carry on with the study?**

If you do agree to take part you will be free to withdraw at any time before or during the focus group, without giving a reason. This would not affect your position as a mental health practitioner. Once the focus group has taken place you will have a two-week period for reflection. After this time, I will contact you again and you will be given the opportunity to withdraw parts of your data. At this stage it will only be possible to withdraw specific comments you may have made. Due to group interaction it would be impossible to entirely withdraw your data at this point. Again, you can withdraw your data without giving a reason. Any data that you withdraw will not be used in the analysis or write-up of this research.

- **Expenses and payments**

Arrangements are in place for you to receive reimbursement for any travel expenses incurred by participating in this research (e.g. travel to interview). Should you choose to withdraw from the study you will still be reimbursed for any travel expenses incurred. However, it is not possible to reimburse you for any time that you may decide to take away from work to attend the focus group.

Appendix 13

Links to Chapter 8: Mental health professionals' experiences of caring and mental health difficulties – Extract illustrating data analysis.

This extract illustrates the way in which the protocol for using interpretative phenomenological analysis with focus group data (see Appendix 6) can be used to start thinking about the integration of multiple cases. Although brief, this example highlights the sense of clustering common concerns and differences between participants and groups.

1. Experiential claims	2. Positionality	3. Roles and relationships	4. Organisations and systems	5. Stories	6. Language
<p>Input into cared-for person's life and impact on own life.</p> <p>Distinctions between <i>caring</i> and <i>parenting</i>.</p> <p>Who's <i>really</i> caring?</p> <p>Labelling – impact on role reinforcement/ability to change.</p> <p>Developing meaningful relationships.</p> <p>Carers' assessments – engagement tools/statutory responsibilities.</p> <p>Carers' support groups - valuable.</p>	<p>Groups all tend to have one dominant participant: G1 – Liz G2 – Adele G3 – Nadia</p> <p>Importance of being able to share experiences with peers.</p> <p>Learning from others – sharing knowledge and expertise.</p> <p>Being part of formal and informal networks.</p>	<p>Key roles and relationships mentioned:</p> <p>Carers (specific relatives, friends, neighbours, anybody who offers support).</p> <p>Service-users (Early intervention approach, risk management).</p> <p>Family members and groups (individual family culture).</p> <p>Mental health team members (colleagues).</p> <p>Professionals working in other services.</p>	<p>Key organisations and systems mentioned:</p> <p>Early Intervention and Early Detection and Intervention teams (ethos of family work, inclusion and hope). Expectations of these things. Statutory responsibilities.</p> <p>Formalised learning and training opportunities.</p> <p>The 'system' – health and social care systems.</p> <p>Benefits system.</p> <p>Family systems – individual family culture and ways of relating.</p> <p>Carers' organisations.</p>	<p>Thinking about what a carer is, and what a carer does.</p> <p>Expectations of services – service-users', carers', professionals' and organisational expectations.</p> <p>Impact of labelling.</p> <p>Information sharing.</p> <p>Developing meaningful relationships with families and supporting relationships within family systems.</p>	<p>Metaphors used, e.g. engagement tools "it was like a carrot", professionals "having the keys to everything", Early Intervention services "taking a blanket view of carers", professionals performing "a balancing act".</p> <p>Formalised language and jargon used, e.g. over-medicalisation/pathologisation of circumstances, working to normalise the condition/family situation, 'EI'</p>