

Assistant, trainee and qualified psychologists' personal experiences of caring for others and the influence of caring on clinical practice.

Thesis submitted to the University of Hertfordshire in partial fulfilment of the requirements of the degree of Doctor of Clinical Psychology

Angela Burrows

Cohort 17: 13091440

January 2021

Word count: 33,694

(excluding abstract, tables, references and appendices)

ACKNOWLEDGEMENTS

To my participants, who trusted me to share their innermost thoughts, thank you for your openness and honesty.

To Dr Saskia Keville, Dr Claire Warner, Dr Becky Adlington and Dr Jennifer Heath thank you for your support and encouragement.

To Dr Ken Gannon and Lindsay Royan, thank you for supporting my learning and development.

To the peers, colleagues and supervisors who, in different ways, helped me to continue to move forwards.

To a great bunch of friends.

And to my partner and family, blended and loved, and most particularly to my aunt and to my brother, I dedicate this thesis.

Contents

Abstract	7
Chapter One: Introduction	9
1.1 My relationship to the topic	9
1.2 My epistemological position.....	10
1.3 Use of language	11
1.3.1 Mental health.....	12
1.3.2 Mental health distress.....	12
1.3.3 Mental health difficulties	13
1.3.4 Functional and organic mental health conditions	13
1.3.5 Neurodevelopmental conditions.....	15
1.3.6 Client and service user	15
1.3.7. Psychologist.....	15
1.3.8 Loved one and/or cared for	16
1.4 The context of caring in the UK	16
1.4.1 Identifying as a carer	18
1.4.2 Carers of people with functional and organic mental health difficulties	19
1.4.3 Carers of people with life limiting physical health conditions and disabilities	20
1.4.4 Factors affecting the caring dyad	22
1.4.5 Involvement of carers and service users/clients in NHS services, including training	23
1.5 The construction of empathy within clinical practice.....	24
1.6 Lived experiences	28
1.7 Literature search.....	30
1.7.1 Results	32
1.7.2 Synthesis of findings.....	38
1.7.3 Critical evaluation of literature.....	38
1.7.4 Summary of literature pertaining to the study area and the literature review.....	40
1.7.5 Research questions	42
Chapter Two: Methodology	43

PSYCHOLOGISTS' EXPERIENCES OF CARING FOR OTHERS

2.1 Overview.....	43
2.2 Choice of a qualitative design.....	43
2.2.1 Epistemological position	44
2.2.2 Consideration of qualitative methods.....	44
2.2.3 Choice of thematic analysis and its fit with my epistemological position	46
2.3 Participants.....	47
2.3.1 Inclusion and exclusion criteria	48
2.4 Ethical issues.....	54
2.4.1 Informed consent.....	56
2.4.2 Confidentiality.....	57
2.4.3 Consultation	57
2.5 Data collection.....	57
2.5.1 The interview schedule	57
2.5.2 The interview.....	58
2.6 Data analysis.....	59
2.6.1 Phase one: data familiarisation	59
2.6.2 Phase two: generating initial and overarching codes.....	60
2.6.3 Phase three: searching for themes	60
2.6.4 Phase four: reviewing themes.....	61
2.6.5 Phase five: defining and naming themes	61
2.6.6 Phase six: producing the report	63
2.7 Quality assurance	63
Chapter Three: Results.....	69
3.1 Overview.....	69
3.2 Theme one: Personal and professional roles.....	71
3.2.1: The professional context: mental health as a complex phenomenon	71
3.2.2 Subtheme: Opening up about mental health/distress as a professional	77
3.2.3 Subtheme: Questioning of the self.....	79
3.3 Theme two: The emergence of a carer identity	81

PSYCHOLOGISTS' EXPERIENCES OF CARING FOR OTHERS

3.3.1 Sub-theme: Moving from struggling to accept carer 'label' to realising that I'm a carer.....	81
3.3.2 Subtheme: Emotional responses.....	86
3.4 Theme three: Changing/evolving relationship with loved one.....	92
3.4.1 Subtheme: Strengthening the bonds between us.....	93
3.4.2 Subtheme: Sense of loss	95
3.5 Theme Four: Carer stress and strain.....	99
3.5.1 Subtheme: Dependency on carer.....	99
3.5.2 Subtheme: Changed relationships with personal others	102
3.6 Theme Five: Impact on professional practice	105
3.6.1 Subtheme: Depth of ability to empathise	105
3.6.2 Subtheme: Interconnection between personal and professional selves	110
3.6.3 Subtheme: Towards and away from career/specialism	113
3.7 Theme six: Dual positioning.....	117
3.7.1 Subtheme: Connections which challenge	119
3.7.2 Subtheme: Professional knowledges as resources.....	124
Chapter Four: Discussion.....	128
4.1 Overview.....	128
4.2 Summary of the findings.....	128
4.2.1 Summary of themes	129
4.3 Links to theories and models in the existing literature.....	130
4.3.1 Constructions of mental health.....	130
4.3.2 Diagnostic labelling	132
4.3.3 Managing the stigmatisation of mental health	136
4.3.4. Theories of stigmatization and the impact of stigmatization	138
4.3.5 Dual position of carers and psychologists	140
4.3.6 The construction of empathy in clinical practice	148
4.4 Wider implications.....	153
4.4.1 Clinical implications.....	154
4.5 Methodological strengths and limitations	157

PSYCHOLOGISTS' EXPERIENCES OF CARING FOR OTHERS

4.6 Future studies.....	161
4.7 Final self-reflections.....	162
References.....	164
Appendix 1: Extracts from reflective journal.....	190
Appendix 2: Ethics approval LMS/PGR/UH/0376.....	195
Appendix 3: Ethics approval LMS/PGR/UH/0376 (1).....	197
Appendix 4: Ethics approval LMS/PGR/UH/0376 (2).....	199
Appendix 5: Ethics approval LMS/PGR/UH/0376 (3).....	201
Appendix 6: Ethics approval LMS/PGR/UH/03676 (4).....	203
Appendix 7: Participant information sheet.....	205
Appendix 8: Consent form.....	208
Appendix 9: Initial interview schedule.....	209
Appendix 10: Final interview schedule.....	211
Appendix 11: Extract of coded interview.....	213
Appendix 12: Initial themes and sub-themes.....	217
Appendix 13: Summarised thematic table shared with participants.....	242
Appendix 14: Cross participant thematic table.....	248

List of tables and figures

Table 1: Terms used to search databases	31
Table 2: Inclusion and exclusion criteria for systematic review of papers	32
Figure 1: PRISMA method flowchart of selection process	34
Table 3: Participant demographics	51
Table 4: Participants' caring experiences	52
Table 5: Quality criteria for this research	63
Table 6: Themes and subthemes	67

Abstract

The aim of the study is to explore the relationship between the unpaid personal caring experiences of psychologists and the perceived impact on their clinical practice and sense of self. The intersection between psychologists as a staff group, their reflections on unpaid caring experiences and the relationship between informal caring and their professional practice was explored in the literature. Due to the paucity of published research in the area, the introduction explored the theoretical base of carer research, the construction of empathy in clinical practice and the lived experiences of psychologists. In this way, a theoretical context for the study was set.

Using a Thematic Analysis methodology, fifteen psychologists were recruited and interviewed about their current and/or historical caring experiences. Six themes were established from analysis of the data set: personal and professional roles; the emergence of a carer identity; changing/evolving relationship with loved one; carer stress and strain; impact on professional practice; dual positioning.

Within these results there was a strong sense of the heightening of empathy for clients/service users and carers, and the complexity of holding dual identities on the individuals themselves as they fulfil their clinical roles. The study's findings suggest that psychologists' own processed experiences of emotional pain, arising from caring experiences, may enable a closer understanding and regard for empathic connections with clients/service users and carers. Whilst undertaking these personal caring roles may also enable

psychologists to feel more empathic attunement to clients and carers within the healthcare system, and this can have clinical benefits, it may also have potential drawbacks. Within this, there was also the suggestion that there may continue to be some aspects of residual emotional pain. This pain may be susceptible to being triggered within clinical practice, which psychologists were cognizant of, as they would be of any potential stimulus within their professional work.

Chapter One: Introduction

This study explores the relationship between personal unpaid caring experiences of psychologists and the perceived impact on their clinical practice. The introduction considers the theoretical base of carer research, the construction of empathy in clinical practice and the lived experiences of psychologists. The literature search pursued literature pertaining to the intersection between psychologists as a staff group, their reflections on unpaid caring experiences and the relationship between informal caring and their professional practice. The paucity of published research in the area sets the context for the study, and its potential importance to clinical work.

1.1 My relationship to the topic

Whilst on training I became fascinated by the “them and us” positioning dichotomy and curious about what it meant for me as a trainee to hold an insider and an outsider perspective on my training experience. This included being a sibling carer of a loved one with psychosis, a carer of a loved one with dementia, and a former professional commissioner of mental health (MH) services in the National Health Service (NHS). My engagement with psychologists who held dual identities led me to a more complex understanding of, and curiosity for, exploring the intersection between personal and professional identities. Having previously researched a carer intervention (Burrows & Gannon, 2013), I was also keen to

draw on my personal and professional experiences to merge my current and historic parts of self into a cohesive and integrated whole prior to qualifying.

1.2 My epistemological position

I adopted a phenomenological-hermeneutic approach to the study, being interested in participants' thoughts, feelings and interpretations of their caring experiences. I was also influenced by constructivist thinking and the notion that "constructivism is an epistemological premise grounded on the assertion that, in the act of knowing, it is the human mind that actively gives meaning and order to that reality to which it is responding" (Balbi, 2008, p. 21). Accepting that we make individual meanings from our experiences, I therefore aimed to access the implicit, and potentially unconscious, meanings conveyed by participants (Barker, Pistrang & Elliott, 2015). My epistemological position and methodology is elaborated upon further in *Section 3.2.1*.

At points throughout my thesis, I have used the pronoun "I" to own my positioning, and I have included an extract of my reflective journal to evidence my use of bracketing to evaluate any potential pre-existing assumptions I held about the meaning of the participants' narratives (Tufford & Newman, 2012). In this way I hoped to demonstrate my reflexivity in the selection and interpretation of the participants' extracts included within this thesis (*see Appendix 1: Extracts from Reflective Journal*).

1.3 Use of language

I recognise the challenge language can present in drawing us into interpreting a phenomenon from a more collectivist stance which may be influenced by our social, historic and cultural context, and which, in turn, may shape our social and political values (Barker et al., 2015). However, I also acknowledge the role of our individual agency, cognitive processes and individual values.

Within this framework, I endorse the critiques of diagnostic criteria and the label “mental health conditions” due to its ability to subsume differences in individual experience of distress (Johnstone & Dallos, 2013, p.139); however, I also acknowledge the value of a shared shorthand for communicating in the NHS. For many clinicians, the difficult task of alleviating distress can be facilitated by the clustering of a set of shared experiences of MH distress and access to a treatment pathway (Perkins, Ridler, Browes, Peryer, Notley & Hackmann, 2018). Service users and carers may perceive a diagnostic framework to be of benefit to them, particularly if the diagnosis is given in a timely way, and not revised at a later date with no apparent change of symptomatology (Perkins et al., 2018).

Furthermore, I recognise that secondary mental health services are provided for people with MH conditions identified as being more severe or enduring in nature than the common MH difficulties more ably treated in primary care (Taskforce, 2016). These secondary MH services may be provided in the community or in inpatient settings, where

clients experiencing more chronicity, and/or with more associated risk, may be managed (Taskforce, 2016).

For the purposes of narrowing and deepening the focus and comprehensibility of my research, I have outlined a pragmatic way forward for the way in which I use terms.

1.3.1 Mental health

One definition of health is the absence of illness and disease (NHSE, 2014). Every individual has MH and physical health, and it exists on a continuum, but the NHS's focus has historically been on physical health, and NHS investment has historically been prioritised on the treatment of physical health illnesses (NHSE, 2014). It could be argued that the NHS's investment patterns have historically followed societal biases around MH's positioning and a lack of parity of esteem with physical health (Department of Health (DoH), 2011).

1.3.2 Mental health distress

Distress is defined as thoughts, beliefs and behaviours which trigger suffering both to people and to those connected to, and concerned for, them (Johnstone & Dallos, 2013). Every individual is vulnerable to experiencing MH distress as a response to events or circumstances in their lives (Cromby, Harper & Reavey, 2013). MH distress can be thought of as existing on a continuum; when it impacts on an individual's functioning, perhaps for an extended, yet indeterminate period of time (and the individual or others seek help for its alleviation), it may become labelled as a "condition" or "disorder" by medical practitioners

(Cromby et al., 2013, p.57). Labelling conditions can facilitate an appropriate treatment pathway within the NHS (DoH, 2011).

1.3.3 Mental health difficulties

This term may be used to suggest a place on the continuum of MH distress in which an underlying difficulty may not have been diagnosed, whether because an individual has not sought help for whatever reason, or because the assessment and diagnostic process has not concluded and resulted in a medical label for the difficulties or issues being experienced (DoH, 2011).

1.3.4 Functional and organic mental health conditions

Functional MH conditions are broadly defined as conditions which impact on mental wellbeing and functioning but are not known to be related to a physiological cause (Denning & Milne, 2013). They are perceived to range in their severity and treatability, and accordingly attract varying levels of stigma (Corrigan, Druss & Perlick, 2014). Conditions such as anxiety have become more normalised in society, and conditions such as psychosis are still associated with “danger” and attract higher levels of stigma (Corrigan et al., 2014, p.35; Tay, Tay & Klainin-Yobas, 2018). Fear of stigmatisation from receiving a diagnosis is one of the main factors deterring clients from seeking help for MH distress (Corrigan et al., 2014).

The stigma around MH draws on the language surrounding the biomedical model (Rapley, Moncrieff & Dillon, 2011). In the biomedical model the language used to construct

health is defined through our understandings of the 'well'¹ and the 'sick' and ideological concepts of normality (Rapley et al., 2011). These ideological concepts of normality help to create a sense of "other" for example, a person being seen as inferior to others due to a perceived difference as we seek to identify ourselves through our understandings of what we are not (MacCallum, 2002, p.87; Rapley et al., 2011). Moreover, we also seek to maintain our social status by distancing ourselves from associations with those who are "shamed" in society, such as those with MH difficulties (MacCallum, 2002, p.88). A sense of "othering" is, therefore, both implicit (in how we create meaning in language i.e. something exists by virtue of what it is not), and also a mechanism by which our differences can also distance us from groups of people (MacCallum, 2002, p.87). As such, it is bound up in the dualist language that we use to name phenomena, in which oppositional pairings are constructed such as client/staff, man/woman and well/sick (MacCallum, 2002).

Organic MH conditions are those perceived to be permanent or temporary changes in brain functioning due to injury or disease, trauma to the brain or degenerative disorders, such as Alzheimer's disease (NHSE, 2014).

¹ Throughout the text I use singular speech marks to denote the secondary or connoted meaning of the word given. In doing this, I hope to indicate that I do not concur with the connoted meaning of the word, and have taken an alternative, more critical stance.

Participants' quotes and quotes from texts are in double speech marks.

1.3.5 Neurodevelopmental conditions

Neurodevelopmental conditions are widely conceptualised as conditions typically occurring from childhood onwards, and affecting areas of cognitive function such as memory, inhibition control and emotion regulation (Cunningham, Thomas & Warschausky, 2007). Conditions may include disorders of multivariate origin such as autism spectrum conditions, Attention Deficit Hyperactive Disorder (ADHD), dyslexia, dyspraxia and dyscalculia, and neurological disorders of known origin such as Down's syndrome and cerebral palsy (Cunningham et al., 2007). The former may be categorised through behavioural presentation, and the latter through aetiology (Cunningham et al., 2007).

1.3.6 Client and service user

In this study the words client and service user are often used interchangeably to identify those individuals who receive secondary care services whilst recognising that these terms are widely critiqued for their limitations in depicting an individual's relationship to the service (McLaughlin, 2009) and may unintentionally be interpreted to infer that clients/service users do not also have professional status (Morant, 2006; Prytherch, Lea & Richardson, 2018; Cath, 2016).

1.3.7. Psychologist

In order to value all individual participants' contributions equally, no distinction between qualified, trainee, assistant or any other variance in the profession is drawn in the analysis of results. The conceptualisation of dual identity, that of a professional psychologist

in their working life who is also a service user or a carer in their private life, is considered in more detail in *section 2.7, Lived Experiences*.

1.3.8 Loved one and/or cared for

The terms loved one and cared for are deployed interchangeably throughout the text. When the term loved one is used, it is to intentionally recognise the strength of the bond that exists between carers and those they are looking after, and to assume a level of reciprocation in the relationship. It is not, however, intended to subsume, devalue, or deny any relational complexities, associated emotions, or historical patterns of relating that may be inevitable amongst caring dyads. In instances where it feels more appropriate to use the terminology cared for this is also deployed.

1.4 The context of caring in the UK

“A carer is anyone, including children and adults, who looks after a family member, partner or friend who needs help because of their illness, frailty, disability, a mental health problem or an addiction and cannot cope without their support. The care they give is unpaid.” (NHSE, 2014, p.6).

Based on the 2011 census figures, one in eight of the adult population of the UK is a carer (Carers UK, 2012). Carers are twice as likely to suffer from ill health as the general population (NHSE, 2014). The unmet physical and psychological health needs of unpaid carers have long been recognised by policy makers (Hirst, 2004). In addition, research into

carer health has found that the caring role can lead to emotional, physical and psychological problems, including anxiety and depression (Whitney, Haigh, Weinman & Treasure, 2007; Mannion, 2008). There is a gender gap in caring, with 58% female carers and 42% male (Carers UK, 2012).

It is widely acknowledged that societal roles tend to assume that women are the 'natural' carers and that responsibility for caring sits with women (Ussher & Sandoval, 2008). However, within Black and Minority Ethnic (BAME) communities, there may also be expectations around eldest children taking on carer roles for parents (Pelle, 2013); and collective responsibility for caring may be more likely to be located within the extended family network than in UK birth nationals (Pelle, 2013).

There is now a year-on-year increase in recognition across governmental departments of the economic value unpaid carers provide to the economy (Department of Work and Pensions (DoWP), 2017/18; Department of Health and Social Care (DoHSC), 2020; Baguley & Sprung, 2012; Buckner & Yeandle, 2011). Whilst NHS staff already have the right of up to a week of carers' leave, the government have signalled their support for expanding this initiative to other sectors, and a consultation exercise is currently underway to understand how unpaid carers might be given a new right to a week of leave (DoHSC, 2020).

1.4.1 Identifying as a carer

Carers have a long history of campaigning for their value and their rights as carers to be recognised (Carers UK, 2004). However, it is widely recognised that many carers do not recognise themselves as such, due to a pre-existing relationship with the person they are looking after (NHSE, 2020). Whilst the issue of carer identification is prevalent throughout the carer demographic, and the journey of recognition varies, it is acknowledged that it may take on average up to two years for an adult or child to recognise that they are a carer (NHSE, 2020).

In addition, there is heterogeneity within sub-groups of the carer population around carer identification processes. Young carers have historically been particularly at risk of having their needs unmet due to a lack of visibility in society generally and other factors such as children wanting to protect their parents from the perceptions of others (Charles, 2011; Smyth, Blaxland & Cass, 2011). There may also be cultural differences, for example, in how carers from BAME communities may perceive their role due to more collective responsibility discourses around looking after vulnerable individuals within their family systems (Ochieng, 2003). Whilst Western cultures perpetuate more of a sense of the needs of individuals, and therefore, may facilitate a more accessible carer identification process, generational differences amongst older white British carers also exist. Amongst older white British carers, gender norms may preclude identification as carers in the context of marriage, because of

generational beliefs around the perceived duties of husbands and wives (Greenwood & Smith, 2016).

1.4.2 Carers of people with functional and organic mental health difficulties

NHS England have recognised the wide-ranging nature of the type of support provided by carers, and how the role and shape of the carer's experience of providing care may impact on them (NHSE, 2020). Through experience, carers of people with MH difficulties are likely to be aware of the stigma around MH and the social inequality and disadvantage that surrounds service users (Schulze & Angermeyer, 2003; Corrigan & Watson, 2002; Saunders, 2003; Brohan, Slade, Clement, & Thornicroft, 2010). Carers may have been influenced by, and/or internalised, some of the "shame, blame, and contamination" dialogues which can surround families of service users (Corrigan and Miller, 2004, p. 537; Wallcraft, Amering, Freidin, Davar, Froggatt, Jafri & Steffen, 2011). Carers frequently report feeling unsupported by services and may also experience contradictory, complex and shifting emotions around their caring role, such as a sense of reward, then frustration, anxiety and then relief; or these emotions may coexist simultaneously (Mallinckrodt, 2010; Constantinidis, 2017). They may also experience a sense of isolation and shame around feeling less able to share their experience with others due to stigma (Magliano et al., 1998).

Carer research has shown that there is a correlation between the number of hours of care provided and physical and mental strain (Carers UK, 2012). Carers of people with dementia looking after loved ones at home have reported particularly high hours of weekly

care being provided (Bolt, van der Steen, Schols, Zwakhalen, & Meijers, 2019). There is a spectrum of support that a carer might provide to someone with MH difficulties depending on the presentation of the loved one's condition at any time (McCann, Bamberg & McCann, 2015). This may include practical assistance, emotional support and advocacy to access and maintain contact with services (Carers UK, 2012). Service users and carers may share the experience of having contact with MH services, but the support they receive and their experiences and perspectives of services and the health care professionals (HCPs) within those services may differ (DoH, 2011). Service user and carer constructions of MH and the acceptability of treatment offered may also vary (DoH, 2011).

1.4.3 Carers of people with life limiting physical health conditions and disabilities

Carers of people with physical health conditions and disabilities report high levels of emotional and physical tiredness through the loved one living with them, and their responsibility to provide care day and night, with infrequent access to respite provision (Carers UK, 2014). In common with other subgroups of carers, they report poorer health outcomes, and some difficulties in addressing their own needs for support, due to the focus on addressing their loved one's health needs (NHSE, 2014).

Historically, the discourse around caring had primarily focused on the construct of caring as a burden (Shah, Wadoo & Latoo, 2010). Central to this construct was the premise that Western capitalist societies operate on concepts of individualism and financial independence. Any individual unable to function without the support of the family system,

whether for practical, physical or psychological reasons was construed to be dependent (Shah et al., 2010). There were two notions of burden: objective and subjective. Objective burden was conceived of as the practical factors impacted on by caring responsibilities such as loss of earnings, disruption to family relationships, limitations to work, leisure and other activities (Shah et al., 2010). Subjective burden was the psychological response to the loved one's difficulties and the impact on the carer. This included emotional reactions such as grief for the loss of the person the loved one was before their difficulties, and feelings of anxiety and frustration around this, which can also lead to unconscious hostility and anger (Magliano et al., 2005).

Studies have shown there are some gender differences in terms of psychological responses to caring. In a study on caring dyads and partners with cancer, it was found that men were more likely to repress their emotional responses to their loved one's illness, and to self-silence rather than share their feelings (Ussher & Perz, 2010). This was largely a response to constructs around masculinity and the expression of emotional needs or vulnerability suggesting a less masculine identity for some men, but also a desire to focus on their partner's needs and avoid conflict (Ussher & Perz, 2010). Female carers of partners with cancer also wished to avoid conflict through not expressing their needs in favour of prioritising their partner's needs. However, they were also more likely to be aware of external judgement from others in relation to their positioning as natural carers (Ussher & Perz, 2010).

More recently, there have been moves to reconceptualise carer burden, and there are carer discourses which highlight how the caring relationship may have supported a sense of self growth and facilitated the development of personal understanding (Andrén & Elmståhl, 2005). Some carers also report the strengthening of existing bonds and connections with the person they care for and are appreciative of the loved one's sense of contentment and appreciation of the care being provided for them (Whiting, 2014). Sharma's (2018) study of father carers demonstrated the commitment of fathers to providing unconditional support for their adult children with psychosis, despite the inherent challenges in caring for children with psychosis; through their paternal commitment, they felt they were in some ways able to gain a deeper appreciation of the parent-child relationship.

1.4.4 Factors affecting the caring dyad

A service user or clients' relationship to, and perception of, their conditions will vary, with some clients having a neurodevelopmental condition, a degenerative physical health condition and/or accepting a biomedical model of MH. Clients' perceptions of the stigma surrounding their condition and discrimination experienced will again vary dependent on the nature of their condition, their own awareness of the condition, and its positioning within mainstream society (Corrigan & Watson, 2002; Schulze & Angermeyer, 2003).

Clients' conceptions of MH may influence how they feel towards the treatment offered to them and their acceptance and adherence to this (Constantinidis, 2017). Others with MH issues may endorse a psychosocial model which recognises that triggers for their

difficulties may lie within their environment (Saunders, 2003; Westerhof, & Keyes, 2010). As chronicity of any physical or MH condition may fluctuate, some clients may have ongoing contact with a service for monitoring, whereas other clients may only access services sporadically during episodes of ill health (Albert & Simpson, 2015).

Divergent and possibly conflicting views about the treatment of their family or friend may also affect the relational dynamics between carers and clients (Smallwood, 2016). In addition, carers may arrive at different interpretations of the meaning of the caring experience to those they are caring for (Goodwin & Happell, 2006). As meaning making is both a process and an outcome (Park, 2010; Frankl, 2014), the meaning of caring for an individual will be idiographic but also socially constructed through language and perception (Krauss, 2005). The nature of caring, with its potential for being both a source of satisfaction but also stress, might have a parallel with client work for clinicians (Sciberras & Pilkington, 2018).

1.4.5 Involvement of carers and service users/clients in NHS services, including training

There is now an expectation across health and social care services that service users and carers will be engaged in the design and evaluation of services (Cree, Brooks, Berzins, Fraser, Lovell & Bee, 2015). Previously criticised by some service users and carers for being 'tokenistic', consideration around the practical measures required to facilitate 'real' engagement of service user and carer expertise in training programmes has been in progress for some time (Cree et al., 2015, p.208). Within psychology training, courses provide a range

of mechanisms to increase trainee awareness of service user and carer insights into, and perspectives on, MH services (Prytherch et al., 2018; Curle & Mitchell, 2014). Some of the enablers of effective and authentic engagement with service users and carers include raising awareness of the power dynamic that exists between the psychologist and client in therapy (Harding, 2010), also the power dynamics that exist between service users/clients, carers and psychologists (Curle & Mitchell, 2014).

The guidelines of the professional body for psychologists, the British Psychological Society (BPS) (2017), uphold that reflective practice is essential for psychologists to understand how they bring their personal selves into their professional practice. As such, the BPS assert the need for psychologists to be aware of their cognitive biases, and their personal experience and motivation for joining the profession (BPS, 2017). Further, the BPS code of conduct identifies psychologist values and asserts “the importance of compassionate care, including empathy, sympathy, generosity, openness, distress tolerance, commitment and courage” (BPS, 2018, p.5).

1.5 The construction of empathy within clinical practice

Empathy is one of the “common factors” and fundamental values of clinical practice (Laska, Gurman & Wampold, 2014, p. 467). Empathy is associated with more efficacious outcomes for clients, which relate to the practitioner’s ability to build and maintain a therapeutic alliance irrespective of modality (Neukrug, Bayne, Dean-Nganga, Pusateri, 2013).

Rogers' original definition of empathy centred on the skill of *sensing*. For example, Rogers (1957) cited in Neukrug et al. (2013, p.99):

“To sense the client’s private world as if it were your own, but without ever losing the “as if” quality – this is empathy, and this seems essential to therapy. To sense the client’s anger, fear, or confusion as if it were your own, yet without your own anger, fear or confusion getting bound up in it, is the condition we are endeavouring to describe. When the client’s world is this clear to the therapist...then he can both communicate his understanding of what is clearly known to the client and can also voice meanings in the client’s experience of which the client is scarcely aware.”

For Rogers (1957) empathy is relational, and leads to the therapist demonstrating their understanding of the client’s inner world and the facilitation of their increased self-awareness. Other definitions of empathy describe constituent parts; these include the intellectual and emotional ability to identify, understand and imagine the client’s emotions, and moral and behavioural intentions (Stepien & Baernstein, 2006). Stepien and Baernstein (2006) assert that the clinician’s desire to empathise, and their ability to demonstrate their understanding of the client’s perspective to the client, is of paramount importance. Larson and Yao (2005, p.1100) have stressed that emotional engagement requires “emotional labour” and that all four elements of empathy are required to enable the client to feel understood. Larson and Yao (2005, p.1100) also suggest that “intentional modification of

one's true emotions", can be "deep acting", and are required to enable a clinician to be effectively empathic.

The perspective of Larson and Yao (2005) positions empathy as something which requires development and effort, which is mirrored in its status as a critical dimension of skills practice on clinical training courses (Alma & Smaling, 2006). The view from counselling psychology literature varies; some authors posit that empathy around others' emotional states is dispositional and malleable (Schumann, Zaki & Dweck, 2014; Rizq & Target, 2008); and others suggest the ability is a personality trait (Hemmerdinger, Stoddart & Lilford, 2007), which "cannot be taught" (Davis, 1990, p.32); it is authentically felt, rather than manufactured (Davis, 1990).

Indeed, Hodges, Kiel, Kramer, Veach and Villanueva (2010) concur and assert that a therapist giving a generalised expression of concern may not enable the client to feel contained. Furthermore, Hodges et al (2010) suggest that this is because there are risks of the client feeling misunderstood if the empathic communication is not sufficiently specific and particular to the client. There is a sense the client may perceive their empathic connection with their therapist being based on the accuracy of the expression of the empathic connection (via the cognitive dimension of the exchange), rather than the amount the therapist shares with the client (Hodges et al., 2010).

The essence of the question of the centrality of empathy within the therapeutic alliance, therefore, does not only seem to focus on whether a therapist needs to have had a shared experience of a phenomenon to convey appropriate empathy in relation to the client's experience, but also to be able to convey their full engagement in the evolving relationship (Hodges et al., 2010). This can be achieved by being fully present, listening to, hearing and seeing the person in front of them (Hodges et al., 2010; Burks & Robbins, 2012).

This demonstration of full engagement in the evolving relationship is a consideration which Ritz and Target (2008) explore in depth. They assert that counselling psychology trainees come into the profession because of a sense of striving towards self-realisation or wanting to make a difference to others' lives (Ritz & Target, 2008). They also speak to the concept that trainees may be motivated through a "wounded healer" experience in which they, themselves, experienced psychic pain and want to help others through similar experiences of distress (Ritz & Target, 2008, p.131). The postulation is that, due to a "wounded healer's" needs for self-gratification, it is only after the resolution of painful or traumatic experiences that empathy for others might be available to a therapist (Ritz & Target, 2008, p.131; Cristy, 2001).

Ritz and Target suggest that the process of using one's own therapy to work through one's own emotional wounds can lead to the embodiment of the "healed helper" (Ritz & Target, 2008, p.131). Consequently, therapy is mandatory for trainees within counselling psychology training programmes, thus, conveying the positioning of one's own experience of

therapy as central to professional development as a counselling psychologist (Dooley & Peyton-Lander, 2020).

However, within clinical psychology training, reflective practice is posited to enhance a psychologist's reflexivity and reflectivity and ability to empathise with clients' distress through exercises designed to enhance emotional relativity (Keville, 2018). It may also be that funding arrangements and recruitment demographics (and potential life experiences) of those entering the profession differ between counselling psychology and clinical psychology (Ogunfowara & Drapaau, 2008).

Nevertheless, irrespective of any perceived differences in recruitment demographics or in conceptualisations of empathic development within the two professions, the centrality of empathy (Omylinska-Thurston, McMeekin, Walton, & Proctor, 2019) and mechanisms of facilitation and measurement remain fundamental to psychological training and research (Jung, Wiesjahn, Rief & Lincoln, 2015; Gaume et al., Hallgren, Claire, Schmid Mast, Carrard & Atkins, 2019). Understanding this more fully can involve looking more closely at the relationship that professionals have with their personal experiences.

1.6 Lived experiences

Critical psychologists and the service user movement have been vocal in their assertions that the sharing of lived experience enables a reduction of the demarcation between client and professional, or "us and them", with the inference that this is beneficial

to therapeutic practice (May, 2001, p.14; Lofgren, Hewitt & das Nair, 2015; Richards, 2010). Indeed, some psychologists have posited that lived experience of MH difficulties may add a quality to the therapeutic relationship which may not be present if a therapist has not had experience of MH difficulties (Hacker Hughes, 2016; Richards, Holttum & Springham, 2016). The underlying assumption has been that psychologists with lived experience of MH difficulties can have more insight into MH and are, thus, more readily able to understand and empathise with their clients (Hacker Hughes, 2016; Richards et al., 2016). Two clinical psychologists (Emma Harding and Rufus May) are open about their MH history, having written about how their experience heightens their awareness of the power dynamics within therapy (Harding, 2010; May, 2000).

Harding takes the view that disclosure of her experience is not necessary to build a therapeutic connection because her awareness of being a service user leads to her rejecting the "expert position" in her practice (Harding, 2010, p.58). Others go further, for example, by disclosing experiences of voice hearing with some clients (Corstens, May & Longden, 2011), feeling that this can enhance the positive risk taking within therapy through increasing clients' ability to share more in the relationship (Corstens et al., 2011; Hermansson, 1997; Hartmann, 1991). For some psychologists the suggestion that lived experience might enhance the therapeutic connection is refuted and allegiances to the scientist-practitioner approach and notions of objectivity are declared (Lindsay, 2017). It might be postulated that some of these differences in interpretation of the value of lived experience may be linked to

different motivations for training in the therapeutic field (May, 2000; DiCaccavo, 2002; Fussell & Bonney, 1990; Gonzales & Melton, 2017).

Awareness has been drawn to the likelihood of a proportion of psychologists in training and qualified, having their own experiences of MH issues and/or services but feeling reluctant to share this because of fears around how this would impact on training or their employment situation (Grice, Alcock & Scior et al., 2018). Within the training programmes for all MH professions there have been moves to highlight how lived experience and appropriate disclosure can become more valued in clinical work (Grice et al., 2018; Meehan & Glover, 2007).

Having considered the theoretical base of carer research, the construction of empathy in clinical practice and the lived experiences of psychologists, I will now complete a literature search to locate this study within the existing research.

1.7 Literature search

This study was seeking to understand how psychologists' personal experiences of caring for others may have impacted on clinical practice, so the initial search terms focused on four areas: psychologists as a staff group; terms associated with unpaid caring experiences; terms related to loved one/cared for; and terms related to practice. Specific search terms were combined in various ways; *see Table 1*.

Table 1: Terms used to search databases

Terms relating to participant group		Terms relating to caring		Terms relating to cared for		Terms relating to practice
Psycho* <i>("healthcare professionals")</i>	AND	"unpaid caring" "looking after" "personal experiences of caring" <i>("dual caring")</i> <i>("informal caring")</i>	AND	"others" "family members" "friends" "partners"	AND	"practice" "clinical practice" "professional practice"

Initial searches were then expanded to include search terms to recognise the dual nature of caring crossing the personal and professional spheres. Unpaid care was also widely known as "informal caring" in the literature, hence its inclusion.

PubMed, Scopus and PsychINFO were searched. The inclusion and exclusion criteria can be seen in Table 2.

Table 2: Inclusion and exclusion criteria for systematic review of papers

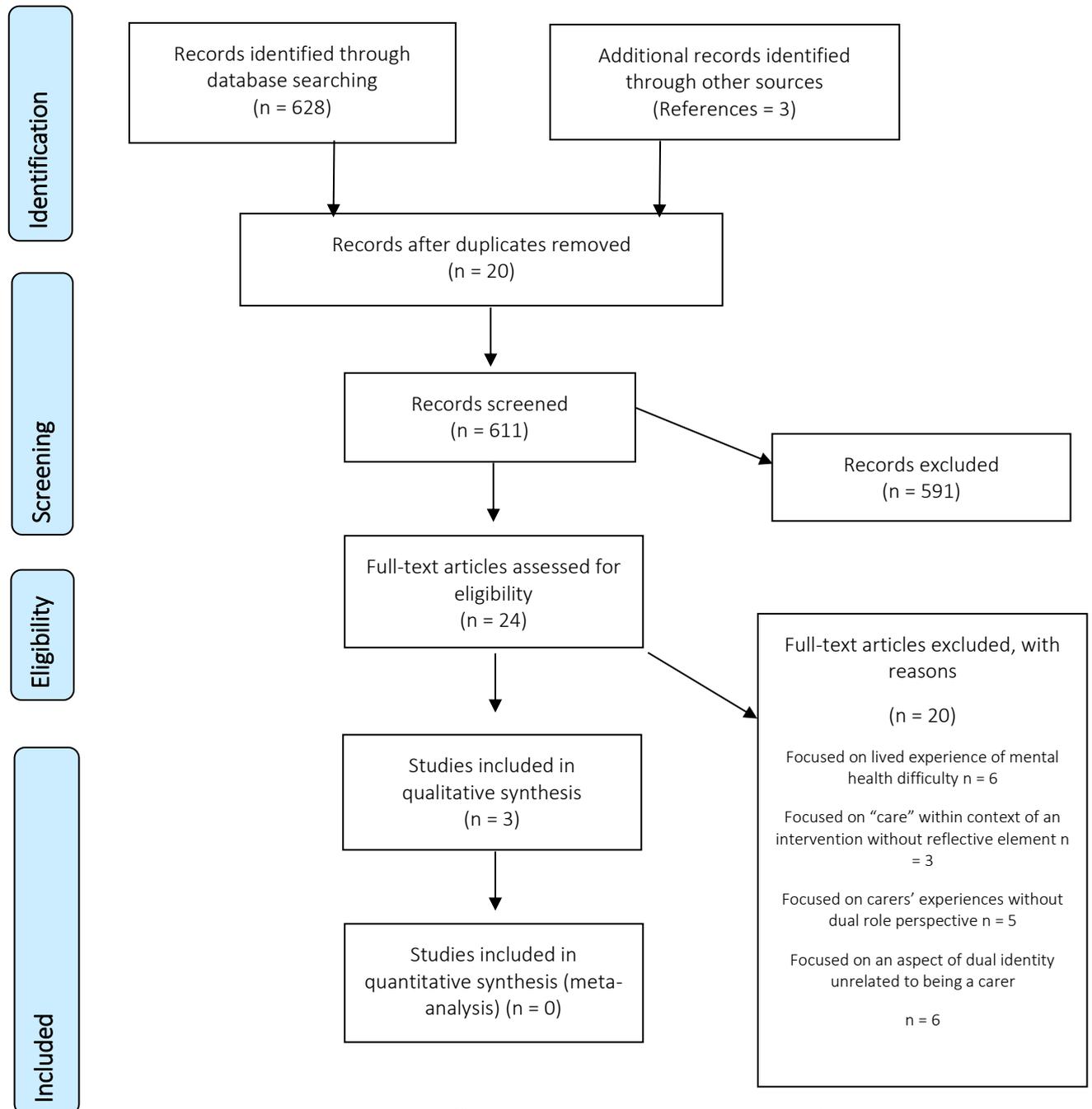
Inclusion criteria	Exclusion criteria
<p><u>Focus on:</u></p> <p>psychologists' reflections on caring for others in a personal role</p> <p>psychologists' reflections on caring for others with MH difficulties from a professional perspective</p> <p><u>Focus on:</u></p> <p>relevance to clinical or professional practice</p> <p>relevance to boundaries around personal and professional selves</p> <p>relevance to personal/professional identities</p> <p>peer reviewed</p> <p>thesis</p> <p>published in English in the last 20 years</p>	<p>dual identities of psychologists pertaining to service user and professional roles</p> <p>dual identities of psychologists</p>

1.7.1 Results

I deployed the "Preferred Reporting Items for Systematic Reviews and Meta-Analyses" (PRISMA) method (Moher, Liberati, Tetzlaff, Altman & Prisma Group, 2009) to complete my review. The PRISMA method involves using a 4-phase process to identify, screen, select and include eligible papers for review, and thus is a stringent reporting process for literature

reviews (Moher et al., 2009; Siddaway, Wood & Hedges, 2019). A flowchart of the PRISMA process for the papers included in the study is included below.

Figure 1: PRISMA method flowchart of selection process



From: Moher D, Liberati A, Tetzlaff J, Altman DG, The PRISMA Group (2009).

Preferred Reporting Items for Systematic Reviews and Meta-Analyses: The PRISMA Statement. PLoS Med 6(7): e1000097. doi:10.1371/journal.pmed1000097

The reasons for papers being excluded at different stages of the review were numerous. The breadth of the search terms included a number of papers relating to psychologists having dual identities and experiencing ethical issues relating to their practice, such as military psychologists (Johnson, 2008; Kennedy & Johnson, 2009). A number of papers came up relating to psychologists and care within the context of the delivery of interventions (Luker, Bernhardsson, Lynch, Murray, Hill, & Bernhardt, 2015; Joling, van Hout, Scheltens, Vernooij-Dassen, van den Berg, Bosmans, & van Marwijk, 2008; Cramond, Fletcher & Rehan, 2020) and a large number of papers considered different carer groups' experiences of caring (Onwumere, Learmonth & Kuipers, 2016; Askey, Holmshaw, Gamble & Gray, 2009; McCann, Bamberg & McCann, 2015). The abstracts of some of these papers were read in order to ascertain if psychologists or staff members from other healthcare professional groups had been recruited onto the studies.

The literature search demonstrated that psychologists' experiences of caring and the relationship between providing personal care and its impact on clinical practice had not been explored previously through a qualitative study. At this point, I considered alternative strategies for locating the study with my primary supervisor. We discussed how the study could potentially be situated within a search of other helping professions' experiences of caring. Studies of nurses and caring for older family members were reviewed (Ward-Griffin, Brown, Vandervoort, McNair & Dashnay, 2005; DePasquale, Davis, Zarit, Moen, Hammer & Almeida, 2016), however, these studies had a focus on a more practical aspect of caring, such

as physical exhaustion and the emotional component of caring, but they did not focus on the carers' reflections on caring and the impact on their professional practice.

Two alternative literature searches were then considered. The first centred on re-focusing the literature search on carers' experiences of caring for people with different types of difficulty and/or condition and then using this framework to provide an in-depth context for locating the empirical research element of the study. This would have provided insights into generic experiences of caring across different carer populations and provided a broader synthesis of material to locate the study within, but it would not have examined the interaction between personal caring experiences and being in a professional caring role. It would also not have included reflections on this interaction. The second focused on drawing on the existing literature around psychologists and their personal caring experiences and sought to embed this within the phenomenological approach being adopted by the study. In this way, the study would be situated within the paradigm of lived experience and build on existing understandings of psychologists' thinking around the influence of personal caring on their clinical practice. The search for grey literature through Google Scholar was limited in its scope because its focus had already been narrowed down into psychologists' reflective accounts of the interactions between their personal and professional selves. These materials had been subject to a peer review process, but due to their personal nature, could not be evaluated from an academic lens. Whilst this could potentially be considered a limitation to the formal academic literature review process, it was also an intentional decision to locate

the study within the knowledge base derived from the lived experiences of psychologists with personal caring experiences. This was in accordance with the phenomenological-hermeneutic approach to the study, and my central concern with participants' thoughts, feelings and interpretations of their caring experiences, rather than published work of carers' experiences. However, it should also be acknowledged that the Google Scholar search conducted had not identified specific and focused search terms. This therefore prevented the search from being repeated in a systematic way by other researchers. In addition, the initial literature search could have been broadened to include searches of thesis and dissertation repositories, conference proceedings and grey literature databases such as PsychEXTRA. Expanding the literature search may have revealed further literature and enabled the expansion of the selection of items for review. The small size of items for review (four), and from only 3 sources, involved a very small number of authors. As such, whether these are the only available literature on the topic or not is a limitation of the literature search conducted because it may have potentially precluded other potential sources of literature available on psychologists' personal experiences of caring.

In summary, the initial literature search had demonstrated that the interaction between the personal caring experiences of psychologists and their professional roles had not previously been considered. Rather than explore alternative literature searches which would not explore the interaction between the personal and professional caring experiences of psychologists, it was agreed that the search should reflect that of an empirically based

reflective study. This guided me to including two theses which contained carer psychologists' reflections on their experiences (Stillwell, 2016; Sharma, 2018) and a paper written by the author of one of the theses (Sharma, Green & Keville, 2020). A peer reviewed reflective account by the primary supervisor was also included for review (Keville, 2018). I have acknowledged that the size of the sample of materials for review was a limitation of the literature review conducted and have suggested how the existing literature search could usefully have been expanded.

1.7.2 Synthesis of findings

In the absence of existing literature around carer psychologists' experiences, I drew on two published papers, and two theses. These psychologists have reflected on their caring experiences in explicit ways, and therefore met the inclusion criteria for the study.

1.7.3 Critical evaluation of literature

As the accounts detail reflections of and on personal experiences, it would not have been appropriate for me to critically appraise these. My consideration of these accounts attended to selected extractions of the descriptive content. However, the paucity of literature around the lived caring experiences of psychologists highlighted the sense in which the literature base would benefit from being extended beyond the personal accounts of these experiences into further systematic and empirical research in the area.

In the first paper, a psychologist reflected on her experience of being both a clinical psychologist and a carer and her perceptions of the implications of her experiences on practice (Keville, 2018). Reflecting on personal experiences, the experience of the silencing of her input into a transparent and equitable decision-making process around her child's education and care is set out. In a professional context, Keville (2018) reflected on an experience of being (unintentionally) silenced from contributing to discussions around carer perspectives within her work; as if it was only her identity as a psychologist which was allowed or enabled to be present in the professional sphere. Keville made recommendations around how equality and inclusion could be promoted in healthcare through the eradication of the notion of 'them and us' (Keville, 2018, p.376)

In the first thesis, "*Caring over the lifespan: experiences of caring for a sibling with schizophrenia*", Stillwell (2016) reflected on her experience of caring for a sibling with psychosis. In this Interpretative Phenomenological Analysis (IPA) study of six carers, Stillwell identified three superordinate themes: "*the "terrible weight" of having a sibling with a diagnosis of schizophrenia*", "*evolution of the caring role*", and "*life-cycle expectations.*" Stillwell deployed a reflective diary to reflect on how she engaged with the participants' narratives and how their experiences resonated with her own caring experiences.

She reflected on how she is particularly drawn into connecting with other carers through the similarities in their experiences, and how "*incredibly important (it felt) for someone to truly understand my experiences and how I felt*" (Stillwell, 2016, p.110). She also

reflected on her positioning as an insider researcher, and a carer with lived experience undertaking hermeneutic research.

In the second thesis, of which a peer reviewed paper was also published (Sharma et al., 2020), *"Fathers' experiences of caring for an adult child with psychosis: a qualitative study"*, Sharma (2018) identified five superordinate themes in the thesis: *"Father vs. carer"*, *"Change in quality of the relationship with child"*, *"To share or not to share"*, *"Acceptance is a struggle"*, and *"Mental health services: inconsistency vs. luck."* Within this thesis, a reflective diary was used to examine the evolution of the themes and how an experience of personal and professional caring increased her insight into the inner and sometimes conflicted emotional world of carers within her sample. *"I really wondered about what journey him and his wife have to go through to come to the conclusion that it would be better for their daughter if she passed away. At the same time, I was really surprised by how well he was coping in such on-going, uncertain, difficult circumstances"* (Sharma, 2018, p.197).

1.7.4 Summary of literature pertaining to the study area and the literature review

The introduction considered how mental health distress is constructed; the experiences of subgroups of carers and how carers are positioned within society. The introduction then moved on to consider psychologists' experiences of living with MH difficulties and the impact on professional practice. The construction of empathy, and the debate around dispositional and situational empathy has been considered, particularly in

relationship to its centrality within clinical training programmes. The component parts of an empathic communication have been appraised, and a psychologist's ability to convey empathy discussed.

The debate around lived experience appears to pivot on a consideration of whether lived experience can give a clinical psychologist an enhanced ability to relate and connect within the therapeutic relationship (May, 2000). This debate has not yet been investigated from a carer perspective, and neither has a carer psychologist's perspective on their relationship to the wider system been considered. The paucity of literature currently available demonstrates the value of conducting research in this area, hence the development of the current study. Further dialogue around the experiences of carer psychologists and how they make sense of these experiences is warranted. In this way, the potential significance of these experiences on their ways of relating to others within their personal and professional systems may be more fully understood. Integral to this could be the way in which these experiences influence their therapeutic practice. Central to this study was my reflective engagement around how the explicit and implicit positioning of ourselves as carers and/or psychologists may have the potential to impact on our personal and professional selves. Reflecting on this may add to the ongoing debate about the potential impact of lived experience on clinical work and reflective practice. The study may have the potential to influence the trainings of psychologists and other MH professionals in order to enhance

understandings of carers and their collective and individual positionings within the health and social care system from a psychological perspective.

1.7.5 Research questions

Given the gap in the literature around psychologists' personal experiences of caring for others and what this might mean in terms of the potential influence on clinical practice, the research questions to be addressed were:

- How do psychologists make sense of their unpaid personal experiences of caring for others and the relationship to their clinical practice?
- How do psychologists make sense of their unpaid personal experiences of caring for others and the relationship to their sense of personal and professional self?

Chapter Two: Methodology

2.1 Overview

This section considers the rationale for the selection of a qualitative methodology and the epistemological position taken. It evaluates the qualitative methods that could have been used and appraises the decision to adopt thematic analysis as the method for analysing the data collected. The process of recruiting participants onto the study is then considered, along with the ethical issues presented. The approach taken towards consulting psychologists with personal experiences of caring for others is subsequently described, along with the data collection and data analysis processes. Finally, the section concludes with an appraisal of the quality, validity and self-reflexivity of the study.

2.2 Choice of a qualitative design

The study was exploratory research focused on the beliefs, attitudes and values of a small sample of psychologists in relation to their carer and psychologist identities. As such, a qualitative approach was deemed appropriate in order to consider the under-investigated area of psychologists' personal experiences of caring for others (Frith & Gleeson, 2012; Gair, 2012). Semi-structured interviews conducted face to face were selected as the most appropriate medium for giving voice to these experiences (Barker et al., 2015).

2.2.1 Epistemological position

Phenomenology is concerned with participants' thoughts, feelings and interpretations of their experiences (Barker et al., 2015). Therefore, the perceived meaning of what we do, think and feel becomes our central concern, rather than a focus on any conception of any objective reality, or the perceived facts of a situation (Barker et al., 2015). Hermeneutics highlights the interpretative aspect of our experiences (Barker et al., 2015). Within a phenomenological-hermeneutic epistemological framework, a researcher's interpretation of data is seen as both "desirable" and "inevitable" (Willig & Billin, 2012, p.117).

It is desirable because it creates an in-depth understanding and appreciation of the phenomena being researched, and inevitable because of the need to reflect the emotional tone of the original account (Willig & Billin, 2012). In this way, a researcher who adopts a phenomenological-hermeneutic framework can convey a participants' articulated meaning, rather than presenting an extraction or theme of the content of the dialogue, but devoid of the participants' expressed meaning (Willig & Billin, 2012).

2.2.2 Consideration of qualitative methods

When thinking about how to implement a phenomenological-hermeneutic framework to the study, I was initially drawn to considering Interpretative Phenomenological Analysis (IPA) as an appropriate methodology because of its robust approach to understanding people's experiences (Biggerstaff & Thompson, 2008).

IPA emphasises the way in which events can be interpreted by individuals at certain points in time (Smith & Shinebourne, 2012). Through the “double hermeneutic”, it is accepted that the researcher plays an active role in the research process, and that the researcher will not only influence the collection of the data, but also its interpretation (Willig & Billin, 2012; p.117). IPA centres reflexivity as a core principle within its methodological framework and conceptualises IPA as an enabler of the co-construction of participants' experiences (Smith, 2011). Participants' meaning-making is construed as first order, and researchers operate second order processes, construed as sense-making (Smith, 2011).

The in-depth, idiographic nature of the IPA approach and its focus on the particular rather than the general (Smith & Shinebourne, 2012) would, however, have restricted the examination and analysis of themes across participants. Grounded theory was also evaluated for its ability to analyse data from a sample of carer psychologists. However, the study was concerned with the psychological impact of caring and its influence on clinical practice, but did not seek to generate theory. Grounded theory was, therefore, not considered suitable (Willig, 2001). Narrative analysis was also appraised for its ability to understand how stories are told, which stories become elevated and which become subjugated (Wells, 2011). Whilst narrative analysis may have generated an in-depth understanding of the stories depicted, the main aim of the study was to highlight how psychologists' experiences of caring for others may impact on professional practice.

2.2.3 Choice of thematic analysis and its fit with my epistemological position

Thematic analysis is a flexible qualitative method which aims to identify and analyse patterns within data sets (Braun & Clarke, 2006; Clarke & Braun, 2013). Although the fifteen participants shared the professional identity of psychologist, they had a range of diverse caring experiences, and I anticipated that there might be differences in participants' perceptions and attitudes.

Whilst adhering to the principles of a phenomenological-hermeneutic framework, I also recognised that the term carer had been socially and culturally constructed, and was mediated through an individual's meaning-making system (Park, 2010). As Harper and Thompson (2012) stated, language is both constitutive and constructive of meaning.

Within a constructivist approach there are four key tenets (Balbi, 2008). The first is that people actively construct their own experience; the second is that people anticipate how events and situations will play out, because of the proactive nature of the mind (Balbi, 2008). The third is that mental processes can operate either consciously or unconsciously; and the fourth is that an individual's psyche inclines them towards patterns of experiences (Balbi, 2008). Taking a constructivist approach to the study situated within an overarching phenomenological-hermeneutic framework, my intention was to access the implicit and, potentially, even unconscious meanings conveyed by participants (Barker et al., 2015).

As psychologists' experiences were likely to be multi-faceted, it was appropriate for these meanings to be analysed for their "affective, cognitive and symbolic dimensions" through thematic analysis (Joffe 2012, pp 209). In addition, thematic analysis can offer insights into historical and contextual dynamics and their influence on participants' inner worlds (Joffe, 2012). Thematic analysis was, therefore, selected as the most appropriate method for analysing a data set of this size because of its ability to report on patterns of commonality and divergence across a heterogenous sample (Joffe, 2012).

2.3 Participants

The study aimed to recruit between twelve to fifteen participants and 15 participants were recruited. The original research plan focused on the recruitment of trainee and qualified clinical psychologists with experience of caring for friends or family members with severe and enduring mental health difficulties. The snowballing technique was approved as the main vehicle for recruitment. In addition, a generic invitation to participate in the study was circulated to trainees on the University of Hertfordshire, University of Essex, Canterbury University, and the universities in the North Thames area programme. The invitation was also advertised through colleagues promoting the opportunity through informal networks and forums, including three university psychologist What's App groups, the local assistant psychologist What's App group and the national Psychologists in Private Practice Facebook group. Such methods resulted in carers of other conditions/psychology professions

expressing an interest in participating. Through reflective discussions several amendments were made to the inclusion criteria.

2.3.1 Inclusion and exclusion criteria

The original study inclusion criteria specified the recruitment of trainee and qualified clinical psychologists who were, or had been, looking after clients with MH difficulties seen within secondary mental health services (MHS). The rationale was that these psychologists would have experience of looking after loved ones with severe and enduring MH conditions of a chronicity seen in secondary care (Taskforce, 2016).

The study's original inclusion criteria were amended during the recruitment phase. The amendments to the inclusion criteria reflected my commitment to being as inclusive as possible to carer psychologists approaching me and wishing to participate in the study. The integrity of the research was maintained through reflective conversations with my primary supervisor to understand how the research might be impacted before a revised ethics application was submitted. There was an appreciation that this opportunity had not previously been offered to carer psychologists and a sense that it felt ethical to reconsider the inclusion criteria to enable a wider pool of willing participants to engage with the study. There was also a desire to recruit a full sample of participants so that the study could maximise its potential contribution to research about carer psychologists' experiences and professional practice.

A counselling psychologist in an academic role and with extensive clinical experience approached the researcher for inclusion in the study after the initial advertisement to universities was circulated. It was felt that her clinical experience and academic knowledge of clinical models might provide rich data for the study if she were allowed the opportunity of an interview. A second counselling psychologist also with academic and clinical experience subsequently approached the researcher for inclusion in the study, and specifically highlighted the interaction between physical health and mental health distress.

The first amendment made was to recognize that MH distress can co-exist with other health conditions, including co-morbidities. The criteria that caring experience could be current or historical was maintained. The next two amendments were focused on expanding the inclusion criteria to include assistant and counselling psychologists. Whilst these participants did not meet the original study inclusion criteria, due to slight variations in their employment and training status, they were very keen on participating in the study. They felt that the research might make a valuable contribution to the positioning of carers within employment and training and welcomed the opportunity to reflect on their experiences of caring with another psychologist with lived experience. The decision was taken to include all psychologists' experiences as a professional grouping, and not to analyse any variations in their accounts which pertained to either their training status or their professional registration.

Through the snowballing technique, two clinical psychologists had become aware of the study and had approached the researcher for inclusion in the research, but did not have experience of caring for a loved one with a MH condition. The fourth amendment was therefore to expand the nature of caring to include the experiences of psychologists caring for others with physical and/or neurodevelopmental conditions. The fifth amendment was to include an interview taking place by telephone rather than face to face because of the travel time between the researcher and participant's locations.

Revising the study's original inclusion criteria to include counselling psychologists and carers of loved ones with other difficulties/conditions led to a broadening of the study beyond its original scope. Including a wider range of experiences across a broader range of carer groupings and the psychology profession added more heterogeneity and complexity to the analysis of the data and the member checking process (*see section 2.6.5 Phase five: defining and naming themes*).

However, as an exploratory study which was primarily designed to reflect on the dual positions of psychologist carers within the profession, and to generate other areas of investigation into lived experience, this was an approach felt to enhance the breath of empirical knowledge that could potentially be derived from the study. The approach also enabled the recruitment of an appropriate sample size for a medium size study utilising thematic analysis (Braun & Clarke, 2013).

Participants originated from five different doctorate training providers, from three different NHS trusts and from two different third sector organisations. *See Table 3 for Participant demographics and Table 4 for Participants' caring experiences.*

PSYCHOLOGISTS' EXPERIENCES OF CARING FOR OTHERS

Table 3: Participant demographics

Gender	Male n = 3, female n = 12
Ethnicity	European n = 1, Indian n = 2, Middle East n = 1, white British n = 9, white Welsh n = 1, white Irish and Scottish n = 1
Religion	Agnostic n = 1, atheist n = 6, Christian n = 1, Hindu n = 2, spiritual n = 1, not stated n = 3, Jewish n = 1
Sexuality	Gay n = 2, straight n = 12, not identified n = 1
Age	25 – 30 years n = 4, 31 – 35 years n = 4, 36 – 40 years n = 4, 41 – 45 years n = 1, 46 – 50 years n = 1, 60 > n = 1
Current job role	Assistant psychologist n = 2, trainee counselling psychologist n = 2, qualified counselling psychologist n = 2, trainee clinical psychologist n = 5, qualified clinical psychologist n = 4
Most recent post held, including post held prior to training if trainee	Inpatient forensics including learning disabilities n = 3 Prisons and/or probation services n = 2 Adult Inpatients n = 2 Adult community mental health n = 1 Tutor n = 2 Private practice n = 2 NHS n = 13 Child and Adolescent Mental Health Services (CAMHS) n = 2 Learning disability and/or neurodevelopmental conditions n = 2 Hospice n = 1

Table 4: Participants' caring experiences

Participant pseudonym and caring experiences			
Pseudonym	Context of primary caring experience (relationship; issue; main setting described)	Duration of caring experience (current, historic)	Frequency of direct care provided
Simon	Brother; psychosis; secondary mental health services (SMHS), forensic	10 years (current)	Sporadic; indeterminate
Janice	Sister; acute psychotic episode, depression, severe anxiety; SMHS, inpatient	10 years (historic, occasional currently)	2/3 x a month
Katie	Partners; depression, ADHD, attachment trauma; SMHS, home	1 year (current); 1 year (previous)	1 hr a day
Joshua	Father; psychotic depression; SMHS, inpatient and home	30 months (current)	2 hrs per day
Alice	Father; psychosis and substance/alcohol use; SMHS, community	17 years (current)	Sporadic; indeterminate
Christine	Son; muscular dystrophy; home	24 years (current)	40 hrs a week
Amy	Mother; dementia; care home	> 4 years (current)	4 hrs a week
Antonio	Grandmother; cancer; home	8 months (historic)	24 hrs a month
Belinda	Grandmother; dementia; home	1 year (historic)	24 hrs a month
Azma	Sister; cerebral palsy Mother; mental health distress; home	10 years (sister, historic); 8 years (mother, current)	4 - 12 hrs per day
Linda	Mother; psychosis; SMHS, inpatient, community	> 20 years; more intensive support past 2 years	over 16 hrs a week
Barbara	Mother; psychosis; SMHS, inpatient, community	12 years (historic)	2 hrs a day

Participant pseudonym and caring experiences			
Pseudonym	Context of primary caring experience (relationship; issue; main setting described)	Duration of caring experience (current, historic)	Frequency of direct care provided
Aanisha	Mother; bipolar; SMHS, outpatient/home	17 years (current)	Daily if unwell
Denise	Brother; ASD and LD; home	21 years (historic)	1 hr a day
Niru	Brother; addiction; anxiety; home (current) Grandfather; Parkinson's disease (historic)	7 years (current); 5 years (historic)	15 hrs a week

2.4 Ethical issues

As a researcher with lived experience of caring, I had a keen sense of the potential power imbalance between the interviewer and interviewee, or questioner and respondent, and I reflected on how to manage this with my principal supervisor. We agreed that I should take steps to address this, including bracketing my own experience (Yardley, 2000), but also adopting the empathic stance I take within my clinical work, where empathy and understanding or appreciation of a person's experience can be conveyed in a multitude of ways (Keville, 2018).

The study involved the recruitment of psychologists at different stages of their careers. The confidentiality agreement was emphasised pre- and post-interview so that participants were assured of my adherence to professional conduct and boundary setting. The participants were reminded of their right to withdraw from the study at any point during

the interview, and to choose whether they wished to decline any questions they might be uncomfortable answering.

Ethics was granted by the University of Hertfordshire Health, Science, Engineering and Technology Ethics Committee with Delegated Authority University of Hertfordshire (ethics number: LMS/PGR/UH/03676; (*appendix 2*), and several amendments were subsequently approved (LMS/PGR/UH/03676 (1),(2),(3),(4); (*see appendices 3, 4, 5 and 6*). The first amendment made was to recognize that MH distress can co-exist with other health conditions, including co-morbidities. The next two amendments were focused on expanding the inclusion criteria to include assistant and counselling psychologists. The fourth amendment was to expand the nature of caring to include the experiences of psychologists caring for others with physical and/or neurodevelopmental conditions. The fifth amendment was to include an interview taking place by telephone.

All participants were given the opportunity to have their transcribed interviews sent to them for review to check that their anonymity had not been compromised before the data was analysed. Whilst understanding the confidential nature of the interview process, one participant had been uncomfortable with the level of detail they had shared in the interview, and on reading the full transcript, felt they may have potentially compromised their loved one's privacy. The participant was keen to reiterate that they valued the study and understood that the interview would remain confidential, but wanted a redacted version to

be used for the analysis. I had some emotional awareness of why the participant felt this might be necessary and agreed without hesitation.

2.4.1 Informed consent

Interested participants were asked to email or contact the researcher by phone, and any queries about eligibility to participate in the study were addressed. Participants were emailed the participant information sheet (*appendix 7*) and consent form (*appendix 8*) after the screening for their eligibility was completed. All participants were asked to consent to participate in the study and to sign the consent form before the interview was scheduled at a time and location of their convenience. Their verbal consent was also checked before the start of the interview and re-checked at the end of the interview. The researcher re-confirmed to the interviewee that their participation was voluntary. All participants were offered a debrief after the interview. One participant accepted this.

2.4.2 Confidentiality

Participants were informed that their data would be stored securely and confidentially. The interviews were transcribed by the researcher and the audio files were stored securely on a password protected computer and deleted after the transcripts and coding of the transcripts were completed. The data was stored in accordance with the UK Data Protection Act and the EU General Data Protection Regulation (Goodard, 2017). Pseudonyms were used to protect participant confidentiality.

2.4.3 Consultation

The researcher was a trainee representative on the University of Hertfordshire Experts by Experience Committee. The research proposal and the research questions were considered by the committee at the November 2018 meeting. Service user and carer consultation was initially provided from within the supervisory team and professional contacts. A carer consultant was subsequently engaged in the pilot interview process. The research participants were asked to comment on the themes and sub-themes from the thematic analysis, and some themes were combined and re-worded as a result.

2.5 Data collection

2.5.1 The interview schedule

Clarke and Braun (2013) recommend the use of open-ended questions so that the participant's response is not led by the researcher. The semi-structured approach to the

interview schedule and the use of prompts enabled the researcher to gain an in-depth understanding of the participants' experience. The original schedule was drafted based on the researcher's implicit knowledge derived from her lived experience of caring, and the draft schedule was reviewed for its appropriacy by the supervisory team prior to the pilot interview (*appendix 9*). After slight alterations were made following feedback, a pilot interview with a carer consultant was completed and the original interview schedule was further amended. One of the questions was moved to earlier on in the schedule, one question was amalgamated into another and two questions were re-worded to increase the clarity and comprehensibility of the questions (*appendix 10*).

2.5.2 The interview

Fourteen interviews were completed face to face and the final interview was completed by telephone due to the distance between the researcher and the participant's locations. The interviews lasted between 40 to 90 minutes. Some qualitative researchers have concerns about the quality of data able to be captured by telephone, and I had originally anticipated that telephone interview might impede the building of rapport and reduce the richness of the data to be collected (Novick, 2008). However, similarly to recent research demonstrating the parity of the quality of telephone interviews, I did not perceive any qualitative difference in the data collected in this final telephone interview (Heath, Williamson, Williams & Harcourt, 2018).

2.6 Data analysis

In accordance with the epistemological position set out by the study, which uses a phenomenological-hermeneutic framework, it was imperative that the data was analysed to highlight the emotional meaning(s) behind the participants' narratives (Todres, Galvin & Dahlberg, 2014). An inductive approach to data analysis was, therefore, used using the steps proposed by Braun and Clarke (2006) in their model of undertaking thematic analysis. Inductive analysis relies on themes being generated from the data itself, rather than from theories around what the data might suggest (Braun and Clarke, 2006).

Braun and Clarke's model focuses on highlighting the explicit or surface-level meanings in data, through *semantic* themes or codes, and the underlying assumptions or notions within the data, through *latent* themes or codes (Braun and Clarke, 2006). Below I have outlined the six phases of thematic analysis used. Throughout the process of analysing the data, these phases were interconnected and iterative.

2.6.1 Phase one: data familiarisation

I transcribed each interview myself, reflecting on the dialogue, the emotional content of the interview, and implicit and explicit messages about the participant's experience and their reflections on this. My reflections are encapsulated in an extract of my reflective journal (*see appendix 1*).

2.6.2 Phase two: generating initial and overarching codes

A transcript was presented to the Advanced Research Methods Thematic Analysis workshop and workshop participants trainees from the University of Hertfordshire Doctorate in Clinical Psychology Programme coded a section of the interview individually and then reflected on the process as a group.

The multiple coding sheets of this transcript were reviewed by the researcher and the primary supervisor, and points of similarity and difference in the researcher's line-by-line coding of the same transcript were considered. The researcher continued to code each transcript individually and to meet with the primary supervisor to hold reflexive and reflective sessions in which researcher biases could be attended to. During this phase, a coded transcript was shared with the secondary supervisor and minor differences in coding were considered by the researcher.

The next stage of the process involved dividing each transcript into a further three columns, to add in reflections on parts of the transcript and overarching codes from the line-by-line coding (*see appendix 11: Extract of coded interview*).

2.6.3 Phase three: searching for themes

The overarching themes and sub-themes were generated by the primary researcher through an iterative process of reviewing the line-by-line coding of the transcripts and cumulatively entering initial themes and sub-themes into one document (*see appendix 12*).

2.6.4 Phase four: reviewing themes

The themes and sub-themes were reviewed with the researcher and the primary supervisor and overlapping themes and areas where themes needed to be more fully drawn out through further reflection were considered.

2.6.5 Phase five: defining and naming themes

After a further meeting with the primary supervisor to consider the “essence” of the individual and overall themes (Braun & Clarke, 2006, p. 92), I consolidated some themes and sub-themes. A summarised thematic table was shared with participants by email (*see appendix 13*). Feedback around whether the themes and sub-themes broadly resonated with the participant’s individual experience of caring was sought from all participants.

Of the fifteen participants, 8 gave feedback on the themes and sub-themes from the thematic analysis; the carer consultant also gave feedback. There were originally nine themes and 25 sub-themes. Nine of the respondents confirmed that the themes reflected their sense of their interview experience. Of these, two respondents made suggestions about which themes might be further collapsed, which I reflected on, and another 2 respondents suggested slight re-wordings to sub-themes. One respondent felt that some of the themes did not match her experience, but she did not specify which themes she accepted, and did not respond to my request for clarification. My sense was this divergence may have related to her views around MH distress, and beliefs around health and illness.

Following on from a further meeting with the primary supervisor to consider the participant feedback, I entered the five themes and 12 sub-themes into a cross-participant thematic analysis table to show how individual participant responses mapped over onto the overarching themes (*see appendix 14*). The final themes and sub-themes were used to produce the results section.

During the viva process, my examiners drew my attention to some of the analysis which had started to consider some of practical implications of holding a dual identity within clinical practice. They probed me to consider some of the potential benefits and drawbacks of holding a dual position in more depth. I reflected on my personal experiences of clinical work, the phenomenological-hermeneutic epistemological position that I had taken and my reflections as a scientist-practitioner on my professional sense of self.

Following the viva, I reviewed the results section and could see where some of the quotes implicitly suggested the advantages and disadvantages of holding a dual position, that of a carer psychologist. I subsequently returned to the raw transcripts at a later date and re-read these and highlighted data relevant to the new overarching theme: "*Dual position of carer psychologists*". I could clearly identify that all participants had spoken of "*Connections which challenge*" and fourteen out of the 15 participants had spoken of "*Professional knowledges as resources*". The quotes selected for the write up of the new theme were identified because they elucidated the themes more explicitly. The majority of the coding for these new subthemes was contained within the original subtheme 3.6.2 "*Interconnection*

between personal and professional selves", which had been renamed during the defining and naming themes phase of the data analysis.

2.6.6 Phase six: producing the report

The coding facilitated the selection of quotes from participants to guide the production of the results section. The phenomenological-hermeneutic framework to the study guided the process of full engagement with the intensity, complexity and sometimes contradictory experiences which emerged from the heterogeneity of the caring experiences described by the participants.

2.7 Quality assurance

Throughout the research process I have been transparent about my personal connection to the study. My interest in researching carer experience developed through personal experience of caring for family members and professional experience of conducting research into an intervention for carers (Burrows & Gannon, 2013). Through acknowledging my position and maintaining a self-reflexive stance throughout the research process, I aimed to enrich the validity of the research and its outcomes (Elliott, Fischer & Rennie, 1999).

Differences in epistemological principles between qualitative and quantitative research mean that while it is not possible to standardise the results or to identify an objective truth in qualitative research (Barker & Pistrang, 2002), qualitative studies still need to demonstrate rigour and validity. Various guidelines can be used to evaluate qualitative

research studies (Elliott et al., 1999; Yardley, 2000; Tracy, 2010). I was drawn to Tracy's eight markers of quality to evaluate this study, partly because they enabled me to highlight the value of an insider researcher's perspective on undertaking a qualitative study. Throughout the study I was mindful of my ethical responsibility to portray the participants' caring experiences with sincerity. I highlight my approach in *Table 5: Quality criteria for this research*, before moving onto the presentation of results.

Table 5: Quality criteria for this research

Criteria for quality (Tracy, 2010)	Description of the ways of demonstrating quality criteria have been met (Tracy, 2010)	How the research met this criterion
Worthy topic	"The topic of the research is relevant, timely, significant, interesting" (Tracy, 2010, p.840)	<ul style="list-style-type: none"> • The topic is relevant and timely given how the NHS has progressed in understanding the value of engaging service users and carers in the shaping of services. • The topic is significant and interesting because it further develops the debate and discussion around dual identities. How do those people who use services, whether through being a service user or carer, who are also psychologists, manage the personal professional divide, with particular relevance to disclosure, its contextual appropriacy and the centrality of empathy in the therapeutic alliance.
Rich rigour	<p>"The study uses sufficient, abundant, appropriate, and complex</p> <ul style="list-style-type: none"> • Theoretical constructs • Data and time in the field • Sample(s) • Context(s) • Data collection and analysis processes" (Tracy, 2010, p.840) 	<ul style="list-style-type: none"> • A sufficient sample of psychologists with caring experience (n = 15) were recruited onto the study. Participants were recruited from different institutions and employers, with a relatively heterogenous composition of professional backgrounds, career stage, ages, gender, sexuality and ethnicity. • The process of recruitment and data collection took place over a six month period, which enabled the recruitment of a diverse sample of participants and with a range of experiences of caring for others. • The interview schedule was refined by carer consultants which enabled the formulation of questions to address the study questions and to gather rich, relevant and interesting data. • The methodology chapter details the data collection and analysis processes. Extracts from the reflective diary underpin the processes and demonstrate the researcher's processes of reflexivity and reflectivity.

<p>Sincerity</p>	<p>“The study is characterized by:</p> <ul style="list-style-type: none"> • Self-reflexivity about subjective values, biases, and inclinations of the researcher(s) • Transparency about the methods and challenges” (Tracy, 2010, p.840) 	<ul style="list-style-type: none"> • Self-reflexivity was enhanced through maintaining a reflective diary during the data collection, transcription and data analysis processes. • Engagement with carer consultants throughout the process of the study enabled questions about the development of the study to expose presuppositions about its direction, including the researcher’s inherent implicit and explicit values and cognitive biases. • The researcher was transparent about her insider positioning with participants, and throughout the write up of the study. This process is also demonstrated through the reflective diary. • The researcher maintained transparency around the ethical challenges presented by the study, including demonstrating integrity about the level of previous research in this area, as highlighted by the paucity of research able to be examined through the literature review, and the establishment of a different theoretical basis on which to begin this study.
<p>Credibility</p>	<p>“The research is marked by:</p> <ul style="list-style-type: none"> • Thick description, concrete detail, explication of tacit (non-textual) knowledge, and showing rather than telling • Triangulation or crystallization • Multivocality • Member reflections” (Tracy, 2010, p.840) 	<ul style="list-style-type: none"> • The phenomenological-hermeneutic framework adopted by the study necessitates that the researcher seeks to highlight the emotional meaning conveyed during the interaction between the researcher and participant, rather than focusing on the content. Extracts from the interviews have been selected for inclusion in the results section which provide the reader with ‘thick’ and ‘rich’ data, and support Tracy’s vision of enabling the reader to experience the vibrancy of the data for themselves (Tracy, 2010). • Data was crystallized throughout the data analysis process and the involvement of the supervisory team in validating the coding process and the carer consultants and the carer participants in the evolution of the themes and sub-themes. • The carer consultants and carer participants enabled some multivocality to be expressed within the study. • In order to ensure that the descriptions and interpretations of the data remained faithful to the data itself, there were multiple meetings with the supervisory team to reflect on the write up of the results section.

<p>Resonance</p>	<p>“The research influences, affects, or moves particular readers or a variety of audiences through:</p> <ul style="list-style-type: none"> • Aesthetic, evocative representation • Naturalistic generalizations • Transferable findings” (Tracy, 2010, p.840). 	<ul style="list-style-type: none"> • The insider perspective assisted me to reflect on the emotional content of the interactions between the participants and myself after the interviews. Carer consultants and study participants confirmed that the themes and sub-themes resonated with their personal experiences of caring, indicating that the study’s findings could be generalised and demonstrating what Tracy refers to as “aesthetic merit” (Tracy, 2010, p. 845). “Aesthetic merit” is the ability for the reader to be similarly affected by the study’s findings (Tracy, 2010, p.845). • The findings can also be transferred to psychology readers without personal experiences of caring for others, to provide insight into the depth and complexity of emotions which can be experienced in the context of caring for loved ones.
<p>Significant contribution</p>	<p>“The research provides a significant contribution:</p> <ul style="list-style-type: none"> • Conceptually/theoretically • Practically • Morally • Methodologically • Heuristically” (Tracy, 2010, p.840). 	<ul style="list-style-type: none"> • The study enables new conceptual and theoretical insights to be drawn into the experiences of psychologists with personal experience of caring for others. It expands on the existing studies around the experience of having dual identities for psychologists who are also/have been service users. • It explores the potential links between experiences of caring for others and the enrichment of empathy in the therapeutic alliance, and the potential links between emotional experience and overidentification in therapeutic work. • The study concludes with recommendations for future research and policy considerations.
<p>Ethical</p>	<p>“The research considers:</p> <ul style="list-style-type: none"> • Procedural ethics (such as human subjects) • Situational and culturally specific ethics 	<ul style="list-style-type: none"> • Procedural ethics were demonstrated through gaining ethical approval through the University of Hertfordshire Health, Science, Engineering and Technology Ethics Committee. Steps were taken to ensure confidentiality, informed consent and the right to withdraw. • Throughout the research process ethical issues were addressed in accordance with the researcher’s relationally ethical position as an insider researcher. The use of my reflective diary and regular supervision at all stages of the research process enabled me to consider my position, and positioning, throughout the data collection, analysis and reporting procedures.

	<ul style="list-style-type: none"> • Relational ethics • Exiting ethics (leaving the scene and sharing the research) (Tracy, 2010, p.840) 	<ul style="list-style-type: none"> • The moral goals of the study were considered to outweigh any potential distress experienced by participants. Many participants were appreciative of the opportunity to share their stories, and to convey their values around the research being utilised to widen knowledge of carer experience beyond their immediate settings. • In addition to showing participants respect and warmth, and bracketing her personal experience to avoid engendering assumptions and leading the interview, when asked to, the researcher gave a bounded account of her personal narrative and rationale for the study. In this way, relational ethics were upheld and the power imbalance between researcher and participant was narrowed. • A debrief was offered at the end of each interview, along with the opportunity to review the themes and sub-themes of the analysis, and to be sent a research summary after thesis submission. Participants will also be kept informed about any journal publications.
<p>Meaningful coherence</p>	<p>“The study:</p> <ul style="list-style-type: none"> • Achieves what it purports to be about • Uses methods and procedures that fit its stated goals • Meaningfully interconnects literature, research questions/foci, findings, and interpretations with each” (Tracy, 2010, p.840). 	<ul style="list-style-type: none"> • The phenomenological-hermeneutic framework was centred throughout the study and this is demonstrated through the introduction, methodology, results and discussion sections. • The lived experiences of the participants have been highlighted through a semi-structured interview, developed by carer consultants, and carer consultants and participants have been utilised to review all stages of the study to ensure that the study draws together the existing literature, the aims of the study and the findings, interpretations and recommendations in a coherent and meaningful way. • In addition, I brought my perspective of my lived experience, and I drew on the insider researcher perspectives of members of my supervisory team to add further depth to the study.

Chapter Three: Results

3.1 Overview

This chapter presents the results of the thematic analysis. Six themes were established from analysis of the data set: “personal and professional roles”; “the emergence of a carer identity”; “changing/evolving relationship with loved one”; “carer stress and strain”; “impact on professional practice” and “dual positioning.” The themes and subthemes are highlighted in the table below.

Table 6: Themes and subthemes

Themes	Subthemes
Personal and professional roles	The professional context: mental health as a complex phenomenon <i>“Mental health can cover a whole range of things”</i>
	Opening up about mental health/distress as a professional <i>“Perhaps my view of what’s normal is this big”</i>
	Questioning of the self <i>“...then I started thinking ‘is something happening to me?’”</i>
The emergence of a carer identity	Moving from struggling to accept carer ‘label’ to realising that I’m a carer <i>“So I almost don’t think I’ve done anything to care for him...”</i>
	Emotional responses <i>“...it was quite disgusting but...I did it with no problems...”</i>

Themes	Subthemes
Changing/evolving relationship with loved one	Strengthening the bonds between us <i>"...she's curious about what's going on for me"</i>
	Sense of loss <i>"You're almost grieving for a person that's still alive..."</i>
Carer stress and strain	Relying on me <i>"...sometimes he'll phone me and cry down the phone..."</i>
	Changed relationships with personal others <i>"...fearing people's judgements and whether it was OK to share..."</i>
Impact on professional practice	Depth of ability to empathise <i>"...until you go through something within your own personal life..."</i>
	Interconnection between personal and professional selves <i>"...I experienced...some difficulties...that brought me into the profession...Being a carer...broadens that even more..."</i>
	Towards and away from career/specialism <i>"...being a young carer...I saw myself as helping other people..."</i>
Dual positioning	Connections which challenge <i>"...it's just too close to home..."</i>
	Professional knowledges as resources <i>"Now I have a bit of a formulation of my dad"</i>

The diverse sample of participants (see *Methodology section: 3.3.1 Table 3: Participant demographics*) spoke of different relational caring experiences, some historical and some current (see *Methodology section: 3.3.1 Table 4: Participants' caring experiences*).

3.2 Theme one: Personal and professional roles

In this theme, participants gave elaborate accounts of their conceptualisations of MH and their professional and personal relationships with MH. Whilst there was shared agreement around the need to address the stigmatisation of MH amongst the sample, there were distinct differences in how participants positioned themselves in relation to the language of MH and MH distress. The subtheme "*The professional context, mental health as a complex phenomenon*" detailed the intricacies of mental health, and the constructs of mental health, mental distress and mental illness. The subtheme "*opening up about mental health/distress as a professional*" highlighted the ways in which participants expanded their ideas around normality, whilst also challenging stigma. The final subtheme "*questioning of the self*" considered the participants' reflections on the impact on themselves of caring for their loved ones.

3.2.1 Subtheme: *The professional context: mental health as a complex phenomenon*

In adopting a phenomenological-hermeneutic framework to the study, the central concern was to present an interpretation of the collective and individual meaning(s) of the participants' caring experiences and how these may have influenced their clinical practice. Understanding how participants conceptualised MH in broad terms, and the nature of MH distress in particular, could help to situate participants' individual and collective narratives within their personal and professional identities.

All participants individually described their notions of MH. The majority of participants focused on a “*challenge*” to an individual’s way of being in the world as the catalyst for distress. The participant below gave a stronger account of the ruptures in the person’s belief system and linked this to psychological distress.

“...mental health can cover a whole range of things... Sometimes if someone’s belief system is challenged in some way, or shattered in some way, that could lead to some level of psychological distress.” (Janice)

All participants highlighted distress as a universal human phenomenon. The phenomenon existed on a continuum with the markers of the perceived intensity of the distress demarcated as: “*mental health distress*”, “*psychological distress*” and “*acute distress*”.

“...psychological distress...encapsulates the idea that we are all humans, and we can all have distress even if it doesn’t necessarily tick 7 criteria of a DSM box...” (Amy)

“I work in an inpatient unit...there’s acute distress and then there’s the distress that we all feel, so I...would say that...we all get distressed at different times and to different levels.” (Denise)

There was a focus on the association between MH and stigma amongst the majority of the participants with different views on how MH might be destigmatised. The divergence in views seemed to originate from different experiences of caring. Those caring for loved

ones with physical health illnesses were more likely to prefer more medicalised language to describe MH difficulties. For example, Christine, the mother of a son with muscular dystrophy, disliked the use of the term “*mental health*” as an umbrella term and preferred the use of “*mental illness*” as a way of understanding peoples’ experiences.

“It’s not mental health, it’s mental illness...calling an illness health...it’s not going to deal with the prejudice...I’ve been around long enough to see six incarnations of terminology and every time we do it nothing changes...we need to deal with the problems in attitude, not the terminology.” (Christine)

Christine’s view was that the move towards conceptualising MH in terms of distress would not achieve the intended aim of destigmatising MH. Her perception was that the focus on iterations of terminology was a deflection from dealing with the more embedded and ingrained difficulties in attitude towards “*mental health*.”

Whilst Christine spoke of the need to address attitudes around MH, rather than hide this need through a relabelling process, Antonio, who cared for his grandmother through her cancer journey, was concerned that the term “*mental health distress*”:

“...contributes to the maintenance of a stigma around mental health issues, because mental health distress can mean absolutely everything from schizophrenia to mild anxiety...I imagine people thinking that it’s something wrong with the brain...this really angers me because it doesn’t give justice to the people who are experiencing mental

health distress...one of the most important things is normalising for example intense anxiety, but that doesn't mean that there is anything wrong with you, there are reasons why this has developed for you right now..." (Antonio)

Antonio inferred that taking a more inclusive stance towards the construction of MH was problematic. By using the term "*distress*" to encapsulate the range and spectrum of MH difficulties he believed the stigma attached to more severe and enduring MH conditions might prevent the wider population from accessing support for their MH when they experienced normative distress in response to a difficult situation. Antonio's response appeared to substantiate Christine's argument that the underlying stigma attached to experiencing a difficulty with one's MH had not been addressed through changes in terminology, but had widened the pool of people affected by stigma through the broadening of terms deployed to depict difficulties with emotions and mental functioning by including the universal experience of distress.

Participants expressed different views in relation to the perceived value and function of diagnoses, with some criticism for the medical model. Amongst carers of loved ones with psychosis, there appeared to be a more nuanced consideration of the implications of diagnostic labelling. For example, Aanisha spoke of a dislike of MH "*labels*", but also recognised that they can create a shared understanding of a MH difficulty for her and her mother, and thus, may be perceived as being helpful for carers.

"...when I worked in acute inpatient services, there were a lot of people that were being labelled with bi-polar or personality disorder and I don't like those labels, but when I read about why certain people might have those labels then it creates an understanding for me for my mum." (Aanisha)

Niru, working in a forensic unit and caring for her brother, spoke of the potentially validating nature of diagnosis and its benefits for clients, but also held some of its potentially negative aspects in mind. She connected to the diagnostic power of labelling in a reductionist sense and alluded to a sense in which it may be useful to create demarcations around people experiencing MH difficulties through offering a "label" or a "diagnosis". In this way, people with MH conditions can seemingly become classified as a distinct group of people and different from the majority of the population.

"I know some people look for a diagnosis and that offers them that kind of safety and containment...but my default isn't to label somebody...I'm very much about the person's narrative and their experience and what's led them to where they are now, so I think saying it's a condition it's quite powerful but in a potentially quite derogatory way." (Niru)

Azma, a psychologist working with terminally ill patients, described the function of diagnosis as being used to "move us away from having to understand and tolerate the pain

that people go through". She spoke of how easy it was to receive a diagnostic label, rather than seek to address the underlying factors of the individual's distress.

"...if you're experiencing mental health distress and you can't work, and you need to access benefits, they don't care what your life experience is, they just want to know what the diagnosis is...so we function on diagnoses, which really moves us away from having to understand and tolerate the pain that people go through..." (Azma)

In summary, all participants concurred with the notion of the human experience of distress, but they expressed a range of views around the conceptualisation of MH. Differences between how participants viewed MH largely appeared to relate to differences in personal caring experiences. There appeared to be a division in how MH was conceived of between those who cared for people with physical health difficulties and those who cared for people with MH difficulties. Participants who cared for people with physical health conditions preferred the use of medical terminology such as *"mental illness"*. Participants who cared for people with MH conditions were more welcoming of developments in mental health terminology and accepting of holding dual positions around the process of diagnostic labelling.

3.2.2 Subtheme: Opening up about mental health/distress as a professional

In this subtheme, participants described how their caring experiences had enabled them to broaden their perspective on “normal” ways of being in the world. There was a sense that this expansion facilitated their acceptance of a different relationship with, and connection to, people who were experiencing MH distress, giving this a relational quality. This relational quality might be experienced as a growth in the potential to accommodate more of another’s experiences without judging them.

“I imagine that people who haven’t experienced living with my mum would have a view of what’s normal as like this, yeah, big, and perhaps my view of what’s normal is this big (hands placed wide apart and above and below her head). And that therefore leads me to be more open to that more...” (Barbara)

Belinda, who cared for her grandmother, also identified that her mother had MH difficulties in her interview. She spoke about how the process of labelling aspects of human experience as “mental health” led to the creation of boundaries around human experience. This positioning curtailed the “richness” of human experience and could be experienced as a loss, as a desire to contain the potential breadth of humanity through the bracketing of “the crazy people”. In this way, “the crazy people” could be separated out. Her personal process had led her to consider that “actually maybe there’s more in certain ways.”

"...there's so much more to offer there, there's so much richness and I think if we label things as mental health, you know, 'the crazy people', it's almost like there's less to offer, whereas actually maybe there's more in certain ways." (Belinda)

Here Simon, a psychologist in forensic services, also appeared to voice the potential for personal growth through his connection to his brother and his brother's experience of MH difficulties. He detailed his shift in the feeling of embarrassment about his brother's situation to a feeling of pride in his brother, suggesting that his own process around moving towards a state of acceptance had had intrinsic value to his sense of personal self. This process extended to a sense that he wished to use his personal experience to be of service to "patients" in a clinical setting. Perhaps it might be assumed that he felt that sharing the outcome of his personal journey, his acceptance of his brother's diagnosis, might give some hope for others to grow to a state of acceptance around their own, and others', mental health.

"...when it first happened, I felt quite embarrassed about the whole thing because I remember when I...realised he'd been sectioned, I almost expected the van to go past the (course building) window...now I'm not that bothered about saying that my brother has schizophrenia. I've occasionally said it to patients if it's in some kind of context where it's felt appropriate to say that...I don't feel embarrassed about it, I'm proud of my brother." (Simon)

In this subtheme, the majority of participants with experience of caring for people with psychosis reflected on constructs of social norms and how their sense of 'normality' had grown as they moved beyond their original understandings and interpretations of socially acceptable ways of being in the world. This journey appeared to enable them to accept, and transition towards valuing, the behaviours of their loved ones. Some participants also spoke of ways in which they used appropriate contexts to disclose their loved one's MH if they felt it would assist a patient or a carer towards a state of increased acceptance.

3.2.3 Subtheme: Questioning of the self

In this subtheme, participants talked about the impact of reflecting on caring for their loved one and what this brought up for them. For some participants who were new to caring for a family member, the lack of a demarcation between their personal and professional lives, seemed to trigger a questioning process about their self, including a reappraisal of their own mental health. It also seemed to elicit an existential question around their personal identities, through the questioning statements "*who am I? what's my mental health like?*"

"So I felt like there was this strange blurring of my personal and professional life...I was questioning myself a bit really, 'who am I? what's my mental health like?'" (Simon)

For all participants this questioning of the self was far reaching and extended to a questioning of the capacity of the personal self to continue to execute professional responsibilities whilst managing to care for a loved one. Here Janice explained the outcome

of this process was her negotiation with her sister to come to a revised understanding around their individual personal boundaries in their relationship.

“And last year I had a frank conversation with her about my ability to cope because of training, and I said there are conversations we have that are distressing for me and for you...so we’ve come to a collaborative agreement as to when it’s becoming too much...and that’s been very explicit and very transparent.” (Janice)

In the subtheme, *“Professional knowledges as resources”*, section 3.7.2, there is further consideration of the intersection between personal and professional boundaries and their value to the personal self of the carer and the professional self of the psychologist.

Another aspect of the questioning process related to the healthcare system itself and its treatment of the loved one in its care and how that impacted on the carer’s sense of things and their sense of self. For example, this questioning process appeared to translate into an enhanced understanding of Janice’s own values, by considering *“what was really important”*:

“I was like I don’t understand how this sort of system can be operating so I think that had a real impact on my sense of things and my sense of self and what was really important...one of the things that came out of that was the idea of talking to the person like a person and talking to their family members...and like having a better understanding of...what you’re doing and why you’re doing it...” (Janice)

Janice also highlighted her sense of awareness and appreciation of behaviours and their relational value within working settings as expressed by *“talking to the person like a person and talking to their family members”*. Janice and Simon, both working within forensic settings, highlighted how their caring experiences had enhanced their ability to sit with distress in clinical settings through their own questioning process around their values, and what felt important to them in clinical practice.

3.3 Theme two: The emergence of a carer identity

In this theme, participants reflected on their understandings of the label 'carer' and the meanings they attributed to identifying as carers. They then reflected on their journeys towards being associated as carers and the key markers in these journeys. The sub-theme *“struggling to accept carer 'label' to realising that I'm a carer”* explored how carers reflected on the process of identifying as carers. The final sub-theme *“emotional responses”* detailed a range of emotions which seemed to be either held internally by the carer, remaining unexpressed, or shared with others and externalised.

3.3.1 Sub-theme: Moving from struggling to accept carer 'label' to realising that I'm a carer

There were a number of complexities around the struggle to accept the carer label. All participants spoke of familial expectations around caring, however, of the sample of participants, it was notable that the three carers of black and minority ethnic (BAME) heritage seemed to emphasise the strength of cultural norms within their communities.

For Azma, who had previously been a young carer for her sister, this meant that she was unable to envisage how a potential carer identity could exist outside the expectations of her as a daughter looking after her aging parents. She highlighted the prevalence of cultural norms as potentially precluding this possibility through her wording, *“(caring is) just something that we’re expected to do.”*

“I don’t see myself as a carer...I’m very aware of my parents’ expectations of me in terms of what I should be doing for them, and I’m not sure that I’d call myself a carer, and I’m not sure that...especially another Indian person, would say she’s in a caring capacity, because it’s just something that we’re expected to do.” (Azma)

Aanisha also described her disconnect with the term carer. She questioned the validity of the term in the context of her cultural and familial values.

“I don’t like the term carer, I never have, because it doesn’t make sense to me, because I just see myself as my mother’s daughter and my brother’s sister and in my culture that’s just it, and I think in most cultures family is family...” (Aanisha)

She also elucidated the wider pressures on carers within BAME communities. In the interview Aanisha went on to detail how her and her family were disowned from sections of their community because of a lack of understanding and stigma around MH. She alluded to periods of familial isolation when *“it was just us.”*

"...our extended family...disowned us, and friends because they didn't understand, so there were a lot of periods it was just us." (Aanisha)

For other carers there was a rejection of the label carer because of the relational aspect to caring which a carer felt could or should be subsumed within a familial role.

"I defined myself as a granddaughter, looking after my grandmother. The term carer feels like a professional responsibility or a defined role and responsibility, whereas I was doing it out of love for my grandmother...it makes things a bit colder... it's something outside of the family, it's something out there...there's something medicalised about it for me as well." (Belinda)

Belinda's perception of the term carer was of a professional role, something separate to a familial relationship, as if the caring element of the relationship belonged elsewhere. For her, it also suggested the removal of love and warmth from the relationship, and she associated it as being a medical term.

Simon also described how he perceived a conflict between his understanding of the role of a carer and a familial role, the role of a brother. He then detailed a shift in his acceptance of a carer's identity based on him representing his brother in a public forum.

"So I almost don't feel I've done anything worthy of the term caring...it's more I've been his brother...what I did do which may be more about caring is my parents made a complaint to the mental health trust that he was being looked after and I went with

them to a meeting to talk more about our concerns, so I suppose that felt a bit more like being a carer.” (Simon)

Extending this beyond the family role, Denise, a young carer of a sibling with learning disabilities suggested that part of the struggle in accepting the term carer for carers of people with MH difficulties might be related to the stigma associated with MH.

“I definitely was a carer back then, I think there’s something about learning disabilities where the term carer has possibly got less stigma, as opposed to perhaps mental health difficulties, in my experience people struggle with that word more whereas in learning disabilities I didn’t particularly struggle with it and I related to it.” (Denise)

In total, six participants reflected on how they felt they had not fulfilled their understanding of the criteria required to identify as a carer for a range of reasons. These criteria included associations with the carer label that carers looked after people with physical disabilities, were live-in and cared for a pre-set number of hours, criteria which appear to be aligned to the eligibility criteria for Carer’s Allowance benefit. For example, one young carer of a parent with MH difficulties spoke of her previous understanding that carers were looking after people with physical health difficulties. She acknowledged her questioning of the carer identity had led to “*assumptions*” around who young carers were and whether or not she might find a place of belonging within a group of young carers.

"I remember one of my mum's CPNs that used to come round always used to nudge me, 'you should go to Young Carers' and...I was kind of like 'well I don't know that I feel like a carer' so I don't know that I would fit in with that crowd, and I'd obviously made assumptions about what that crowd was...most people that went to Young Carers' were, in my mind, looking after people with physical disabilities." (Barbara)

For some carers there was a clearly defined transition point in their process of identifying as a carer. For Christine, who had previously viewed her care of her son in the context of him being a child and her being his mother, this transition point came when her son grew into a man.

"Up until the age of 11, you just see everything in relation to him as a child. We did physiotherapy but I always saw that just as part of the normal mother thing, but from senior school onwards it was more and we didn't have any carers from outside the family...he was 22, so I did do all the care and I gave up work." (Christine)

In summary, participants may have originally questioned the applicability of the carer identity due to perceived social parameters and associations around what it meant to be a carer. Participants from BAME heritages and from white heritages conveyed a sense of the cumulative experience of caring leading to a realisation that they performed caring responsibilities, however, the experiences of participants from BAME heritages also showed a more complex interplay between cultural norms and familial positioning. For all participants,

the journey of accepting the carer label was impacted by notions of familial roles and perceived responsibilities, but it appeared that the cumulative nature of caring led to a shift in acceptance of a caring identity, whether this was initially conceived of, or not.

3.3.2 Subtheme: Emotional responses

In this subtheme participants conveyed a mixed range of emotional responses to their caring experiences, which were at different intensities at different junctions of their caring journeys. It should be noted that this subtheme mainly reflected some of the more difficult emotional aspects of their caring relationships, and that the next theme: *changing/evolving relationship with loved one*, addresses the more emotionally rewarding elements of caring (see *Strengthening the bonds between us*, section 3.4.1).

In her interview, Alice spoke of her sense of disappointment at her relationship with her father and how this had influenced her caring responses. She believed that her approach to care would have been different if her childhood relationship with her father had been nurturing, as opposed to there being “*quite a lot of abuse of different sorts*”. She also described how she continued to care for her father despite others not understanding her wish to care for him, and how she had set parameters around her caring relationship to enable her to care.

“...as a child growing up with someone with substantial problems and alcohol use there was quite a lot of abuse of different sorts so I think that has influenced the way

in which I want to care so some people have said to me, 'I don't know why you do it all, why do you stand for it, but I think I still want to care and I still want to do some things...whereas I think if we'd had a really good relationship...the way in which I care would be very different...' (Alice)

In the *Dual positioning theme*, section 3.7, Alice further considers how her experience of caring for her father may have contributed in part to her ability to see the complexity within the behaviours of others, and thus enhanced her non-judgemental stance to her clinical work within a forensic setting.

Aanisha spoke of the split in her personal and professional selves, and the sense of internal conflict created by the feeling of *"anger even though I understand it"* which was generated after caring for her mother with MH difficulties. There was also a sense of needing to disconnect from her professional self as expressed by *"when I'm in that position I can't be a psychologist"* and her need to continue to care for others in her professional role.

"...I still feel anger even though I understand it, because when I'm in that position I can't be a psychologist, I can't...I do get angry sometimes, tired, and frustrated, because I still need to go on with my day-to-day life and I don't have a break, which is why carers need to have a break, and there's no services for that really." (Aanisha)

Aanisha also expressed awareness of the need for resources to support carers to continue to care. Resources were an issue for Christine, the carer of a son with muscular

dystrophy, who spoke about the inequity in the housing system in relation to different client groups. She was unable to understand how the transition from child into adult had different resourcing implications for people with physical and learning disabilities; resulting in her getting “cross” with “the system”.

“Unlike people with a learning disability who automatically get housed at 18, he would only get housed if we threw him out, because he has a suitable place to live...it’s like you’re not allowed to be an adult if you’re physically disabled but you are if it’s a learning disability...so I get a bit cross that the system doesn’t provide as much support for him.” (Christine)

A common feeling amongst carers was a sense of internalised guilt and the impact on a carer’s sense of self. Here Christine named this as blame. She denied that her son or her husband “blame” her for being the genetic carrier of a progressive health condition but she articulated a sense of “physical” responsibility for her son having his condition.

“He doesn’t blame me, his dad doesn’t blame me, but I blame me because I think that if he was somebody else’s child he wouldn’t have had it so I feel...I don’t feel as if I’m psychologically responsible but physically I am...” (Christine)

A feeling expressed by all carers was of feeling overwhelmed at key moments. Christine spoke about the consuming nature of her caring role, and how only her partner was able to understand the impact on her life. She conveyed how this sense of others not being

able to understand how it has impacted her fed into a feeling that she wanted to escape the situation. In her *“negative moments, it’s stolen my whole life”* evoking a sense that her personal agency had been subjugated due to the centrality of care for her son within her life.

“I don’t think anybody, other than my partner, understands what effect it has on you...sometimes I just wanna run away, and it’s about time, which I don’t get really...in my negative moments...it’s stolen my entire life, everything I do, everything I think about, centres around it.” (Christine)

Carers of people with psychosis spoke vividly of the *“scary”* experience of visiting their loved one in inpatient settings and witnessing the impact of medication, funding and staffing issues. Despite the time that had elapsed between this experience and her recollection, this experience was still vivid for Janice. She described how her sister was *“just completely gone”* and the role of evidence-based medicine in this process.

“Like one of the scary things was when I saw her in an acute unit and she was just completely gone...she wasn’t her anymore...they’d given her a concoction or a cocktail of sort of whatever it was that was evidence based at the time...” (Janice)

Participants’ views on medication are further considered in the subtheme *Connections which challenge, section 3.7.1*. While this related to a more recent experience of caring for his father, Joshua described the feeling of wanting to escape from the inpatient

unit. A sense of shock is conveyed through the use of the wording, *"(it was) just God awful...it made me feel like running out."*

"I think having to visit my father in an inpatient unit and deal with...some of the people who work in these places and the lack of funding and just God awful...it made me feel like running out." (Joshua)

Barbara recollected her memories of being scared when she visited "mum" as a child.

"I think I was terrified. I had memories of people trying to jump off the hospital roof when I went to visit mum and I think I was so unhappy and really scared." (Barbara)

Here Amy appeared to want to protect her mother from the potential shame of how she might be perceived of by others (evoked from the term "mortified") because of behaving in a socially unacceptable way. There is a sense that Amy wanted to create a demarcation around her mother's current and historic behaviours by saying *"this is not how she normally behaves."*

"...my mum was wandering around...because she was disinhibited...things that I knew she would be mortified about...doing in front of other people and I think it was her being witnessed by these people and wanting to say 'this is not how she normally behaves.'" (Amy)

There was also a sense in which carers of people with MH issues felt the need to protect other family members because of the stigma attached to the difficulty. Niru spoke earlier in the interview about her perception of differences in understanding of MH issues within the British Indian community. Here she articulated the impact of older people not *“having that fuller understanding of mental health and addictive behaviour”*, which inferred a sense that her parents might be blamed for her brother’s MH difficulties, through the words *“it must be something to do with my parents, something (they) must have done.”*

“...I think there’s a natural thing for older people there is something around, ‘my brother’s got this problem,’ and they think it must be something to do with my parents, something my parents have done, as opposed to having that fuller understanding of mental health and addictive behaviour.” (Niru)

Here Barbara, a young carer, spoke of her sense of isolation from the feeling of being unable to vocalise her experience of caring for her mother with others, as she identified as a carer, but did not know whether it was safe to share this with others or not.

“I think the thing that most affected me emotionally was the quandary of could I tell people or not, and how isolating that felt...I felt like it was part of my identity but I felt like I couldn’t share it.” (Barbara)

In summary, participants described a range of emotional responses, internalised and externalised, and to different levels of intensity and severity. Some of these emotional

responses were able to be safely shared with others through personal relationships, but other emotional responses appeared to rest heavily with the participants and impacted on their sense of self. Christine, the mother of a son with muscular dystrophy, spoke of a difficult sense of internalised blame, whereas carers of people with psychosis spoke of a number of fear related responses associated with their recollection of visiting their parent or sibling on inpatient units. A sense of shame was conveyed by the daughter of a mother with dementia because of the change in her behaviours. When participants expressed a sense of anger and/or resentment at caring, this appeared to relate to the overwhelming nature of caring and the lack of resources available to support them to care.

Yet this was not the only experience. Explored in the next theme was an evolution of their relationship with the person they cared for, sometimes for the better.

3.4 Theme three: Changing/evolving relationship with loved one

In the subtheme "*strengthening the bonds between us*" participants described how the sense of emotional experience had deepened connections. There was an appreciation of how the acuity of the loved one's distress at that time had led to strengthened relational bonds as the carer strove to meet the loved one's needs. The subtheme "*sense of loss*" relayed how keenly carers could feel for the loss of their loved one, or an aspect of their relationship with their loved one. In some cases, the sense of loss was gradual but it was also

experienced as a sense of *space* or not knowing the potential of what the relationship could have been.

3.4.1 Subtheme: Strengthening the bonds between us

"I once got told a story about my father which touched me so much that I can't even say it without crying...given the amount of distress he was in, there was something so kind and generous about him that came through even though he was just on another planet and to know that he was still himself..." (Joshua)

Joshua conveyed how his emotional connection to his father was strengthened through the sharing of a story and what this said about his father's innate kindness and generosity. This was in spite of him being so unwell, that the participant described him as being *"on another planet."*

In the quote below, Antonio described how his relationship with his grandmother had been strengthened through the reversal of their roles. His grandmother had transitioned from a powerful parental figure who had taken care of him, into someone who had become fragile because of cancer and now needed his support. In the interview, he described the shift in dependency between them and his desire to *"really take care of her"* as an act of willingness, not duty.

"...it strengthened it (the relationship) because it made me see the fragility of this human being that had been so...powerful in my life up until then...it is for every child

someone that they depend on to an individual who loses a bit of that power because of a disease...they become more fragile...I noticed her inability to perform whatever she was doing before...it was accompanied by my desire to help, to really take care of her. It wasn't even a duty. I thought I want to do this..." (Antonio)

Christine also spoke of the intense nature of caring for her son with muscular dystrophy and how liberating it would feel to "not to have to worry about it". However, she also spoke of the value she placed in the strength of their connection in their relationship, and she perceived this to be reciprocal and equal and enhanced due to her role in providing his care.

"Sometimes I think it would be nice not to have to worry about it, but then I think, 'I wouldn't know what to do with myself, he's my best friend'...he and I just click...he'll look at me and I'll be in hysterics..." (Christine)

This subtheme conveyed a sense of how the son, grandson and mother carer psychologists recognised and celebrated their relationships through appreciating the qualities of their loved ones. There was a sense of the reciprocal nature of caring taking place within the lifecycle conveyed by Antonio, when he reflected on his experience of caring for his grandmother.

3.4.2 Subtheme: Sense of loss

The sense of loss experienced by participants appeared to have been particularly compounded when the caring relationship continued over a period of years. Aanisha conveyed the disappointment and sadness around the temporary loss of her 'mother' figure during her mother's episode. She experienced her own sense of temporary withdrawal from the mother-daughter relationship; she expressed this as *"I can't be that person for a while"*.

"...as a young person I used to get more physically tired because I had to do more physical things, but as I grew older, I became emotionally tired...my mum goes through her episode and then she wants to become my mum...then I hit a low and I'm so tired...I just shut myself away, which is sad...because talking about it now when she's not well, I'm like her mum and when she's getting better and she needs me as her daughter to do things like go shopping, or watch movies, I can't be that person for a while." (Aanisha)

For other carers of loved ones with MH difficulties the change in the loved one may have been a contributory factor in a shift in the felt sense of security within their relationship. There was a questioning of how they would be received, trying to engage with the loved one. Here, Simon's sense of vulnerability and the undermining of his security was conveyed through, *"I wasn't sure if he'd actually see me."* There was also a sense of relief and a welcome reconnection expressed by, *"he did see me which surprised me."*

"...then the last time he got sectioned, I went to the hospital to see him and I wasn't sure if he'd actually see me. He did see me which surprised me, we hadn't spoken for several months...and he's never gone back to being the same way he was before, but he went back to just being my brother." (Simon)

For Denise, a young carer who had looked after her brother with severe learning disabilities and autism, the normative *"relationship"* had been subsumed by the caring role and she had no experience of any aspect of loss to a pre-existing relationship. She spoke of the all-consuming nature of the care she provided for her brother and how her boundaries of acceptable behaviours towards her had been extended into violence. She situated her acceptance within a complex picture of duty, love and being accustomed *"there's a sense of this is what I do"*.

"...he doesn't know I'm his sister. He doesn't have an awareness of that...what is love? I give to him unconditionally...whatever he needs, or did, he gives me nothing back. If anything, he is violent to me, or whatever, wrecks the house...There's a sense of duty, there's a sense of love, there's a sense of this is what I do...How has it affected my relationship? It is the relationship." (Denise)

Christine spoke of her grief at the loss of how she imagined her son *"would have been"* if he had been able bodied and not had a progressive physical condition through *"the*

one time that I got a flash of who he would have been, and that's the only thing that upsets me."

"...I've never understood this with people who say, if you've got a child with a disability you mourn the child that you didn't have...I didn't expect a perfect child, but it was the one time that I got a flash of who he would have been, and that's the only thing that upsets me." (Christine)

Amy, whose mother had dementia, described the loss of her ability to think of her mother as the same person due to the severity of the changes in her mother's behaviours. Her mother had lost the *"bits of her that would have kept her other parts in check they kind of melted away."* These changes in their relational dynamics led to the daughter's struggle with maintaining a sense of relational *"warmth"* towards her mother, as expressed further by, *"it was...oh it was just so difficult."*

"I find it very difficult to think of her as my mum...cos she's not...she looks like her, but she isn't...prior to that when she was more like her old self but becoming ill because of...the bits of her that would have kept her other parts in check they kind of melted away...at that stage it was difficult to retain a kind of sense of warmth towards her because it was...oh it was just so difficult..." (Amy)

For other carers, there was a lessening in the quality of the relationship because of the loss of a critical element in the relational dynamic. Niru spoke of the irrevocable changes

in trust that followed on from her brother's behaviours in the context of his addiction through the words: *"our relationship now and going forward will never be what it used to be."*

"I think we have rebuilt it in certain ways, and I think we've both come to terms with the fact that our relationship now and going forward will never be what it used to be, which is a shame but, I guess it is what it is." (Niru)

In summary, the sense and depth of loss from taking on a caring role seemed to be associated with a number of different variables and the sequencing around these. For Denise, the nature of her brother's neurodevelopmental condition denied her a 'normative' relationship with her sibling, and the relationship had been subsumed within the caring role. For Christine, the progressive nature of her son's muscular dystrophy brought the loss of how she imagined her son might have been as he grew older, of *"who he would have been"*. For Amy, her mother's dementia and associated behaviours meant a deterioration in Amy's ability to relate to her. For Aanisha, the transient nature of her mother's episodes impacted on their relationship temporarily and constituted a break in Aanisha's ability to be her daughter *"I can't be that person for a while"*. Finally, Simon and Niru conveyed a sense of increased vulnerability in their relationships with their siblings, brought about by the changes in their siblings' behaviours attributed to their MH difficulties.

3.5 Theme Four: Carer stress and strain

In this theme, carer psychologists spoke of their expectations of themselves. In the subtheme, "*dependency on carer*" there was a sense in which the carer understood the loved one's needs, largely because of their desire to help them as part of a loving relationship, but there was also some reliance on the carer to fulfil the loved one's needs. This may have felt less welcome and, sometimes, somewhat burdensome or onerous. The subtheme, "*changed relationships with personal others*" described the need to ensure that the loved one's needs were taken care of, whilst also having a wider impact on other personal relationships, such as those with partners. There was also sometimes a distancing between the caring dyad and others, because others' understandings of the dyad's needs might not have been fully considered or developed.

3.5.1 Subtheme: *Dependency on carer*

Sometimes a carer psychologist's positioning as a familial member brought societal presuppositions of who they thought they "*should*" be in relation to their loved one, and their ability to manage their loved one's distress, "*on top of my own*". Janice, a psychologist in a forensic setting spoke of the conflict she felt in relation to getting her own needs met, whilst trying to care for her sister and her sister's needs.

"It's a little bit of a battle, 'I should be that person, because she's my sister', but at the same time, I can't always be that person because I'm not sure I could manage her acute distress, on top of my own." (Janice)

As Joshua depicts below, for carers of loved ones with MH issues, the nature of the support provided varies, but includes elements of company, social engagement and interaction.

"In the first stage...the caring was...turning up...just being around, giving support to my mum just sort of sitting in a room with my dad...my mum felt that he couldn't be left on his own in the house..." (Joshua)

There was also a sense of pressure from others to perform the task of keeping the loved one safe, which again related to familial positions.

"I've had phone calls from A & E in the night saying, 'you need to do this'...one particular time, 'oh you need to do more as a daughter.'" (Alice)

Alice then went on to describe her father's reliance on her for emotional support and how she encouraged him to access his own resources, through reminding him that he was her father, an adult in the dyad, and was *"perfectly capable of working it out."*

"...sometimes he'll phone me and say that he's suicidal or he'll phone me and cry down the phone or say, 'I've run out of pills, what do I do?' I'm like, 'you're an adult, you're perfectly capable of working it out.'" (Alice)

Christine described how she had needed to stop working because of the intermittent interruptions to her working pattern due to the unpredictability of her son's practical support needs, and the "impossibility" of the situation.

"it just got impossible, I would be working and I'd stopped my NHS job because I just couldn't do any regular hours and I was doing a bit of private work...I'd get a call...something's happened." (Christine)

At an earlier point in the interview, Christine talked about the losses in financial and social resources available to her, in having to give up her work to take on the caring role full time. The complex interactions between her personal and professional positions at that time impacted her wellbeing.

"...before I was sitting at home, I think I was depressed to be honest...suddenly the more I do the more energy I've got...I started booking theatre trips, I actually got in contact with a friend I hadn't seen for 25 years and now we're meeting up and doing things." (Christine)

She went on to say that her working situation had now changed and she had a more flexible working pattern. She had also employed paid carers through a Care Package,

however, there was still a high level of organisation of care required to ensure that her son's needs were met when she worked, and it was *"still hard to do...to find someone who you're happy to leave him with"*. In the extract below, Christine described the impact of having personally fulfilled her son's care needs, the absence of holidays on her own with her husband.

"The last holiday we had on our own (as husband and wife), until last year, was...36 years ago, and we had a week last year and it was just wonderful...it's still hard to do, because you've got to find someone who you're happy to leave him with completely at the power of somebody else..." (Christine)

In summary, there were a range of impacts on carer psychologists through the loved one having a level of reliance on the carer for their needs to be met. As the primary carer of her son, Christine had been unable to continue her professional career until a more flexible employment option became available to her, and this impacted on her mental health. Whilst the sense of dependency on their care was more transient for carers of loved ones with MH difficulties, Joshua and Alice's roles as son and daughter still elicited expectations of the care they would provide from family members and from NHS staff.

3.5.2 Subtheme: Changed relationships with personal others

The interaction between the expectations around their professional work roles and unpaid personal caring roles could create a sense of the carer feeling overwhelmed by the

need to be present for others within the family. In her interview, Amy expressed the particular challenges in working and also caring for her mother and her child. This experience of being a professional carer and providing cross-generational care seemed to compromise her ability to have time for personal reflection and thinking. Amy described how difficult this was to navigate, expressed by the comment, *"I've had to listen to all this stuff at work and I just want to be in my head."*

"...sometimes I think have a fucking conversation amongst yourselves and leave me out of it because I'm done today, I've had to listen to all this stuff at work and I just want to be in my head, and I am having to listen to all this other shit." (Amy)

Here Janice spoke of her husband's support in understanding her sister's needs, however, she also spoke of the pressure to contain her emotional responses from family members. Her connection with her sister meant that she did not feel that she should share her feelings with them due to their lack of understanding about her sister's MH issues.

"I can't do that with family because they don't understand and it feels like I would be doing her a disservice if I shared my emotions with them." (Janice)

Christine spoke of the disappointment of her extended family's underdeveloped understanding of her son's support needs and the frustration this triggered, given *"nobody understands it."*

“So thinking about my extended family I think for me it’s the fact that nobody understands it, nobody, you know they will say ‘oh come out, come and do this with us’ and nobody gets it, ‘I’m like, is there a ramp in the restaurant?’” (Christine)

In an earlier part of the interview, Niru contrasted her experience of living in a small community and growing up with childhood friends with her sister’s experience of living in London and said that the size and closeness of the British Indian community precluded her from sharing her experiences with friends. She conveyed a sense of the stigmatisation around MH within some sections of the British Indian community when she said that she assumed that her friends would not understand her experiences or *“they’ll give me judgements.”*

“You know mental health, addiction, it’s very poorly understood in British Indians like horrendously poor...so I think there’s a lack of knowledge, and I think that’s with my friends as well alongside that I’m assuming that they’ll give me these opinions that I don’t want to listen to, or they’ll give me judgements.” (Niru)

In summary, there was a sense of the carers of loved ones with MH issues holding onto their own feelings and distress, because of a perceived lack of understanding of MH from family or friends. Christine’s experience of looking after her son with muscular dystrophy was that her extended family had an underdeveloped understanding of her son’s support needs, and this led to feelings of frustration. Amy’s experience of providing cross generational care may have led to a heightened sense of dependency on her, and seemed to

impact on her own emotional wellbeing and ability to meet their own needs. Whether these factors were experienced in isolation or in combination they appeared to contribute to the stress and strain on the carer impacting on their sense of self.

3.6 Theme Five: Impact on professional practice

In this theme, participants detailed how their personal experiences had broken down the boundaries between their personal and professional lives and positioned them differently in relation to their professional selves. The subtheme "*depth of ability to empathise*" conveyed how the shift in the psychologists' relational positioning had enabled another level of connection between their professional selves and their client base. The subtheme "*interconnection between personal and professional selves*" depicted the influence between participants' personal caring experiences and the impact on their personal selves, and the interplay between their personal and professional selves. The final subtheme "*towards and away from career/specialism*" explored how caring experiences influenced their career choices.

3.6.1 Subtheme: *Depth of ability to empathise*

Moving into the realm of the working context and considering participants' professional working relationship with clients referred to their services, all participants spoke of their increased awareness and understanding of the client and the systems around the client. Caring for her brother and working in forensics increased Niru's awareness of the

ripple effect of distress on the client's wider system and the recognition that, whilst one person may have directly experienced the difficulty, their family and friends had also been impacted.

"...even though that's that one person that's gone through the problem, the families and the friends have gone through something as well alongside that...How has that left them impacted...and what support do they need?" (Niru)

All participants conveyed how their relational capacity for empathising and being compassionate towards others had grown because they were able to identify themselves as similar to other carers and families they might meet through their work. For Joshua, a carer for his father, there was no longer the sense that people were protected from experiencing MH difficulties within their families and that *"that can never happen to people I know."*

"...prior to training I worked in a Home Treatment Team...there were families I'd visited there who I could identify with and others...I definitely wouldn't have identified with them and I felt more compassion towards them...I thought, you're similar to my family, whereas before I would have thought, that can never happen to people I know." (Joshua)

Several participants caring for people with MH difficulties of recent onset spoke of how the 'us and them' divide had been effectively destroyed by their experience of

witnessing the deterioration of their loved one. For Joshua and Simon it had given them self-acceptance of their own vulnerabilities.

"I think seeing...someone that I care for and love slide off the last bit of that ladder, slide into more of a psychosis...I think that made me think, yes this could happen to anyone." (Joshua)

"It was very difficult at the time but I think it's just made me realise very explicitly that we all have mental health of some sort and we all have vulnerabilities..." (Simon)

In a small number of cases, participants spoke of how taking on a caring role had felt difficult for them due to pre-existing relational difficulties in the caring dyad. Alice spoke of difficulties in her relationship with her father in her interview, due to his MH difficulties and alcohol misuse, but this did not diminish her ability to empathise with carers.

"I do think that when I work with carers in my professional life, I do have a lot of empathy for them, I do see how really hard it is. Even if they had a good relationship beforehand it might be hard still." (Alice)

It seemed that all participants shared an enhanced connection with clients and family members related to their personal experience of caring, which they communicated outwardly to colleagues, and other parts of the clients' support system. It also seemed to bring a reduced judgemental positioning and empathic stance in relation to working with carers than, perhaps, other professionals might experience.

“When I started this job the people that I related to the most were the mothers of the young clients...whereas...colleagues might say ‘that mother’s really controlling’ but I’d say put yourself in their position, you’ve got to be doing that, I think I could empathise more with the over-involvement where necessary, I don’t think I’ve ever seen any over-involvement or infantilising or whatever....” (Christine)

In the quote below, Simon described how his brother’s treatment led to a process of questioning the systems and procedures in place for forensic patients. His personal and professional boundaries became blurred and accessing and processing his own emotional responses enabled him to access a deeper level of compassion and understanding in his work with clients and family members. He described a shift in relating to clients and family members.

“He (my brother) ended up in prison for indecent exposure on the sex offenders’ register even though he had a hospital record...that boundary between a sexual offence that would have seemed like...just something I would see at work, it’s like...that can happen in my personal life...I feel like when I’m with a patient or a family member, I feel like there’s a part of me that’s quite personally invested in trying to help them.” (Simon)

In her interview Linda, a carer for her mother with psychosis and a psychologist working in an inpatient setting with a high turnover of patient admissions, spoke of how she

felt her caring experience had developed her relational understanding and acceptance of each individual. Through this there was a suggestion that there was a lack of relational warmth alongside a distancing that could be generated by the diagnostic system and the categorising of individuals under an umbrella label, which potentially led to *“just seeing someone in a cold, clinical way.”*

“...not judging people, being really accepting of people, who they are, valuing people, not seeing someone as a label, a diagnosis, but thinking that they're a whole person, they're just unwell. They've got lots of talents and experiences, got lots of skills and qualities, not just seeing someone in a cold, clinical way if that makes sense. I think that those things help.” (Linda)

In summary, it seemed that participants' caring experiences may have facilitated the growth of compassion and empathy for carers and clients. For participants of loved ones with MH difficulties, this process of enhancement appeared to have been realised through gaining an increased appreciation of their vulnerable self through their connection with a vulnerable other and the sense of a breaking down of 'us and them'. Alice and Niru spoke of an appreciation of some of the challenges that personal caring might entail, and the impact of caring for someone on family and friendship networks. For participants such as Christine there appeared to be a potential distancing from some of the judgements of other healthcare professionals through her alignment with the experiences of other mothers. These processes may have facilitated a deeper relationship within the compassionate part of the carer

psychologists' professional selves, and perhaps increased their relational capacity for empathising.

3.6.2 Subtheme: Interconnection between personal and professional selves

All participants identified that there were aspects of their personal experiences of caring which were perceived to be both helpful and unhelpful in clinical work.

Katie, working in community services and carer for her partner, described how her pre-existing awareness of the power imbalance between therapist and client became even more alive due to her personal caring experiences. She spoke of increased awareness of psychologists' ways of working with others, "*the power we hold*" and the importance of considering the narratives we use to depict others' lives.

"It's just made me think even more about the power we hold and how we work with people and the stories that we tell about people and stuff..." (Katie)

This enhanced awareness of how the system could work and how this could feel for a family member dealing with a difficult situation enabled carers to take a more understanding and considered stance towards other healthcare professionals executing their daily responsibilities.

"...I've shouted at a nurse before on the phone when she told me that my brother was being discharged and that he had nowhere to live, not thinking that she was just someone who had answered the phone to me." (Simon)

Similarly, Joshua, working in community services and caring for his father, spoke of how his experience had developed his understanding of compassion and his resultant frustration around the rhetoric of the healthcare system in relation to taking on board the “*carer perspective*”. He conveyed a sense of false demarcations between professionals and service user or carer perspectives.

“I often see lines being drawn between professionals and bringing in the service user or carer perspective and...having been both...if you’re truly compassionate...you would be considering that all the time anyway...you wouldn’t need to be prompted to focus on the carer perspective...” (Joshua)

Amy, working in MH inpatient services and caring for her mother with dementia, spoke of the impact of staff changes on the ability of the service to progress her mother’s care because of uncertainty around her diagnosis. She spoke of how the team positioned themselves as “*the experts*” and negated her clinical view on her mother’s presentation, possibly due to her personal position. Through being a service recipient, she also spoke about her experience of the reality of standards of service provision.

“They were the experts... (I was) trying to say, ‘I think this is Lewy Body Dementia’, and they were like, ‘we’re not sure because...’...you’d see someone for two or three sessions and then they moved on to a different team, so there were those sort of frustrations...you become more aware of, being on the receiving end.” (Amy)

Painful personal experiences could still resonate and impact on the professional context and could draw a psychologist into interacting differently with other professionals based on “*assumptions*” derived from personal experience. Janice conveyed the difficulty in bracketing her personal experience of caring for her sister and tacit assumptions around inpatient services. She felt her experience had been brought into interprofessional exchanges.

“I think maybe initially my assumptions around services and systems was that they were quite poor and didn’t work...I think it’s mainly the experience of seeing her on the acute unit, created assumptions...potentially some of the debates and battles with psychiatrists that I’ve worked with I might not have even gone into, had those residual feelings not been present...” (Janice)

Aligned to the personal sense of self becoming drawn into the professional sphere, Katie spoke about the need for self-care and the importance of trying to ensure that she found a way to manage her needs. She inferred that these had the potential to get lost or subsumed in the context of personal and professional caring.

“There are times when I’ve been particularly bad at managing...being there for someone else at work, you come home and you’re there for someone else...you get to the point where you don’t know what you want or need anymore...” (Katie)

Some participants also described some of the difficulties they had experienced in terms of their positioning as trainees with caring responsibilities within course training programmes and associated systems. Alice suggested that she had felt judged.

"I would have expected...them to have their own opinion about whether or not I'm a carer...I expected... 'ok that's your decision to do that, how can we support you, given your decision', ...not to judge me...I didn't really feel that was their place." (Alice)

In summary, participants depicted their awareness of the inherent power differentials between clients and professionals. They illustrated how they were able to use their personal experience to heighten their sensitivity to how power manifests itself in client-professional interactions. Participants gave examples of how this awareness could be extended to bring compassion to other professionals within the system. They conveyed awareness and frustration at how the system may disregard the professional intelligences of the carer. Finally, participants detailed the potential subjugation of their own needs due to caring responsibilities extending outside of their professional role and into their personal lives.

3.6.3 Subtheme: Towards and away from career/specialism

All participants conveyed a strong sense of the value in caring, however it was particularly noticeable that the four participants who were young carers conveyed a strong sense of the role of caring for others as a very normative experience. Here, Denise identified

a link between her caring experience and caring becoming an integral part of her personhood.

"I think being a young carer, it influenced my values in that I saw myself as helping other people...it becomes part of you doesn't it? So I was certainly aware that I was drawn to taking on that role, but I also placed value in that, so actually I quite like caring, it comes naturally." (Denise)

Whilst there was also an association between their personal experiences of caring and going into the profession, the majority of young carers reported that these personal experiences led to choosing a different specialism than their personal experiences. Denise's awareness of potential triggers in learning disabilities work led her away from specialising there, despite her supervisor commenting on *"how good I was in working with people with LD on placement."*

"I don't want to put myself in that situation, where I've got constant reminders of my brother...we all bring our stuff, but I don't want to be bringing all that, I just don't think that is helpful...you never know what could trigger you, so I decided not to." (Denise)

Joshua described an enhanced connection with inpatient work, whether this was related to his familiarity with the service setting through his father's inpatient admission and his *"whole experience"* caring for his father, or to an increased connection with nursing colleagues. He did not perceive this to be problematic in terms of a future career choice.

"I felt a bit more connected to the nurses in some ways, or connected to the whole experience, I could probably go and work there, I liked it...I think that they were quite keen for me to go and work in inpatient, I certainly connected to that side of things."

(Joshua)

Alice conveyed an increased awareness of the complexity of the personalities of others and the importance of retaining an awareness of the positive qualities of others, despite the presence of other difficult behaviours. Her experience of caring for her father, through relational complexity, enabled her to work in forensic settings. She could see "*the grey*" - how people could be "*both good and bad.*"

"You can be a father and a parent, who's got authority and cares in their own way...I think it's probably led to me working in forensic settings more because...even if they've done something people might label as bad, it doesn't mean that they don't need help in other ways, and so I think it's helped me see the grey areas more I think probably..."

(Alice)

Janice also worked in forensic settings. She described her preference for working with male prisoners, and perceived this to be related to her understanding and appreciation of men having a direct and honest communication style. Whilst she did not feel that this was necessarily connected to the experience of caring for her sister, she was able to recognise a potentially unconscious link around her preference.

"I tend to prefer working with men and working with male prisoners...eating disorders or female prisoners has never previously been something that I've wanted to go into and potentially that's very significantly female distress...so maybe there is a link there, but if there is, it isn't a conscious one." (Janice)

Conversely, Katie described how her personal caring experiences had consciously led towards her positioning herself as a community psychologist and exploring new areas of clinical interest. She described herself as being *"inspired"*, and it being a *"pulling towards."*

"My experiences have made me really interested in experiences of marginalisation and injustice and I'm really interested in neurodiversity now my girlfriend's got ADHD and it's definitely inspired me for sure....it's always been a pulling towards." (Katie)

In summary, there was a mixed response where several factors impacted on psychologists' decision making towards, and away from, careers and/or specialisms. Some participants recognised how personal experiences were beneficial in terms of the development of their personal values, leading them towards a specialism. However, other participants were mindful of the potential for the work to retrigger difficult personal experiences and unresolved emotional complexity, which influenced their decision to opt for a different specialism.

3.7 Theme six: Dual positioning

Some of the complexities of holding both a carer and a psychologist role have been highlighted in earlier themes. In theme one, *'Personal and professional roles'*, the empirical knowledges brought into being from holding this dual position diverged across participants. For example, in the subtheme, *'The professional context: mental health as a complex phenomenon'*, diagnosis was valued for its ability to give the loved one and carer *"a shared understanding"* (see *Aanisha, section 3.2.1*), but was also considered to be *"reductionist"* (see *Niru, section 3.2.1*) and to function as a protection against connecting to the *"emotional pain that people go through"* (see *Azma, section 3.2.1*). Some of the commonalities in experience were forefronted by Simon and Belinda, who articulated how their explorations of notions of normality and reflections on their personal and professional identities had enabled them to embody different ways of relating to others (see *Opening up about mental health, section 3.2.2 and Questioning of the self, section 3.2.3*).

The complexities of holding dual identities were further considered in the *'The emergence of a carer identity'* theme, in which a number of carer psychologists struggled with the process of accepting a carer identity largely due to their perceptions that the relational aspect to caring was subsumed within familial roles (see *Moving from struggling to accept carer 'label' section 3.3.1 and Emotional responses, section 3.3.2: Simon, Aanisha, Belinda, Niru, Azma*).

Linked to this sense of familial roles shaping the carer identification process, the subtheme *Dependency on carer* considered how participants' familial positioning may have brought societal expectations of their carer roles from others (see section 3.5.1). It also conveyed how the interaction between the expectations around their professional work role and unpaid personal caring roles could create a sense of the carer feeling overwhelmed by the need to be present for others (see *Alice and Joshua*, section 3.5.1).

Moving on from some of the challenges that the carer role might entail to some of the potential gains for clinical practice, the fifth theme '*Impact on professional practice*' focused more on the intersection between participants' personal and professional selves. Subthemes summarised how participants grew in their relational capacity for empathising through their awareness of the client and systems, and how participants reflected on the power held by professionals, in particular the professional's role in creating narratives about their clients (see *Amy and Katie*, *Interconnection between personal and professional selves*, section 3.6.2). Impacts on decision making processes around careers and specialisms were considered in the final subtheme (see *Denise and Joshua*, *Towards and away from career/specialism*, section 3.6.3).

In the '*Dual positioning*' theme, participants more explicitly conveyed how having either a current or historic carer identity impacted on their clinical practice, and how their professional knowledges impacted on their carer role. The subtheme "*connections which challenge*" spoke to the ability of painful personal experiences to resonate and have the

potential to influence the psychologists' cognitions, emotions and behaviours during work-based moments. The subtheme "*professional knowledges as resources*", described how the psychologist's explicit and implicit knowledges could be used for the benefit of the loved one's care.

3.7.1 Subtheme: *Connections which challenge*

All participants reported experiences of cognitive dissonance in relation to aspects of professional practice and their personal sense of self. For example, Alice, a carer for a father with psychosis and substance use/alcohol issues, talked about her ability to "*split*" parts of herself into the personal and professional spheres. She also voiced her discomfort with this "*split*", suggesting that there was an internal conflict about her feelings in relation to this.

"It's almost like there are two parts of me...when I talk about my dad in my personal life I will refer to him as an alcoholic but I would never use that word about someone that I was working with...it's quite a pejorative label which feels ok for me...to use about my own personal experience but it wouldn't feel ok for me to use as a professional so maybe there's something about splitting these things off...there is some cognitive dissonance there..." (Alice)

The complexity and sometimes contradictory appraisals of carer psychologists were explored in the earlier subtheme *Interconnection between personal and professional selves*, section 3.6.2. This subtheme considered carer psychologists' comments about needing to

find a way to balance their needs with the needs of loved ones, particularly when the dyad live together. Below Katie highlights both the “*challenges*” of connecting to her personal experiences in work based moments but also the value of her client work in “*teaching*” her.

“It gets challenging...when you’re in the therapy room with somebody and you connect with something...but I like to...see my clients as teachers as well...” (Katie)

However, subsequent to this, Katie then moved onto speak of the difficulty in “*turning off*” the therapist part of the self which suggested that her professional self had also become embodied within her personal life.

Another illustration of the complexity of carer psychologist experience brought about by the intersection between the personal and professional selves in the work context was highlighted when Niru spoke of the impact of caring for her brother with anxiety and addiction difficulties. Through her work in forensics she also routinely encountered patients with addiction issues. She described how she gained support in an environment in which she might previously have felt that she needed to explain herself more fully by being open with her manager and sharing the emotional challenges of managing her personal situation in conjunction with her work responsibilities, as encompassed by the expression “*it’s just too close to home.*”

“I have to just say, this is happening I don’t want to go into any details, but it’s not me being avoidant it’s not me being that I have these judgements about this, it’s just too

close to home and actually that's been helpful, it's been respected and it's helped me care for myself, because it's made me realise actually I've held all of this for so long and what's the impact on me." (Niru)

Belinda, who was in a tutoring post at the time of the interview, reflected on her ability to perform at work in the way she might ordinarily envisage through her empathic connection with a carer. She appeared to voice an internal conflict when she spoke of the potential for her therapeutic capability as a psychologist of a psychodynamic orientation to be compromised by the experience of caring for her grandmother with dementia. She spoke of how the qualities of "*understanding*" and "*sensitivity*" had potentially inhibited her ability to voice her countertransference and share her psychodynamic formulation of a particular client's distress with him.

"I did have a client with a mother suffering from dementia at the time...I could empathise with the whole situation on a level that I wouldn't have been able to without my caring experience, understanding, sensitivity...thinking about psychodynamic formulation this man did have a...huge amount of anger that he couldn't access so he was very soft and I would be left feeling infuriated at the end of these sessions...(I was never able to say to him when his mother died during treatment), 'I wonder if actually you feel quite relieved and actually there was a lot of anger for you in that relationship'." (Belinda)

Simon, a psychologist working in a forensic setting, was professionally “*challenged*” through his brother’s recovery from psychosis from medication. This appeared to have led to a fundamental shift in his thinking about the need for medication and a sense of a cognitive reduction in the ability to conceive of the potential of treating psychosis through talking therapies alone.

“My brother got better after he was given medication and he took it...that challenged me professionally because up until then I’d been...finding it quite shocking seeing patients taking all these drugs and so it...changed my view about drugs so now I’ve probably swung the other way, ‘I’m like get this person some drugs’ and I’m less sympathetic to, ‘oh let’s treat psychosis, but just by talking’...we (the family) did everything we could do to try and help him and actually what helped him most in the end was a psychiatrist and the nursing team, literally restraining him and injecting him...” (Simon)

Simon’s acceptance of the efficacy of medication for the treatment of acute psychosis did not however extend to the widespread use of psychotropic medication for his clients hearing voices in forensic settings. He continued to question the commonly held understanding of psychosis, but also the potential need for medication.

“Although I sometimes wonder what do we mean by psychosis? Because a lot of my patients here hear voices and have symptoms that look a bit like psychosis but I don’t necessarily think that they need medication.” (Simon)

Linked to this notion of medication having a value, but potentially being overused within the NHS for treatment in acute settings, Joshua, a carer for his father, also conveyed his sense of the “normalisation” of medication obscuring the rationale for its use, and potentially hiding something which has not yet been voiced through the use of the words “or is it because there’s something that’s not being talked about?”

“There’s a sense of normalisation around medication which also disguises the fact that it’s not OK. Why is someone taking that and no one’s explaining why they’re taking that? Does it mean that there’s something wrong with them, internally, biologically? Or is it because there’s something that’s not being talked about?” (Joshua)

Belinda also reflected on her personal experience of the negative impact of medication on her grandmother, through her perception of its connection to her grandmother’s experience of nightmares and the distress surrounding this. This brought her to question the decision-making processes in services.

“We just kind of churn out pills to people...so just wondering who makes these decisions in the professional world...she was getting really bad nightmares...but when we took off the Aricept she stopped having nightmares and other things, she was a lot

calmer, but Aricept made her be a lot more coherent, so it was easier for others to be around her, but actually she was suffering so much..." (Belinda)

In summary, participants conveyed a range of challenges to their sense of self, personal and professional, as a result of their carer psychologists' experiences. They drew on some of their professional skills to enable them to reflect on these challenges, namely reflective processes. Some cognitive dissonance around what constitutes the appropriate use of medication is a thread running throughout psychologists caring for loved ones with MH conditions, as is a sense that carer psychologists who live with their loved ones may face particular challenges in terms of getting their own needs met within their personal environment.

3.7.2 Subtheme: Professional knowledges as resources

Understanding psychological processes appeared to enable psychologist carers to make sense of and derive meaning from their processed experiences of emotional pain. In her interview Belinda spoke about the change in caring responsibilities as her grandmother's dementia progressed. Shortly before her death, her grandmother had sometimes defecated on the stairs, and Belinda had needed to provide personal care for her. Belinda conveyed the personal pain involved to her sense of self through her use of the term "*there's like an inner child involved there*" and drew on her professional experience to convey how in clinical practice a professional's experience of emotional pain may be bracketed.

"In my sense of self there's like an inner child involved there, what did I do with that when I was looking after my grandmother and it was painful for that part of me probably, in losing the grandmother who used to look after me but I think at work, and in professional practice you kind of bracket that..." (Belinda)

Belinda appeared able to use her experience of bracketing her emotional responses in her professional life to manage the task of completing her thesis whilst coping with the gradual deterioration of her grandmother's health and the "loss of the person" which was "so painful".

"There might be an element of denial in my process, there must be a part that was so painful, that I managed to push away, but there might have been a need for me to have been doing that and actually writing up my thesis at that time and I...had to have my head screwed on...there was a deterioration there, a loss of the person..." (Belinda)

Linked to this notion of a psychologist's skill base benefiting carer psychologists, Joshua identified his ability to formulate as an enabler, which facilitated more compassion and understanding of his father's beliefs/behaviours, thus he felt able to reflect on the appropriateness of his verbal interventions with his father.

"I guess what's different now is that...I might have moments of reflection afterwards where I think that was a bit harsh, or he doesn't need to hear...now I have a bit of a

formulation of my dad, but it's not a shared one and I think that's not a helpful comment to make." (Joshua)

Joshua's caring experience had also facilitated his ability to "see" the impact of childhood experiences on his father and this had opened up his appreciation to some of the "richer" therapeutic models that "can account for trauma and abuse."

"I've understood how a psychodynamic approach can be quite helpful...now I...have this understanding of how being abused as a child has an impact, and it's not just in a formulation, I've seen it...he got CBT, but it just scraped the surface, and there's stuff now that will never be dealt with, and he'll never get therapy for, I don't think he ever wants it, but it's made me appreciate some of those more richer models that can account for trauma and abuse..." (Joshua)

Azma spoke of how she had drawn on her experience of caring for her mother to enhance her clinical skills, and her ability to put in place boundaries to enable her to self-care in her personal and professional lives.

"When my mum was ill, I put in firm boundaries I think that's definitely translated into my therapeutic work...there's something about...being more compassionate towards difficult situations and I think there's something about learning to be more direct, I learnt to be a lot more honest with my mum...'look at what you're doing, that's having

an impact on this'...I think I definitely learnt how to have those conversations and how to hold that." (Azma)

Her understanding of service provision facilitated Katie's ability to draw a direct link to her professional knowledge as a resource to tap into. She felt that she could better guide her girlfriend's responses in a service context, as expressed by "*play the game, say you have these problems.*"

"Knowing erm...how services work. Like I've had conversations with my girlfriend about like if you're gonna miss an appointment, make sure you call so that they don't see you as like...like play the game, say you have these problems, so you get...it's very helpful."
(Katie)

In summary, carer psychologists appeared to overtly and covertly draw on their professional backgrounds to both make sense of their own experiences of emotional pain and wellbeing, but also the experiences of their loved ones. Carer psychologists looking after parents with MH difficulties appeared to particularly benefit from their ability to formulate their parent's difficulties and to set boundaries around their relationship. These abilities were both derived from, and felt to enhance, their clinical work.

Chapter Four: Discussion

4.1 Overview

This chapter evaluates the results of the research in the light of the research questions. It also considers the relevance of the findings of the research in the light of existing published literature and theory. Having considered the results of the study empirically and theoretically, the chapter moves on to draw out the implications of the study for clinical practice and policy. The methodological strengths and limitations of the research are then appraised and suggestions for further research made. The chapter concludes with final reflections on the research, and inferences drawn.

4.2 Summary of the findings

The study aimed to explore the following research questions:

- How do psychologists make sense of their unpaid personal experiences of caring for others and the relationship to their clinical practice?
- How do psychologists make sense of their unpaid personal experiences of caring for others and the relationship to their sense of personal and professional self?

Six themes emerged from the results of the study, “personal and professional roles”; “the emergence of a carer identity”; “changing/evolving relationship with loved one”; “carer stress and strain”; “impact on professional practice” and “dual positioning.”

4.2.1 Summary of themes

The themes depicted the intensity of the emotional pain of the experience, the deepening of bonds in the caring dyad and, through this, the heightening of the connection in the relationship. For the participants caring for loved ones with MH difficulties, which was the majority grouping within the sample, the growth of this connection facilitated an exploration and a questioning of how MH was constructed. Within this, there was a focus on how stigma impacted on the participants, and how this had impacted on the carer's journey around owning the carer label. The stress and strain that all participants within the sample experienced, irrespective of the specific support required by the loved one, was perceived to have the ability to be mediated by greater access to resources supporting carers. These resources included the provision of professional services for carers, such as breaks, but also greater understanding from others, including employers and training providers, to help support them. All carer psychologists described an enhanced empathic connection with clients and carers as an outcome of their caring experiences, which they brought into their professional practice.

However, whilst having a dual identity appeared to bring enhanced understandings of the self in relationship with others, it also appeared to bring increased awareness of the inherent tensions within a health and social care system designed to meet the needs of groups, rather than addressing the needs of individuals. Caring experience also seemed to have the potential to complicate some aspects of clinical practice, such as working within a

predominantly medical framework and fidelity to psychological models, due to the depth of empathic regard released from the caring experience. This suggested that the complex interaction between the personal and professional selves might therefore need to be authentically managed in clinical work and its gains and potential drawbacks supported through empathically attuned supervision frameworks and practices.

4.3 Links to theories and models in the existing literature

In the next section, the study's findings are considered within the context of the biomedical and psychosocial models of MH, the process of diagnostic labelling and the stigmatisation of MH. The findings are subsequently considered in the context of dual positioning of carers and psychologists/therapists and the construction of empathy in clinical practice.

4.3.1 Constructions of mental health²

The positioning of psychiatry as a science is fundamental to psychiatric discourses in which diagnostic labelling plays a pivotal role (Cromby, Harper & Reavey, 2013). In this context medicine is a valid treatment to eradicate or minimize the effects of disease and within this there is an implicit assumption that scientific measures can be used to reify an

² In this section I highlighted the commonalities and divergences in participants' views because of the diverse range of caring experiences considered. As participants' views encompassed a range of perspectives, this meant that I also gave voice to participants who might have been the only ones expressing a particular view.

entity (Cromby et al., 2013). However, biological diseases can be observed through the senses and as there are biological markers, there are tests for these (Cromby et al., 2013).

This is in contrast to MH which is not a tangible phenomenon (Cromby et al., 2013); here we seek to understand MH in an abstract sense through observing the behaviours of others (van der Zanden, Kramer, Gerrits, & Cuijpers, 2012) and through assessing these behaviours against societal norms (Cromby et al., 2013). The study's findings demonstrate some of the complexity surrounding the conceptualization of MH within the clinical field. Whilst distress was conceived of as a universal human experience, it was notable that there were differences in the way participants constructed their knowledge about MH, and in the perceived value of medication. Three of the participants had a fundamentally different appreciation of MH to other participants. Christine and Antonio's personal caring experiences were of family members with physical health conditions in which we might assume there is a clear demarcation between the well and the unwell. The participants both shared a more bio-medical model understanding of MH, which implied a more fixed and innate, biological heritability and was associated with the bio-medical model of "mental illness is an illness like any other" (Read, Haslam, Sayce & Davies, 2006, p.303). However, Simon, a carer for his brother with psychosis, also spoke of the centrality of medication in treating his brother's illness and facilitating his brother's recovery, and critiqued the notion of talking therapies as a stand-alone treatment for psychosis (*see Connections which challenge, section 3.7.1*). For Joshua, a carer for his father, however, his stance was more questioning, and he conveyed his

struggle with making sense of his father's MH diagnosis and of the use of medication to treat it (*see Connections which challenge, section 3.7.1*).

The majority of participants embraced the psychosocial model of MH in which MH distress has some association with life events and experiences, and in which the client's narrative is central to making sense of their mental health. This position appeared to have been the perspective taken by the majority of the participants caring for people with MH difficulties; although this perspective also existed on a spectrum. Some participants accepted the pragmatic use of diagnostic labelling but were against the reification of conditions per se, and there were distinctions around what could, and could not, be considered a condition. Connected to this were some differences around participants' appraisals of the acceptability of medication as a treatment.

4.3.2 Diagnostic labelling

Research has shown that carer appreciation of diagnostic labelling sits on a spectrum. Some carers may experience a sense of relief when loved ones are given a diagnostic label, because it may provide an understanding of the nature of their loved one's difficulties (Horn, Johnstone & Brooke, 2007). It may also enable loved ones to find a sense of focus and control through an understanding of their condition (Horn et al., 2007). However, other carers are more equivocal regarding the stigmatizing and damaging effects of receiving a diagnosis (Rogers & Dunne, 2011).

As highlighted in *section 3.3.1 Constructions of MH*, there was a mixed appreciation of the value of diagnosis amongst carers. For some carers of loved ones with psychosis, diagnosis and the medical label of a psychiatric illness was considered the most appropriate construction of their loved one's difficulties. It could also be considered helpful for the loved one and carer because it gave a shared understanding of a condition, and a shared language for MH professionals. On the other hand, diagnostic labelling was positioned by a number of participants as problematic because of its ability to create demarcations between groups of people. There were those who could be perceived of as being 'ill' with a MH condition, which might relate to someone's difficulties in response to traumatic life events, and those who were able to continue to function, who may or may not have experienced traumatic life events. In this way, people with 'mental health conditions' could be reduced to a categorising label, 'othered' and seemingly become a distinct group of people, who are classified as unable to function in a socially acceptable way, deemed as being different from the majority of the 'well' population, and seemingly *offering* less than those people fitting within society's parameters of normality.

This highlights the predicament that carer psychologists may find themselves in when faced with concern about the MH of loved ones. Within wider society, lay people's knowledge of, and beliefs around, diagnosis are influenced by social norms and discourses (Johnstone & Dallos, 2013). These discourses may suggest that a person's thoughts, behaviours and experiences are a *cause* of their suffering because they are related to an

underlying “condition”, disease or disorder (Johnstone & Dallos, 2013, p.5). However, psychological training may be influential in shaping and/or embedding psychologists’ belief systems. Exposure to empirical evidence may facilitate alternative belief systems, and subsequently, some psychologists may believe that these same thoughts, behaviours and experiences may be related to traumatic life events and experiences (Felitti et al., Anda, Nordenberg, Williamson, Spitz, Edwards & Marks, 1998), or a combination of both, to different degrees. Whilst the majority of the participants supported the role of formulation in centering distress as pivotal to understanding their loved one’s distress, there were also some participants who held an appreciation of both formulation and diagnosis.

Indeed, the skill of formulation was one of the ways in which clinical training had assisted some participants in undertaking their caring roles. For example, Joshua identified that his knowledge of formulation assisted him in managing his verbal interactions with his father due to a greater recognition of his father’s childhood and how this had impacted on him (*see Professional knowledges as resources, section 3.7.2*). Aanisha also appreciated that her mother’s MH distress related to traumatic life events and experiences, but she also found the “label” of bi-polar disorder helpful as a way of rationalizing her mother’s behaviours (*see Professional context: section 3.2.1*). Niru also shared a sense of the usefulness of the medical label, in terms of enabling the categorization of people, creating a shared understanding of a difficulty and facilitating the direction of care. However, she also recognized the diagnostic power of labelling in a reductionist sense, and its negative connotations through the words,

“diagnosis is powerful but in a derogatory way” (see Opening up about MH distress, section 3.2.1). This perspective is supported by some of the literature around the use of language highlighted by Kinderman, Read, Moncrieff and Bentall who assert that the language of “disorder” is suggestive of an “underlying defect” (2013, p. 2). It aligns with the position of some of the voices within the service user movement who consider that diagnosis precludes the possibility of an alternative frame of reference – that of formulation (Castillo & Schwartz, 2013).

To conclude then, the views of carer psychologists of loved ones with MH conditions and/or in MH distress appeared to broadly concur with the range of conceptualizations perceived to be held by psychologists working in MH (Lofgren, Hewitt, & das Nair, 2015). However, the views of the two carer psychologists of loved ones with physical health conditions not working within NHS secondary care MH settings contrasted markedly. Whilst a small subgroup, both participants shared a more bio-medical model understanding of MH, which implied a more fixed and innate, biological heritability (*see The professional context, section 3.2.1*).

However, the picture varied across the participant sample more broadly and carer psychologists' experiences of caring for loved ones with MH conditions appeared to have impacted markedly on their views of the role of diagnosis and the centrality of medication in treatment. For example, Simon, a carer for his brother working within forensic MH services, shared a view of his brother's psychosis as an “illness”, for which medication was the most

efficacious treatment, but this involved a substantial shift in his original perceptions on the appropriate use of medication in MH services (*see Dual positioning, section 3.7.1*). Other participants' views on diagnosis remained more critical, for example, Azma, a psychologist working with terminally ill patients who had current experience of caring for her mother in MH distress, described the function of diagnosis as being used to “*move us away from having to understand and tolerate the pain that people go through*” (*see Professional context, section 3.2.1*). Belinda voiced her concern that medication was being used for the benefit of others rather than to meet her grandmother's needs (*see Dual positioning, section 3.7.1*).

4.3.3 Managing the stigmatisation of mental health

As highlighted in the introduction, current research has shown that there is some homogeneity in carer experience (NHSE, 2014) with carers reporting a complex array of emotions, such as frustration, guilt, and feeling overwhelmed as a result of the emotional distress associated with long term caring responsibilities (Mallinakrodt, 2010; Constantinidis, 2017). In addition, existing research has shown that carers of people with MH conditions may characteristically experience shame and some social isolation because of the stigma associated with MH conditions (Magliano et al., 1998). This may manifest itself in carers self-silencing rather than voicing their concerns about their loved ones (Magliano et al., 2005).

However, whilst carers of people with physical health conditions may typically experience less stigmatisation, and hence may feel more readily able to voice their concerns about their loved ones (*see Emotional responses, section 3.3.2*), they may still experience

social isolation as a result of their loved ones needing a greater level of physical care (Carers UK, 2014; see *Emotional responses*, section 3.3.2).

Turning to the particular issue of how stigmatisation is managed by carer psychologists, the study's findings would appear to substantiate the notion that the experience of stigmatization was more prevalent amongst, and experienced more profoundly, by carers of people with MH difficulties (Read, Haslam, Sayce & Davies, 2006). This seemed to be illustrated by the different experiences depicted around the journey towards identifying as a carer of a loved one with MH difficulties (see *Moving from struggling to accept carer label*, section 3.3.1), but also the internal and external resources that could be drawn upon to support them to look after their loved ones (see *Changed relationships*, section 3.5.2).

Despite becoming aware of their carer status, participants seemed uncertain about whether it would be acceptable to share their caring experiences with others. For example, this was described by one participant as a "*quandary*" as she had a feeling that she "*couldn't share it.*" This study finding appears to accord with Charles's (2011) findings that MH stigma can result in carers internalizing a sense of shame around being associated with a person from a stigmatized group. Some of the shame may have related to carers' experiences of others having difficulties comprehending the unpredictability of the behaviours associated with psychosis from a loved one (Magliano et al., 2005). Several participants spoke of how they needed to manage their relationships with their loved ones differently as a coping

strategy (*see section 4.2.3*). They also spoke of difficulties in sharing caring experiences more widely, due to appraisals of risks to their personal sense of self, for example, Niru (*see Changed relationships, section 3.5.2*). In such situations, self-silencing and internalising difficult emotions appeared to have been normalised for many carer psychologists participating in the study (*see Emotional responses, section 3.3.2*).

4.3.4. Theories of stigmatization and the impact of stigmatization

Social and cultural ideologies seek to position MH difficulties within families as resulting from either a “blame or brain” scenario (Boyle, 2013, p.5). In essence, there is either something “wrong” with an individual’s upbringing, or they have an illness (Boyle, 2013, p.5). Indeed, social evolutionary theory asserts the importance of the social ranking system for human survival (Gilbert, 2003). The avoidance of blame is, therefore, associated with families seeking to maintain a place of status within the social hierarchy (Boyle, 2013). In this context, some families may find a relative’s diagnosis of an illness helpful, particularly as receiving a diagnosis can assist in the provision of financial support and the validation of problematic experiences (Cooke & Kinderman, 2018).

In contrast, research has shown that receiving the diagnosis of a MH “illness” can increase the prejudice and discrimination experienced by the person diagnosed, and friends and family members (Read et al., 2006, p.210). Social psychologists extend this further and assert that the demarcations around societally endorsed “normal” and “abnormal” behaviours are perpetuated through our participation in the boundaries of social control

mechanisms (Boyle, 2013, p.5; Cromby et al., 2012). For family members this can consequently mean they experience a sense of shame around the behaviours of loved ones because of seeking to maintain their status of normality (Magliano et al., 1998).

Conceptualizations of 'normality' and demarcations around 'normal' and 'abnormal' behaviours are enabled by the social interaction of stigma identified by Thornicroft, Rose, Kassam & Sartorius (2007). The study's findings demonstrated how the three elements of stigma combined and impacted on participants and their families; these elements were: lack of knowledge (whether through ignorance or misinformation), attitudes (in the form of prejudices or biases), and behaviours.

In considering the complexities within the current study's findings, all participants caring for a loved one with MH difficulties seemed to voice experiences of relational uncertainty around their interpersonal safety with others, whether this related to their own sense of self, or whether it was in the service of protecting their loved one. This was a shared experience, however, it seemed particularly present for Niru, Aanisha and Azma - three participants from BAME heritages (*see Changed relationships, section 3.5.2*). They expressed concerns about their families and their loved ones being the unwelcome recipients of ill-informed attitudes and effectively being 'blamed' for their relatives' MH difficulties (*see Changed relationships, section 3.5.2*). As with Thornicroft et al's (2007) theory, these ill-informed views were thought to originate from a perceived lack of knowledge about MH in their wider BAME communities (*see Changed relationships, section 3.5.2*). For one participant

from BAME heritage, this experience had extended to social ostracization as her extended family “disowned” her family (see *Moving from struggling to accept carer ‘label’, section 3.3.1*). This is an example of the final element of the social interaction of stigma, discriminatory behaviours (Thornicroft et al., 2007).

Relational discord with family members was also experienced by Christine, a white British participant caring for her son with mobility difficulties. She voiced her experiences of family members’ lack of awareness of the needs of her son and the impact on family life (see *Changed relationships with personal others, section 3.5.2*), a finding reported by other families of children with disabilities (Whiting, 2014). Moreover, in common with other mothers whose children may have inherited genes associated with hereditary conditions (Moses, 2010), Christine appeared to have internalised some of the biological discourses around the “blame” of mothers for “passing on” their “faulty” genes (Moses, 2010, p.103) through the expression, “*he doesn’t blame me... but I do*” (see *Emotional responses, section 3.3.2*).

4.3.5 Dual position of carers and psychologists

“*Dual positioning*” was identified as an additional theme following a process of additional analysis of transcripts post viva. Harper (2010) considered positioning in relation to psychologists’ professional identities and positioning with service users and carers in his work, but the term “*dual positioning*” was originally written about by Keville (2018) in relation to practising psychologists who are also carers. The term therefore encapsulates the

intersectionality of carer psychologists and highlights the interplay between their personal and professional identities and roles.

In this section the study considers carer psychologists' generic experiences of caring alongside the commonalities and differences identified through some participants' accounts. The potential impact of holding a dual position and its influence on clinical practice is considered. The intersection between carer psychologists with different familial roles and experiences of caring for loved ones with different conditions and/or difficulties and the impact on their personal and professional selves is both extrapolated and explored.

Turning first to one of the largest subgroups of carers within the study, psychologists with experiences of caring for loved ones with psychosis ($n = 7$), there are parallels with existing studies into carer experiences (Stillwell, 2016; Allard, Lancaster, Clayton, Amos & Birchwood, 2018; Chang & Horrocks, 2006). In these studies, relational positioning within families may add a further layer of complexity to caring experiences which may already have contradictory and complex tones. For example, Sharma's (2018) study of father carers depicted both the deepening of paternal love for their adult child through the caring role, but also conveyed how relationships with loved ones with psychosis may also entail an internal emotional world which may be both conflicted and difficult to share with others.

Stillwell's (2016) IPA study of sibling carers also considered this aspect of caring experience. One of her superordinate themes was "*the "terrible weight" of having a sibling*

with a diagnosis of schizophrenia". This theme considered how the sibling may have felt a sense of obligation to care for their loved one and occasional feelings of resentment around this, but this was mediated by the role of empathy on the perceived negative impact on the sibling's wellbeing and lifestyle choices. Other themes considered the outcomes of internalised stigma, in particular decisions around who the sibling might feel able to share their emotions and cognitions with, in order to support them to maintain their connection with their loved one during their episodes of ill health (Stillwell, 2016).

Within this study, being an adult daughter and caring for a parent appeared to involve a particularly complex familial relationship, possibly heightened when the loved one had a MH condition. There was also sometimes a perceived sense of obligation to care for them (*see Moving from struggling to accept label, section 3.3.1*). This finding is also supported by cross cultural research into gender expectations in caregiving within families with relatives with MH difficulties (Sharma, Chakrabarti & Grover, 2016). When the normative family roles were reversed and the parent looked to their child for more direct practical and emotional care during their episodes, states of frustration and tiredness were reported for three of the daughter carer participants in the study (*see Emotional responses, section 3.3.2*).

The complexities of the interaction between the personal and professional selves were also highlighted by participants through their appraisals of therapeutic models, and their value within clinical work (*see Connections which challenge, section 3.7.1*). Further tensions that the caring role brought to the carer psychologists' identities appeared to relate

to their positioning as empathic insiders within the health and social care system and a questioning of the system itself (*see Questioning of the self, section 3.2.3*). Carer psychologists of loved ones with psychosis also spoke of interactions with colleagues, nurses and psychiatrists, in which their positioning as carers raised uncomfortable dilemmas around perceived service priorities within the overall management of the NHS (*see Interconnection between personal and professional selves, section 3.6.2*). This finding is also shared by the carer population more broadly (Askey et al., 2009). Direct observations of how inpatient services operated, the lack of funding available to run services as they might aspire to be run, including sometimes how inpatient staff may be desensitised to the vulnerabilities of those receiving their care, were, in the words of Simon, particularly “*shocking*” for psychologist carers (*see Connections which challenge, section 3.7.1*). Carers of loved ones experiencing MH crises which result in admission to hospital (Albert & Simpson, 2015) also share this perception of a lack of empathy from inpatient staff. This may suggest that carer psychologists of loved ones with MH health conditions may be able to draw on their discomfort to engender a different way of relating and being with clients.

An associated thread was the participants’ critical understandings of the way in which decision-making processes in services may operate to the potential detriment of individual clients’ needs, such as that suggested around the use of medication to contain challenging behaviours (*see Connections which challenge, section 3.7.1*). This outcome accords with one of the substantial findings of a recent study in which many psychologists played a role in

questioning and challenging the use of medication with colleagues and prescribers (Aston, Smith, De Boos, & Tickle, 2020).

In the Aston et al 2020 study it was noted that the professed professional psychologist view is perceived to be broadly critical of the use of psychotropic medication, and that this understanding is derived from vociferous psychologist discourses which endorse working beyond diagnostic labelling processes (Randall-James & Coles, 2018). However, perhaps one of the novel findings of this study is how some psychologists with loved ones with psychosis such as Simon may find it difficult to voice support for the use of medication. Whilst only Simon directly spoke of this dilemma, it appeared that some of the prevailing psychologist narratives centring the use of medication within the medical model and within psychiatric practice may have precluded a more nuanced consideration of the potential benefits for the use of antipsychotic medication to support the recovery of loved ones with psychosis.

Considering the use of medication to treat other mental health conditions and mental health distress more widely within the broader medical context, the majority of carer psychologists considered medication as a tool to avoid engaging with the levels of emotional pain experienced by service users/clients within services (*see Emotional responses, section 3.3.2*). Carer psychologists themselves appeared to manage their own emotional pain through utilising bracketing and other strategies to support the containment of difficult personal emotional experiences within the professional sphere (*see Professional knowledges*

as resources, Belinda, 3.7.2). Whilst using these strategies was helpful in mitigating and managing the psychologist's internal state in a professional context, it was notable that participants living with loved ones appeared to experience particularly heightened and potentially protracted difficult emotional states related to caring. In some instances, sometimes the cumulative nature of care needing to be provided may have contributed to potential compromises around self-care (*see Interconnection between personal and professional selves, Katie, section 3.6.2*). This finding linked to studies on carer typology, which indicated that the more intense the caring experience or the longer the duration of care provided, combined with the higher number of hours spent caring, the greater the likelihood was of the carer neglecting their own needs in order to fulfil the needs of the loved one (Shah et al., 2010).

Managing the relationship with caring through considering the interpersonal dynamics in the caring dyad and their impact on carer stress and strain appeared to be one strategy to assist with self-care (*see Towards and away from career/specialism, Katie, 3.6.3; Professional knowledges as resources, Azma, 3.7.2*). However, as with the wider carer population, carer psychologists found that their levels of stress and strain were further impacted on by the generic challenges experienced by carers more generally. These included limited social support networks and availability of support services such as specialist housing and respite care (Team & House, 2010; *see Changed relationships, Christine, section 3.5.2*).

Similarly, to carer psychologists of people with MH conditions within this study (*see Emotional responses, 3.3.2*) and to Stillwell's (2016) research into sibling carers of people with MH conditions, Christine, carer of her son with muscular dystrophy, conveyed a sense of the 'weight' of caring responsibilities on her (*see Emotional responses, section 3.3.2*). She also expressed difficulties in sharing her experiences with others, but this was different to the experiences of carer psychologists of loved ones with psychosis, whose awareness of the stigma around MH often did not allow them to feel sufficiently safe enough in their relationships with others to take the relational risk of sharing their experiences (*see Emotional responses, section 3.3.2*), a finding shared with the Sharma (2018) and Stillwell (2016) studies.

The importance of a carer's experiences being understood was highlighted by Stillwell (2016) in her reflective account as a sibling carer psychologist. Carers in the wider population reported difficulties with others understanding their emotional responses around the loss of aspects of their loved ones that they may have particularly valued in their relationships (Mannion, 2008; McGoldrick, Carter & Garcia-Preto, 2001). Within this study, witnessing the deterioration of a loved one due to the exacerbation of a long-term health condition whilst providing personal and professional care was highlighted as particularly difficult (*see Sense of Loss, section 3.4.2*). This finding is also supported by studies into the dual caring experiences of professional carers working with health conditions and providing personal care across generations (Ward-Griffin et al., 2005).

Indeed, carers' emotional responses at the loss of aspects of their loved ones may also intensify during role transitions (McGoldrick et al., 2001) and midlife may be one of the life stages in which role responsibilities may overlap (Carr, 2012), as in Amy's situation (*see Sense of loss, section 3.4.2*). These role responsibilities and potential role transitions can induce stress and anxiety as family systems make necessary and fundamental changes to their structures (Roper-Hall, 1998; Fredman, 2018).

All participants shared feelings of being overwhelmed at different junctures in the carer journey (*see Dependency on Carer, section 3.5.1*). This feeling held the potential for appraisals of being unable to cope with the stress and strain of looking after a loved one whilst continuing to perform a professional caring role, and associations of not being able to cope through the internal and external resources available to them (Folkman & Lazarus, 1984).

To conclude, dual positioning appeared to bring a deepened empathic regard for service users/clients and carers and a heightened valuing of the role of providing care for others. Familial positioning, cultural heritage, life stage and life cycle, the availability of social and economic resources, the nature of a loved one's health condition and its positioning within society added to the uniqueness of the carer psychologists' experiences of caring. However, while the emotional responses associated with the caring experience were frequently contradictory, complex, painful, elaborate and sometimes ambiguous (*see Emotional responses, section 3.3.2*), within this there was also a sense of the strength and

depth of the connections within caring relationships, and how these may have also deepened in the caring dyad (*see Strengthening the bonds between us, section 3.4.1*).

Carer psychologists' experiences conveyed the awareness of an empathic insider within the system and a sense of discomfort around this experience. The diversity of experiences considered within the sample also highlighted the impact of how these dynamics may impact on the carer psychologists' sense of personal and professional self, and some variations in carer experiences amongst the subgroupings of carer psychologists. More generally, carer psychologists sometimes struggled to combine the pressures and responsibilities of providing care in the personal and professional spheres.

Finally, whilst heightened empathic regard and insider positioning may increase empathic connection with service user/carers experiences of the system and this should be valued within professional care, some carer psychologists also spoke of how they recognised that some unresolved emotional pain may have been less helpful in their clinical work. In the next section, empathy and empathic connection is considered more broadly within clinical practice.

4.3.6 The construction of empathy in clinical practice

Reflecting on psychologists' motivations for joining the profession, psychologists Ritz and Target (2008), suggested that there are two primary drivers: an individual's own experience of emotional pain and the desire to help others to overcome their pain and/or

personal development and growth. Ritz and Target asserted the value of a psychologist's own therapy to facilitate the transition from "wounded healer to healed helper" (Ritz & Target, 2008, p.131). "Healed helper" is a term they use to describe how the process of working through one's own emotional pain can lead to the ability to support another with their personal journey, through the enhancement of their own ability to empathise (Ritz & Target, 2008, p.131).

Qualitative researcher, Susan Gair (2012) considered whether it was possible to truly gain an appreciation of another's inner world without a shared experience of the phenomenon being considered. Her inference was that empathy was situational and malleable (Schumann, Zaki & Dweck, 2014; Ritz & Target, 2008), rather than dispositional (Davis, 1990). In common with psychologists generally, most participants perceived that their ability to be empathic drew them into being motivated to join the profession (*see Towards and away from career/specialism, section 3.6.3*; Warner & Bradley, 1991; Davies, 2018). However, all participants considered that their ability to empathise with carers and with clients had been enhanced by their caring experiences, indeed Simon described this as being "*personally invested*" in his clients' recovery journeys and his relationships with family members (*see Depth of ability to empathise, section 3.6.1*). This suggests that participants experienced their empathy as intuitive and instinctual, possibly due to their ability to connect to their own experience of emotional distress and discomfort (DiCaccavo, 2002).

Nevertheless, Gair also postulated that “common wounds” (Gair, 2012, p.136) might involve overidentification and potentially be triggering. Carer psychologists had shown how reflective processes and therapy had enabled them to manage the emotional pain they had become consciously aware of through either consciously avoiding work in clinical areas likely to be triggering for them (*see Towards and away career specialism, Denise, 3.6.3*) or through using clinically derived strategies to detach from their emotional pain in the professional sphere (*see Connections which challenge, Belinda, 3.7.1*).

Gair also considered how it may be a struggle to have empathy with those with whom one may share experiences, but have different understandings of those experiences. She subsequently concluded that relating to others through “an experience in common” rather than “common wounds” might be more helpful for building empathic connection (Gair, 2012, p.136). This “experience in common” (Gair, 2012, p.136) and its ability to have facilitated empathic regard appears to have been vindicated through this study.

Conversely, work-based moments of connection in which residual emotions might be present but that the carer psychologists were less consciously aware of were perceived to be more difficult to manage (*see Interconnection between personal and professional selves, Janice 3.6.2*). This may link to the ability of unprocessed emotional pain to be triggering and Gair’s concern about “common wounds” (Gair, 2012, p.136). However, it could also be postulated that its prevalence within the findings of this study illustrated carer psychologists’ self-awareness of their emotional states. Indeed, perhaps it is also the case that psychologists

who remain attuned to their own lived experiences of emotional pain and process this pain through reflective spaces will be able to remain empathically engaged in their clinical work.

Notwithstanding service demands, the NHS perhaps needs to be able to tolerate and accept, with compassion and care, the notion that we are all “them and us” and support psychological therapists/practitioner psychologists accordingly through empathically attuned supervision practices in which they can feel both listened to, and heard (Rhinehart, Johnson, & Killick, 2019; Keville, 2018). Studies into the impact of service demands and potential burnout related to stress in the psychological therapy profession are widely available (BPS, 2017; Westwood, Morison, Allt & Holmes, 2017; Simpson, Simionato, Smout, van Vreeswijk, Hayes, Sougleris, & Reid, 2019), however, the impact of dual caring is perhaps less widely understood within the profession and should perhaps be given further consideration by employers, as the findings of this study may suggest.

For the majority of the participants, compassion towards clients with enduring MH conditions appeared to deepen through the process of accepting others as ‘whole people’ who are ‘unwell’, rather than seeing loved ones as members of a group of people labelled by a diagnosis. Compassion towards others also deepened as participants became more aware of human vulnerability and an appreciation of how readily anyone’s MH could deteriorate. Participants caring for people with psychosis conveyed the depth of emotional pain around hospitalisation (Sharma, 2018). These included feelings of guilt and shock at observing their loved ones in inpatient settings, similar to those expressed in earlier studies of carers’

experiences (Taylor, Mellotte, Griffiths, Compton & Valsraj, 2016), which were conveyed by participants' expressions of wanting to escape the situation.

Linking this back to the question posed by Keville (2018), in which she questioned the ability of our professional training and personal life experiences to really understand either the context or the experiences of others that we do not know (Keville, 2018), I drew on an extract from my reflective diary to consider my own perspective. Whilst I experienced no doubt about the value of empathy in an exchange with another demonstrated by full engagement in the evolving relationship by being fully present, listening to, hearing and seeing the person in front of me (Hodges et al, 2010; Burks & Robbins, 2012), I also appreciated how much more deeply I had empathised with psychologists caring for loved ones with MH difficulties. There was a real resonance in me when they spoke of the shock at the witnessing of a loved one being hospitalised.

I subsequently reflected that perhaps it is the case that a clinician's ability to attend to the content of the communication, whilst having an awareness, and appreciation of how and why it might have been said, may be what is meant by empathy. It appeared that this was what participants were alluding to when they spoke of the depth in their empathic regard. In the words of Christine, "*colleagues might say 'that mother's really controlling' but I'd say put yourself in their position...I think I could empathise more with the overinvolvement where necessary*" (see *Depth of ability to empathise, section 3.6.1*).

4.4 Wider implications

The NHS's origins centre on the delivery of medical models of healthcare (NHSE, 2014). As the profession which promotes a medical model of understanding distress, psychiatry advocates treating distress with medicine which may, in the short term, be intended to reduce distress. However, in the longer term this can lead to dependency, and a reduction of relief and utilization of a client's internal resources (Moncrieff, 2017). Within MH, psychiatry remains a dominant professional group. As such, psychiatry plays a key role, alongside psychology, in shaping and disseminating the preferred discourses and systems for making meaning (Foucault, 1999).

It is perhaps unsurprising that the central concept of the 'disease model' with its paradigms of 'illness' and 'wellness' became highlighted within some of the discourses shared with me by some participants. Some of the differences in psychologists' constructions of MH and diagnostic labelling appear to relate to participants' different experiences of caring, and some of these differences may relate to their professional orientations, personal beliefs and value systems.

As highlighted in the introduction, BPS guidelines denote the importance of psychologists questioning their cognitive biases and belief systems during their working practice (BPS, 2017). Courses may also include sessions with service users and carers designed to facilitate the clinical understanding of service user and carer perspectives, and

some courses have engaged service users in mentoring schemes (Prytherch et al., 2018; Curle & Mitchell, 2014). However, perhaps courses have not yet considered how those who hold dual positions might be able to contribute to further questioning within the 'them and us' debate.

4.4.1 Clinical implications

As considered in the introduction, the profession is starting to open up the debate about psychologists having experienced MH difficulties, and what experiences of MH difficulties might bring to the therapeutic relationship (Hacker Hughes, 2016). Steps have been taken to value lived experience in clinical work (Grice et al., 2018; Meehan & Glover, 2007), however psychologists and other MH professionals have expressed concerns about sharing their experiences (Grice et al., 2018; Woodward et al., 2015). Some of these fears relate to concerns about perceived impact on employment and training opportunities (Grice et al., 2018) but they also narrate the potentially exposing nature of disclosing a personal experience in a profession which advocates adherence to boundaries around the personal and professional selves (Grice et al., 2018; Woodward et al., 2015; Nash & Chapman, 2019).

The importance of boundaries is highlighted by ethical standard 3.4 of the profession's code of conduct (BPS, 2018), which states that psychologists "should consider: (i) Honesty, openness and candour...and (v) Maintaining personal and professional boundaries" (BPS, 2018, p.7). Harper (2010) suggests that the profession's construction of professional boundaries was primarily designed to protect vulnerable clients from potentially exploitative

psychologists, rather than designed to protect the profession from the inherent challenges from engaging with people in different positions to ourselves. He locates the 'us and them' divide not as a question of identity, but as a question of professional power and political positioning (Harper, 2010, p.3).

Elaborating on the notion of positioning further, Harding's rejection of the "expert position" in her practice came as the result of her experience as a service user and her discomfort with the power imbalance (Harding, 2010, p.44). Some recipients of therapy have voiced concerns about the power imbalance that exists between psychologists and clients, and how this can be detrimental in terms of therapeutic alliance and therapeutic outcomes (Holttum, 2017). Awareness and due consideration of the dynamics of power within all aspects of service delivery may be one of the fundamental knowledges that 'service users/clients' and carers have (Harper, Cromby, Reavey, Cooke & Anderson, 2007). It is no longer the case that the "expert position" is perceived to be held by the professional (and the service provider) rather than the consumer (recipient of a service) (Mayer & McKenzie, 2017, p.1181). Indeed, in relation to the profession's stance on equality and inclusivity (BPS, 2018), Rosemary (2006) states the need to sustain self-reflexivity and maintain a critical awareness of the work with the client and the psychologist's relationship with the client (Rosemary, 2006). She considers that this is essential in order to prevent psychologists from being part of a profession which has notions of superiority over clients (Rosemary, 2006).

As a profession, psychology may, therefore, need to reconsider how it can open up relational thinking spaces in which the voices of 'service users/clients' and carers from within the profession can become full participants in decision making processes. This idea of creating relational thinking spaces for 'service users/clients' and carers is akin to the maintenance of a "thinking space" in therapy (Ogden, 1994, p.24). This is a space in which there is no "push or pull" to each other's positions, but the space to move outside of the relational perspectives brought about by our personal and professional identities (Rosemary, 2006, p.613).

At the current time, it would appear that a number of participants from the study experienced being constrained by being given identities which have curtailed their ability to contribute as full and equal partners in discourses around the delivery of care and its impact on their lives. Their experiences of indirect and direct experiences of stigmatisation related to engagement in the care for their loved ones is also borne out by the findings of research into carers of people with mental health issues (Corrigan & Miller, 2004; Schulze & Angermeyer, 2003).

These experiences have also included recollections of interactions whilst training. It may be questionable whether empathic regard and attunement to distress is a phenomenon able to be taught to trainees, so perhaps the selection process will remain critical in identifying candidates with inherent empathic abilities, which can be further developed through training through the vehicle of reflective practice opportunities, and the building of

emotional connections with service user and carer experiences. Psychologists are invariably drawn from privileged social groups (BPS, 2017), in which exposure to conditions of social and economic disadvantage may have been much more limited than those people that they will be working with, and on behalf of (Harper, 2010). Perhaps this disparity in resourcing may not always enable psychologists to fully comprehend the feelings of vulnerability and disempowerment which 'service users'/clients may experience when needing to use NHS funded services (Pembroke & Hadfield, 2010; Campbell, 1999; Keville, 2018). The findings suggest that training courses and employers will play a vital role in inviting psychologists in dual positions to participate in sharing, from their lived experiences, how services and systems can choose to include or exclude clients and carers within decision making processes. It is now widely accepted that quality of care initiatives, in which 'service user/client' and carer experience is centred, rather than decentred, in the set up and organisation of services, is critical to facilitating improvements in care (NHSE, 2014). Enabling those from within the profession to overcome self-silencing because of fears of being judged and potentially stigmatised if they speak out will help greater understanding of dual positionings, and in turn, what compassionate care might look and *feel* like.

4.5 Methodological strengths and limitations

The study questions remained consistent throughout the duration of the study, however, the study's framework deviated from its original focus purely on the experiences of

trainee and qualified clinical psychologists who were or had cared for loved ones in secondary MH services. The study's predominant recruitment strategy was the snowballing technique, rather than social media methods, and using this method led to a number of psychologists without personal experience of caring for loved ones with severe and enduring mental health conditions approaching the principal researcher to ask for consideration as participants in the research.

Amending the inclusion criteria of the study to broaden the spectrum of carer psychologists' experiences considered by the study has highlighted some of the complexities around the impact of caring on the personal and professional selves of psychologists and the differences in experience that exist between carer subgroupings. Due to the larger size of the subgroupings some commonalities and differences were able to be considered. However, as there were sometimes only one or 2 voices within the smaller subgroupings, such as carers of loved ones with neurodevelopmental, genetic or physical health conditions, or maternal carers, these were less able to be explored. The variations in carer psychologist experience may therefore merit further studies.

The strength of the sample was in its diversity. It represented the profession in terms of its gender, sexuality and ethnic composition (Turpin & Coleman, 2010; Goodyear, Lichtenberg, Hutman, Overland, Bedi, Christiani & Grant, 2016), it also included psychologists at different stages of their career journeys, thus enabling reflections on the personal-professional intersection from different perspectives and increasing the richness of the data.

However, one of my reflections on the interface between the interviews process, data generation and analysis parts of the study was that it became more complex due to the heterogeneity of the study sample derived from professional background. For example, I perceived some qualitative differentials between the personal accounts of clinical and counselling psychologists during the interviews process which are outlined in *Appendix 1: Extracts from reflective journal; see "Being with' intense emotional pain"*. I had a sense of being drawn into the emotional worlds of counselling psychologists more readily than clinical psychologists, irrespective of their stage in their training journey, and wondered whether counselling psychologists' experiences of personal therapy facilitated their earlier expression of their emotional states in an interaction with a researcher. I also sensed that some of the clinical psychologist participants wished to utilise the interview to process some of the more challenging emotional components of their caring experiences, perhaps because they might have had less engagement with personal therapy. Managing some of these complexities within the interviews process was a learning curve for me as a professional researcher and necessitated maintaining professional boundaries within an empathic but contained frame.

One of my perceptions during the later stage interviews was that participants were more readily able to give more generous accounts of their reflections when I felt more comfortable with the interviewer role. I was then more readily able to allow interviews to deviate naturally and then return to the key questions and prompts in a more nuanced way as the interviews progressed.

Throughout the study design process, I engaged carer consultants. The interview schedule was developed in consultation with my specialist tutor, who had caring experience, and it was piloted with a carer consultant before further revisions were made. The themes and subthemes were circulated to the participants for their feedback (Tracy, 2010). Adjustments to themes and further reflections on the process were facilitated through engagement with my reflective diary and critical consideration of the insider researcher process (Gair, 2012).

During the research process, my position as an insider researcher connected me to the study in an authentic way (Tracy, 2020), and I maintained a curiosity about the individual and collective themes which were discovered through the coding process. Prior to coding, I undertook the process of transcription myself enabling reflection on the interaction, the emotional content of the dialogue and what messages implicitly and explicitly conveyed in the exchange from the outset of the analysis. This concurs with the rich rigour element of Tracy's quality criteria, and with the theoretically robust approach to phenomenological research highlighted by qualitative researchers (Tracy, 2010; Todres, Galvin & Dahlberg, 2014).

Aiming to adopt a position of "emotional distance" throughout my work, rather than either being embroiled in the research, or removed from it (Gair, 2012, p.134), I reflected on the process in my diary. When I perceived a sense of frustration and fusion with the writing

up process, I endeavoured to minimise it to avoid compromising a more analytic way of considering the results.

Whilst this was qualitative research and, therefore, cannot claim to be generalizable, the size of the sample at fifteen participants provides a strong base for further studies in this area. The literature search process evidenced the paucity of research around psychologists' personal experiences of caring and its impact on clinical practice. Reflecting on Tracy's quality criteria, perhaps the most significant contribution that the study makes is to phenomenological-hermeneutic understandings of caring experiences evoked from the quality of the transcriptions and the development of the themes (Tracy, 2010). For example, the study may be considered to have "aesthetic merit" (Tracy, 2010, p.845) because of its resonance with participants conveyed through the member checking process.

4.6 Future studies

The study's findings suggested that psychologists' own experiences of processed emotional pain enabled a closer understanding and regard for empathic connections with clients/service users and carers. This suggests that studies considering the development of empathy, and how this is authentically conveyed should be a central concern in the recruitment and selection process of psychologists within counselling and clinical psychology. As the aim of the study was to explore a sample of carer psychologists' experiences in depth, there was relatively limited analysis of the qualitative differences in appraisals of caring

experiences across time, which could be the subject of further enquiry. There were also some differences in carer psychologists' experiences across the subgroupings, most noticeably those caring for those with loved ones with MH conditions, and those caring for loved ones with neurodevelopmental and/or physical health conditions, which other studies might usefully explore. Further research on all aspects of the caring experience, from those within and outside of the profession should also be considered, in order to support carers to negotiate this part of their lives.

4.7 Final self-reflections

Having reviewed my personal and professional development through the research process, I reflected that my appreciation of empathic regard in healthcare environments became more profound, as I recalled those managerial, clinical and non-clinical exchanges with colleagues in which I had felt understood and valued. I gained a new way of framing empathy, and it became more nuanced than a verbal utterance, it became *a being with*.

I gained a sense of the depth of some of the participants' experiences of emotional pain derived from their caring experiences. This gave me an enhanced appreciation of the nature of clinical training, and its value and role to me as a carer in my personal life and as a psychologist in my professional life. I reflected that one of the foremost challenges in clinical work is retaining the empathic stance which invariably brought all psychologists into this area of work, irrespective of whatever privileges a psychologist may personally have. In doing so,

we also need to maintain our self-awareness and recognise where one's own subjective experiences and professional knowledge may lead us to bias within the dynamics of an NHS in which the needs of those more vulnerable than ourselves may sometimes be compromised by the perpetual pressures of service delivery.

Finally, my hope would be that this study provides a stepping off point for other researchers to take forward the notion of dual positioning within the psychology profession, and in this way, to embrace a fuller and richer understanding of how we might move beyond "us and them".

References

- Albert, R., & Simpson, A. (2015). Double deprivation: A phenomenological study into the experience of being a carer during a mental health crisis. *Journal of Advanced Nursing*, 71(12), 2753-2762.
- Allard, J., Lancaster, S., Clayton, S., Amos, T., & Birchwood, M. (2018). Carers' and service users' experiences of early intervention in psychosis services: Implications for care partnerships. *Early Intervention in Psychiatry*, 12(3), 410-416.
- Alma, H. A., & Smaling, A. (2006). The meaning of empathy and imagination in health care and health studies. *International Journal of Qualitative Studies on Health and Well-being*, 1(4), 195-211.
- Andrén, S., & Elmståhl, S. (2005). Family caregivers' subjective experiences of satisfaction in dementia care: Aspects of burden, subjective health and sense of coherence. *Scandinavian Journal of Caring Sciences*, 19(2), 157-168.
- Askey, R., Holmshaw, J., Gamble, C., & Gray, R. (2009). What do carers of people with psychosis need from mental health services? Exploring the views of carers, service users and professionals. *Journal of Family Therapy*, 31(3), 310-331.
- Aston, A., Smith, S., De Boos, D., & Tickle, A. (2020). Do clinical psychologists have a role in clients' use of psychotropic medication? A mixed methods investigation exploring

current forms of involvement. *Psychology and Psychotherapy: Theory, Research and Practice*.

Baguley, F., & Sprung, S. (2012). Carers: The keystone of communities and families. In S.

Chilton & H. Bain (Eds.), *A Textbook of Community Nursing* (p.123). London;

Routledge.

Balbi, J. (2008). Epistemological and theoretical foundations of constructivist cognitive

therapies: Post-rationalist developments. *Dialogues in Philosophy, Mental and Neuro Sciences* 1(1), 15-27.

Barker, C., & Pistrang, N. (2002). Psychotherapy and social support: Integrating research on

psychological helping. *Clinical Psychology Review*, 22(3), 361-379.

Barker, C., Pistrang, N., & Elliott, R. (2015). Research methods in clinical psychology: An

introduction for students and practitioners. New York: John Wiley & Sons.

Biggerstaff, D., & Thompson, A. R. (2008). Interpretative phenomenological analysis (IPA): A

qualitative methodology of choice in healthcare research. *Qualitative Research in Psychology*, 5(3), 214-224.

Bolt, S., van der Steen, J., Schols, J., Zwakhalen, S., & Meijers, J. (2019). What do relatives

value most in end-of-life care for people with dementia?. *International Journal of Palliative Nursing*, 25(9), 432-442.

- Boyle, M. (2013). The persistence of medicalisation: Is the presentation of alternatives part of the problem? In S. Coles, S. Keenan, & B. Diamond (Eds.), *Madness contested: Power and practice* (pp. 3-22). Monmouth: PCCS Books.
- Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology, 3*(2), 77-101.
- British Psychological Society Practice Guidelines. (2017). London: British Psychological Society.
- British Psychological Society (2017). *New Savoy Survey Shows Increasing Mental Health Problems in NHS Psychotherapists*. <https://beta.bps.org.uk/news-and-policy/new-savoy-survey-shows-increasing-mental-health-problems-nhs-psychotherapists>.
- Code of Ethics and Conduct. (2018). London: British Psychological Society.
- Brohan, E., Slade, M., Clement, S., & Thornicroft, G. (2010). Experiences of mental illness stigma, prejudice and discrimination: A review of measures. *BMC Health Services Research, 10*(1), 80.
- Buckner, L., & Yeandle, S. (2011). Valuing carers. London: Carers UK.
- Burks, D. J., & Robbins, R. (2012). Psychologists' authenticity: Implications for work in professional and therapeutic settings. *Journal of Humanistic Psychology, 52*(1), 75-104.

Burrows, A., & Gannon, K. (2013). An evaluation of health and well-being checks for unpaid carers. *Journal of Integrated Care, 21*(3), 148-156.

Carers UK. (2014). Facts about carers 2014. London: Author. Retrieved from:

<https://www.carersuk.org/for-professionals/policy/policy-library/facts-about-carers-2014>

Carr, A. (2012). *Family therapy: Concepts, process and practice*. London: Wiley-Blackwell.

Castillo, L. G., & Schwartz, S. J. (2013). Introduction to the special issue on college student mental health. *Journal of Clinical Psychology, 69*(4), 291-297

Cath, A. (2016) Clinicians with mental health difficulties. *The Psychologist, 29*, 55.

Chang, K. H., & Horrocks, S. (2006). Lived experiences of family caregivers of mentally ill relatives. *Journal of Advanced Nursing, 53*(4), 435-443.

Charles, G. (2011). Bringing young carers out of the shadows. *Reclaiming Children and Youth, 20*(3), 26.

Clarke, V., & Braun, V. (2013). Teaching thematic analysis: Overcoming challenges and developing strategies for effective learning. *The Psychologist, 26*(2).

Constantinidis, T. C. (2017) Mental health professionals and family members of people with mental distress: encounter or disagreement? *Psicologia USP, 28* (1), 23-32.

- Cooke, A., & Kinderman, P. (2018). "But what about real mental illnesses?" Alternatives to the disease model approach to schizophrenia. *Journal of Humanistic Psychology, 58*(1), 47-71.
- Corrigan, P. W., & Watson, A. C. (2002). Understanding the impact of stigma on people with mental illness. *World Psychiatry, 1*(1), 16.
- Corrigan, P. W., & Miller, F. E. (2004). Shame, blame, and contamination: A review of the impact of mental illness stigma on family members. *Journal of Mental Health, 13*(6), 537-548.
- Corrigan, P. W., Druss, B. G., & Perlick, D. A. (2014). The impact of mental illness stigma on seeking and participating in mental health care. *Psychological Science in the Public Interest, 15*(2), 37-70.
- Corstens, D., May, R., & Longden, E. (2011). Talking with voices. *Psychosis as a personal crisis: An experience based approach*, 166-178.
- Cramond, L., Fletcher, I., & Rehan, C. (2020). Experiences of clinical psychologists working in palliative care: A qualitative study. *European Journal of Cancer Care, 29*(3).
- Cree, L., Brooks, H. L., Berzins, K., Fraser, C., Lovell, K., & Bee, P. (2015). Carers' experiences of involvement in care planning: A qualitative exploration of the facilitators and barriers to engagement with mental health services. *BMC Psychiatry, 15*(1), 208.

- Cristy, B. L. (2001). Wounded healer: The impact of a therapist's illness on the therapeutic situation. *Journal of the American Academy of Psychoanalysis and Dynamic Psychiatry, 29*(1), 33-42.
- Cromby, J., Harper, D., & Reavey, P. (2013). *Psychology, mental health and distress*. London: Palgrave Macmillan International Higher Education.
- Cunningham, S. D., Thomas, P. D., & Warschausky, S. (2007). Gender differences in peer relations of children with neurodevelopmental conditions. *Rehabilitation Psychology, 52*(3), 331.
- Curle, C. & Mitchell, A. (2014). Hand in hand: User and carer involvement in training clinical psychologists. *Clinical Psychology, 33*, 12–15.
- Davies, J. M. M. (2018). The role of developmental/relational trauma in therapists' motivation to pursue a psychotherapeutic career: A grounded theory exploration. Doctoral dissertation, University of West of England.
- Davis, C. M. (1990). What is empathy, and can empathy be taught? *Physical therapy, 70*(11), 707-711.
- Dening, T., & Milne, A. (2013). Care homes for older people. Dening & Thomas (Eds.), *Oxford Textbook of Old Age Psychiatry* (p. 343). Oxford: Oxford University Press.

Department of Health. (2011). No health without mental health: A cross-government mental health outcomes strategy for people of all ages. London: Author.

Department of Health and Social Care. (2020). *Carer's leave consultation*. Retrieved from <https://www.gov.uk/government/consultations/carers-leave>

Department for Work and Pensions. (2018). *Family Resources Survey, 2017/18*. London: Author.

Office for National Statistics. (2019). *Living longer: caring in later working life*. Newport: ONS.

DePasquale, N., Davis, K. D., Zarit, S. H., Moen, P., Hammer, L. B., & Almeida, D. M. (2016). Combining formal and informal caregiving roles: The psychosocial implications of double-and triple-duty care. *Journals of Gerontology Series B: Psychological Sciences and Social Sciences*, *71*(2), 201-211.

DiCaccavo, A. (2002). Investigating individuals' motivations to become counselling psychologists: The influence of early caretaking roles within the family. *Psychology and Psychotherapy: Theory, Research and Practice*, *75*(4), 463-472.

Dooley, C., & Peyton-Lander, T. (2020). *Policy on Supervision*. London: Division of Counselling Psychology.

Felitti, V. J., Anda, R. F., Nordenberg, D., Williamson, D. F., Spitz, A. M., Edwards, V., & Marks, J. S. (1998). Relationship of childhood abuse and household dysfunction to many of

the leading causes of death in adults: The adverse childhood experiences (ACE) study. *American Journal of Preventive Medicine*, 14(4), 245-258.

Foucault, T. A. (1999). Foucault and therapy: The disciplining of grief. In A. S. Chambon (Ed.), *Reading Foucault for social work* (p. 157). New York: Columbia University Press.

Fussell, F. W., & Bonney, W. C. (1990). A comparative study of childhood experiences of psychotherapists and physicists: Implications for clinical practice. *Psychotherapy: Theory, Research, Practice, Training*, 27(4), 505.

Frankl, V. E. (2014). *The will to meaning: Foundations and applications of logotherapy*. New York: Penguin.

Fredman, G. (2018). *Death talk: Conversations with children and families*. New York: Routledge.

Frith, H. and Gleeson, K. (2012) *Qualitative Data Collection: Asking the Right Questions*. In D. Harper & A.R. Thompson (Eds.), *Qualitative research methods in mental health and psychotherapy*. London: Wiley Blackwell.

Gair, S. (2012). Feeling their stories: Contemplating empathy, insider/outsider positionings, and enriching qualitative research. *Qualitative Health Research*, 22(1), 134-143.

- Gaume, J., Hallgren, K. A., Clair, C., Schmid Mast, M., Carrard, V., & Atkins, D. C. (2019). Modeling empathy as synchrony in clinician and patient vocally encoded emotional arousal: A failure to replicate. *Journal of Counselling Psychology, 66*(3), 341-350.
- Gilbert, P. (2003). Evolution, social roles, and the differences in shame and guilt. *Social Research: An International Quarterly, 70*(4), 1205-1230.
- Goddard, M. (2017). The EU General Data Protection Regulation (GDPR): European regulation that has a global impact. *International Journal of Market Research, 59*(6), 703-705.
- Goodyear, R., Lichtenberg, J., Hutman, H., Overland, E., Bedi, R., Christiani, K. & Grant, J. (2016). A global portrait of counselling psychologists' characteristics, perspectives, and professional behaviors. *Counselling Psychology Quarterly, 29*(2), 115-138.
- Goodwin, V., & Happell, B. (2006). Conflicting agendas between consumers and carers: The perspectives of carers and nurses. *International Journal of Mental Health Nursing, 15*(2), 135-143.
- Gonzales, M., & Melton, L. (2017). The Wounded Healer. *Journal of the Advanced Practitioner in Oncology, 8*(5), 453.
- Greenwood, N., & Smith, R. (2016). The oldest carers: a narrative review and synthesis of the experiences of carers aged over 75 years. *Maturitas, 94*, 161-172.

- Grice, T., Alcock, K., & Scior, K. (2018). Mental health disclosure amongst clinical psychologists in training: Perfectionism and pragmatism. *Clinical Psychology & Psychotherapy, 25*(5) 721-729.
- Harding, E. (2010). User involvement: Why bother? Trainee clinical psychologist and/or service user? *Clinical Psychology Forum, 209*, 7-8.
- Hacker Hughes, J. (2016). Experiencing what clients experience. *The Psychologist, 29*, 810-815.
- Harper, D., Cromby, J., Reavey, P., Cooke, A. & Anderson, J. (2007). Don't jump ship: New approaches in teaching mental health to undergraduates. *The Psychologist, 20*(5), 302–304.
- Harper, D. (2010). Tensions and dilemmas in clinical psychology's relationship with the service user movement. *Clinical Psychology Forum 209*, 35-38.
- Harper, D. & Thompson, A.R. (2012) Emerging issues and future directions. In D. Harper & A.R. Thompson (Eds.) *Qualitative Research Methods in Mental Health and Psychotherapy*, London: Wiley Blackwell.
- Hartmann, E. (1991). *Boundaries in the mind: A new psychology of personality*. New York: Basic Books.
- Heath, J., Williamson, H., Williams, L., & Harcourt, D. (2018). "It's just more personal": Using

multiple methods of qualitative data collection to facilitate participation in research focusing on sensitive subjects. *Applied Nursing Research*, 43, 30-35.

Hemmerdinger, J. M., Stoddart, S. D., & Lilford, R. J. (2007). A systematic review of tests of empathy in medicine. *BMC Medical Education*, 7(1), 24.

Hermansson, G. (1997). Boundaries and boundary management in counselling: The never-ending story. *British Journal of Guidance and Counselling*, 25(2), 133-146.

Hirst, M. (2004). *Health inequalities and informal care: End of project report*. York: Social Policy Research Unit, University of York.

Hodges, S. D., Kiel, K. J., Kramer, A. D., Veach, D., & Villanueva, B. R. (2010). Giving birth to empathy: The effects of similar experience on empathic accuracy, empathic concern, and perceived empathy. *Personality and Social Psychology Bulletin*, 36(3), 398-409.

Holttum, S. (2017). Research watch: is social inclusion for service users increased when mental health professionals "come out" as service users? *Mental Health and Social Inclusion*, 23(4), 149-155.

Horn, N., Johnstone, L., & Brooke, S. (2007). Some service user perspectives on the diagnosis of borderline personality disorder. *Journal of Mental Health*, 16(2), 255-269.

Joffe, H. (2012) Thematic Analysis. In D. Harper & A.R. Thompson (Eds.) *Qualitative Research Methods in Mental Health and Psychotherapy*. London: Wiley-Blackwell.

- Johnson, W. B. (2008). Top ethical challenges for military clinical psychologists. *Military Psychology, 20*(1), 49-62.
- Johnstone, L., & Dallos, R. (2013). *Formulation in psychology and psychotherapy: Making sense of people's problems*. New York: Routledge.
- Joling, K. J., van Hout, H. P., Scheltens, P., Vernooij-Dassen, M., van den Berg, B., Bosmans, J., & van Marwijk, H. W. (2008). (Cost)-effectiveness of family meetings on indicated prevention of anxiety and depressive symptoms and disorders of primary family caregivers of patients with dementia: design of a randomized controlled trial. *BMC Geriatrics, 8*(1), 2.
- Jung, E., Wiesjahn, M., Rief, W., & Lincoln, T. M. (2015). Perceived therapist genuineness predicts therapeutic alliance in cognitive behavioural therapy for psychosis. *British Journal of Clinical Psychology, 54*(1), 34-48.
- Kennedy, C. H., & Johnson, W. B. (2009). Mixed agency in military psychology: Applying the American Psychological Association ethics code. *Psychological Services, 6*(1), 22.
- Keville, S. (2018). Across the Great Divide: Reflecting on dual positions in Clinical Psychology to enhance equality and inclusion between those working in and those referred to services. *Reflective Practice, 19*(6), 791-805.

- Kinderman, P., Read, J., Moncrieff, J., & Bentall, R. P. (2013). Drop the language of disorder. *Evidence-Based Mental Health, 16*(1).
- Krauss, S. E. (2005). Research paradigms and meaning making: A primer. *The Qualitative Report, 10*(4), 758-770.
- Laska, K. M., Gurman, A. S., & Wampold, B. E. (2014). Expanding the lens of evidence-based practice in psychotherapy: A common factors perspective. *Psychotherapy, 51*(4), 467.
- Larson, E. B., & Yao, X. (2005). Clinical empathy as emotional labor in the patient-physician relationship. *Jama, 293*(9), 1100-1106.
- Folkman, S., & Lazarus, R. S. (1984). *Stress, appraisal, and coping* (pp. 150-153). New York: Springer Publishing Company.
- Lindsay, R. (2017). Mental health revelations – enough is enough? *The Psychologist, 30*, 2.
- Lofgren, A., Hewitt, V., & das Nair, R. (2015). Doing fence sitting: A discursive analysis of clinical psychologists' constructions of mental health. *Qualitative Health Research, 25*(4), 470-485.
- Luker, J. A., Bernhardsson, S., Lynch, E., Murray, C., Hill, O. P., & Bernhardt, J. (2015). Carers' experiences, needs and preferences during inpatient stroke rehabilitation: a protocol for a systematic review of qualitative studies. *Systematic Reviews, 4*(1), 1-5.

- Magliano, L., Fadden, G., Madianos, M., de Almeida, J. C., Held, T., Guarneri, M., & Maj, M. (1998). Burden on the families of patients with schizophrenia: Results of the BIOMED I study. *Social Psychiatry and Psychiatric Epidemiology*, *33*(9), 405-412.
- Magliano, L., Fiorillo, A., De Rosa, C., Malangone, C., Maj, M., & National Mental Health Project Working Group (2005). Family burden in long-term diseases: A comparative study in schizophrenia vs. physical disorders. *Social Science & Medicine*, *61*(2), 313-322.
- Mallinckrodt, B. (2010). The psychotherapy relationship as attachment: Evidence and implications. *Journal of Social and Personal Relationships*, *27*(2), 262-270.
- Mannion, E. (2008). Alzheimer's disease: the psychological and physical effects of the caregiver's role. Part 1. *Nursing Older People*, *20*(4).
- MacCallum, E. J. (2002). Othering and psychiatric nursing. *Journal of Psychiatric and Mental Health Nursing*, *9*(1), 87-94.
- McCann, T. V., Bamberg, J., & McCann, F. (2015). Family carers' experience of caring for an older parent with severe and persistent mental illness. *International journal of mental health nursing*, *24*(3), 203-212.
- McGoldrick, M., Carter, E. A., & Garcia-Preto, N. (2001). *The expanded family life cycle: Individual, family, and social perspectives*. London: Pearson.

- May, R. (2000). Routes to recovery from psychosis: The roots of a clinical psychologist. *Clinical Psychology Forum*, 6-10.
- May, R. (2001). Crossing the "them and us" barriers: An inside perspective on user involvement in clinical psychology. *Clinical Psychology Forum*, 14-17.
- Mayer, C., & McKenzie, K. (2017). '...it shows that there's no limits': the psychological impact of co-production for experts by experience working in youth mental health. *Health & Social Care in the Community*, 25(3), 1181-1189.
- McLaughlin, H. (2009). What's in a name: 'client', 'patient', 'customer', 'consumer', 'expert by experience', 'service user' – what's next? *The British Journal of Social Work*, 39(6), 1101-1117.
- Meehan, T., & Glover, H. (2007). Telling our story: Consumer perceptions of their role in mental health education. *Psychiatric Rehabilitation Journal*, 31(2), 152.
- Moher, D., Liberati, A., Tetzlaff, J., Altman, D. G., & Prisma Group. (2009). Preferred reporting items for systematic reviews and meta-analyses: the PRISMA statement. *PLoS Medicine*, 6(7), e1000097.
- Moncrieff, J. (2017). Opium and the people: The prescription psychopharmaceutical epidemic in historical context. In *The sedated society* (pp. 73-99). Cham: Palgrave Macmillan.

- Moses, T. (2010). Exploring parents' self-blame in relation to adolescents' mental disorders. *Family Relations*, 59(2), 103-120.
- Morant, N. (2006). Social representations and professional knowledge: The representation of mental illness among mental health practitioners. *British Journal of Social Psychology*, 45(4), 817-838.
- Nash, B., & Chapman, N. A. (2019). Building a culture of caring: Lessons learned from managing professional expectations while navigating the emotional upheaval of divorce. *Journal of Psychotherapy Integration*, 29(2), 95.
- Neukrug, E., Bayne, H., Dean-Nganga, L., & Pusateri, C. (2013). Creative and novel approaches to empathy: A neo-Rogerian perspective. *Journal of Mental Health Counseling*, 35(1), 29-42.
- NHS England. (2020). *Who is considered a carer?* Retrieved from <https://www.england.nhs.uk/commissioning/comm-carers/carers/>
- NHS England. (2020). *Understanding Carers*. Retrieved from <https://www.nhs.uk/conditions/social-care-and-support-guide/>
- NHS England & NHS Improving Quality. (2014). *Commitment for Carers: Report of the findings and outcomes*. Medical directorate and Nursing directorate.

- Novick, G. (2008). Is there a bias against telephone interviews in qualitative research? *Research in Nursing & Health, 31*(4), 391-398.
- Ochieng, B. M. (2003). Minority ethnic families and family-centred care. *Journal of Child Health Care, 7*(2), 123-132.
- Ogden, T. H. (1994). The analytic third: Working with intersubjective clinical facts. *International Journal of Psycho-Analysis, 75*, 3-19.
- Ogunfowora, B., & Drapeau, M. (2008). Comparing counselling and clinical psychology practitioners: Similarities and differences on theoretical orientations revisited. *International Journal for the Advancement of Counselling, 30*(2), 93-103.
- Omylinska-Thurston, J., McMeekin, A., Walton, P., & Proctor, G. (2019). Clients' perceptions of unhelpful factors in CBT in IAPT serving a deprived area of the UK. *Counselling and Psychotherapy Research, 19*(4), 455-464.
- Onwumere, J., Learmonth, S., & Kuipers, E. (2016). Caring for a relative with delusional beliefs: A qualitative exploration. *Journal of psychiatric and mental health nursing, 23*(3-4), 145-155.
- Park, C. L. (2010). Making sense of the meaning literature: An integrative review of meaning making and its effects on adjustment to stressful life events. *Psychological bulletin, 136*(2), 257.

- Pelle, J. (2013). African and African Caribbean carers' experience of caring for a family member with an enduring mental health problem in contemporary Britain. Doctoral dissertation, University of Southampton.
- Pembroke, L., & Hadfield, J. (2010). Psychological research mentored by a survivor activist: Having your cake and eating it. *Clinical Psychology*.
- Perkins, A., Ridler, J., Browes, D., Peryer, G., Notley, C., & Hackmann, C. (2018). Experiencing mental health diagnosis: A systematic review of service user, clinician, and carer perspectives across clinical settings. *The Lancet Psychiatry*, 5(9), 747-764.
- Prytherch, H., Lea, L., & Richardson, M. (2018). Mentoring trainee psychologists: Learning from lived experience. *The Journal of Mental Health Training, Education and Practice*, 13, 197-208.
- Randall-James, J., & Coles, S. (2018). Questioning diagnoses in clinical practice: a thematic analysis of clinical psychologists' accounts of working beyond diagnosis in the United Kingdom. *Journal of Mental Health*, 27(5), 450-456.
- Rapley, M., Moncrieff, J., & Dillon, J. (2011). *De-medicalizing misery: Psychiatry, psychology and the human condition*. London: Palgrave Macmillan.

- Read, J., Haslam, N., Sayce, L., & Davies, E. (2006). Prejudice and schizophrenia: A review of the 'mental illness is an illness like any other' approach. *Acta Psychiatrica Scandinavica*, *114*(5), 303-318.
- Rhinehart, M., Johnson, E., & Killick, K. (2019). On being a practitioner and a client. Surviving clinical psychology: Navigating personal, professional and political selves on the journey to qualification. London: Routledge.
- Richards, C. (2010). 'Them and us' in mental health services – Christina Richards looks behind the dichotomy and calls for change. *The Psychologist*, *23*(1), 40.
- Richards, J., Holttum, S., & Springham, N. (2016). How do “mental health professionals” who are also or have been “mental health service users” construct their identities? *Sage Open*, *6*(1), 2158244015621348.
- Rizq, R., & Target, M. (2008). 'The power of being seen': An interpretative phenomenological analysis of how experienced counselling psychologists describe the meaning and significance of personal therapy in clinical practice. *British Journal of Guidance & Counselling*, *36*(2), 131-153.
- Rogers, C. R. (1957). The necessary and sufficient conditions of therapeutic personality change. *Journal of consulting psychology*, *21*(2), 95.

- Rogers, B., & Dunne, E. (2011). 'They told me I had this personality disorder... All of a sudden I was wasting their time': Personality disorder and the inpatient experience. *Journal of Mental Health, 20*(3), 226-233.
- Roper-Hall, A. (1998). Working systemically with older people and their families who have 'come to grief'. In *Working with the dying and bereaved* (pp. 177-206). London: Palgrave.
- Rosemary, R. (2006). Training and disillusion in counselling psychology: A psychoanalytic perspective. *Psychology and Psychotherapy: Theory, Research and Practice, 79*(4), 613-627.
- Saunders, J. C. (2003). Families living with severe mental illness: A literature review. *Issues in mental health nursing, 24*(2), 175-198.
- Schulze, B., & Angermeyer, M. C. (2003). Subjective experiences of stigma. A focus group study of schizophrenic patients, their relatives and mental health professionals. *Social Science & Medicine, 56*(2), 299-312.
- Schumann, K., Zaki, J., & Dweck, C. S. (2014). Addressing the empathy deficit: Beliefs about the malleability of empathy predict effortful responses when empathy is challenging. *Journal of Personality and Social Psychology, 107*(3), 475.

- Sciberras, A., & Pilkington, L. (2018). The lived experience of psychologists working in mental health services: An exhausting and exasperating journey. *Professional Psychology: Research and Practice, 49*(2), 151.
- Shah, A. J., Wadoo, O., & Latoo, J. (2010). Psychological distress in carers of people with mental disorders. *British Journal of Medical Practitioners, 3*(3).
- Sharma, N., Chakrabarti, S., & Grover, S. (2016). Gender differences in caregiving among family-caregivers of people with mental illnesses. *World Journal of Psychiatry, 6*(1), 7.
- Sharma, B. (2018). Fathers' experiences of caring for an adult child with psychosis: A qualitative study. Doctoral dissertation, University of Hertfordshire.
- Sharma, B., Green, N., & Keville, S. (2020). Fathers' experiences of caring for an adult child with psychosis: A qualitative study. *Psychosis, 1-12*.
- Siddaway, A. P., Wood, A. M., & Hedges, L. V. (2019). How to do a systematic review: A best practice guide for conducting and reporting narrative reviews, meta-analyses, and meta-syntheses. *Annual Review of Psychology, 70*, 747-770.
- Simpson, S., Simionato, G., Smout, M., van Vreeswijk, M. F., Hayes, C., Sougleris, C., & Reid, C. (2019). Burnout amongst clinical and counselling psychologist: The role of early maladaptive schemas and coping modes as vulnerability factors. *Clinical psychology & psychotherapy, 26*(1), 35-46.

- Smallwood, J. (2016). Who cares for the carers? *Psychologist*, 29(9), 698-699.
- Smith, J. A. (2011). Evaluating the contribution of interpretative phenomenological analysis. *Health psychology review*, 5(1), 9-27.
- Smith, J. A., & Shinebourne, P. (2012). *Interpretative phenomenological analysis*. American Psychological Association.
- Smyth, C., Blaxland, M., & Cass, B. (2011). 'So that's how I found out I was a young carer and that I actually had been a carer most of my life'. Identifying and supporting hidden young carers. *Journal of Youth Studies*, 14(2), 145-160.
- Stepien, K. A., & Baernstein, A. (2006). Educating for empathy. *Journal of General Internal Medicine*, 21(5), 524-530.
- Stillwell, K. (2016). Caring over the lifespan: Experiences of caring for a sibling with schizophrenia. Doctoral dissertation, University of East London.
- Taskforce, M. H. (2016). *The five year forward view for mental health*. London: Department of Health.
- Tay, J. L., Tay, Y. F., & Klainin-Yobas, P. (2018). Mental health literacy levels. *Archives of psychiatric nursing*, 32(5), 757-763.

- Taylor, R., Mellotte, H., Griffiths, M., Compton, A., & Valsraj, K. (2016). Carers matter: promoting the inclusion of families within acute inpatient settings. *Journal of Psychiatric Intensive Care, 12*(2), 69-77.
- Team, C. P., & House, W. (2010). Recognised, valued and supported: Next steps for the Carers Strategy. London: Stationery Office.
- Thompson Jr, E. H., Futterman, A. M., Gallagher-Thompson, D., Rose, J. M., & Lovett, S. B. (1993). Social support and caregiving burden in family caregivers of frail elders. *Journal of Gerontology, 48*(5), S245-S254.
- Thornicroft, G., Rose, D., Kassam, A., & Sartorius, N. (2007). Stigma: Ignorance, prejudice or discrimination?. *The British Journal of Psychiatry, 190*(3), 192-193.
- Todres, L., Galvin, K. T., & Dahlberg, K. (2014). "Caring for insiderness": Phenomenologically informed insights that can guide practice. *International Journal of Qualitative Studies on Health and Well-being, 9*(1), 21421.
- Tracy, S. J. (2010). Qualitative quality: Eight "big-tent" criteria for excellent qualitative research. *Qualitative inquiry, 16*(10), 837-851.
- Tufford, L., & Newman, P. (2012). Bracketing in qualitative research. *Qualitative social work, 11*(1), 80-96.

- Turpin, G., & Coleman, G. (2010). Clinical psychology and diversity: Progress and continuing challenges. *Psychology Learning & Teaching, 9*(2), 17-27.
- Ussher, J. M., & Sandoval, M. (2008). Gender differences in the construction and experience of cancer care: The consequences of the gendered positioning of carers. *Psychology and Health, 23*(8), 945-963.
- Ussher, J. M., & Perz, J. (2010). Gender differences in self-silencing and psychological distress in informal cancer carers. *Psychology of Women Quarterly, 34*(2), 228-242.
- van der Zanden, R., Kramer, J., Gerrits, R., & Cuijpers, P. (2012). Effectiveness of an online group course for depression in adolescents and young adults: a randomized trial. *Journal of medical Internet research, 14*(3), e86.
- Wadey, K. (2015). Young carers' experiences of caring in an inner London borough. An interpretative phenomenological analysis (IPA). Doctoral dissertation, University of East London.
- Wallcraft, J. A. N., Amering, M., Freidin, J., Davar, B., Froggatt, D., Jafri, H., & Steffen, S. (2011). Partnerships for better mental health worldwide: WPA recommendations on best practices in working with service users and family carers. *World Psychiatry, 10*(3), 229-236.

- Ward-Griffin, C., Brown, J. B., Vandervoort, A., McNair, S., & Dashnay, I. (2005). Double-duty caregiving: Women in the health professions. *Canadian Journal on Aging/La Revue Canadienne du Vieillissement*, 24(4), 379-394.
- Warner, D. L., & Bradley, J. R. (1991). Undergraduate psychology students' views of counsellors, psychiatrists, and psychologists: A challenge to academic psychologists. *Professional Psychology: Research and Practice*, 22(2), 138.
- Wells, K. (2011). *Narrative inquiry*. Oxford: Oxford University Press.
- Westerhof, G. J., & Keyes, C. L. (2010). Mental illness and mental health: The two continua model across the lifespan. *Journal of Adult Development*, 17(2), 110-119.
- Westwood, S., Morison, L., Allt, J., & Holmes, N. (2017). Predictors of emotional exhaustion, disengagement and burnout among improving access to psychological therapies (IAPT) practitioners. *Journal of mental health*, 26(2), 172-179.
- Whiting, M. (2014). Children with disability and complex health needs: the impact on family life. *Nursing children and young people*, 26(3).
- Whitney, J., Haigh, R., Weinman, J., & Treasure, J. (2007). Caring for people with eating disorders: Factors associated with psychological distress and negative caregiving appraisals in carers of people with eating disorders. *British Journal of Clinical Psychology*, 46(4), 413-428.

Willig, C. (2001). *Qualitative research in psychology: A practical guide to theory and method*.

Buckingham: Oxford University Press.

Willig, C., & Billin, A. (2012). Existentialist-informed hermeneutic phenomenology. *Qualitative*

Research Methods in Mental Health and Psychotherapy, 117-130.

Woodward, N. S., Keville, S., & Conlan, L. M. (2015). The buds and shoots of what I've grown

to become: The development of reflective practice in trainee clinical

psychologists. *Reflective Practice*, 16(6), 777-789.

Yardley, L. (2000). Dilemmas in qualitative health research. *Psychology and Health*, 15(2),

215-228.

Appendix 1: Extracts from reflective journal

The insider researcher position and the influence of previous knowledges of each other

The carer consultant I piloted the initial interview schedule with reflected that she had felt comfortable with me during the interview. I had asked for feedback about whether she had felt the presence of a power imbalance between us or any hesitancy about answering the questions because of her knowledge that we would connect again via professional networks. However, I wondered whether this had been to do with her previous understanding of my carer role within my family, and one conversation about how this had impacted me on training. Whilst neither of us could really know how our previous conversations and knowledges might have impacted on the exchange, I carried this reflection with me into my first interview.

This participant was again known to me through a professional context, and met the criteria for the original study. I found myself very drawn into his analysis of the constructions of mental health and mental health distress and his reflections on the 'them and us' debate. The interview felt like a very natural conversation between two psychologists and it led me to a far greater understanding of how he had also questioned his sense of self whilst training, in part because of the stigmatising nature of psychosis and its framing within the profession of clinical psychology.

I drew parallels with the therapeutic alliance and how readily trust can be built when there is some shared understanding but again, I wondered whether trust had been built in our pre-existing knowledges of each other, and I wondered how I might continue to build trust with participants not

previously known to me in order that they would feel as able to share with me their experiences as fully as possible.

Building trust – to share or not to share, and if to share something of the self, how much

Before starting another interview with a participant who was unknown to me, I was mindful of the imbalance of power between researcher and participant, and sensed some anxiety in our interaction in our pre-interview briefing. Unsure of whether this was my anxiety because this was the first interview I had completed in private accommodation, or her anxiety, I asked her whether it might help to know anything more about me before we started the interview, as I appreciated that it may feel a bit uncomfortable to be sharing so much of a personal experience with someone unknown to her. She thanked me for this, said that she was feeling quite anxious about talking about her experience, but had noted my lived experience of caring from the participant information sheet, and this had reassured her that I would have some understanding of her experience.

Mindful of my conversation with my primary supervisor about the need to bracket my personal experience, we proceeded with the start of the interview. As she spoke, she drew me into images and knowledges of the mental health inpatient system, and I connected with her sadness and sense of isolation at key points on her journey. At the end of the interview, she reflected that she had felt able to convey the depth of her experience. However, during the interaction, I had observed a sense of myself as moving between 'insider' and 'outsider' positions, as the exchange proceeded, and I felt both close and distant to understanding and connecting to her personal experience at key points. I reflected on this observation in a meeting with my supervisor, and I was able to reflect that my observation did not relate to a sense of disconnection with the research process, but was located

within my experience of mental and physical tiredness and its impact on my cognitive levels and connection to my empathic regard. I realised that I needed to revise my interview schedules for earlier in the day, to mitigate against tiredness with evening appointments.

“Walking in my shoes”

During an interview with another participant previously unknown to me, I observed myself again moving in and out of intense emotional states as he spoke. On training I had started to become increasingly aware of a level of my own internalised prejudice towards psychologists coming from privileged backgrounds and the increased levels of external resourcing available to them. This connected to my ability to make an internal judgement around a participants' perceived value system and how this aligned, or misaligned with my own.

In this interaction I connected intensively with his experience of inpatient settings, and his 'horror' and desire to 'run away' from the pain of his own experience, but also the love for his father requiring him to face his own pain, and to hold and contain this to be able to care for his father. As we considered his placement and career choices to date, I connected to his reflections around his ability to relate to other mental health professionals in acute settings but felt somewhat compromised in my empathic regard for his description of his reflections on his self-care needs. At the end of the interview he commented that he might have wanted the interview to focus more on the emotional component of his experience, rather than for the interview to move into another question which started to lead into the links between the personal experience of caring and its potential impact on the professional self.

I wondered to what extent he may have picked up on my sense of disconnection, and my need to progress the interview within its time constraints. I also wondered whether there might be a tendency for clinical psychologists not in therapy to wish to use the opportunity presented by the interview to begin to process some of the intensity of their difficult emotions. I wondered both whether I was not being empathic enough, but also potentially being too pulled into participants' emotional needs, and reflected on this as a process point for future interactions.

'Being with' intense emotional pain

I started to sense differences in my ability to be fully present, and to sit with the intensity of others' emotional pain whilst noticing some generalised qualitative differentials between participants who were clinical and counselling psychologists.

It appeared that the majority of the counselling psychologists interviewed shifted more quickly into sharing more of the intensity of their inner worlds with me in response to the same headline question. They appeared to be able to 'hold', contain and explore some questions in more depth without me adding any supplementary questions to lead them into describing the emotional impact on them. I found that this drew me in to be more appreciative and empathic of their inner pain.

I hypothesised that my awareness that some participants who were from a clinical psychology background may have led me into a different way of being with them, and that the space between us led to a different quality of interaction. A later reflection was that I wondered whether the counselling psychologists' experiences of personal therapy enabled them to move more quickly into an expression of their emotional states than perhaps clinical psychologists might. I had a sense that I

sometimes experienced some sense of disconnection from some of the reflective processes of clinical psychologists, as if they were somewhat 'removed' or 'distanced' from their emotions, and were seeking to rationalise them through an intellectualised process, and this was sometimes the case irrespective of my personal connection to them. I wondered about this, and vowed to remain mindful of this as the study progressed.

Appendix 2: Ethics approval LMS/PGR/UH/0376

**HEALTH SCIENCE ENGINEERING & TECHNOLOGY ECDA****ETHICS APPROVAL NOTIFICATION**

TO Angela Burrows

CC Dr Saskia Keville

FROM Dr Rosemary Godbold, Health, Science, Engineering & Technology ECDA Vice Chair.

DATE 28/02/2019

Protocol number: **LMS/PGR/UH/03676**

Title of study: Trainee and qualified clinical psychologists' personal experiences of caring for others with mental health difficulties and how they understand any impact this may, or may not, have on their professional practice.

Your application for ethics approval has been accepted and approved by the ECDA for your School and includes work undertaken for this study by the named additional workers below:

This approval is valid:

From: 28/02/2019

To: 30/09/2020

Additional workers: no additional workers named

Please note:

If your research involves invasive procedures you are required to complete and submit an EC7 Protocol Monitoring Form, and your completed consent paperwork to this ECDA once your study is complete. You are also required to complete and submit an EC7 Protocol Monitoring Form if you are a member of staff. This form is available via the Ethics Approval StudyNet Site via the 'Application Forms' page

<http://www.studynet1.herts.ac.uk/ptl/common/ethics.nsf/Teaching+Documents?Openview&count=9999&restricttcategory=Application+Forms>

Any necessary **permissions** for the use of premises/location and accessing participants for your study must be obtained in writing prior to any data collection commencing. Failure to obtain adequate permissions may be considered a breach of this protocol.

Approval applies specifically to the research study/methodology and timings as detailed in your Form EC1A. Should you amend any aspect of your research, or wish to apply for an extension to your study, you will need your supervisor's approval (if you are a student) and must complete and submit form EC2. In cases where the amendments to the original study are deemed to be substantial, a new Form EC1A may need to be completed prior to the study being undertaken.

Should adverse circumstances arise during this study such as physical reaction/harm, mental/emotional harm, intrusion of privacy or breach of confidentiality this must be reported to the approving Committee immediately. Failure to report adverse circumstance/s would be considered misconduct.

Ensure you quote the UH protocol number and the name of the approving Committee on all paperwork, including recruitment advertisements/online requests, for this study.

Students must include this Approval Notification with their submission.

Appendix 3: Ethics approval LMS/PGR/UH/0376 (1)



HEALTH SCIENCE ENGINEERING & TECHNOLOGY ECDA

ETHICS APPROVAL NOTIFICATION

TO	Angela Burrows
CC	Dr Saskia Keville
FROM	Dr Rosemary Godbold, Health, Science, Engineering & Technology ECDA Vice Chair
DATE	29/03/2019

Protocol number:	aLMS/PGR/UH/03676(1)
Title of study:	Trainee and clinical psychologists' personal experiences of caring for others in mental health distress and the influence this may have on their professional practice.

Your application to modify and extend the existing protocol as detailed below has been accepted and approved by the ECDA for your School and includes work undertaken for this study by the named additional workers below:

Modification: Change of study title.

This approval is valid:

From: 29/03/2019

To: 30/09/2020

Additional workers: no additional workers named

Please note:

If your research involves invasive procedures you are required to complete and submit an EC7 Protocol Monitoring Form, and your completed consent paperwork to this ECDA once your study is complete. You are also required to complete and submit an EC7 Protocol Monitoring Form if you are a member of staff. This form is available via the Ethics Approval StudyNet Site via the 'Application Forms' page

<http://www.studynet1.herts.ac.uk/ptl/common/ethics.nsf/Teaching+Documents?Openview&count=9999&restricttcategory=Application+Forms>

Any conditions relating to the original protocol approval remain and must be complied with.

Any necessary permissions for the use of premises/location and accessing participants for your study must be obtained in writing prior to any data collection commencing. Failure to obtain adequate permissions may be considered a breach of this protocol.

Approval applies specifically to the research study/methodology and timings as detailed in your Form EC1/EC1A or as detailed in the EC2 request. Should you amend any further aspect of your research, or wish to apply for an extension to your study, you will need your supervisor's approval (if you are a student) and must complete and submit a further EC2 request. In cases where the amendments to the original study are deemed to be substantial, a new Form EC1A may need to be completed prior to the study being undertaken.

Should adverse circumstances arise during this study such as physical reaction/harm, mental/emotional harm, intrusion of privacy or breach of confidentiality this must be reported to the approving Committee immediately. Failure to report adverse circumstance/s would be considered misconduct.

Ensure you quote the UH protocol number and the name of the approving Committee on all paperwork, including recruitment advertisements/online requests, for this study.

Students must include this Approval Notification with their submission.

Appendix 4: Ethics approval LMS/PGR/UH/0376 (2)



HEALTH SCIENCE ENGINEERING & TECHNOLOGY ECDA

ETHICS APPROVAL NOTIFICATION

TO Angela Burrows

CC Saskia Keville

FROM Dr Rosemary Godbold, Health, Science, Engineering & Technology ECDA Vice Chair.

DATE 28/05/2019

Protocol number: LMS/PGR/UH/03676(2)

Title of study: Trainee and qualified psychologists' personal experiences of caring for others in mental health distress and the influence of caring on clinical practice.

Your application to modify and extend the existing protocol as detailed below has been accepted and approved by the ECDA for your School and includes work undertaken for this study by the named additional workers below:

Modification: detailed in EC2.

This approval is valid:

From: 28/05/2019

To: 30/09/2020

Additional workers: No additional workers named.

Please note:

If your research involves invasive procedures you are required to complete and submit an EC7 Protocol Monitoring Form, and your completed consent paperwork to this ECDA once your study is complete. You

are also required to complete and submit an EC7 Protocol Monitoring Form if you are a member of staff. This form is available via the Ethics Approval StudyNet Site via the 'Application Forms' page <http://www.studynet1.herts.ac.uk/ptl/common/ethics.nsf/Teaching+Documents?OpenView&count=9999&restricttcategory=Application+Forms>

Any conditions relating to the original protocol approval remain and must be complied with.

Any necessary permissions for the use of premises/location and accessing participants for your study must be obtained in writing prior to any data collection commencing. Failure to obtain adequate permissions may be considered a breach of this protocol.

Approval applies specifically to the research study/methodology and timings as detailed in your Form EC1/EC1A or as detailed in the EC2 request. Should you amend any further aspect of your research, or wish to apply for an extension to your study, you will need your supervisor's approval (if you are a student) and must complete and submit a further EC2 request. In cases where the amendments to the original study are deemed to be substantial, a new Form EC1A may need to be completed prior to the study being undertaken.

Should adverse circumstances arise during this study such as physical reaction/harm, mental/emotional harm, intrusion of privacy or breach of confidentiality this must be reported to the approving Committee immediately. Failure to report adverse circumstance/s would be considered misconduct.

Ensure you quote the UH protocol number and the name of the approving Committee on all paperwork, including recruitment advertisements/online requests, for this study.

Students must include this Approval Notification with their submission.

Appendix 5: Ethics approval LMS/PGR/UH/0376 (3)

**HEALTH SCIENCE ENGINEERING & TECHNOLOGY ECDA
ETHICS APPROVAL NOTIFICATION**

TO Angela Burrows
CC Dr Saskia Keville
FROM Dr Simon Trainis, Health, Science, Engineering & Technology ECDA Chair.
DATE 28/06/2019

Protocol number: **aLMS/PGR/UH/03676(3)**

Title of study: Assistant, trainee and qualified psychologists' personal experiences of caring for others and the influence of caring on clinical practice.

Your application to modify and extend the existing protocol as detailed below has been accepted and approved by the ECDA for your School and includes work undertaken for this study by the named additional workers below:

Modification: Detailed in EC2.

This approval is valid:

From: 28/06/2019

To: 30/09/2020

Additional workers: no additional workers named

Please note:

If your research involves invasive procedures you are required to complete and submit an EC7 Protocol Monitoring Form, and your completed consent paperwork to this ECDA once your study is complete. You are also required to complete and submit an EC7 Protocol Monitoring Form if you are a member of staff. This form is available via the Ethics Approval StudyNet Site via the 'Application Forms' page <http://www.studynet1.herts.ac.uk/ptl/common/ethics.nsf/Teaching+Documents?Openview&count=9999&restricttocategory=Application+Forms>

Any conditions relating to the original protocol approval remain and must be complied with.

Any necessary permissions for the use of premises/location and accessing participants for your study must be obtained in writing prior to any data collection commencing. Failure to obtain adequate permissions may be considered a breach of this protocol.

Approval applies specifically to the research study/methodology and timings as detailed in your Form EC1/EC1A or as detailed in the EC2 request. Should you amend any further aspect of your research, or wish to apply for an extension to your study,

you will need your supervisor's approval (if you are a student) and must complete and submit a further EC2 request. In cases where the amendments to the original study are deemed to be substantial, a new Form EC1A may need to be completed prior to the study being undertaken.

Should adverse circumstances arise during this study such as physical reaction/harm, mental/emotional harm, intrusion of privacy or breach of confidentiality this must be reported to the approving Committee immediately. Failure to report adverse circumstance/s would be considered misconduct.

Ensure you quote the UH protocol number and the name of the approving Committee on all paperwork, including recruitment advertisements/online requests, for this study.

Students must include this Approval Notification with their submission.

Appendix 6: Ethics approval LMS/PGR/UH/03676 (4)



HEALTH, SCIENCE, ENGINEERING AND TECHNOLOGY ECDA

ETHICS APPROVAL NOTIFICATION

TO	Angela Burrows
CC	Dr Saskia Keville
FROM	Dr Simon Trainis, Health, Science, Engineering & Technology ECDA Chair
DATE	06/08/2019

Protocol number: aLMS/PGR/UH/03676(4)

Title of study: Assistant, trainee and qualified psychologists' personal experiences of caring for others and the influence of caring on clinical practice.

Your application to modify and extend the existing protocol as detailed below has been accepted and approved by the ECDA for your School and includes work undertaken for this study by the named additional workers below:

no additional workers named.

Modification: Detailed in EC2.

General conditions of approval:

Ethics approval has been granted subject to the standard conditions below:

Original protocol: Any conditions relating to the original protocol approval remain and must be complied with.

Permissions: Any necessary permissions for the use of premises/location and accessing participants for your study must be obtained in writing prior to any data collection commencing. Failure to obtain adequate permissions may be considered a breach of this protocol.

External communications: Ensure you quote the UH protocol number and the name of the approving Committee on all paperwork, including recruitment advertisements/online requests, for this study.

Invasive procedures: If your research involves invasive procedures you are required to complete and submit an EC7 Protocol Monitoring Form, and copies of your completed consent paperwork to this ECDA once your study is complete.

Submission: Students must include this Approval Notification with their submission.

Validity:

This approval is valid:

From: 06/08/2019

To: 30/09/2020

Please note:

Failure to comply with the conditions of approval will be considered a breach of protocol and may result in disciplinary action which could include academic penalties. Additional documentation requested as a condition of this approval protocol may be submitted via your supervisor to the Ethics Clerks as it becomes available. All documentation relating to this study, including the information/documents noted in the conditions above, must be available for your supervisor at the time of submitting your work so that they are able to confirm that you have complied with this protocol.

Should you amend any aspect of your research or wish to apply for an extension to your study you will need your supervisor's approval (if you are a student) and must complete and submit a further EC2 request.

Approval applies specifically to the research study/methodology and timings as detailed in your Form EC1A or as detailed in the EC2 request. In cases where the amendments to the original study are deemed to be substantial, a new Form EC1A may need to be completed prior to the study being undertaken.

Failure to report adverse circumstance/s may be considered misconduct.

Should adverse circumstances arise during this study such as physical reaction/harm, mental/emotional harm, intrusion of privacy or breach of confidentiality this must be reported to the approving Committee immediately.

Appendix 7: Participant information sheet

UNIVERSITY OF HERTFORDSHIRE

ETHICS COMMITTEE FOR STUDIES INVOLVING THE USE OF HUMAN PARTICIPANTS (‘ETHICS COMMITTEE’)

FORM EC6: PARTICIPANT INFORMATION SHEET

1 **Title of study**

Trainee and qualified clinical psychologists' personal experiences of caring for others with mental health difficulties and how they understand any impact this may, or may not, have on their professional practice

2 **Introduction**

You are being invited to take part in a study. Before you decide whether to do so, it is important that you understand the study that is being undertaken and what your involvement will include. Please take the time to read the following information carefully and discuss it with others if you wish. Do not hesitate to ask me anything that is not clear or for any further information you would like to help you make your decision. Please do take your time to decide whether or not you wish to take part.

3 **What is the purpose of this study?**

You are being invited to participate in research into clinical psychologists' personal experiences of caring for others with mental health difficulties. This is a qualitative study which seeks to explore the relationship between caring for loved ones with mental health difficulties and how this may or may not impact on clinical practice. The research questions to be addressed are:

How do trainee and qualified clinical psychologists make sense of their personal experience of caring for others with mental health difficulties and its relationship to their professional practice?

4 **Do I have to take part?**

It is completely up to you whether or not you decide to take part in this study. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form. Agreeing to join the study does not mean that you cannot change your mind at a later date. You are free to withdraw at any stage without giving a reason.

5 **Are there any other restrictions that may prevent me from participating?**

As the study is focused around understanding the impact of caring for someone with mental health difficulties of an enduring nature, the study is seeking to recruit trainee or

qualified clinical psychologists who have been personally involved in caring for someone who has had mental health difficulties for a minimum of six months or more.

6 How long will my part in the study take?

If you decide to take part in this study, the interview will last between 60 to 90 minutes.

7 What will happen to me if I take part?

The first thing to happen will be that I will arrange a time to contact you to check that you are familiar with the aims of the study and are happy to consent to be interviewed. Then we will arrange a time and confidential place at your convenience for the interview to take place.

8 What are the possible disadvantages, risks or side effects of taking part?

Talking about current or past experiences of caring for others with mental health difficulties can bring up difficult and/or strong emotions, which we cannot always anticipate. These experiences might resonate with the demands of training and/or clinical work.

As a trainee with current and past caring responsibilities, I would hope that I can bring an empathic interviewing style to the research, which might help to mitigate against any emotional risks of taking part. There will also be time for debrief at the end of the interview and support to access appropriate resources if you feel these would be helpful for you.

9 What are the possible benefits of taking part?

The study is considering what lived experience of caring can bring to clinical work. There is currently limited research considering clinical psychologists' personal experience of caring in relation to clinical work. You would therefore be contributing to the understanding of lived experience of caring for someone with mental health difficulties within the profession.

10 How will my taking part in this study be kept confidential?

Your privacy, safety and emotional wellbeing will be respected at all times. During the interview itself, you will determine whether or not you feel it is appropriate to answer the questions posed, and how much you choose to share in response to each.

As I am a trainee clinical psychologist, you may engage with me in professional contexts outside of the interviews. I will be adhering to the BPS's guidelines around professional conduct and adherence to professional boundary setting throughout the research process and after the research concludes.

Your contact details, the consent forms and interview transcripts will be stored securely on a password protected PC. During the writing up of the interviews, all personal information ie any references to your gender, ethnicity, service or job role will be removed so that the information is anonymized. This will mean that your confidentiality will be assured. interview recordings will be erased after listening to them and

transcribing them. After the study has been completed and published all transcripts will be destroyed within 2 months.

11 **What will happen to the data collected within this study?**

Demographic data and consent forms will be collected will be stored electronically, on a password protected PC, for 2 months after the study has been completed after which time it will be destroyed under secure conditions.

The interviews will be audio recorded and then transcribed by the researcher or a private company, who will sign a confidentiality agreement. The transcriptions will then be analysed for common themes. The anonymized data will be used to produce a thesis for my doctorate training for the University of Hertfordshire. A summary will also be produced which will be disseminated to all the participants after the viva. The anonymized data will also be seen by my specialist supervisor and second coder and may also be seen by examiners and academic audiences if it were to be published in a journal.

12 **Who has reviewed this study?**

This study has been reviewed by the University of Hertfordshire Health, Science, Engineering and Technology Ethics Committee with Delegated Authority. The UH protocol number is LMS/PGR/UH/03676.

13 **Who can I contact if I have any questions?**

If you would like further information or would like to discuss any details, please get in touch with me, the researcher, Angela Burrows, by email: ab17aeq@herts.ac.uk. My supervisor, Dr Saskia Keville can also be contacted: s.keville@herts.ac.uk. Although we hope it is not the case, if you have any complaints or concerns about any aspect of the study, please write to the University's Secretary and Registrar, University of Hertfordshire, College Lane, Hatfield, Herts, AL10 9AB.

Thank you very much for reading this information and considering taking part in this study.

Appendix 8: Consent form

UNIVERSITY OF HERTFORDSHIRE: ETHICS COMMITTEE FOR STUDIES INVOLVING THE USE OF HUMAN PARTICIPANTS ('ETHICS COMMITTEE')**CONSENT FORM EC3:****Principal Investigator: Angela Burrows****UH Protocol number LMS/PGR/UH/03676.**

Project title: Trainee and qualified clinical psychologists' personal experiences of caring for others with mental health difficulties and how they understand any impact this may, or may not, have on their professional practice.

Statement by participant:

1. I confirm that I have read and understood the Participant Information Sheet for this study.
2. I understand what my involvement will entail and any questions I had about the study have been answered to my satisfaction.
3. I understand that my participation is entirely voluntary, and that I can withdraw up to 10 days after the interview has been conducted. However, if I decide to withdraw from the study, I understand that it is my responsibility to notify the researcher within 10 working days of the interview otherwise I understand that I have given my permission for the interview data to be included in the data analysis.
4. I understand that all information obtained will be confidential.
5. I agree that research data gathered for the study may be published provided that I cannot be identified as a subject.
6. I have been given the researcher's contact details should I wish to find out further information about the study at any time for the purposes of clarification.
7. I have been told how information relating to me (data obtained in the course of the study, and data provided by me about myself and my caring experience) will be handled; how it will be kept secure, who will have access to it, and how it will or may be used.

Signature of participant.....Date.....

Name of participant.....Date.....

Statement by principle investigator:

I have explained this project and the implications of participating in it to this participant without bias. I believe that consent is informed and that they understand the implications of participation.

Signature of (principal) investigator..... Date.....

Name of (principal) investigator..... Date

Appendix 9: Initial Interview Schedule

Caring experience:

How would you describe your caring experience and its emotional impact on you and on the person you care(d) for and/or other family members or friends? (*ie relationality, involvement of others in caring*)

How would you describe any connection between your caring experience and your values as an individual? (*ie homeostasis or any shifts/developments and/or changes in cognitive reasoning*)

Personal and professional background:

Can you tell me something about your professional background to date? (*ie pre and post career choices to date, towards, away from?*)

Personal and professional selves:

How do you make sense of your caring experience in relation to your sense of self? Thinking here about your sense of personal self (*ie identification as a carer, when might this have come about? What might this mean to you?*).

How do you make sense of your caring experience in relation to your sense of professional self? (*ie any sense of this influencing any expression of personal qualities and/or cognitive processes such as decision-making processes*)

Caring and clinical practice:

Trainee CPs:

Thinking about your experience of caring and the relationship between training and your caring experience, is there anything which strikes you as helpful in terms of your clinical practice?

Thinking about your experience of caring and the relationship between training and your caring experience, is there anything which strikes you as less helpful in terms of your clinical practice?

Qualified CPs:

Thinking about your experience of caring and the relationship between caring and your clinical

practice, is there anything which strikes you as helpful in terms of your clinical practice?

Thinking about your experience of caring and the relationship between caring and your clinical practice, is there anything which strikes you as less helpful in terms of your clinical practice?

Prompts:

Decision making ie area of specialism

Qualities of therapeutic engagement ie therapeutic alliance

Any experience of disclosure and perceived impact if appropriate

Towards the end of the interview:

What was the interview like for you?

Is there anything you want to ask?

Is there anything you want to add?

Was there anything you expected to be asked but weren't?

Is there anything that I have not asked you in this interview that you would like to tell me about, or that you think is important for me to know?

Appendix 10: Final interview schedule

Interview question: Assistant, trainee and qualified psychologists' personal experiences of caring for others and the influence this may have on their professional practice

Some of the questions may seem quite long, so just ask if it's helpful for me to repeat them, also, as it's a sensitive area, please let me know if there are any questions you would prefer not to answer, or would like me to come back to later on in the interview. Also, because we may meet in other contexts, I wanted to reassure you of my commitment to professional boundaries and my awareness of the need to consider how the interview may impact on either of us emotionally. In addition to providing you with the numbers of contact organisations at the end of the interview, is there anything you would like me to do during the interview that may help to alleviate any distress you may feel as a result of considering your caring experience.

Caring experience and impact on identity

1. How would you describe your caring experience?

(prompt: relationship, length of time, what was involved ie practical/emotional support)

2. How do you relate to the term "carer" and would you define yourself as a carer now, or have you ever defined yourself as a carer?

(prompt: what may have led you to identify or take on the "label" of carer/not identify as a "carer")

3. Can you tell me how your caring experience may have influenced your personal values and personal sense of self?

(ie have you ever been aware of any shifts or developments and/or changes in your values or sense of self)

4. Can you tell me how your caring experience may have influenced your professional values and professional sense of self?

(ie have you ever been aware of any shifts or developments and/or changes in your values or sense of self)

Caring experience and relationality

5. Can you tell me about how your caring experience has influenced your relationship with the person you care(d) for?

(prompt: how do you think it may have indirectly influenced your relationship; how do you think it directly influenced your relationship, how might others have been involved in the caring relationship)

6. Can you tell me about how your caring experience has influenced your relationships with other people, including family, friends and employers and other organisations?

(prompt: how have you experienced this? would you consider it as a positive or negative experience? ie have you felt heard/understood)

7. Thinking about your experience of caring and the relationship between caring and your clinical practice, is there anything which strikes you more or less helpful in terms of your clinical practice?

(ie how do you perceive any impact on the therapeutic alliance, do you feel it has had any influence on the "common factors" in therapy, how do you think it might have shaped your own awareness of triggers)

Mental health distress

8. Can you tell me what the term "mental health distress" means to you?

(prompt: do you feel more comfortable talking about distress/condition, has your understanding changed over time, has your understanding changed as a result of your caring experience)

Caring experience, impact on self and decision making around career

9. How would you describe the impact of caring for your loved one and its current and past emotional impact on you? How did you manage this?

(prompt: what may have assisted you to cope with your own distress)

10. How do you make sense of your caring experience and choices you have made around your career to date?

(ie how did you approach making decisions around areas of specialism, have you ever found yourself making moves towards or away from different career options, posts, promotions etc)

11. Was there anything you expected to be asked but weren't and think is important for me to know and would like to add at this point?

12. How did you find the interview?

Appendix 11: Extract of coded interview

Reflections	Transcript	Coding	Clustering
<p>Evaluating self-experience against a perception of a pre-defined role?</p> <p>professional backgrounds influencing our internal reasoning processes</p> <p>questioning of the self</p>	<p><i>I: how would you describe your caring experience?</i></p> <p>So I suppose erm when I saw the word carer on the information sheet, I thought that it almost jared with me, would I describe myself as a carer because I'm not sure it was like that..</p> <p>because basically what happened was that when I was a trainee psychologist, so this was probably...I started in 2007, back in 2005/6 basically I was working in an acute psychiatric ward as an assistant psychologist and I just started to notice some things about my brother that were similar to what I was noticing at work.</p> <p>And then I started thinking 'is something happening to me?' 'is work affecting me' and then some of my family members and friends called me and said, 'oh they'd been a bit worried about my brother' and then it kind of like started. It started very very gradually...the odd thing and then you kind of almost forget about your concerns as did everybody else and then it gradually became more concerns, more worrying things.</p> <p>By the time I was actually doing my training he was getting worse and towards the end of my training..</p> <p>I: right...</p>	<p>The word 'carer' 'jared with me' evaluating experience against a perception of a carer</p> <p>recollection of start of brother's difficulties</p> <p>noticing things about brother similar to work in acute ward</p> <p>Thinking something might be happening to me Friends and family worried about brother Brother starts to change very gradually Concerns gets forgotten, then concerns and worries gradually get worse</p> <p>Doing training Brother getting worse Towards end of my training</p>	<p>Querying meaning and perception of carer/ questioning whether to describe self as carer/measuring experience against a perceived identity</p> <p>Working and noticing things about brother were similar to experience at work</p> <p>Linking potential impact of work to personal self Familial support systems show concern for brother Start of cared for's ill health Concerns about changes in brother sometimes forgotten Cared for's deterioration process</p> <p>Cared for's health deteriorates as carer trains</p>

<p>Strong sense of valuing of the connection with brother conveyed</p> <p>Protecting brother from any judgements of his behaviour</p> <p>Idea of carer as person who looks after someone in need</p>	<p>Because of where he was getting sectioned probably 2 or 3 times he got sectioned</p> <p>I: mmm right</p> <p>We always had a good relationship so we were kind of close, I have a sister as well, but being my brother, he's 2 years younger than me, we would go out for a drink together, we had sort of mutual friends and things and</p> <p>I suppose as he became more unwell, there was a point where we didn't have a relationship for a little while, because he was so sort of paranoid and erm actually yeah and last time there was a Christmas where like we'd actually been out as a family, we'd like popped to the pub or something and he'd seemed ok, but then something weird happened</p> <p>I: yeah</p> <p>And then somehow he sort of changed, and something weird happened and somehow how it ended up him sort of chasing me down the road and sort of pushing, me,</p> <p>I wasn't hurt, it wasn't hard and then erm he ended up, it was all a blur to be honest so I didn't feel like his carer, it was more like I was worried about him, and he didn't think that there was anything wrong with him</p> <p>I: right</p> <p>And he would get annoyed if you tried to talk to him about that, or tried to question him and so the person for whom I did feel like more of a carer for during that time was more my mother</p>	<p>Brother getting sectioned</p> <p>Good relationship Close relationship Go out for drink together Mutual friends Brother became more unwell No relationship for a while Brother paranoid Christmas out as family Family gone to pub Brother seemed ok Something weird happened</p> <p>Brother changed somehow Somehow brother changed He chased me/pushed me</p> <p>Not hurt Experience a blur worried about brother, but he did not think anything wrong</p> <p>Brother annoyed Trying to talk to him</p>	<p>Setting of section</p> <p>Close relationship before cared for's episode</p> <p>Temporary loss of relationship due to cared for's illness</p> <p>'Normal' social activity with family interrupted by 'something weird'</p> <p>Change in cared for's behaviours as a result of mental health difficulties</p> <p>Carer denying hurt, clarifying force of push/physical contact Sibling carer does not feel like carer, but identifies worry for brother while brother was unaware of his own difficulties</p> <p>annoyance at brother/carer's attempts to discuss brother's difficulties directly with him Carer looking after mother due to her finding the experience of</p>
--	--	---	---

<p>Avoidance of naming it</p> <p>Feeling connected to the interviewee around the description of 'bizarre' behaviours</p>	<p>I: right</p> <p>Because she found it really difficult. My brother was living in [redacted] at that time and also my university was in [redacted]. So at that time my brother was mostly living in his student house and then sometimes staying at home maybe..he's always been someone who would bring his washing and so on, but because he was in [redacted] he would sometimes be round the house sometimes and then my mum was sometimes, you know, like when it was at it's worst.</p> <p>I was living, before I did my training in [redacted], I was living in like [redacted] and so I'd go and see friends and my mum was really, really upset, saying 'oh, you know, x has just been round and pushed yer dad over, or he's saying that dad works for MI6, just really bizarre things, and she'd be upset, so I'd feel more like, when he got sectioned, so in some ways I felt more like her carer, I wanted to be my brother's carer, but he didn't want a carer, because he thought he was fine</p> <p>I: so you've said in some ways that you saw yourself as a carer for your mum in that period, so how would you say you relate to the term carer?</p> <p>I suppose the term carer makes me think, if my partner had a disability, I'd have to help him up the stairs, or something like that</p>	<p>Feeling more like carer to mother</p> <p>Mother found it difficult Brother lived where I lived Brother lived in house But also stayed at home Brother looked after Brother at house and mother found it really difficult when brother was really unwell</p> <p>Before I did my training Saw friends Mum really upset Brother pushed dad over Brother saying bizarre things Mum upset when brother sectioned Wanting to be brother's carer Brother not wanting a carer Brother thought he was fine</p> <p>Word carer makes me think</p>	<p>her son's mental health difficulties difficult.</p> <p>mother found the experience of the change in behaviours in her son difficult.</p> <p>Practical support for brother provided by mother</p> <p>Carer's concern for mother's distress when brother's health started to deteriorate</p> <p>Carer's concern for mother's distress in context of brother's 'bizarre' behaviours</p> <p>Carer's desire to look after brother, but brother's non-acceptance of support, and carer's move into looking after mother</p> <p>Association of term carer with providing practical support and living with someone</p> <p>Acceptance of level of brother's difficulties but lack of connection to term carer</p>
--	--	--	--

<p>Feeling connected to shared experience of a sibling and the experience of it being difficult to be with them but containing this</p> <p>Feeling empathic</p> <p>Connecting to a similar experience</p>	<p>because of the way my brother was, I probably was a carer, but I don't feel like it massively connects with me, yeah because I had a brother,</p> <p>but he was someone who was increasingly difficult to be around, eventually he refused to,</p> <p>he wouldn't answer the phone to me not for a very long period but probably for a good few months, yeah, there was nothing there</p> <p>and then the last time he got sectioned, I went to the hospital to see him and I wasn't sure if he'd actually see me. He did see me which surprised me, we hadn't spoken for several months and</p> <p>he was saying the psychiatrist was a bitch and all this and erm</p>	<p>Helping partner up stairs</p> <p>Probably was a carer Not massive connection to word carer</p> <p>Brother increasingly difficult to be with</p> <p>Brother didn't answer phone to me For a few months</p> <p>Brother's last section went to hospital to see him unsure if he would see me surprised that he saw me not spoken for several months brother said psychiatrist bitch</p>	<p>Increasing difficulty with maintaining connection with cared for</p> <p>Break in relationship as result of cared for's non-responsiveness to contact attempts</p> <p>Unsure if cared for would accept contact with carer</p> <p>Disconnection in relationship due to brother's ill health</p> <p>Cared for used derogatory language about professional other</p>
---	--	---	---

Appendix 12: Initial themes and sub-themes

Themes	Sub-themes	Codes
Mental health	<p>Conceptualisation</p> <p><i>T2: "...mental health can cover a whole range of things, like the way you are thinking, you can be experiencing other things, experiencing other people and your belief systems. Sometimes if someone's belief system is challenged in some way, or shattered in some way, that could lead to some level of psychological distress".</i></p>	<ul style="list-style-type: none"> • Difference in conceptualisation between mental and physical health • Different cultural representations of mental health – stigma around mother getting blame for children's difficulties • Mental health: sense of something 'wrong' – a difficulty; physical health more neutral term • Mental as derogatory term 'you're mental' • Mental as unable to do things, you're stupid • If autism can exist on a spectrum, why can't other mental health difficulties? • Conditions as socially constructed • Helpfulness of construction of conditions for categorisation • Against reification of a condition • Condition as medical label, diagnosis given • Condition more fixed nature, less transient • Mental health distress equals something wrong with the brain • Word mental has negative associations, emotional health distress more acceptable • Emotional health distress not seen as important • Balance in terminology to fit with majority of population who are not psychologists • Dislike of conditions – separates people out • Not talking about illness or wellness but mental health difficulties, which we all experience at different times • Neurodevelopmental conditions on a spectrum but unchangeable, mental health fluctuates and changes • Mental health distress and mental health conditions similar – people with a mental health condition have sought help, whereas those with distress might not have • Terms like anxiety and depression can take away from the experiences they are having and why they are having them • Diagnoses moves away from having to understand and tolerate the pain that people go through • Society not good at holding difficult feelings • Dislike of mental health labels, but recognition that they create an understanding for us (carer & loved one) • Not minding mental health condition – something that has quite a lot of components to it, open entity • Distress as 'unsettled' state within themselves psychologically – upset, sad, angry, frustrated

		<ul style="list-style-type: none"> • Distress as any emotional response which is uncomfortable for that person for a prolonged period • Mental health condition – potentially powerful, but in derogatory way • Unhelpful assessments of clients used to determine diagnoses • Mental health distress state of mind, individual has diverted from their norm • Uncomfortable – may stop doing or enjoying things • Something has had an adverse impact and caused a reaction • Idea of dysfunctional behavioural response, or bodily sensation • Normalisation of all human beings behaving slightly dysfunctionally • Mental health condition – looked at, treated and diagnosed • Mental health issue – adoption in wider population to suggest 'bizarre' behaviour
	<p>Deconstruction and destigmatisation</p> <p><i>T10: "Towards the end of her life she wanted to go out less, she didn't want people to see her being fed ...everyone would just stare at her..."</i></p> <p><i>T12: "I imagine that people who haven't experienced living with my mum would have a view of what's normal as like this, yeah, big, and perhaps my view of what's normal is this big. And that therefore leads me to be more open to that more..."</i></p>	<ul style="list-style-type: none"> • Experience of caring for loved one led to explicit realisation that everyone has mental health • Anger at injustice at loved one's treatment • Actively dissociating with sex offenders and 'perversity' • Valuing the opportunity to challenge the stigma around psychosis • Disclosing loved one's mental health in appropriate contexts • Moving towards acceptance of loved one's situation, shame reducing • Sharing of loved one's mental health comes up naturally - carer does not prevaricate about sharing • Sharing loved one's mental health as a way of destigmatising mental health • Lowering boundaries enables connections with others with shared similar experiences • Normalisation of mental health and distress • Mental health and the medical model – 'fixing problems' • Normalisation of taking medication • Idea of mental health difficulties as unspoken • Everyone has mental health • Not judging others • Appreciating the suffering of everyone in the system • Trivialisation of mental health through public health campaigns • Different conceptualisation of what 'normal' is – expansion of the band width of normal • People in psychiatric services have a depth of insight into mental health and the human condition which extends beyond other people's 'normal' • Labelling things as mental health, 'the crazy people' – almost like less to offer, but maybe there's more • Loved one used derogatory language about professional other whilst unwell • Loved one apologises for behaviour when in recovery

		<ul style="list-style-type: none"> • Own distress at loved one's discharge without accommodation • Using personal experience of shouting at a professional other to understand family's perspective in crisis • Challenging assumptions around who carers are, by identifying as a carer
	<p>Construction of distress</p> <p><i>T14: "...I work in an inpatient unit...there's acute distress and then there's the distress that we all feel, so I ...would say that we all have mental health distress, we all get distressed at different times to different levels...so distress, uncomfortable, not quite how things were before".</i></p>	<ul style="list-style-type: none"> • Psychosis – losing touch with reality • Overwhelming • Unable to control self • Unable to cope • Uncomfortable • Continuum of distress, universality of distress exists on a spectrum • All experience distress at different times and to different levels • Distress and experience of something coming from the client, rather than diagnosis unless brought up by client • Moves beyond what clinicians can decide is a 'problem with your mind' • Not Cartesian split – body and mind • Discomfort • Internal experience of something • All susceptible to • Questioning of knowledge • Unhelpful ways of referring to mental health distress • Wellbeing as physically and mentally connected – body and mind • Psychological distress more severe than mental health distress • Psychological distress involving 'shattering' of belief systems • Rebranding into distress does not deal with underlying prejudice • Problems are in attitudes not in terminology • Distress maintains stigma because it includes all mental health issues • Normalisation of anxiety as a response to environment you are in
Carer identity	<p>Label given by society</p> <p><i>T9: "It's a political label in a way...and there's something medicalised about it for me as well."</i></p>	<ul style="list-style-type: none"> • Carer as person who looks after someone in need • Carer as person who looks after someone with physical health difficulties • Carer as person who lives with loved one • Carer as someone who provides 35 hours a week of caring, and gets Carer's Allowance • Carer provides practical support – may be 'on call' type of support, liaising with support services • Carer as someone providing a formal support/professional role • Carer as someone providing financial support • 'Real carers' have a Carer's Assessment

	<p>Struggling to accept carer 'label'</p> <p><i>T1: "What I did do which may be more about caring is my parents made a complaint to the mental health trust that he was being looked after by and I went with them to a meeting to talk about our concerns, so I suppose that felt a bit more like being a carer..."</i></p> <p><i>T1: "So I almost don't feel I've done anything worthy of the term caring, I don't think I've done anything to care for him, it's more I've been his brother..."</i></p> <p><i>T5: "...it first came to my attention when I was an assistant and one of my supervisors suggested that I register with a carer's agency and I was like, "what are you talking about?" but she kind of explained why, 'well you are doing those things.'"</i></p>	<ul style="list-style-type: none"> • Carers advocate on behalf of loved ones when there are concerns about their care • Assumptions about meaning precluding association with the term ie not adopted due to preference for sibling identity and role • Not adopted due to primary relationship and role precluding carer label • Not adopted due to love for family member • Not adopted due to perception of carer label as a professional identity • Not adopted due to perception of carer as living with loved one • Acceptance of level of loved one's difficulties but lack of connection to term carer • Role interchangeability – vulnerability and need for carer within everyone • Carer as problematic label, as disliked term • 'coldness' of carer term • Cultural – 'family is family' • Unpredictability of contact with loved one • Other professionals' expectations of carers • Fluctuating and varying support needs • Reluctance to provide professional type input • Pulled into personal and professional role conflict • Conveying relationship dynamics to professional • Maintaining a personal boundary with loved one • Querying meaning and perception of a carer • Questioning whether to describe self as carer • Perception of caring as 'worthy' - having intrinsic value and not having done anything 'worthy' • Minimization of own role in loved one's care • Describing caring as supporting • Perceived intensity of need and duration/involvement in caring • Sense of others defining caring from an outsider perspective • Understanding possibility of remaking self, campaigning from one part of the self, how great it is to be a carer
--	---	--

	<p>Label defined by me – me as a carer</p> <p><i>T9: “The term carer feels like a professional responsibility or a defined role and responsibility, whereas I was doing it out of love for my grandmother and I wanted to be around. I wanted to be there for her.”</i></p>	<ul style="list-style-type: none"> • Supporting other family members to care • Carer as significant support person, whatever shape and capacity • Being present – being with someone with mental health difficulties • Loved one can be unpredictable – need to keep them safe • Carer label given, not self-identified • Carer as a professional role, defined role or responsibility • Professional caring as something outside of the family, or coming into the family • Carer providing personal care, feeding, toileting • Carer as a joint, shared or sole role • Unspoken relationship in joint caring role • Carer as a person where cared for has some impact on you • Not a role accepted within Eastern families – Eastern parents may expect daughters to care, rather than perceive of caring as a ‘role’ • Carer as translator if loved one did not speak English • Emotional support • Extra responsibilities, practical support around house • Supporting other parent to care • Attending appointments • Liaising with services • Young carer’s experience may be different to caring for a person when you’re older
	<p>Transitioning into ‘becoming’ a self-identified carer</p> <p><i>T2: “..in my head a carer is someone who’s living with that person all the time...and I always forget that ...my sister did live with me for about 6 months, so I wouldn’t describe myself as a carer, but in terms of</i></p>	<ul style="list-style-type: none"> • Sense of obligation overriding personal sense of difficulty with taking on the role • Loved one trying to influence carer’s willingness to care now in the context of historic difficulties in their relationship • Relationship dynamics precede caring relationship and impact on quality of caring relationship • Initially resistant to identifying as a carer • Awkwardness of relationship with carer label • Eventual acceptance of carer identity and potential benefits of identifying as a carer ie early morning GP appointments, affiliation with support service • Relationship with term carer changing with increased understanding • Self-evaluation of motivation for caring • Identified as carer when loved one developed physical frailty and physical health problems • Related to it as a carer of someone with learning disabilities • Did not identify as a young carer • Gaining awareness of role from within the system

	<p><i>caring for her, that did happen.”</i></p> <p><i>T12: “..most people that went to Young Carers, were in my mind, looking after people with physical disabilities or they might have been supporting them with personal care, or something like that. I think I'd made a whole heap of assumptions...”</i></p>	
<p>Own internal processes</p>	<p>Introspection and reflection</p> <p><i>T6: “It's the dilemma I think of how to be isn't it? Whether to be in your own head and thinking about how it impacts on you, and then you feel bad, because you think, well, actually I'm in the lucky position here, I'm not them, and I worry about my mum dying, because she organises my dad, how will my dad cope with my mum dying...”</i></p>	<ul style="list-style-type: none"> • Caring experience starts intensive thinking about self, family members and their vulnerabilities • Questioning whether caring experience led to change in 'being with' clients, or whether this might have happened anyway, due to stage in training • Questioning if change in approach to treatment of psychosis was linked to caring experience • Linking change in professional attitude to medication to caring experience • Questioning self about embarrassment around arrest • Own analysis of own mental health • Commonality of all human beings • Medication as covering up something • No explanation as to why loved one taking medication • Medication as necessary to 'correct' internal difficulty within person • Worry about own mental health and potential vulnerability/predisposition to mental health difficulties • Reflections on the self as more self-sufficient because of loved one's difficulties • Self-contained and able to be turned to • Caring experience – new learning and appreciation of mental health distress • Recognition that if patterns continue carer may become loved one ie show same vulnerability to mental health difficulty • Appreciating that carer needs someone to care for them too, and needs to make the self vulnerable to accept the care • Recognition that patterns of being in the world can be unhelpful • Concern about personal and professional boundaries becoming blurred • Reflection on caring as detrimental to own emotional experience • Imposition of caring role, obligation and responsibility

		<ul style="list-style-type: none"> • Sense of conflict about perceptions of acts of caring and their relationship with loved one • Difficulty in admitting to experiencing difficult emotion in relation to cared for • Questioning whether not 'feeling the care' relates to childhood experiences rather than the caring experience now • Questioning whether caring for someone with mental health difficulties may feel more difficult as a result of relational difficulties due to nature of mental health difficulty itself • Questioning whether drawn to inpatient work due to looking after loved which was chaotic • Saying to myself that I'm important too • Considering what the term 'relationship' means • Worry about getting drawn into relationships where my needs will never get met • Perpetuation of a neglectful unconscious dynamic • Wondering if too tolerant of getting nothing back in relationships • Reflecting on the importance of boundaries in clinical work – keeping clinician and client safe • Reflecting that quality of patience comes from when people didn't understand what I was going through • Accepting that loved one's difficulties don't define me, my family or loved one • Containing own feelings, thoughts and reflections for therapeutic relationship - needing to be this right now • Acceptance of challenges of being with people with mental health difficulties
	<p>Questioning of the self</p> <p><i>T1: "...then I started thinking 'is something happening to me?' 'is work affecting me?'"</i></p>	<ul style="list-style-type: none"> • Valuing other professionals sharing their emotional selves/their experience of being with carer's loved one • Questioning if having a historic experience of caring can give us both identities (assumption) • Professional background influences carer's response to loved one • Professional background provides system knowledge • Carer able to rationalise loved one's response to medical situation • Getting pulled into aligning to professional identity and aligning to the system in a public carer's forum • Professional identity subsuming personal identity in a public carer's forum • Questioning career decision in the context of own vulnerability • Potential for caring experience to 'bias' professional response to carers • Professional life involves listening to others in distress, less energy/ability to listen to secondary carer's concerns • Questioning how being seen in same sex relationship, gender roles previously fluid • Questioning capacity of self to go through training and manage loved one's acute distress • Questioning self whilst maintaining personal boundary between self and 'judging other'

		<ul style="list-style-type: none"> • Dilemma around sharing with others – fearing others' judgements and wondering how important it is to share • Questioning if element of denial in own process • Questioning self and own mental health due to blurring of personal and professional selves • Death of the loved one and impact on self of the psychologist • Not able to disentangle innate caring qualities, or qualities brought about by caring experience • Questioning if trying to save loved one, as motivation for joining profession exists on a deep level • Struggle to accept loved one's difficulties and frustrated at self because not more accepting of them • Thinking about my parents and whether I want to offer caring to them • Thinking about what kind of person it would make me not to look after my parents • Labelling of loved one with pejorative label • Different labelling process deployed for loved one and for clients • Awareness of contradiction in personal and professional stance
<p>Relationship with loved one</p>	<p>Strengthening the bonds between us</p> <p><i>T12: "...I notice that if I was to reach out to my mum for example, upset, and say, "I've had a really shit day', it's not that she ever has an answer, but she's curious about my day, she's curious about what's going on for me, she will sit with the emotion and just let me be sad..."</i></p> <p><i>T8: "...it strengthened it (the relationship) because it made me see the fragility of this human being that had been so massively powerful in my life up until then..it was accompanied by a</i></p>	<ul style="list-style-type: none"> • Accepting relationship with loved one changes with their health • Not judging loved one's health for its impact on the relationship with me • Valuing loved one's qualities and ability to sit with carer's emotions • Loved one does not return to same way of being prior to psychotic episode, but relationship with carer is restored • Doing caring out of love • Wanting to be there for loved one • Caring makes me 'who I am' – intrinsic sense of self • Recognition of care role and associated tasks mean I have different responsibilities to non-carers • Close and loving bond – 'my best friend' • Closeness of relationship with loved one • Pride in loved one – overcoming expectations of achievements • Appreciation of loved one's knowledge and ability to share this • Happy to have 'gobbledy gook' conversation with loved one • Love between us • Feeling the bond and the connection, little signs on face and eyes • Acceptance of caring role • Personal value that I should care for a person in need irrespective of their treatment of me • Carer's dependency as a young child being transformed into interdependent relationship with loved one • Giving back • Increased closeness

	<p><i>desire to help, to really take care of...I thought I want to do this."</i></p>	<ul style="list-style-type: none"> • Active decision to care • Noticing loved one's fragility • Reciprocal • Wanting to be the one – sense of connection • Familial support systems show concern for loved one • Protecting loved one – not physically hurt by loved one • Cautioning loved one about appropriacy of disclosing in some situations • Protecting loved one - would be 'mortified' about behaviours if aware of them • Wanting to speak out to professionals to avoid loved one's perceived embarrassment • Contradictory emotions - sometimes a burden, but also a choice
	<p>Sense of loss</p> <p><i>T14: "I mean we haven't got a sibling relationship, he doesn't know I'm his sister. He doesn't have an awareness of that so it's not a brother-sister relationship....i give to him unconditionally...so my relationship to him...is not reciprocated.."</i></p> <p><i>T15: "You're almost grieving for a person that's still alive which is a really bizarre experience and I kind of just carried that and soldiered on..."</i></p>	<ul style="list-style-type: none"> • Close relationship before loved one's first episode • Temporary loss of relationship during height of loved one's deterioration in mental health • Increasing difficulty with maintaining connection with loved one • Disconnection in relationship due to loved one's ill health • Acute mental health difficulties take over/transform a person • Loved one holding things back in relationship – trust changed • Massive strain on our relationship, we were always close • Difficult to learn to trust loved one again • I was being taken care of emotionally and being looked after and then that shifted • I became the adult in the relationship • Younger version of loved one very different • Loss of loved one's former self and former lifestyle prior to illness • Person doesn't 'come back' – change in person • Awareness of vulnerability of loved one • Physical resemblance same, but loved one is not the same • Observation of changes in loved one, particularly changes in personality • Loved one not 'thinking in the same way anymore' • Saw loved one in acute unit 'completely gone' • Loved one became insular • Change in loved one's behaviours due to mental health difficulties • Carer now always worried about loved one • Change in feelings towards loved one as a result of deterioration of their mental health • Relationship always been very 'difficult' • Getting fed up - I sometimes have to look after the person who is meant to look after me • Loss of 'who (he) would have been' - mourning of his (perceived) loss • No sibling relationship because of sibling's disability

<p>Carer stress and strain</p>	<p>Emotional responses</p> <p><i>T12: I think the thing that most affected me emotionally was the quandry of could I tell people or not, and how isolating that felt....I felt like it was part of my identity but I felt like I couldn't share it".</i></p> <p><i>T6: "...sometimes I think have a fucking conversation amongst yourselves and leave me out of it because I'm done today, I've had to listen to all this stuff at work and I just want to be in my head, and I am having to listen to all this other shit..."</i></p> <p><i>T8: "I could only imagine how incredibly alien it must feel and she didn't want to look at this, it smelled...it was quite disgusting but whatever, I did it with no problems..."</i></p>	<ul style="list-style-type: none"> • Avoiding naming 'it' • Anger that loved one was put on sex offenders register despite having a hospital record • Relief that loved one was 'back' • Increased worry about loved one • Embarrassment about loved one's arrest • Shock at concept of loved one being sectioned • Worry about what had led to loved one's arrest • Worry about death of loved one and impact on rest of the family • Relief on knowing what had led to loved one's arrest • Empathy for embarrassment/shame of others at associations and positions taken • Fear and concern for loved one's family • Anger at portrayal of people with mental health difficulties in media • Anger at journalist for not caring about the impact of his words on others • Stressed carer out – did not sleep all night • Guilt at reporting that carer was on same placement as loved one, resulting in loved one's transfer • Guilt if make space for things that are important to me • Guilt at not being able to do what someone else has been able to do for loved one • Overwhelmed by intensity of own distress at loved one's situation • Worry about uncertainty about loved one's future • Judging self for comments about loved one (parent) • Unconsciously and automatically going into professional carer role • My head would cloud • Couldn't think straight • Wanting to leave: 'just God awful...' • Emotional support provided by talking • Caring to absolve feelings of guilt or responsibility • Sense of disappointment and hurt about being let down by loved one historically • Feeling the need to protect younger sibling from aspects of the caring experience • Criticised as a child - impact on adult carer's willingness to care • Repression of anger in response to other HCPs' judgements • Carer 'hopelessness' - loved one not able to change patterns of behaviour • Sense of disappointment - self-care requires creation of boundaries and distance to manage the caring relationship • Stressed at work – relentlessness of stuff (caring) outside work • Stress of caring – caring pressures push carer over the edge, 'the precipice' • 'Soldiered on', made myself unwell physically
--------------------------------	--	---

		<ul style="list-style-type: none"> • Avoiding a case, just not wanting to go there • Feeling a lot of 'kind of' shame, judgement, embarrassment • Not wanting comments, sometimes don't want to hear it • Feeling conflict between loved one's wishes and own and others' emotional responses to loved one's situation • Frustrated - professional understanding of loved one's condition not listened to by other professionals • Experiencing unwarranted feelings – shame or embarrassment at loved one's sectioning • Anger about the power others have • Compassion for clients who don't have own support • Disappointment - expectation that services would have been there for loved one • Felt like 'nothing' no services back then • Could not hold conversations for too long without crying • Being really saddened by the situation and sad for loved one • Waves of managing and not managing the emotional self • Emotionally taxing, draining • Roller coaster of emotions and thoughts • Very difficult and distressing - have not processed it all • Feeling overwhelmed myself • It had all been too much, I went home and burst into tears, I was in bits • Almost grieving for person still alive • Thinking about future and having to deal with seeing loved one dead (father) • Appreciating loved one's wishes about who finds him dead • Genetic condition – emotional impact of being a carrier • Feeling responsible for children inheriting genetic condition • Sense of confusion, difference • Knowing something was different about my family • Knowing that loved one was really unwell • Holding and containing a difficult feeling, a feeling of uncertainty • Understanding patterns around loved one's behaviours and when these indicated they were becoming unwell • Anger at others not standing up for my family, when we needed help • Family disowned us because of stigma around mental health issues • Gaining understanding of loved one's story through attending meetings • Wanting to do something differently...better • Wanting to keep loved one at the centre of the system – • Feeling disappointed with services, judging care
--	--	---

		<ul style="list-style-type: none">• Loved one medicated and unheard• Shock of seeing loved one unwell and hearing people screaming• Shock at how system works – impact on sense of self and my sense of things• Concern for loved one's safety• Questioning what happens next• Too stressed to sleep• Not knowing what to do• Contradictory emotions – wanting to be the one who takes care of loved one, but accepting that cannot always be that person• Increased resilience in managing distress from caring• Feeling own 'disgust' but able to tolerate through love for loved one• Not able to be that person for a while• Feeling angry though understanding need to be loved one's carer• Needing to still go on with day to day life• Worry for loved one's situation• Anxiety for others in the system• Days had huge impact on me, going to work crying• Sense of decay and something's dying there• Thinking about the embodied self and what we absorb• Deflecting the emotional pain• Joking to deflect knowledge that loved one would rather not be alive• Sense of hopelessness of caring• Difficulty of others hearing the underlying distress behind the conversation• Telling comic bit to others• Being unable to stay in contact with distressing emotions• Expressing distress at the caring role think I should be undertaking – sense of guilt• Too tolerant• Too self-sacrificing• Not having sought support for myself, but supporting everyone else• Developing self-awareness of 'me' in all this• Developing boundaries around time and offering• Perception of own fragility• Impact of conflict on own emotional state
--	--	--

<p>Dependency on carer</p> <p><i>T5: “ ..sometimes he'll phone me and say that he's suicidal or he'll phone me and cry down the phone or say, 'I've run out of pills, what do I do?' ”</i></p> <p><i>T7: “In my negative moments, it's stolen my whole life, it's stolen my entire life, everything I do, everything I think about, centres around it.”</i></p>		<ul style="list-style-type: none"> • Physical distance as a way of avoiding too much contact with loved one • Suicidality shared with loved one • Loved one's sense of helplessness • Role reversal • Needs of loved one taking priority over carer's needs • Sense of sole responsibility • Loved one's dependency on carer • Wanting to run away – escape sometimes • Caring has 'stolen my entire life' • Everything centres around caring • Caring rules my life • Loss of freedom around decision making • Loss of autonomy over life decisions • The relationship is care • Relationship not reciprocated - sense of duty, sense of love, sense of this is what I do • 'We haven't got a relationship as you would understand a relationship' • Washing loved one's bottom after defecating on the stairs • Little girl in me looking after loved one – head just not liking • Thinking about loved one when they are sleeping, worrying about how they will cope • Cycle of care – role reversal – loved one wants familial relationship back when better • More freedom for husband within caring relationship • Conflict from Eastern heritage and being brought up in a Western world - different expectations around caring roles • Joint struggle around intergenerational differences in caring – 'that's not who I am' • Different families, different support systems • Protective factors - physical closeness of European families • Younger sibling does not have as much understanding of mental health - no professional background
<p>Inadequate support for carer</p> <p><i>T6: “..we came back and everything just kicks back into place in terms of all the stuff that you have to do and I thought</i></p>		<ul style="list-style-type: none"> • Others not understanding the impact of caring • Can be resentful of caring • Giving up career due to inadequate carer support • Carer's assessment eventually enabled a carer's break • Lack of recognition as a carer – 'nice to have the role recognised' • Unable to continue with work due to demands of caring • Decision to care rather than continue at work and compromise on working role • System not providing support

	<p><i>that the stress that I feel at work, the thing that I think pushes me over the edge and that makes it feel all the more difficult is the stuff that's going on with my mum and dad...it's like being on a precipice..."</i></p>	<ul style="list-style-type: none"> • Carers' life choices limited due to resourcing issues around paid carer support • Loss of tax revenue due to number of carers not in paid employment • Carer found it disturbing when loved one was arrested by police • Connecting to own experience of finding distress overwhelming and responding emotionally • Questioning the 'cause' of the mental health difficulty • Not helpful to carer's psyche – carer also needed support • Emotionally painful – would be unable to do again • Isolated myself from people, people didn't understand • Positive gains from returning to work - energy released, new impetus • Self-realisation through change in circumstances
<p>Impact on personal self</p>	<p>Diminished</p> <p><i>T13: "...as I grew older, I became emotionally tired, it's kind of funny, because my mum goes through her episode and then she wants to become my mum, kind of thing, then I hit a low and I'm so tired, that when my mum's ready to talk then I'm down and I can't, I just shut myself away, which is sad."</i></p>	<ul style="list-style-type: none"> • Others judging carer's willingness to care for loved one • Not talking about it, even to my close friends • Needing to regulate balance of nature of caring • Energy directed onto meeting loved one's needs - sense of depletion of own energy levels • Reached limit of ability to meet loved one's needs • Caring detrimental to own emotional resources/reserves • Experiencing conflicting feelings towards cared for which contradict sense of self and personal identity • Less space for a sense of self - 'me' • Being asked about caring experience but not sharing it fully – simultaneously loving and resentful • Self of the carer – opening up to other experiences • Experiential learning of challenges and injustices, feelings of hopelessness at times • Losing the self in caring and becoming unable to identify own wants or needs • Getting emotionally tired • Linking potential impact of work to impact on personal self • Tolerating uncertainty of loved one's decision around accepting contact with carer or not • Offers of help declined by loved one • Questioning the personal self and own vulnerability • Impact of caring on carer's mental health • Impact on professional self and delivery of a work assignment • Re-positioning of self within the carer-cared for dyad • Wanting to protect the self from knowing about loved one's difficulties in the context of work pressures • Impact on self of the therapist and stirring of emotional responses not experienced as helpful • Caring experience may have increased resilience against experiencing anxiety, but also conversely, the caring experience has created anxiety

		<ul style="list-style-type: none"> • Carer experience may have increased tolerance of own distress • Being a helper is part of sense of self • Wrapped up in wanting to be helpful • Sense of shame internalised, but aware of • Cognitive dissonance – not ashamed, but holding a sense of shame simultaneously • Relevance of who to tell • Choosing when to tell • Terrified by visiting parent in adult mental health setting • Values and sense of self affected • Needs of others taking priority over own needs • Everything revolved around loved one's complex needs • Self-sacrificing • Harder to get in touch with own anger • Struggled with regulating own emotions, isolated myself more, self-harmed • Getting physically tired • Isolating self from others, including friends • Becoming aware of others' attitudes towards things like self harm, mental health stigma • Name calling from friends because not able to go out with them • Impact of caring on time available for other things like school work • Hating self for wanting to get away from family home to get time to think • Feeling sense of pressure to be upbeat person for loved one • Feeling sense of responsibility to try to prevent next trigger happening • Feeling guilty - not doing as much as I perhaps could do • Carrying a sense of pressure to look after others • Appreciating that I've held all of this for so long and the impact on me • Depressed before restarted work
	<p>Changed relationships with personal others</p> <p><i>T12: "I think I saw that there was stigma...I think there was something about fearing peoples' judgements"</i></p>	<ul style="list-style-type: none"> • Irritated by others with 'anti-psychotic medication' views due to perceiving that they were naïve • Friends as emotional supports • Closeness of relationship with supportive other relative increased with age • Able to shared concern for loved one with supportive other relative • Difficulty of partner understanding carer's desire to help loved one • Others' perceptions that relationships should be reciprocal • Anticipation - hard for others to hear about feeding loved one, so talks about looking after other parent • Relational differences in caring in families, gender association • Intersectionality and the shifting of power in relationship with loved one (same sex relationship)

	<p><i>and whether it was ok to share it, but also this weird idea of, 'even if they do think it's ok, they won't know what to say to me and like is it important for them to know, I don't know if it's important'."</i></p> <p><i>T7: "...so thinking about my extended family I think for me it's the fact that nobody understands it, nobody, you know they will say 'oh come out, come and do this with us' and nobody gets it, 'I'm like, is there a ramp in the restaurant'."</i></p>	<ul style="list-style-type: none"> • Working through sharing of things in an equal way in the caring dyad (same sex relationship) • Reduction in time available for other relationships • Noticing that parental frustration is sometimes displaced and projected onto carer • Isolating self from others, including friends • Becoming aware of others' attitudes towards things like self harm, mental health stigma • Name calling from friends because not able to go out with them • Impact of caring on time available for other things like school work • Everyone would just stare - becoming very aware of others staring at loved one • Holding it, because of judgement, stigma of addiction, opinions that I don't want to listen to • Wanting to protect parents from judgements • Generational perception that addiction is something to do with parents, or something they have done • 'normal' social activity with family interrupted by 'something weird' • Concern for parent's distress in context of loved one's 'bizarre' behaviours • Could see relative getting really upset because of things loved one was saying • Thinking about my parents in all of this, how can we support each other in all of this • Perceived pressure to support others: staying in family home and avoiding moving out and relocating after parents suggest that timing is not 'great' • Carer looking at mother differently and revising his perspective on her anxiety • Noticing loved one's avoidance of thinking about mental health difficulties • Becoming aware of societal expectations of eldest daughters to take on caring roles • Less close to other family members now loved one is not around • Thinking about own responses if other family members got unwell • Boundaries around expectations of the self in caring for loved one within family unit
<p>Caring enhances connections with others</p>	<p>Mediation of personal qualities and attributes</p> <p><i>T15: "I think in our profession they drill it into you about care, compassion, not being judgemental, all of those things, but until you go through something within your own personal life, you can't, not that you can't, but I</i></p>	<ul style="list-style-type: none"> • Personal investment in helping clients and families • Caring experience facilitating patience and thoughtfulness about family perspective on relative's care • Intensification of level of desire for carer's clients to 'do well' • Personal connection to client's outcomes intensified • Appreciating own ability through the carer role • Existence of an intrinsic caring nature • Increased awareness of how positive carer's role in supporting others can be • Going above and beyond, conscientious and hypervigilant • Empathy and broader understanding of system and its impact • Sensitivity to service user and carer experience • Benefiting ability to connect to clients • Heightened compassion for caring outcomes

	<p><i>think you have more awareness, more appreciation and more understanding about that..."</i></p> <p><i>T3: "...I think caring is the most helpful thing in my clinical practice..we could very easily just go into tiny rooms with chairs and models and have our questions based on those models and ignore the fact that we're two human beings...and suffering together and like it helps, it helps remind you that you're a human".</i></p> <p><i>T11: "I did find it quite traumatic visiting a close family member in hospital. I think it makes me think more about what people might be going through as carers, and if you haven't been through that, you may not have the same understanding and levels of empathy".</i></p>	<ul style="list-style-type: none"> • Helpful for connecting with families and nurses • Not intimidated or scared by inpatient settings • More compassionate • Care, respect, non-judgmental approach • Able to connect to whole experience • Able to contain the part of the self that would ordinarily get frustrated • Able to speak up and challenge practice • Increased ability to use professional therapy skills to inform work with other professionals • Increased empathy for clients who may have abused others • Developed ability to take a nuanced view of a person • Not judging people from stigmatised groups • Accepting complexity within people • Accepting conflicting emotions towards people • Showing compassion for clients from stigmatised groups • Perspective on who should receive help from services broadened • Development of non-judgmental position • Empathy – thinking how loved one would experience things • Seeing loved one as a person with experiences, not caring about what experiences were called • Patience – appreciation of • Holding others in mind, as well as myself • Attunement to the needs of others • Patience, listening skills, research skills • Believing that quality of listening is so important – giving carers time • Able to subsume own needs for the benefit/care of another • Being aware of my needs, but needing to set them aside • Connecting to non-judgmental and humanising stance • Connecting personal experience of advocating for loved one and their care to how it feels to be the family member in a professional setting • Increased awareness of dependency in patient/professional dynamic • Focusing on the needs of the other • Awareness of the power imbalance therapist/client • Understanding of pain and human response to this • Understanding of how physical distress interconnects with psychological distress • Connecting to client's way of removing emotional pain irrespective of how they do this
--	--	---

	<p>Valuing individuals</p> <p><i>T15: "...for me it's part of my practice, I'm very aware of peoples' kind of backgrounds and cultures and religions I guess my experience of working with my brother's difficulties as well. We've not really experienced it with my brother, in terms of being a British Indian...so what I might say that's culturally very normal or religiously very accepting ...or even my brother might say all that being misinterpreted..."</i></p>	<ul style="list-style-type: none"> • 'Massive' shift in thinking about mental health difficulties as a result of personal experience within family • Change in sense of helping relationship from helping people with 'those' problems to realising own closeness to mental health difficulties within own family • Dismantling of 'us and them' boundary • Acceptance of universality of people's vulnerabilities leading to change in boundary between service user and professional • Accepting that we may all be susceptible to a psychotic episode • Becoming more aware of own stigmatising attitudes • Identifying with families through own experience • Connecting with families and seeing similarities with own family • Seeing people as more equal • Less tolerant of the 'us and them' debate, belief that a focus on the carer or service user perspective would not be necessary if true compassion was always foremost in professionals' minds • Awareness of impact of caring on others – impact on parents' relationship • Tension in family • Naming impact on parents • Validation of parents' efforts • Connecting with clients who remind them of loved one • Harder to manage relationship with clients similar to loved one • Seeing carers as confused • Universal suffering within the person's system • Carers neglected within the system, not offered support • Empathy for carer in professional life • Endorsement of caring as a reciprocal act and defense of family responses in the context of difficult relationships • Empathy with adult siblings experiencing difficulties in the caring relationship • More forgiving of other carers through understanding of own position • Increased awareness and understanding of other relatives' perspectives • Knowing what it's like to be in 'their shoes' and how terrible it may be for carers • Thinking about what carers are going through • Keeping carers in mind – running carers' groups • Sending a message to carers about being important too • Always trying to spend time in a session with the carer too, give them that space • Wanting to give family time alone to talk about how caring is impacting them • More compassionate with families and carers
--	---	---

		<ul style="list-style-type: none"> • Being aware that judgements 'creep in' from time to time • Putting myself in their shoes but without making my experience their experience • Appreciating that families and friends have also gone through something as well as the client • Recognising services are not set up to meet carers' needs
<p>Impact on professional practice</p>	<p>Intersection between personal and professional selves</p> <p><i>T3: "...I think I already came to this profession as someone who had experienced some...of the difficulties that we would be helping people to get through..but I guess by being a carer it just broadens that even more like it really opens you up to experiencing an array of challenges and injustices and feelings of hopelessness at times..."</i></p> <p><i>T1: "...I've been the family member, I mean I've shouted at a nurse before on the phone when she told me that my brother was being discharged and that he had no where to live..."</i></p>	<ul style="list-style-type: none"> • Taking a professional perspective on loved one's care - thinking about what might be helpful for loved one • Professional background influencing internal reasoning processes • Questioning the personal self • Using professional knowledge to challenge professional other on diagnosis of loved one • Eradication of personal and professional selves as self integrates • Formulating loved one • Professional training has increased compassion and appreciation carer able to provide loved one • Recognition that carer is a family member 'in the moment' not able to take professional observer position • Increased recognition of wanting boundaries to demarcate the personal and the professional • Understanding of the impact of medication on a patient – the physical and psychic impacts • Appreciation of the difficulties of disentangling mental health problems from the medication given • Professional understanding of mental health lessened anxiety about loved one's issue • Ability to switch off and compartmentalise • Sense of vulnerability, that carer may be judged • Assertiveness drawn from professional knowledge • Sharing pertinent information with professional • Drawing on professional expertise to support other professionals' work with loved one • Loved one testing/asking for confirmation of a 'diagnosis' • Others judging carer's willingness to care for loved one • Respecting others' opinions about caring roles • Not feeling ready to consider decision making process • Becoming aware that other professionals judged family members' responses to caring situations • Training providing an ability to balance own distress at caring through perspective taking • Sense that other professionals did not want to hear about carer's personal knowledge of loved one's difficulties/condition, which was informed by professional background • Hard to disengage from the therapeutic part of self, can be detrimental to being carer • Professional skill of self-monitoring behaviours and anxieties assists with identifying self-care needs • Frustration with personal self for not accepting loved one's difficulties

		<ul style="list-style-type: none"> • Tolerating difficult circumstances – people say I remain calm, maybe because I've seen a lot • Individual cases triggering – reminding carer of family situation • Having a sense of how the client's situation could develop linking part to personal experience of caring • Able to compartmentalise • Reflecting on the difference in young carer's situation and other children • Reflecting on how considers change, how does carer maintain hope • Recognising struggle of working with others and getting to the extent of their pain, whilst still feeling own • Picking up on things that other clinicians might not pick up on because of caring experience • Bracketing of personal within the professional self • Self-sacrifice and the potential to become distressed not just ending when the caring ends • Thinking about how services are set up to make it easier for others to be around loved ones • Thinking about adverse effects of medication • 'with my background' – providing step by step support for loved one to engage with services • Kind of 'translating' knowledge about services to explain them to loved one and family system • Giving family awareness has been helpful from personal awareness of the family system
	<p>Experience of training</p> <p><i>T3: "...the difficult thing that happened to me was that I was kind of framed as a person that seeks out relationships with people that are damaged...that conversation was like difficult was like...'you just see yourself as a saviour..."</i></p>	<ul style="list-style-type: none"> • Prescriptiveness of training experience • Supportive professional others (supervisors) facilitate re-framing of response • Other professionals naming their dual role with trainee as tutor and as clinician for loved one's care • Trainee wondering how viewed by course tutors • Trainee picking up on course tutors' values and stereotypes • Sense of exposure/vulnerability from personal disclosure in training environment – dual position experienced as difficult • Appreciation of psycho-dynamic model through caring experience, 'richer' model • Perception that layers of emotional distress are not verbally expressed • Part of self of loved one had been so traumatised that had become dissociated • Judgement that CBT 'scrapes' at the surface of emotional pain • Recognition of own power as clinicians, ability to write someone's narrative and the lasting impact of that • Recognition of power imbalance clinician and client • Conscious and unconscious processes at work in our clinical practice • Getting angry inside – 'they're human, you can't talk about them like this' • Bringing more compassion to difficult situations • Increased awareness of how something culturally normal can be labelled something psychiatric

		<ul style="list-style-type: none"> • Concern - how therapists work with awareness of cultural and religious norms and how important this is • Self of the therapist holding back from sharing a psychodynamic interpretation due to empathising with the difficulties of a client's situation • Needing to bracket own experience to a certain degree • Enactment of client's passive response • Learning to be more direct • Asking others to take responsibility for own actions • Impact of earlier family dynamics on tolerance of conflict in simulated settings and perception of different response to other trainees • Increased vulnerability as a result of attunement to conflict in simulated settings • Feeling overwhelmed by training demands and the impact of caring for loved one in crisis • Assessing self against others in terms of resilience • Valuing of lived experience – sense of struggle/difficulty with accepting opinions or decisions which counter/impinge on the experience of those who use services • Connecting with something personal in therapy room unhelpful • Empathy – downside is feeling emotional at work • Not healing self through work • Able to build positive relationships with service users quickly • Caring experience links to enhanced relational ability • Ability to sit with things – not being scared of being told strange or horrible things • Not being scared of emotional expressiveness from others • Personal centred – loved one's perspective mattered • Dislike of medical model and that way of working • Desensitisation after working in an environment • Talking to clients like people and talking to carers • Ability to listen properly developed • Being fully present with clients • Gaining awareness of loved one's responses and metacommunication • Resilience – able to move forward in distressing situation • Not competing while training, didn't feel sense of competition • Acceptance of caring experience on training – exploration of pros and cons
--	--	--

	<p>Relationships with professional others</p> <p><i>T5: "...I've had some good conversations with supervisors who've maybe suggested that I think of things as an invitation rather than an obligation, which has been a really helpful way of thinking about it..."</i></p>	<ul style="list-style-type: none"> • • Feeling unsupported • Feeling affronted • Wanting support from others in positions of responsibility • Feeling judged about decision making • Feeling that others (course tutors) had overstepped an interpersonal boundary with them • Assumption of relational differences in upbringing between professionals • Defending family members' from being judged by other HCPs • Angry at other HCPs' judgements of willingness to care • Discouraged from others (course tutors) of caring for an adult whilst on training • Different standards applied to different types of caring relationships ie children • Implicit judgement of carer's decision making process conveyed by other professional (course tutor) • Carer framed by as a person who seeks out relationships with people that are 'damaged' • Supervisor supportive of request for carer's leave • Challenged by notion of self-care presented by course as an individualistic 'thing' • Residual feelings around looking after loved one in crisis - debates might not otherwise have had • More dependent on supportive others - use of networks to support job seeking • Flexibility in employment relationship critical • Empathic, receptive manager helped carer to cope with her distress • Sharing how impactful how staff talking about people is on clients and carers • Dislike of making others feel uncomfortable, talking to teams to de-personalise • Valuing and praising colleagues' efforts • Perception that carers of children are treated differently • Perception that there's a need to prove or justify needs of the self of the carer • Others not understanding that mental health is not a 'smooth' thing • Others not understanding that loved one's mental health can be erratic, risky and/or require an immediate response • Perception that looking after a mother or father or child is more easily understood • 'Too close to home' not working with a patient, decision respected by manager • When younger - teachers did not talk about mental health • Any struggles with school work put down to loved one's mental health difficulties • Need for support with learning needs overlooked because of school's judgement about loved one's difficulties
--	--	---

<p>Perspective taking</p> <p><i>T9: "...she was suffering so much so take her off the Aricept, she was calmer, she seemed softer...but we lost her...so that's made me wonder about how our services are set up to cater for older adults with dementia and stuff".</i></p>	<ul style="list-style-type: none"> • Arrest beneficial to loved one's treatment • Boundaries on placement to separate trainees from working with loved ones • Connecting to value of perspective taking in MDTs • Connecting to own lens and how this can influence our interpretation • Connecting to challenging services on intervention offered and their perspective on loved one's health status • Increased cynicism about mental health services • Judgement about service offer • Caring experience bringing knowledge of the wider system • Lack of organisational support for carers • Being on the receiving end of services – frustrating • Knowledge of resource allocation and rules around this • Making sense of compromises of care in the system • Broken system – people getting lost • Recognising that carers need a break • Frustration and irritation at service set up and barriers to access • Frustration at lack of services
<p>Strengthening of professional values</p> <p><i>T3: "I already had values of like noticing injustices...that kind of strengthened ...because, particularly with my current girlfriend like has involved a lot of engagement with NHS services that I guess, having that perspective of someone on the receiving end that again kind of strengthens your values.."</i></p>	<ul style="list-style-type: none"> • Doing the right thing, doing things properly, being accountable • Own values strengthened, noticing injustices • Seeing how service experience is from loved one's perspective (austerity) • Seeing what things are privileged and whose voices are heard in services • Caring most helpful thing in clinical practice • Centring the client and psychologists interaction as one of two humans meeting together, rather than the expert-patient position • Carer seeing clients as teachers, respecting clients' knowledge bases • Desire for a label as a carer – to make sense of loved one's difficulties • Needing to understand why loved one acted the way she did • Place value in caring, comes naturally • Legacy • Fighting against injustice • Compassion • Valuing transparency and openness • Honesty integral to sense of self above keeping relationships 'smooth' • Forming relationships with values in mind, caring impacted on these values, taking values into relationships • Person centred, humanistic • Valuing of children born with disabilities – not changed

		<ul style="list-style-type: none"> • Valuing patience – seeing patience as a big thing, for me, for my clients, for my colleagues • More passionate, more vigilant • React to injustices towards others • Realising that family values are important to me • Family extremely important to me • Raising awareness of Eastern philosophy of caring for others in community - caring for and respecting elders
<p>Caring experience and personal Values</p>	<p>‘Towards’ career choice</p> <p><i>T13: “I always wanted to be a teacher..a few times mum had psychology involved it wasn’t a good experience and I didn’t like it, and it got to a point where I thought, ‘I need to do something about this.”</i></p> <p><i>T14: “I think being a young carer, it influenced my values in that I saw myself as helping other people, that I think became part of my role, you don’t know that at the time, it becomes part of you doesn’t it, so I was certainly aware that I was drawn to taking on that role, but I also placed value in that, so actually I quite like caring, it comes naturally..”</i></p>	<ul style="list-style-type: none"> • Relating choice to interest in mental health • Choice taken prior to experience of caring • Not consciously avoided, drawn to work in other areas • Decision to avoid future work with children • Acceptance/ownership of own difficulties as driver/motivator for joining the profession • Choosing psychology because of personality – role in family is one who does not avoid things, names things • Other formative experiences influenced career rather than caring experience • Caring experience influenced career choice • Likelihood that caring experience led to tolerance of forensic client characteristics • Likelihood that caring experience led to career as psychologist • Being drawn into different areas due of personal experience/connection with caring experience • Directing me into working in mental health – positive connection from my experiences • Towards: ‘passion for’ • Dissatisfaction with work and reflecting on values – making a difference, feeling helpful towards others, informed by caring experience • Important to have a career about making a difference • Able to tolerate difficult circumstances – inpatient work, highest levels of distress and violence • Recognising the wounded healer role - going into the profession to try to fix other people and parts of self • Changing career direction towards • Wanting to make a difference to psychology field – ‘needing to do something about this’ • Valuing working in learning disabilities because they see the importance of being patient with people • Choosing to train in this area because of family members with difficulties

	<p>Away from a specialism</p> <p><i>T14: "I don't want to put myself in that situation, where I've got constant reminders of my brother...and I don't want to be a clinician...we all bring our stuff, but I don't want to be bringing all that, I just don't think that helpful...you never know what could trigger you, so I decided not to".</i></p>	<ul style="list-style-type: none"> • Working with children triggering • Connected to powerlessness of children • Needing to protect myself from emotional over involvement • Being kind to myself – avoiding what could trigger me • Being aware of things that I have not processed • Being aware of client groups that I would struggle to work with • Recognising the need to process 'own stuff' before being able to help others • Too close to home, I can't hold that, but being able to tolerate the emotionally challenging nature of the work through putting boundaries in place • Recognising that there's a lot of learning about myself that I can do here • Acute inpatient services being 'too close to home' • Original move into a service to be away from family resulted in seeing the value of the service • Feeling too personal, wanting to steer away • Knowing how much it takes to be around people who are severely distressed • Not being avoidant or judgemental, just 'too close to home'
--	---	---

Appendix 13: Summarised thematic table shared with participants

Themes	Sub-themes
Mental health	<p>Conceptualisation</p> <p>T2: "...mental health can cover a whole range of things, like the way you are thinking, you can be experiencing other things, experiencing other people and your belief systems. Sometimes if someone's belief system is challenged in some way, or shattered in some way, that could lead to some level of psychological distress".</p>
	<p>Deconstruction and destigmatisation</p> <p>T10: "Towards the end of her life she wanted to go out less, she didn't want people to see her being fed ...everyone would just stare at her..."</p> <p>T12: "I imagine that people who haven't experienced living with my mum would have a view of what's normal as like this, yeah, big, and perhaps my view of what's normal is this big. And that therefore leads me to be more open to that more..."</p>
	<p>Construction of distress</p> <p>T14: "...I work in an inpatient unit...there's acute distress and then there's the distress that we all feel, so I ...would say that we all have mental health distress, we all get distressed at different times to different levels...so distress, uncomfortable, not quite how things were before".</p>
Carer identity	<p>Label given by society</p> <p>T9: "It's a political label in a way...and there's something medicalised about it for me as well."</p>
	<p>Struggling to accept carer 'label'</p> <p>T1: "What I did do which may be more about caring is my parents made a complaint to the mental health trust that he was being looked after by and I went with them to a meeting to talk about our concerns, so I suppose that felt a bit more like being a carer..."</p>

	<p>T1: "So I almost don't feel I've done anything worthy of the term caring, I don't think I've done anything to care for him, it's more I've been his brother..."</p> <p>T5: "...it first came to my attention when I was an assistant and one of my supervisors suggested that I register with a carer's agency and I was like, "what are you talking about?" but she kind of explained why, 'well you are doing those things."</p>
	<p>Label defined by me – me as a carer</p> <p>T9: "The term carer feels like a professional responsibility or a defined role and responsibility, whereas I was doing it out of love for my grandmother and I wanted to be around. I wanted to be there for her."</p>
	<p>Transitioning into 'becoming' a self-identified carer</p> <p>T2: "...in my head a carer is someone who's living with that person all the time...and I always forget that ...my sister did live with me for about 6 months, so I wouldn't describe myself as a carer, but in terms of caring for her, that did happen."</p> <p>T12: "...most people that went to Young Carers, were in my mind, looking after people with physical disabilities or they might have been supporting them with personal care, or something like that. I think I'd made a whole heap of assumptions..."</p> <p>T4 "I would say it's only in hindsight I thought of myself as a carer..I recognised that I had been fulfilling a carer's role, I think at the time, I think I've come to realise since it's a bit in my nature to be doing this stuff, I guess it makes me who I am"</p>
<p>Own internal processes</p>	<p>Introspection and reflection</p> <p>T6: "It's the dilemma I think of how to be isn't it? Whether to be in your own head and thinking about how it impacts on you, and then you feel bad, because you think, well, actually I'm in the lucky position here, I'm not them, and I worry about my mum dying, because she organises my dad, how will my dad cope with my mum dying..."</p>
	<p>Questioning of the self</p>

	<p>T1: "...then I started thinking 'is something happening to me?' 'is work affecting me?'"</p>
<p>Relationship with loved one</p>	<p>Strengthening the bonds between us</p> <p>T12: "...I notice that if I was to reach out to my mum for example, upset, and say, 'I've had a really shit day', it's not that she ever has an answer, but she's curious about my day, she's curious about what's going on for me, she will sit with the emotion and just let me be sad..."</p> <p>T8: "...it strengthened it (the relationship) because it made me see the fragility of this human being that had been so massively powerful in my life up until then..it was accompanied by a desire to help, to really take care of...I thought I want to do this."</p>
	<p>Sense of loss</p> <p>T14: "I mean we haven't got a sibling relationship, he doesn't know I'm his sister. He doesn't have an awareness of that so it's not a brother-sister relationship....i give to him unconditionally...so my relationship to him...is not reciprocated.."</p> <p>T15: "You're almost grieving for a person that's still alive which is a really bizarre experience and I kind of just carried that and soldiered on..."</p>
<p>Carer stress and strain</p>	<p>Emotional responses</p> <p>T12: I think the thing that most affected me emotionally was the quandry of could I tell people or not, and how isolating that felt....I felt like it was part of my identity but I felt like I couldn't share it".</p> <p>T6: "...sometimes I think have a fucking conversation amongst yourselves and leave me out of it because I'm done today, I've had to listen to all this stuff at work and I just want to be in my head, and I am having to listen to all this other shit..."</p> <p>T8: "I could only imagine how incredibly alien it must feel and she didn't want to look at this, it smelled...it was quite disgusting but whatever, I did it with no problems..."</p>

	<p>Dependency on carer</p> <p>T5: "...sometimes he'll phone me and say that he's suicidal or he'll phone me and cry down the phone or say, 'I've run out of pills, what do I do?' "</p> <p>T7: "In my negative moments, it's stolen my whole life, it's stolen my entire life, everything I do, everything I think about, centres around it."</p>
	<p>Inadequate support for carer</p> <p>T6: "...we came back and everything just kicks back into place in terms of all the stuff that you have to do and I thought that the stress that I feel at work, the thing that I think pushes me over the edge and that makes it feel all the more difficult is the stuff that's going on with my mum and dad...it's like being on a precipice..."</p>
Impact on personal self	<p>Diminished</p> <p>T13: "...as I grew older, I became emotionally tired, it's kind of funny, because my mum goes through her episode and then she wants to become my mum, kind of thing, then I hit a low and I'm so tired, that when my mum's ready to talk then I'm down and I can't, I just shut myself away, which is sad."</p>
	<p>Changed personal relationships</p> <p>T12: "I think I saw that there was stigma...I think there was something about fearing peoples' judgements and whether it was ok to share it, but also this weird idea of, 'even if they do think it's ok, they won't know what to say to me and like is it important for them to know, I don't know if it's important'."</p> <p>T7: "...so thinking about my extended family I think for me it's the fact that nobody understands it, nobody, you know they will say 'oh come out, come and do this with us' and nobody gets it, 'I'm like, is there a ramp in the restaurant'."</p>
Caring enhances connections with others	<p>Mediation of personal qualities and attributes</p> <p>T15: "I think in our profession they drill it into you about care, compassion, not being judgemental, all of those things, but until you go through something within your own personal life, you can't, not that you can't, but I think you have more awareness, more appreciation and more understanding about that..."</p>

	<p>T3: "...I think caring is the most helpful thing in my clinical practice..we could very easily just go into tiny rooms with chairs and models and have our questions based on those models and ignore the fact that we're two human beings...and suffering together and like it helps, it helps remind you that you're a human".</p> <p>T11: "I did find it quite traumatic visiting a close family member in hospital. I think it makes me think more about what people might be going through as carers, and if you haven't been through that, you may not have the same understanding and levels of empathy".</p>
	<p>Valuing individuals</p> <p>T15: "...for me it's part of my practice, I'm very aware of peoples' kind of backgrounds and cultures and religions I guess my experience of working with my brother's difficulties as well. We've not really experienced it with my brother, in terms of being a British Indian...so what I might say that's culturally very normal or religiously very accepting ...or even my brother might say all that being misinterpreted..."</p>
<p>Impact on professional practice</p>	<p>Intersectionality of personal and professional selves</p> <p>T3: "...I think I already came to this profession as someone who had experienced some...of the difficulties that we would be helping people to get through..but I guess by being a carer it just broadens that even more like it really opens you up to experiencing an array of challenges and injustices and feelings of hopelessness at times..."</p> <p>T1: "...I've been the family member, I mean I've shouted at a nurse before on the phone when she told me that my brother was being discharged and that he had no where to live..."</p>
	<p>Experience of training</p> <p>T3: "...the difficult thing that happened to me was that I was kind of framed as a person that seeks out relationships with people that are damaged...that conversation was like difficult was like...'you just see yourself as a saviour..."</p>
	<p>Relationships with professional others</p> <p>T5: "...I've had some good conversations with supervisors who've maybe suggested that I think of things as an invitation rather than an obligation, which has been a really helpful way of thinking about it..."</p>

	<p>Perspective taking</p> <p>T9: "...she was suffering so much so take her off the Aricept, she was calmer, she seemed softer...but we lost her...so that's made me wonder about how our services are set up to cater for older adults with dementia and stuff".</p>
	<p>Strengthening of professional values</p> <p>T3: "I already had values of like noticing injustices...that kind of strengthened ...because, particularly with my current girlfriend like has involved a lot of engagement with NHS services that I guess, having that perspective of someone on the receiving end that again kind of strengthens your values.."</p>
Caring experience and personal values	<p>'Towards' career choice</p> <p>T13: "I always wanted to be a teacher..a few times mum had psychology involved it wasn't a good experience and I didn't like it, and it got to a point where I thought, 'I need to do something about this.'"</p> <p>T14: "I think being a young carer, it influenced my values in that I saw myself as helping other people, that I think became part of my role, you don't know that at the time, it becomes part of you doesn't it, so I was certainly aware that I was drawn to taking on that role, but I also placed value in that, so actually I quite like caring, it comes naturally.."</p>
	<p>Away from a specialism</p> <p>T14: "I don't want to put myself in that situation, where I've got constant reminders of my brother...and I don't want to be a clinician...we all bring our stuff, but I don't want to be bringing all that, I just don't think that's helpful...you never know what could trigger you, so I decided not to".</p>

