Towards a Critical Theory of Mental Health Carer Knowledge; understanding carers experiential knowledge for research, policy making, and social change

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Declaration

I certify that the thesis I have presented for examination for the PhD degree at the London School of Economics and Political Science is solely my own work other than where I have clearly indicated that it is the work of others (in which case the extent of any work carried out jointly by me and any other person is clearly identified in it). The copyright of this thesis rests with the author. Quotation from it is permitted, provided that full acknowledgement is made. This thesis may not be reproduced without my prior written consent. I warrant that this authorisation does not, to the best of my belief, infringe the rights of any third party. I declare that my thesis consists of 63385 words.

Acknowledgements & Thanks

Naturally I would like to thank all the people who support someone living with mental illness who took part in this work - whether they identify as carers or otherwise, hearing, sharing, and drawing on their stories for my own personal gain will forever be a privilege, a burden, and a place of shame for me.

In these acknowledgements I would like to draw attention to the fact that in doing this PhD I am losing my lived experienced background. Currently, academically and politically holding both lived experience and perceived positions of power is impossible. You cannot co-exist as someone with lived experience expertise and someone with professional expertise. So, I mourn the lived experience work, roles, and colleagues I am becoming increasingly disconnected from, and fear entering professional workplaces where I know they will look down on me.

Onto the thanks!

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As with everything I do, Ciera, this is for you.

Abstract

Background

Mental health carers are significant stakeholders in the mental health landscape in the United Kingdom despite being a neglected group in research, policy making, service design and improvement initiatives. Whilst some knowledge and practical gains have been made in working with mental health carers as part of the care team, there has been little research into what mental health carers experiential knowledge is, how it is learned, and how it equips mental health carers as social actors. The aim of the study, therefore, was to investigate how mental health carer knowledge existed within current lived experience epistemologies and indeed if it should.

Method

The study was conceptualised within the social theory of symbolic interactionism and used constructivist grounded theory methods and an innovative use of autoethnographic research methods to develop substantive theory about how mental health caring impacts people's identity, knowledge, and access to different social worlds. The study utilised three distinct data gathering techniques including constructivist interviews, participant observation of a cognitive interviewing process, and a set of autoethnographic self-interviews, consistent with the interpretivist qualitative research tradition. Data analysis occurred concurrently with data collection and incorporated open coding, focused coding and member checking that led to generation and confirmation of propositions of the theory.

Results

The results from the study identified the multiple ways mental health carers conceptualise their role, how it influences their sense of self, and their ability to access a range of social worlds. The carers in the study go on to describe the different ways they have learned their experiential knowledge and their experiences sharing it as change makers within mental health research and policy making fields, primarily. This thesis goes on to present an argument towards a critical theory to understand mental health carers, mental health caring, and the value of those experiences for social change.

Keywords

Unpaid carers, mental health, critical theory, autoethnography, systems change

Contents

1 Introduction or The Prologue ... 9

1.1 How I got here ... 9

1.2 What is mental health and who are mental health carers? ... 10
  1.2.1 Definitions for this thesis ... 12

1.3 Autoethnographic approaches in this thesis ... 13
  1.3.1 Thesis structure ... 14

2 Methodology and Positionality or Isn't it obvious who I am will influence all this? ... 16

2.1 A qualitative approach to the research design ... 16
  2.1.1 Symbolic Interactionism ... 17
  2.1.2 Constructivism and constructivist grounded theory ... 18
  2.1.3 Autoethnography, constructivism, and co-creating narratives ... 20

2.2 So, who am I? ... 21
  2.2.1 Insider/Outsider: Exploring 'self' ... 23
  2.2.2 Autoethnographic writing & the self-interview ... 24

2.3 Instilling rigor; reflexivity, critical friends, and the research diary ... 24
  2.3.1 Critical Friends ... 24
  2.3.2 Practicing reflexivity ... 27
  2.3.3 Research diary ... 28
  2.3.4 Research diary contents ... 29

3 Literature Review or All this literature yet nothing changes? ... 33

3.1 Conceptualising caregiving ... 33
  3.1.1 Policy Understandings of caregiving ... 34
  3.1.2 Medical and health services definition of (unpaid) caring ... 34
  3.1.3 Sociological interpretations of caregiving ... 35

3.2 Mapping mental health carer involvement in research and policy making ... 36
  3.2.1 Aims of the literature review ... 38
  3.2.2 Methods ... 38
  3.2.3 Search strategy and extraction ... 39
  3.2.4 Results ... 40
  3.2.5 Study aims ... 47
  3.2.6 Number of carers ... 47
  3.2.7 Format of inclusion ... 48
  3.2.8 Rationale for inclusion ... 48
  3.2.9 Reporting ... 49
  3.2.10 Acknowledgements and thanks ... 50

3.3 Discussion ... 50
  3.3.1 Where is the policy? ... 51
  3.3.2 Triangle of Care ... 52

3.4 Gaps in the literature ... 53

4 Study design or Is this a story worth telling? ... 56

4.1 Constructivist Interviewing ... 56
  4.1.1 The sample ... 57
  4.1.2 The pilot study ... 59

4.2 Participant observation via cognitive interviewing ... 60
  4.2.1 Cognitive interviewing ... 61

4.2.2 Questionnaire section 64
4.2.3 Observation sample 65
4.2.4 The Sequence of Cognitive Interviewing/Observation Activities 68
4.2.5 Processing data from the observations 69

4.3 Data Analysis 70
4.3.1 Open coding 71
4.3.2 Focused/selective coding 71
4.3.3 Theorising 72
4.3.4 Memoing 74

4.4 Autoethnographic data analysis 74
4.4.1 Synthesizing results 75
4.4.2 Trustworthiness 75
4.4.3 Credibility and transferability 75
4.4.4 Confirmability and dependability 75
4.4.5 Ethical considerations 76

5 Theory Building on Carer Identity or Sorry, you guys know who you are? 79

5.1 What constitutes a mental health carer identity? 79
5.1.1 Trying to make sense of this experience called caring 79
5.1.2 Caregiving tasks 80
5.1.3 Education, Learning and Information Getting 81
5.1.4 The Role of Harm 82
5.1.5 Relationship Management 83
5.1.6 Maintaining the Day-to-Day 83
5.1.7 Emotion Work 84
5.1.8 ADLs/IADLs 85

5.2 The complex landscape of carer identities 91
5.2.1 Sense of control 91
5.2.2 Achieve or ascribed? 92

5.3 Mental health carer identities 92
5.3.1 Fluid mental health carer 92
5.3.2 The labelled mental health carer 93
5.3.3 Embracing the mental health carer identity 94
5.3.4 Rejecting the mental health carer identity 95

6 Theory building on carer learning types or OMG I saw that tweet too 99

6.1 Knowledge formation, experiential learning theory & carers 100
6.1.1 Experiential learning theory 101

6.2 Mental health carer learning types 102
6.2.1 Pre-diagnosis learning 102
6.2.2 Collective learning 103
6.2.3 Action learning 104
6.2.4 Self-directive learning 105
6.2.5 Formal learning 106

6.3 Mental health carer as a community of knowers 107

7 Theory building on carer knowledge for social change or Is incremental social change enough for the mental health system? 110

7.1 Components of carer knowledge 111
7.1.1 Identity 111
7.1.2 Ownership and sensemaking of story 112
7.1.3 Capacities and the caring role within wider life 113

7.1.4 Interactions with statutory services 114

7.2 Carer knowledge within system change efforts 115

7.2.1 Carers as equivalents not extras 115
7.2.2 Carers draw on distinct and unique ways of navigating the mental health field 116
7.2.3 Carers as change makers and motivators for change 117
7.2.4 Building on existing competencies 118
7.2.5 Being controlled 118
7.2.6 Feeling respected as a person 119

8 Substantive theory and discussion: Toward a critical theory of mental health carer sense making, knowledge, and its influences for social change 121

8.1 Towards a critical theory of mental health caring 122

8.1.1 Critical theory led carer knowledge as a social epistemology 124
8.1.2 The role of epistemological domination in carer knowledge 125

8.2 Critical carer knowledge and justice driven models of understanding mental health caring 126

8.2.1 Models of social justice and care ethics in mental health and care 126
8.2.2 Social justice as it pertains to mental health caring 127
8.2.3 Giving and Receiving Care: Care as preforming oppression and caring as being oppressive 129

8.3 Connecting carer knowledge with justice driven approaches for social change in mental health 130

8.3.1 Theoretical barriers to mental health carer knowledge for social change 131
8.3.2 Mental health carers and epistemic injustice 132

8.4 The classificatory politics of lived experience 133

8.4.1 Critical theory to resist institutionalisation of carer knowledge 134

8.5 Third spaces for knowledge generation and research 135

9 Conclusion or Whelp 138

9.1 What this research adds 138

9.2 Meeting the criteria for a grounded theory 138

9.2.1 Credibility 138
9.2.2 Originality 139
9.2.3 Resonance 139
9.2.4 Usefulness 139

9.3 Limitations 139

9.3.1 Methodological Issues 140
9.3.2 Heterogeneity of the sample 140
9.3.3 Analysis 140

9.4 Final personal reflection 141

10 Instantly 142

11 Appendix 145

11.1 Interviewee invite letter 145

11.2 Consent form 148

11.3 Debrief letter 149

11.4 Constructivist interview guide 151

11.5 Observation study information 154

11.6 Triangle of Care feedback questionnaire 158
11.7 Recruitment advert 161
11.8 Recruitment strategy 162
11.9 Themes around identity 163
11.10 Themes for caring tasks 164
11.11 Identity Paper Manuscrpit 165
11.12 Carer Learning Types Manuscript 178

12 References 191

1 Introduction or The Prologue

Attempt #1

I was 9 and was use to walking home alone from school, terribly singing to pass the mile walk down the hill. All my friends have been picked up by their parents or are at afterschool club. Later in life I'll reflect on if 9 was too young to walk alone. Later in life I'll reflect maybe you can never be old enough for all of this. At the end of the road we lived on, I saw my sister at the bus stop. Nothing weird, maybe she was going somewhere. I'll never know if she knew I was watching but I stared, some sense of dread swelling from my feet upward. Getting caught in my throat, I couldn't have taken a step, I couldn't have made sound even if I hadn't wanted to. She steps into the road. She steps in front of the bus.

I was 9 and I was brave enough to call an ambulance myself, but someone does it for me.

1.1 How I got here

At its highest level, the purpose of this thesis is to narratively examine the potential paradigm shifts occurring in the lived experience in mental health space as they pertain to unpaid mental health carers, though I admit it took a while to narrow down the purpose to something so succinct. The framing of this thesis lies within my lived experience as an unpaid carer for my sister (see chapter 2) who was autistic and lived with dissociative identity disorder and whom I supported (was a carer for) for over 10 years through my teen hood into young adulthood before her completed suicide in 2016.

My initial academic journey began as a sensemaking activity, to conceptualise, formulate, and just try understand both my sister's life and my role caring within it. The competing obligations, aspirations, and inspirations I was holding (Bochner, 2012) prompted this academic journey where initially I learned to conceptualise and frame my caregiving as a burden (Jones, 1996; Maurin & Boyd, 1990) where it had kept me from living a "normal" tween to teen to twenty-something life alongside my friends, who were traveling, partying, kissing people of every and no gender, and immersing themselves in secondary school to university life to new careers.

As I journeyed into caregiving in mental health literature, I observed fractures between my identity, the storylines I was seeing of carers lives, and the narrative I grasped so firmly in an effort to make sense of my history of caregiving. I did not fit into the mould of 'caregiver' in young carers, young adult carers, or mental health carers literature. The caregiver stories I was learning about couldn't possibly exist within my own self narrative. I was somewhere in between identities, and I found that traditional academic theory and research failed to provide answers or pathways for coping with the increasing complexity of my self-identity. Arriving at lived experience literature was a blessing and a curse – finally a literature where I felt my self-narrative was reflected but this literature was not for me. Getting enthralled in writing about co-production in research and policy making, of ethical inclusion of different knowledges, of the communities of scholars and activists fighting for different ways of knowing to be treated as equal as a form of anti-oppressive practice.

But where were the carers? The space existed for service users, survivors, and patients. It was for my sister. To make space and institutional legitimacy for injustices so many for have contact with the mental health system face. Thus, the question rose – how do carers fit into lived experience paradigms and ways of knowing, and, should we even be there?

1.2 What is mental health and who are mental health carers?

Defining and explaining mental health and illness is a complex task, laden with ambiguity and controversy (Heinrichs, 1993; Connor-Greene, 2006), with the challenges around diagnosing and treating mental illness prompting a range of complex questions. What is the line between normal and abnormal? Who decides what that line is and when it has been crossed? What are appropriate and effective interventions and who should be delivering them?

The epistemologically ambiguous nature of mental illness and mental health is contested by scholars and activists across a wide range of fields. The uncritical adoption of psychiatric knowledge, clinical practice, and that fields classifications of mental health and illness as increasingly coming up for discussion (Bracken & Thomas, 2017; Kleinman, 2012). The psychiatric, clinical, and economic understandings of mental health and illness generate an understanding of it shaped by money and disorder. For example, mental ill health accounted for 7% of the total Disability Adjusted Life Years (DALYs) lost in the UK in 2019, with major depression and anxiety disorders being among the top causes of both morbidity and disability (McDaid & Park, 2022). It is estimated that 1 in 6 people have mental ill health (McManus et al., 2016). Mental ill health can impact physical health, relationships, education, and reduce work options for those who live with it, and for their family (Mental Health Taskforce, 2016). In terms of cost, mental ill health costs the UK economy £117.9 billion annually and accounted for 7% of all ill health in the UK (McDaid, Park & Wahleck 2019), with this number likely to have risen over the course of the Covid-19 pandemic (Ahmed, et al, 2023).

Clinical interpretations of mental health are rule by diagnosis and symptomology, viewing menta illness as a scientific-objective neutral, acultural deviation from the expected norm; with mental health care being organised by diagnosis and symptomology to reflect the clinical understanding (Bracken & Thomas, 2017; Pickersgill, 2012). Mental health care in the UK is provided at three levels: primary care, secondary care, and specialist services, with mental health treatment supporting both those with common mental disorders (CMDS) such as anxiety or depression and those with severe mental illness (SMI) such as schizophrenia or bipolar disorder.

Critical mental health scholars place value on the human intersubjectivity that is embedded in social, historical, and cultural contexts in their understandings of mental health and illness. Viewing it as a valued-laden notion that is grounded in specific cultural constructions, as well as relationships between the mind, body, and society (Teo, 2015). Building primarily on the work of Foucault, critical mental health scholars examine the impacts of mental health constructs on both individuals and wider society; with Rose (1998, 2009) illustrating how neoliberal and biopsychiatric interpretations of mental health and illness are being centred in our society's discourses. With the *enterprising self*, becoming increasingly present in domains of life such as leisure, education, and media.

Within this pervasive sense of individualism being layered into western, but particularly British interpretations of mental health, the question of what are mental health carers, and where do they fit into this theoretical landscape becomes apparent. Traditional – psychiatric, clinical, and economic – understandings of mental health carers dub them a 'hidden resource' in our society and health and social care fields, with an estimated 6 million people providing unpaid support to a family member, friend, or neighbour with mental or physical health issues (Carers UK, 2020). A carer is anyone, including children and adults who look 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 (Five Year Forward View, 2014).

It has been repeatedly evidenced that both the National Health Service (NHS) and the social care systems in the UK would be unable to cope if unpaid carers withdrew their support – support which has been estimated to generate approximately £162 billion per year in savings (Petrillo and Bennett, 2023). Besides monetarily, carers play a key role in supporting and enhancing the care recipient's quality of life both by advocating for and by supporting the care recipient to live their life to the best of their ability. Being a carer is known to have 'adverse' effects: with 30% of careers describing their mental health as bad or very bad, with those caring over 50 hours a week being more likely to report their mental health in those categories (Petrillo and Bennett, 2023). What's more carers report increase experiences of loneliness and isolation when compared to their non-caring equivalents and 63% state they are extremely worried about manging monthly costs contributing to anxiety (ibid).

Of the 5.7 million carers in the UK identified via the 2021 census, there are not up to date statistics about the number supporting someone with mental illness but it is likely this number has risen due to societal factors such as the Covid-19 pandemic and subsequent Cost of Living Crisis. Carers often support service users in the community i.e., not currently an inpatient in hospital; support in the community has increased year upon year due to the steady decline of mental health inpatient beds in the UK (Wyatt et al, 2019). The number of NHS overnight mental health beds has decreased by 73% between 1987-2020 (Ewbank et al, 2021) meaning the subsequent lack of NHS beds leading to the majority of care being provided in the community, with many service users having informal carer support.

The evidence laid out above illustrates how mental health carers are conceptualised and understood within traditional academic fields. While this evidence illustrates the impacts mental health carers have across mental health care, mental health social work and the mental health system in general, we are rarely situated as expert on anything related to mental health (Kara, 2016). Our knowledge is neither professionalised or lived experience, we are missing from dominant ideologies, epistemologies and praxis within mental health academia (ibid). Carers are readily missing from efforts to be involved or co-produce research, policy making, and service design and improvement efforts; cited reasons for this include lack of resources, lack of time, and simply not remembering to include them, or a focus on including service users (Kara, 2013, 2016).

Critical perspectives and interpretations of mental health and illness have rarely been extended to understanding and interpreting mental health carers experiences and knowledge. The lived experience, co-production, and involvement literature exists in a parallel that in some cases can be applied to mental health carers (see chapter 3). The growing impetus for the involvement of service users in research and policy making developed out of the disabled people's movement and the perception of many users that, generally, studies by able-bodied researchers objectified, stereotyped and contributed to the oppression of people with disabilities (Beresford 2002, p.99). Some people are now arguing that, with involvement being mandated in research agendas through Patient and Public Involvement initiatives, it has gone far enough to become commodified (Carr, 2019).

Carers rarely feature and are often invisible even in user-led research (Richardson and Laird, 2013, p. 70). When carers do appear, in the vast majority of research in the mental health field, they are usually bracketed with service users as "users and carers", as if the two were one (Kara, 2013, p. 129). Being a carer for someone with mental illness is qualitatively different from being a service user (Rowe, 2012, p. 81), with mental health carers having a range of differing unique experiences. Indeed, the "strong tradition" of including service users in mental health research (Gillard et al., 2015) is yet to be extended to mental health carers despite considerable research illustrating that carers too can be useful contributors to mental health research (e.g. Kavanagh et al., 2012; Kara, 2013; Simpson et al., 2014).

1.2.1 Definitions for this thesis

For the sake of this thesis the terms “service user”, “consumer,” “client,” and “patient” refer to a person using statutory mental health services in the UK and will be used interchangeably. Historically, the term patient has been associated with disempowerment (Christmas and Sweeney, 2016), with other subsequent terms being developed and adopted such as user or service user. The term survivor has an embedded historical foundation based in mad activism and will be used to mean this in the thesis. While this thesis pays some attention to service users/survivors, limited consideration has been paid to the language use when talking about them, given the primary focus is on unpaid mental health carers.

The term ‘carer’ is widely accepted, being used, not only in social and health-care settings and research but also by the government of the UK (Heaton 1999). Previously it has been preceded by words such as ‘informal’ or ‘family’ but, whether this is the case or not, it is used to describe people who care for others in a non-professional context (Thomas, Morris and Harman 2002). Emerging feminist literature in the 1960s made known the types and amount of unpaid care work, which was dominated by women, challenging the social norms that women are obliged to care. Thus, caring came to be viewed as a responsibility that is forced upon (in the most part) women (Montgomery 1999), and it became impossible to overlook caring as an unproblematic phenomenon. As a result, given that ‘carers’ are considered a vast economic resource (Guberman et al. 2003), ‘carers’ have received increasing recognition within social and political arenas.

The term ‘carer’ or ‘caregiver’ is used widely across health and social care research and practice (Fine, 2004). Despite the label’s best intentions – promoting the recognition and support of carers’ – the term is increasingly becoming a political tool over an identity. As argued by Foster (2005), academic, charity, and government habit has resulted in the term carer being a politicised activity rather than a norm in human experience (Molyneaux et al, 2010). Further, Gunarathnam (1997) suggested that carer is an unnecessary term in Asian languages and culture, arguing that the term is a product of a specific cultural way of conceptualizing this facet of relationships.

Within the mental health research field in particular, the term carer is heavily resisted. Henderson’s (2001 p.152) qualitative study with people with bipolar disorder and their partners showed a ‘rejection of the term ‘carer’ or ‘cared for’, with both participants failing to associate with either term. Instead, the person with bipolar disorder and their partner saw their role to each other as nothing more than partner, husband or wife; with the role of partner and carer being mutually exclusive.

Diary Extract #28

I stumbled across the term carer as an adult. We had, had lessons on what caregiving was in secondary – those poor children who support severely ill adults who can’t wash or feed themselves properly. This biomedical definition of caring made my stomach crawl for so many reasons: (1) I didn’t do anything of those things so my experience couldn’t count; (2) I wasn’t pitiful and my sister wasn’t a burden; (3) my sister wasn’t an adult; (4) I sure as hack didn’t feel like a child.

Pilgrim (1999:15) suggested that we should “abandon the notion of ‘‘carer’’ and use other words instead, according to specific roles and contexts, such as relatives, friends, supporters or advocates”. In his opinion piece on the appropriateness of the term ‘carer’ in mental health services, he argued that the label often implies blame on the part of the ‘carer’ either in causing or in maintaining the other person’s problems. Furthermore, Pilgrim reiterated the point that being a ‘carer’ does not necessarily mean that one person cares about the other. Rather, they may share an abusive history either from the ‘carer’ to the person they are caring for or vice versa.

Within the mental health field, therefore, this can be seen as evidence for policy-driven terms such as ‘carer’ existing for the advantage of statutory services, meaning it is likely services benefit from ‘carers’ accepting the role despite any detriment to the relationship with the service user. Further, the universality of the term ‘carer’ in mental health services fails to see the nuance of relationships where the label is applied by services. For example, someone labelled as a carer in secondary mental health services may also have mental health needs managed by primary services. That does not take away from the care their partner provides them, but only the person with mild symptoms gets labelled a carer.

Naturally, the categories or identities of ‘carer’ and ‘service user’ are not black and white or even mutually exclusive from each other. As mentioned above, caregiving can have detrimental impacts on someone’s mental health and therefore carers are likely to become services (Hughes et al., 2013, p. 70; Stanbridge et al., 2013, p. 177). Caring is linked with highly stressful situations, including high levels of uncertainty, fear for the ill person’s safety, issues with sleep, and significant life changes such as those related to jobs or work pattern, loss of social life, or relationship breakdown (Kara, 2016).

1.3 Autoethnographic approaches in this thesis

Autoethnography examines the social world through the lens of the researcher's personal experience (Wall, 2016). Spry (2001) defines it as a "self-narrative that critiques the situatedness of self with others" (p.710), and Anderson (2006) highlights the "narrative presence" (p.375) of the researcher in the autoethnographic text. In practice, this usually entails introspective first-person accounts of the research process, often including emotional, personal, and self-conscious accounts of lived experience, rooted in a social, cultural, and historical context (Ellis & Bochner, 2000; Holt, 2003).

Classically, there are a wide range of approaches to ‘doing’ autoethnography in research (Ellis & Ellingson, 2008) but Anderson (2006) identified the two foundational ways; (1) The first and most dominant tradition is "evocative autoethnography", which developed from a post-modern tradition and takes a descriptive literary approach. This is demonstrated via Ells and Bochner (2006) who suggest that autoethnography is the mode of storytelling is akin to the novel or biography and thus fractures the boundaries that normally separate social science from literature ... the narrative text refuses to abstract and explain" (p.744). The second tradition attempts to reconnect autoethnography with these traditional principles of social science research. Anderson describes this tradition as "analytic autoethnography", resting upon what would be typically understood as symbolic interactionist epistemological assumptions (2006). Wall (2016) succinctly summarises analytic autoethnography as "traditional ethnography with the personal commitments of the ethnographer made explicit" (p.2).

Autoethnography allows for the reclamation of the voices of family members – voices which are absent from the majority of discourses in mental health spaces unless explicitly sought out. As I tell my story and the stories of the many mental health carers who I spoke with, you’ll see a common thread of feeling lost within mental health discourses, narratives and knowledge; feeling disempowered and unable to access the dominant ways of knowing. Autoethnography has the potential to raise consciousness and shift representations of power within social and cultural borders. As an approach to research and writing, it creates opportunities to restore a sense of community and promote shared power, inclusion, and collaboration (Canales, 2010) for others. In this way, it utilizes power within relationships for transformation and coalition building rather than “animosity, division, and hierarchy” (Ellis & Bochner, 2006, p. 434).

In this thesis, thus, I will be reflecting on my own caregiving story, as something foundational to my understanding of my data, myself, and how I move through different social worlds. I am subject, a participant within the narratives I am trying to relay and the conclusions I come to. Extracts of my life litter this piece of work, highlighted in italics and generated from my self-interviews (see chapter 2), through the research diaries I kept through the thesis process, through the reflexive practice I engaged in each step of the thesis journey, and through the constructivist grounded theory I was privileged to co-create with a range of people. While this thesis is not an autoethnography, it would be naïve to not consider and incorporate autoethnographic principles through this work. For this thesis, I have grounded my own experience and the experiences of the mental health carers I spoke with in narrative ways because this is the best way I know to provide a complex emotional, psychological, and physical trajectory of human experiences over time (Frank, 1995; Ellis, 2004; Richardson, 2000; Bochner & Riggs, 2014; Bochner, 2017).

Hospitalisation #1

I was 9 the first time I went to A&E and met who I would now call liaison psychiatry, but back then I just called a doctor. My sister was scratching at ***my*** *skin, the repetitive motion I think calming her down as she dug her nails deep into my arm creating long red scratches. Breaking the skin at points my blood slid slowly down my arm onto my grey pinafore uniform. The nurses took a look but didn’t stop her, saying it was better she did this than cause a fuss. I was 9 and found the blood strangely mesmerising and the pain muted. They admitted her and me.*

When I got older, I conceptualised this as my first PTSD experience. As blunted PTSD according to the DSM. As a trauma according psychiatric critical mental health practitioners. As an experience of abuse according to the social workers which buzz around on and off for the rest of my teen years. But really it was just adults letting me down for the first time. Regardless of the framework they chose to understand my pain the fact is, they left me to understand that pain alone.

1.3.1 Thesis structure

Each chapter of this thesis is given a traditional academic title, followed by the title generated from the multiple self-interviews conducted before the writing up commenced. Further, between chapters are ‘interludes’ extracts from a poem drawn from the data. I’d encourage you to go back read them all together at the end of this thesis (interlude 10).

Interlude 1

Take for instance you,

Take for instance me,

Take for instance the trouble we use to get in immediately.

Like the time you shoved me to the bottom of a sleeping bag and proceeded to ride me down the stairs,

Your cares evaporated until the crunch *of my skull as it collided with the ground,*

A sound that haunted you until your last day every time you were an inpatient you'd grasps my hand to say

Sorry.

As if it had only just happened.

You were a good sister.

2 Methodology and Positionality or Isn’t it obvious who I am will influence all this?

Self-Harm #1

I was 10 the first time I watched my sister dig a knife into her skin. It was certainly not the first time she had done it. She’d always had these scratches on her arms and her thighs; little raised deep brown coloured scars along her caramel skin. She’d always thrown herself against walls, played with fire with just a little bit too much conviction. I was 10 the first time I wiped up her blood from the bathroom, stark red against the bath tub and dirt tile on the wall. Using basically an entire roll of toilet paper and some bleach I burned my fingertips with the chemicals and my brain… my brain it went silent.

I’d spend the rest of my sister’s life hunting for that silence in between the chaos.

This chapter reflects on the selected methodology, positionality, and reflexivity present in the study. The research in this thesis comprises of 40 constructivist interviews and 8 in-depth case studies observing mental health carers doing an ‘involvement activity’, conceptualised within the constructivist research paradigm (O'Donoghue, 2006). To achieve the aim of developing theory regarding mental health carers understandings of their lived experiences, how they impact their social worlds, and if and how they fit within the current academic, theoretical and activism lived experience paradigms. The study uses autoethnographic methods (Ellis 7 Bochner 2000, 2006; Ellis, 2004, 2011) in an innovative manner within the constructivist grounded theory study (Charmaz, 1995, 2000, 2002; 2005) undertaken to achieve this aim.

2.1 A qualitative approach to the research design

Qualitative researchers “study things in their natural settings, attempting to make sense of, or interpret, phenomena in terms of the meanings people bring to them” (Denzin and Lincoln 2005, p3, in Denzin and Lincoln, 2011). The decision to use a qualitative research design was multi fold; primarily, however, qualitative methods were selected due to the nature of the study being exploratory (Hammarberg, Kirkman & de Lacey, 2016). Exploring mental health carers sense making around their experiences, knowledge and relations to their social world was not amenable to counting or measuring, thus qualitative methods ensure the mental health carers own words and perspective were centralised in the study.

As well as the importance of meaning, a qualitative approach addresses the importance of context, social and personal processes, and allows for in-depth and rich understandings of the studied phenomena. In this case, a qualitative approached allowed me, not only to investigate the carers’ perceptions of their knowledge’s inclusion in policy-making and research spaces, but also made space for me to autoethnographically draw on my experiences of this topic. These aspects would not have been present if a quantitative approach had been used.

Denzin and Lincoln (2005 p.22 in Denzin and Lincoln, 2011) outline how personal beliefs and experiences cannot be held completely separate throughout any research processes. My own beliefs and feelings about the world and how it should be understood and examined have influenced the choice of research paradigm, determined the research strategies and methods of this study. This study recognises that the dominant positioning of traditional ways of knowing have rendered other ways of knowing, such as through lived experience or through interpreting meaning, as unexplored and under-developed. It also recognises that the emphasis on objectivity, generalisability, and finding one singular unique truth serves to reduce the complexities of human experience into something easily understood (Charmaz, 2006, p.5).

Any assumptions around objectivity, or at least, classical norms of objectivity in social sciences have been eroded (Denzin & Lincoln, 1994); with postmodernists believing that hat the methods and procedures that are employed in research are ultimately and inextricably tied to the values and subjectivities of the researcher (Bochner, 2000). Particularly in work taking autoethnographic approaches, attempting objectivity is foiled from the outset given the basis for the research, what they choose to describe and how they choose to describe it and that are grounded in a "set of intellectual assumptions and constitutive interests" (Stivers, 1993, p. 410).

I would argue, however, that striving for objectivity implies a level of self-deception. It fails to acknowledge the researcher as a subjective system with thoughts, values, and biases who is a member of a social world whose constructions are mediated by individual and social characteristics (Denzin and Lincoln, 2011). To achieve objectivity, there has to be an uncoupling of epistemology (knowledge of the other as constructed) and methodology (scientific knowledge as untouched by the beliefs and actions of researchers and their culture). If this were possible, it would imply that all researchers are interchangeable, and would invariably draw the exact same conclusions from any data. The researcher implied in textbook methodologies has no age, sex or gender, smell, ethnicity, disability, or socially conditioned habitus. Many qualitative social scientists treat interpersonal differences as extraneous variables that lead to errors and need to be minimised or, where possible, completely eliminated (Charmaz, 2006). They tend to forget them – because they want to forget them – and are therefore in good company in a scientific community that shares this tacit consensus.

Diary extract 5

Do I even want to be a researcher? To be given the privilege and the burden of making sense of other people's experiences. To be complicit in an academic system which perpetually causes harm. Stepping away from the meanings people ascribe to their own experiences and pushing them into westernised, colonial academic lenses.

2.1.1 Symbolic Interactionism

This study was initially conceptualised within the social theory of symbolic interactionism (Blumer, 1969). Chicago sociologist Herbert Blumer first coined the term 'symbolic interactionism' in 1937, and this approach required the study of people in their natural environment, not through abstracted forms or artificial experiments (Woods, 1992). Symbolic interactionism describes both a social theory and an approach to the study of human behaviour (Blumer, 1969).

According to Patrick Williams (2008), the term 'symbolic interaction' is comprised of two concepts: 'symbol' and 'interaction' where 'symbol' refers "to any social object (e.g., a physical object, a gesture, or a word) that stands in place of or represents something else" and 'interaction' "highlights the significance of interpersonal communication in transmitting the meaning of symbols" (p.1). Through such interaction culture arises where 'culture' is understood to be the "ideas, objects and practices that constitute everyday life" (Patrick Williams, 2008, p. 1). Hence, human beings have, as interpretive beings, the ability to negotiate, modify, or reject the meanings they encounter and may therefore, shape the culture in which they find themselves (Patrick Williams, 2008).

Atkinson and Housley (2003) currently indicate that as sociologists "we are all interactionists now … in the sense that many of the key ideas of interactionism have become part of the contemporary mainstream of sociological thought" (p. xiv). For the purposes of this study, symbolic interactionism is understood through Blumer's three central principles:

(1) human beings act toward things on the basis of the meanings that the things have for them, (2) this attribution of meaning to objects through symbols is a continuous process, and (3) meaning attribution is a product of social interaction in human society (Woods, 1992, p.338).

Blumer's three central principles are an attempt to unravel the various aspects of the symbolic interactionist central notion of interdependency between the individual and society. Such notions as self, significant others, time, place, culture and structure are key components of 'situation' and these exist only if the individual deems them important (Blumer, 1969).

As indicated by Woods (1992) "people act on the basis of meanings that objects have for them. They do not respond to an objective reality or to how others perceive it but, rather, to how they interpret it" (p. 351). Specifically, this study sought to generate theory regarding how interviewees 'deal with' the situation of supporting someone with a mental illness over time and how that shapes their social worlds. O'Donoghue (2007) advises the following in relation to such studies:

… as symbolic interactionists what we are really doing when we pose the question: 'how do participants 'manage', 'deal with', or 'cope with' situations?'

is asking what are the patterns that can be detected over a particular period of time from an investigation of:

i. the perspectives which the participants have on a phenomenon at the outset;
ii. how the participants act in the light of their perspectives;
iii. the changes, if any, which take place in the participants' perspectives as a result of their actions; and so on, as the cycle repeats itself time and again. In other words, there is a major focus on trying to generate theory about process (p.33).

This study therefore explored what symbolic meanings participants held and shared in terms of 'dealing with' their situation, how and why these meanings existed and if they changed over time and how such meanings translated into social action. This 'understanding' was then used to "generate theory about process" (O'Donoghue, 2007, p. 33).

Attempt #45

By 20 I was very use to the harm and suicide attempts. My behaviours and emotions around them became layered in between the hard-fought neutrality I clung to for safety. I thought I knew how to deal with them down to the moment, each method, motivation mapped out carefully in my brain to 'deal with' this situation.

Attempt 45 shattered my palace of carefully balanced playing cards and neutrality. My understanding of this 'thing' called caregiving fell away when a ward called the police on my sister. When the police knelt on her neck. When services, the people meant to be providing care just watched.

2.1.2 Constructivism and constructivist grounded theory

A paradigm or worldview is defined as a basic set of beliefs that guide action (Denzin and Lincoln 2005, in Denzin and Lincoln, 2011; Creswell 2009, p6). For this study, the research paradigm incorporated my own ontological perspective (my own worldview); my epistemological perspective (how my ontological perspective on existence/reality related to the theories and analysis used); and methodological perspectives (the assumptions that guided my choice of research methodologies). Given my own philosophical beliefs and assumptions, and my values in relation to knowledge development, constructivism and interpretivism were chosen as the research paradigms for this piece of work. Constructivism and interpretivism are frequently combined (Creswell 2009, p8), meaning there are multiple understandings available, as well as methods of gathering data and interpreting it in accordance with the paradigms.

In relation to the decision to use both the social theory of symbolic interactionism and constructivist grounded theory method in this study, Bryant and Charmaz (2007) indicate that “the fit between symbolic interactionism and grounded theory is extremely strong” (p. 21). The theory method “is currently the most widely used and popular qualitative research method across a wide range of disciplines and subject areas” (Bryant & Charmaz, 2007, p. 1). Since grounded theory’s inception different forms have emerged including those emphasizing its ‘constructivist’ elements (Charmaz, 2001, 2006).

Constructivist grounded theory “assumes the relativism of multiple social realities, recognizes the mutual creation of knowledge by the viewer and the viewed, and aims toward interpretive understanding of subjects’ meanings” (Charmaz, 2000, p. 510). The constructivist grounded theory research method is consistent with the symbolic interactionist theoretical perspective of human conduct adopted in this study and offers a comprehensive systematic framework for inductively building theory (Charmaz, 2006; O'Donoghue, 2007).

Charmaz (2000) contends that theory construction is a co-construction and is reflective of both the researcher’s and participants’ perspectives and “recognizes that the viewer creates the data and ensuing analysis through interaction with the viewed” (p.523). Charmaz (2006) further asserts that “researchers are part of what they study, not separate from it” p. 178). Hence, this study used ‘constructivist’ grounded theory methods to “form a revised, more open-ended practice of grounded theory that stresses its emergent, constructivist elements” (Charmaz, 2000, p. 510).

A constructivist research paradigm presumes a relativist ontology and a subjectivist epistemology – meaning there are multiple realities understood by different people, and researchers and research participants co-create meaning to understand and explain those realities (Denzin and Lincoln, 2011). The major elements and assumptions of a constructivist-interpretive worldview that were incorporated into this research include:

i. That individuals seek understanding of their world and that they develop meanings of their experiences through interaction with others – the term “others” is not limited to people, but also includes systems.

ii. That participant meanings are multiple and layered.

That reality is co-created by the participants and the researcher, and that the researcher is a part of the world they study and the data they collect.

I recognise that this piece of work cannot completely share mental health carers’ perceptions and understandings. In this constructivist grounded theory, data and the analysis processes were formed from my shared experiences with the interviewees, my relationships with them, and other data sources (Charmaz, 2006, p.130). The study examined the ways in which mental health carers understood their experiences as a source of knowledge. This was achieved by my moving as close to the “insider experience as possible” whilst reflecting that the experiences I had in common did not replicate those of the interviewees (Charmaz, 2006, p.130). This approach required: a sense of reciprocity between myself as researcher and the interviewees in the co-construction of meaning; the recognition of potential power differentials and ways of modifying these; and clarification of my own (as researcher's) position (Mills et al. 2006, p10).

Diary extract 12

Four interviews down, however many to go. I'm getting lost in applying theory to the experiences people are telling me. Yes we exist in a social world, yes that social world is individualised to each person but why does my experience of caring feel so different to these. If caring is the lens I am suggesting people move through the social worlds, then how are boundaries drawn around that? If co-creating an understanding of ways carers move through social worlds good science? Or should I be aiming for something health science impact related. Wouldn't [funding body] think that's better? It feels like no one cares about this stuff anyway.

Various critiques of grounded theory as a method include claims of epistemological gullibility; these critiques remark on a "slipshod" attention to data collection and the claim that an inductive nature of the method is "ad hoc". Further, the over-reliance on secondary sources ends up exposing the method to potential biases; a questionable justification for small samples; and an incompatibility with macro questions (Bryant and Charmaz 2007a, p36). Charmaz (1995) argues that a constructivist approach to the "interactive nature of both data collection and analysis resolves the criticisms of the methods and reconciles positivist assumptions and postmodernist critiques" (p62).

2.1.3 Autoethnography, constructivism, and co-creating narratives

Ellis and Bochner (2000) describe 'autoethnography' as "an autobiographical genre of writing and research that displays multiple layers of consciousness, connecting the personal to the cultural" (p. 739). They argue the power in autoethnography exists in allowing "readers to feel the moral dilemmas, think with our story instead of about it, join actively in the decision points that define an autoethnographic project, and consider how their own lives can be made a story worth telling" (Ellis & Bochner, 2000, p. 735). Autoethnographic projects have come to comprise many forms including: "systematic sociological introspection, biographical method, personal experience methods, feminist methods, narrative inquiry, co-constructed narrative, interactive interviewing and autoethnographic performance" (Ellis, 2008, p. 1).

Anderson (2006) differentiated between analytic autoethnography and evocative autoethnography, with the former representing a more traditional scientific approach (advocated by Anderson) and the latter representing the more free-form style (Ellis, 2000; Ellis & Bochner, 2000). Analytic autoethnography aligns with postpositivist and constructivist paradigms whilst evocative autoethnography tends to be best placed in a critical–ideological paradigm. The analytic approach tends toward objective writing and analysis, whereas the evocative tends toward empathy and resonance within the reader.

The inclusion of autoethnographic methods in this study is embedded in the understanding that "discourses are about what can be said and thought, but also about who can speak, when, where and with what authority" (Ball, 1994, p. 21). To this end, this study engaged in evocative autoethnography, both to allow the researcher to become the researched and acknowledge the role of 'self.'

Punch (2005) warns however, that taking on such a role to obtain an 'insider perspective' raises a number of important issues that need to be addressed: including the ethical issues associated with this method of data collection; the conceptual issues of the importance of the researcher's prior picture and the role of exploration and inspection in participant observation (Blumer, 1969); and the more practical issues of gaining access to the situation, overt versus covert observation, ‘front management’ or the researcher’s presentation of self, and how to record what is being observed (Fielding, 1996b) (p.183).

To address such issues, throughout the research process there has been an attempt to be continually self-reflective and balance my own understandings of the research area against those of my interviewees. I did not wish to raise the importance of my own rendition of the research area above that of my interviewees. On this point, Charmaz (2006) advises the following:

> *Thus, constructivists attempt to become aware of their presuppositions and to grapple with how they affect the research. They realize that grounded theorists can ironically import preconceived ideas into their work when they remain unaware of their starting assumptions. Thus, constructivism fosters researchers’ reflexivity about their own interpretations as well as those of their research participants (p. 131).*

To this end, I engaged in both the use of a research diary (see section 2.2.3) and within that a modified form of ‘bracketing’ (Ahern, 1999). The bracketing occurred explicitly at starting points in the study with the aim of ensuring I did not privilege my own story over the experiences of my interviewees, and to ensure I did not pre-emp the analysis with foregone conclusions before the grounded theory could start. This modified ‘bracketing’ (Ahern, 1999) consisted of a lengthy autoethnographic self-interview to ensure that I understood my own starting assumptions regarding the research area before formal engagement occurred with the other participants of the study. This ‘bracketing’ was imported for use from phenomenological research where an ‘epoche process’ is often employed and the researcher is encouraged to write down all of his or her suppositions or prejudgments regarding the research before interviewing of participants occurs and throughout the research process (Moustakas, 1994).

2.2 So, who am I?

Given the constructivist research paradigm assumes a subjectivist epistemology, together with autoethnographic approaches it is necessary for me to detail who I am within the study parameters and what I carry when approaching co-creation and meaning-making activities with interviewees. My worldviews shaped the approach to the study in the following ways: they influenced the choice of research topic; the choice of research paradigm to guide the study; the choice of theoretical framework and major data gathering and data analysis methods; the choice of context; the ways in which values already present within the context were managed; and the ways in which findings were presented (Guba, Lynham & Lincoln 2011).

What I, the researcher, I, the writer, I the auto ethnographer, sought to do in this thesis was “reveal ourselves to ourselves, allowing or facilitating a perspective on our experience that we did not have before we undertook autoethnographic inquiry” (Bochner, 2017, p. 69). By taking an autoethnographic lens to this study and to myself I reflexively exposed my own vulnerabilities and enabled learning about how the cultural stories about others and ourselves that influence the ways in which we see ourselves in relationship to others.

But more than all of this, my selfhood was paramount in the development of this study, I have to understand my background, assumptions, and sense of self as they impacted my perception of mental health services, how carers are treated in the UK, the wider political implications behind care and caregiving, and my thoughts and feelings on the wider systems that mental health carers move within. In this vein, then, who am I?

I am Black mixed-race growing up in a predominantly white area and learning my Blackness through the name's bullies called me and the graffiti scrawled on the walls of the school bathrooms (Lovelock, 2023). A demisexual, gender confused person existing in a body that chooses its functioning seemingly based on the direction of the wind. When in my wheelchair I am both present and invisible, 'positive discrimination' positioning me as an ideal person to make institutions look like their commitments to diversity and diverse knowledge are palpable while disability makes me invisible to the majority of people.

I keep company with homeless people through to MPs and peers of realm. I scroll my contacts on my phone and find more dead people than perhaps I should at under 30. I am invited into spaces and given a platform to speak and sometimes be heard; It is a privilege and a pressure. I have escaped poverty but still feeling it under my feet. I can't eat jam sandwiches after 6 weeks of the only thing I consumed because it was all I could afford.

I'm a former mental health service user is an identity I can barely hold when I have borne witness to so much pain the system has caused, I cannot step into that space and claim space.

As an autoethnographic storyteller, I am able to reflexively embrace and illustrate, through storytelling, the many relational paradoxes of having a voice as an academic, a writer, the identities above and a "caregiver" for my sister detailed below. Reflexivity requires a deconstruction of ingrained cultural and social norms, including the power of 'norm identities'. My Black mixed race, gender queer identity is a construction that is articulated as relevant to my experience throughout a caregiving literature that I fail to be reflected within. Much of the caregiving literature is founded upon the marginalisation of white women (Wood, 1994) and as I journeyed through this thesis and told my own and others stories, it was my goal to deconstruct my own marginalisation and caregiver marginalisation and attend to some of the implications around differing identities in the context of caregiving relationships and mental illness.

I am a former 80-hours-a-week mental health carer for someone who was severely mentally ill, abusive, and violent. From the ages of 9-21 I supported my sister who was autistic, living with dissociative identity disorder and schizoaffective disorder. I was growing up with absent parents, bouncing in and out of state care and watching as my sister entered the mental health system as a problem, not a person who needed help. I watched, somewhat helpless and very hopeless, as statutory services stripped away my sister's rights, her humanity, layer by layer. We got lost in a system whose flaws outnumber fingers on broken hands but I am complicit in her awful treatment, and I am sorry. I cannot and would not want to separate my memories and experiences, my love and hatred, my loss and my gain through from this PhD experience. My sister is foundational in who I am and the very foundation this thesis is built upon and asking me to erase that would be asking me to erase the reason I have struggled through.

The ideas in Behar's (1996) *The Vulnerable Observer: Anthropology that Breaks Your Heart*, to me describes how storytelling offers more opportunities to break one's heart as a motivator for change than academic writing. Behar described the experience of anthropology:

> *Loss, mourning, the longing for memory, the desire to enter into the world around you and having no idea how to do it, the fear of observing too coldly or too distractedly or too raggedly, the rage of cowardice, the insight that is always arriving late, as defiant hindsight, a sense of utter uselessness of writing anything and yet the burning desire to write*

> *something, are the stopping places along the way. At the end of the voyage, if you are lucky, you catch a glimpse of a lighthouse, and you are grateful. (p. 3)*

This passage moved me as a writer and as a confused researcher.

Behar (1996) compared writing vulnerably with skill and nuance to writing in a traditional scientific style that she argued takes less skill. Writing vulnerably is more dangerous as its failure to move the reader is more humiliating. The same is true for writing autoethnography. The fear of writing a bad story that no one wants to read is another vulnerability to face. If "the exposure of the self who is also a spectator has to take us somewhere we couldn't otherwise get to" (Behar, 1996, p. 14), then autoethnography must do the same. It must allow readers to respond in a way that reveals their own vulnerability, their own connection to the participants and the researcher. Behar (1996) asked, "Does emotional response lessen or enhance intellectual understanding?" (p. 16).

My answer is that in qualitative research, it not only enhances understanding but is also necessary for understanding. It produces a stronger connection between the research and the reader. Autoethnography can heighten comprehension of research subject matter and move public policy by drawing on the reader's emotional connection to the writer. For the purpose of this thesis, therefore, extracts of the self-interviews have been littered through each section. Written in italics, the autoethnographic extracts falling under one of three titles: attempt, self-harm, abuse. Each describes a historical event in my caring experience, linked to the wider section of the thesis.

2.2.1 Insider/Outsider: Exploring 'self'

When researchers do ethnography, they study a culture's relational practices, common values and beliefs, and shared experiences for the purpose of helping insiders (cultural members) and outsiders (cultural strangers) better understand the culture (Ellis, Adams & Bochner, 2011; Maso, 2001).

> *"When researchers do autoethnography, they retrospectively and selectively write about epiphanies that stem from, or are made possible by, being part of a culture and/or by possessing a particular identity"* (Ellis, Adams & Bochner, 2011, para.7).

From a Foucauldian perspective, the concept of the self as a singular and coherent entity is a fictional construct; rather, the individual is composed of conflicting tensions, contradictory positions, and competing knowledge (Berg, 1993). Chang (2008) explained how self is depicted from multiple perspectives in terms of social roles the individual plays, people groups the individual belongs to, diversity criteria by which the individual judges self, and primary cultural identities that the individual gives their self.

The self, or "Ethnographic I" as Ellis (2004) illustrated, is multi-vocal in its meaning and has capacity to hold/move between multiple positions, including positions of insider/outsider. Berg (1993) offered a position of "betweenness" (p. 491) to illustrate how competing positions (subjective/objective), rather than being conceived as confined by epistemological barriers, can be seen as "dynamic and fluid extending along the lines of tension, continuity, and discontinuity" (p. 491).

For me, dwelling on this liminality meat attempting to make order of my thoughts and reconcile the boundaries between the seemingly subjective positions of carer, PhD student, researcher, expert. In doing so, I adventured through and with the identities and other subject positions became available and unavailable to me through the PhD process. Uncovering and valuing multiplicities and multiple subject positions within autoethnography creates opportunities to disrupt those binary positions.

2.2.2 Autoethnographic writing & the self-interview

A lengthy self- interview conducted at the multiple beginnings of the study including – before ethics submission, before each meeting with critical friends, and, before any data gathering could commence. The self-interview captured the historical aspects and my current conceptualisation of my experiences 'dealing with' my role caring for my sister. The self-interviews that took place were framed by my sisters 1-52 suicide attempts she made over 11 years, reflecting on each one in turn and how that experience was shaping this thesis. The self-interview was conducted using a comprehensive series of 'aide memoire' (Burgess, 1984).

The 'aide memoire' was similar to a semi-structured interview, following Punch's (2000) 'Hierarchy of Concepts' which determines research questions organised from general to specific in an inductive-deductive hierarchy. A second set of 'aide memoire' questions was designed to be done at the end of each interview or data gathering to aid my processing of the data (Punch, 2000). Informing the construction of both general and more specific 'aide memoire' questions were recommendations by Lofland (2002) that there be 'questions of type, structure, process and agency' (p. 145) when conducting analytically ethnographically inclined research. The questions were further expanded to include a contextual understanding of the participants' lives given the potential impact of 'context' on participant action. This fits with Strauss and Corbin's (1990) notion of the 'conditional matrix' that operates in the life of a participant at any given time. According to Strauss and Corbin (1990), a conditional matrix "denotes a complex web of interrelated conditions, action/interaction, and consequences that pertains to a given phenomenon" (p. 161). This need for contextual understanding is also apparent in the social theory of symbolic interaction that underpins both the research and guiding questions of this study. Human conduct is always 'situated' and can often only be understood in the context in which it is found. Such notions as self, significant others, time, place, culture and structure are key components of 'situation' and these exist for the individual only if the individual deems them important (Blumer, 1969).

It might be that, in my attempts to avoid emotion and defensiveness and thus to attain objectivity, as I was repeatedly advised to by various academics, I actually undermined the purposes of writing an autoethnography. Ellis (1999) explained that in autoethnography the writer tells a story that allows readers to enter and feel part of a story that includes emotions and intimate detail and examines the meaning of human experience. Autoethnography is a form of writing that should allow readers to feel the dilemmas, think with a story rather than about it, join actively with the author's decision points (Ellis & Bochner, 2000), and become co-participants who engage with the story line morally, emotionally, aesthetically, and intellectually (Richardson, 1994).

2.3 Instilling rigor; reflexivity, critical friends, and the research diary

As mentioned prior, it was vital during both the autoethnographic and data gathering processes I considered how to instil rigor and be transparent about the knowledge claims I was making through the PhD process. The autoethnographic nature of this work was one space for reflexivity and reflection, I also engaged with external experts (critical friends) and a research diary.

2.3.1 Critical Friends

Patient and Public Involvement (PPI) is considered a method to improve the way research is prioritised, commissioned, undertaken, communicated, and used. A range of models for doing 'involvement' or Patient Public Involvement (PPI) in research and policy making have been developed with the overriding method being 'co-production.' Arnstein (1969) generated the Ladder of Participation which defines varying levels of participation ranging from non-participatory action, through tokenism to citizen control. The move towards co-production and personalisation began in the 1970s and since then has gained significant ground in terms of policy context and in practice (Brett et al, 2014; NIHR, 2015, 2022).

There are inconsistencies between the many definitions of co-production that exist. However, there are some key features of co-production:

i. People are defined as assets with skills and their existing capabilities are built upon.

ii. Barriers between users of services and professionals are broken down.

iii. Mutuality and reciprocity are present – people work together to achieve their shared interests and get something back for being involved.

iv. Services are facilitated to be more than service providers enabling them to be agents for change

v. Power in the room is shared between stakeholders

Taking this into consideration during a PhD co-production, therefore, becomes an impossibility due to a range of reasons. A doctoral project's primary aim is upskilling the student, and thus the student cannot draw on the co-producers' skills and capabilities to their full extent. Further, the mutuality in co-production is not possible in a doctoral journey as the student is the one who is set to gain the most and thus there is no equal gain for being involved.

When I set out on this thesis journey, I set up a lived experience advisory board of people who had various experiences supporting someone living with mental illness. I envisioned the group meeting quarterly to guide the study and hold me accountable to the community I was aiming to learn with. Coming to terms with this and the Covid-19 Pandemic altering the classical ways that involvement in research is done, I shifted towards a Critical friend's model.

The pandemic saw a significant rise in mental ill health (Ahmed, et al, 2023), and changes to mental health caregiving activities which led to the carers I had recruited as co-creators advisory board members needing to step down or have significantly reduced responsibilities within the project. For this reason, five Critical Friends were recruited with a range of experiences within research, mental health, and mental health caring. They were deliberately sought out from a range of geographical locations across the UK, with a range of ethnicities, gender identities and sexualities, disabilities, and ages.

Further, engaging with people as critical friends was a pragmatic decision - it was more practical to meeting with people 1:1. Beyond that, however, meeting 1:1 ensured a higher level of confidentiality for critical friends sharing their lived experience. Related to this was my ability to rapport with individuals creating a safe and empowering environment for them to share their lived experiences, as much as their reflections on the research process and data.

In the context of this study, the critical friends were positioned as a trusted people, empowered to ask provocative questions and examine the study and data through their own personal lens. The critical friends took time to fully understand the context of the work presented within the ever-shifting social world. The critical friend's role was not to provide answers, but to provide honest, confidential viewpoints and feedback, ensuring I was accountable to my personal goals and the community of people I had the privilege of interacting and co-creating with in this thesis process.

Critical friends were reimbursed for their time and expertise, as well as provided expenses where needed. Critical friends were paid on a half/full date rate, as reflected in NIHR guidelines (2022). Payment was done to facilitate a 'level playing field' between critical friends, as well as create a more equal partnership between the critical friends and myself as researcher. Payment ensured that critical friends who may otherwise have not been able to contribute were able to be involved in the study. In an effort to make the critical friends process as accessible as possible, feedback was given in arrange of formats including written (emails, texts) and verbal 1:1 online meeting and in person meetings. Critical friends were welcome to share the space with people in their lives that would make the process easier e.g. carers or friends.

Initials	Location	Role	Ethnicity	Sexuality	Disability	Age
MH (he/him)	Nottingham Derby	PhD Student	White British	Heterosexual	N/A	40's
HC (she/her)	London Liverpool	Service User	White British	Questioning	Anorexia + co-occurring physical	20's
ED (they/them)	Kent	Service User	White French	Pansexual, Poly	Schizophrenia chronic pain	30's
WR (she/her)	Durham	Carer	Chinese	Heterosexual	N/A	60's
RC (any)	Kent	Carer	Mixed Black African, White	Bisexual	Mobility issues	50's

Table 1 Critical Friend Demographics

Transparency and consent were the primary values when it came to engaging with the critical friends. They were given options about which parts of the study to engage with and to what extent they were interested. To this end different critical friends engaged in the following activities:

i. Co-learning from the self-interviews (MH, HC, ED, WR)

ii. Acting as a sounding board for the study design and methodology (HC, ED, WR, RC)

iii. Accountability around the aims and objectives (all)

iv. Input into designing the interview guides (all)

v. Group coding and analysis exercise (HC, ED)

vi. Discussion around application of findings, including presenting at 1 academic conference (MH, HC, RC)

2.3.2 Practicing reflexivity

This research is grounded in a constructivist interpretivist approach to learning. The constructivist approach places value in the researcher as an active knower whose opinions, values, and biases are acknowledged and built into the research methodology (Mills et al, 2006). This contrasts with the classic conventions which require the interviewer to be careful in the way they ask questions; always aiming to be neutral and nondirectional in order to prevent bias or contamination of the interview (Gubrium and Holstein 2003, p31).

Reflexivity refers to ‘a researcher's background and position as this affects what they choose to investigate, the approach to investigation, the methods judged adequate for this purpose, the findings considered most appropriate, and the framing and communication of conclusions’ (Malterud, 2001 pp. 483-484). Reflexive researchers are seen to engage in critical self-reflection: reflecting ‘critically’ on the impact of their own background, assumptions, positioning, feelings, behaviour while also attending to the impact of the wider organisational, discursive, ideological and political context. The terms reflection, critical reflection and reflexivity are often confused and wrongly assumed to be interchangeable. Finlay and Gough (2006) find it helpful to think of these concepts forming a continuum. At one end stands reflection, defined simply as ‘thinking about’ something after the event. At the other end stands reflexivity: a more immediate and dynamic process which involves continuing self-awareness. Critical reflection lies somewhere in between.

To understand reflexivity as an iterative ‘activity’ I could incorporate into the research design, initially I draw on the work of Jay and Johnson (2002) who describe a typology of reflection which emphasises the importance of engaging in reflexivity, critical self-reflection, and a combination of personal reflection and social critique (Finlay 2008: p.8) with Finlay’s (2008) model for reflection, which calls for a critical reflection on the influence of our upbringing, beliefs, values, emotions, and behaviours as well as the discourses, ideologies, organisations, and political conditions that are part of our lives.

Below is a table which presents typical questions I asked myself during engaging in reflexive practice. This activity was part of the wider self-interview process.

Dimension	Definition	Typical Questions
Descriptive	Describing the matter for reflection	“What is happening?” “Is this working, and for whom?” “How am I feeling?” “What do I not understand?” “Does this relate to any of my stated goals and to what extent are they being met”
Comparative	Reframes the matter for reflection in light of alternative views and perspectives (including the critical friends)	“How do other people who are directly or indirectly involved describe and explain what is happening?” “What does research contribute to an understanding of this matter?” “How can I improve what is not working?”
Critical	The implications of the mater to establish a new perspective or understanding	“What are the implications of the matter when viewed from these alternative perspectives?” “Given these various alternatives, their implications, and my own morals and ethics, which is the best for this particular matter? How does this reflective process inform and renew my perspective”

Table 2 Examples of reflexive practice

Reflexivity, as an activity, sometimes reveals hard truths that require opportunities to process and debrief the understandings that are revealed. When I initiated this autoethnography, centring and making transparent my lived experience revealed a number of vulnerabilities, further opening and updating my ‘perception’ of how my interviewees make deliberate choices about what story to share, with whom, the range of motivations.

To scrutinize both my personal and professional experiences and how they might impact my research questions, methodology, data collection and analysis, I engaged in both narrative autobiographical writing and in drawings of clinical vignettes followed by interviews (Chang, 2008; Ellis & Bochner, 2000). The following questions guided each stage of the methodological process: *How do my personal and professional experiences influence my understandings of other carers’ stories? How might these new insights shape and guide my conduct and thinking as a researcher?* The critical friends and I created questions aimed at generating insight into experiences that might be similar to those of my interviewees. For example, what is being a caregiver for mentally ill family members like? What influenced me to channel the experience into work, where my interviewees have not?

2.3.3 Research diary

The third way I aimed to manage subjectivity, be transparent about knowledge claims and subsequentially instil rigor in the work was in the form of a research diary. Gerstl-Pepin and Patrizio (2009) write of a research diary as acting as a repository for personal reflection. Writers are known to use research diaries as a tool to facilitate development of skills, research practice, and document decisions and changings in thinking within context of themselves and wider society. The articulation of thoughts becomes the catalyst for change in beliefs and practice, thus the narrative inquiry of diary writing is a tool which mediates teachers’ professional development. Through the narratives and self-dialogues in the journal, teachers externalize their knowledge and then re-internalize knowledge and concepts about teaching (Golombek & Johnson, 2004; Johnson, 2007).

The aim of research diaries, traditionally, is multi fold: (1) it keeps record of the project as it unfolds, (2) it provides a reference point for decision making and change within the research process, (3) for PhD students in particular, it allows the student to track and monitor their development throughout the study, (4) it is a space to form opinions about the learning process, and (5) importantly for this thesis, it provides a place to reflect on the research; and consistently keeping the diary allows it to become a living reflexive piece of study (Morell-Scott, 2018)

Most commonly used within an action research project, a diary aims to “makes visible both the successful and (apparently) unsuccessful routes of learning and discovery so that they can be revisited and subject to analysis” (Altrichter et al 1993;12). It is often described in research methodology literature as a way to log decisions made and write down reflections on the research process (Gibbs, 2007).

Reflexivity is one of the pillars of 'critical' qualitative research (Fontana 2004) and relates to the degree of influence that the researcher exerts, either intentionally or unintentionally, on the findings. The debates on positionality, meaning, and the value of reflexive practice within qualitative research led to the question of how subjectivity can be adapted to increase rigour in qualitative methods. Whilst inherent to all research processes, within qualitative work subjectivity is known to impact data collection, analysis, and interpretation (Finlay, 2008). Varying views exist on how reflexivity can be employed in relation to researchers’ subjectivity to add credibility to qualitative research (Finlay and Ballinger, 2006). Studies show that reflexivity can be used both as a tool to guide the research process and to limit the bias of researchers and their subjectivity (Jootun et al, 2009; Lambert et al, 2010).

As a tool for reflection on the research journey, a research diary creates the space for reflection to become reflexive. As understood in qualitative research, reflexivity is a constant journey while reflection is understood as a one-off activity. Doing reflexivity requires the creation of dedicated times, spaces and contexts within which to be reflexive (Mauthner and Doucet, 2003) and using a research diary is one way of creating such as space. The diary allows for self-reported longitudinal data to be generated.

In practice, using the research diary as a reflexive tool involved:

i. Self-Evaluation – i.e., critically analysing and evaluating the actions and feelings associated with the experience including the use of academic theory.
ii. Re-orientation – i.e., using the results of self-evaluation to influence future approaches to similar situations or experiences (Quinn, 2000, p.82).
iii. Emotion work – i.e., identifying emotions and identifying internal, data, and external reasons for them and their impact on the research process at that moment
iv. Assumption identification – i.e., identifying and labelling assumptions and what motivates them – lived experience or academic learning.
v. Constant questioning of oneself

Questions are an indicator of thinking rather than just reporting or sharing procedural information and, as such, I do not think that there needs to be answers to the questions. In narrative form such as a diary, questions are evidence of thinking and considering possibilities. The questions I posed myself represented a window into the process of constructing knowledge.

2.3.4 Research diary contents

As Wilton (2004 p.147) notes, the kind of individuals likely to self-select in research concerning their intimate lives may be more confident and interested in talking about their own experience, which is likely to affect the kinds of experiences and discourses available for analysis. Diaries, outside of academia, have been positioned as a place for confessional; particularly within pop culture they exist as a space for people to say what cannot be said out loud. Within research it is likely the same, as individuals build up animated narratives for public sharing of their lived experience; and are likely to reflect more on their discourses and narrative on a personal stage such as a diary.

It has been noted that participants sharing such intimate details enter a relationship similar to the confessional or 'therapeutic encounter' (Birch and Miller, 2000: 189; Foucault, 1976). When examining diary work, we can position the auto-ethnographer as both the participant/confessor and the researcher/therapist. In doing so, auto-ethnographic diaries exist as a space for researchers to have discussions with their 'other'; whether that 'other' is as a citizen, or as someone with lived experience of the research topic.

i. Acknowledging the uniqueness of my lived experience; where it diverged from the 'classic experience' of UK mental health services, helping me develop a sense of ownership over my lived experience.
ii. Basking in the bitter feelings where people within academic studies had more positive experiences than my own and mourning for those who experiences were more tragic.
iii. Trying to reconcile the fact that the 'severity' of mental illnesses and subsequently the caring experience was unimportant.

iv. Attempting not to score the narratives read against my own.
v. Sitting with feelings of rejection within academic communities

The research diary was a sprawling set of handwritten and digital notes, visited particularly during data collection, but at every part of the research process. It became a container for my reflection activities – as detailed in the table below – and a host for my further reflexive considerations. The diary became a forum for concerns, successes, passing thoughts, and knowledge claims. Used in this way, the research diary served a range of practical and emotional functions within the project. Throughout this thesis you will find extracts of the research diary – sometimes these are written in verbatim from vocal recordings, other times pulled from various reflected documents made throughout the thesis process.

Practically, the diary allowed me to explore methodological issues such as adequacy of the topic guides, my own skill level in cognitive interviewing, and how in-depth I should be explaining the project to my interviewees. It acted as supplementary data for the interview data where relevant – by noting down themes, internal comments, non-verbal aspects of communication with the interviewee and any thoughts/knowledge claims that came from the interview data but correlated or contrasted with my lived experience.

Emotionally, the diary allowed me to explore each interview as a social encounter, making a space for me to record my own observations about myself as a researcher, about the context in which the data gathering was taking place e.g., the Partygate political scandal.

Comments relating to how I had experienced the interview as a social encounter enabled me to record my own observations of myself as a researcher (e.g., noting my emotional state, such as feeling angry), leading to a consideration of what this revealed about my own assumptions, values and beliefs and how these impacted upon my research. Additionally, the diary acted as a useful organizational aid to help me keep track of the research process as a whole.

Three examples and extracts taken from the diary are now presented as a way to illustrate how the diary was used at varying points in the research process. The impact of each example is then considered at two levels: firstly, the practical or methodological implications, and secondly, the impact that using the diary had on enabling me to think about my values as a Research diaries researcher. Additionally, in highlighting the examples I seek to demonstrate that reflexivity is an ongoing process, with the diary enabling reflection long after the research had concluded.

Research Stage	**Extract**	**Interpretation**
Planning	*"How do I make sure this project isn't just revenge? Can I even get revenge through academia?"*	Reflecting upon my personal motivations for doing the thesis
Recruitment	*"This is luck right? As if this many people have come forward. What am I gonna do?"*	Expressing confusion at having people actually come forward to speak with me, a level of panic at the sheer number
	"What if no one comes forward cause of covid?"	Concern that no mental health carers will be interested in speaking with me

Data Gathering	*"Am I… do I skilled enough to cope with this?"*	Self-doubt around skills, capacity, and a sense of imposter syndrome that someone 'better' than me should be doing this work
	"part of me is upset that [interviewee] didn't get the blame. I wish I didn't"	Reflecting on the experiences of an interviewee who similarly lost their care recipient to suicide, but had no blame placed on them at inquest
	*"f*ck [interviewee] they have no idea how hard this f*cking system can be"*	Experiencing anger at an interviewee who I interpreted as naïve about how the mental health system functions
Analysis	*"am I just looking for IDLE is or it there? Am I seeing things?"*	Self-doubt around if the data I have gathered generated new knowledge
	*"this is just so f*cking hard. I can't do it, I can't. I hate it"*	On going feelings of self-doubt about being able to complete the project
Write-up	*"Where do I even draw the line between concepts"*	Expressed confusion around drawing together the theory generated from the data and wider theoretical concepts
	"I think I've over-simplified it? In the end the theory is just, who you are and what you do impacts knowledge? How do I even turn that into a thesis"	A sense of despair around trying to make complex the substantive theory of the thesis
In conversation with others (non-participant)	*"Today I spoke with Angie – she was super helpful but it has made me feel isolated. Mental health caring studies don't fit anywhere'*	Reflecting on how the data does not fit easily in any one discipline – a good thing for academia, a bad thing for developing an academic identity

Table 3 Examples from research diary

Interlude 2

Take for instance your first hospitalisation when you asked me if seeing you like this was heart breaking,
And I felt myself faking a smile and I stuttered through tears
No
No, my heart isn't breaking
It's just bending
…
Take, for instance, you
Take, for instance, me
Take, for instance, the word instantly
And before you it was used to describe porridge and soups and coffee
And before this it was used to illustrate a love at first sight
But now they use it to sum up your life
They tell me you died
Instantly

3 Literature Review or All this literature yet nothing changes?

Self-harm #3

I was 11 and my teacher had pulled me out of my history class. I could feel the anxiety rising, had I don't something wrong? Was my homework bad? But why would the head of year be bothered about that? The teacher tries to make eye contact with me, placing what they thought was a comforting hand on my shoulder but weighed more than anything they could ask. I nailed my eyes to the floor as they tell me my sister is self-harming in the sixth form bathroom. She had a weapon, she wants to talk to me, can I please go talk to her? I was 11 sat against the bathroom door talking to a crying, intensely suicidal person on the other side of the door.

I was 13 when I realised maybe teachers had safeguarding responsibilities. I was 14 when I decided maybe I was not worth safe guarding.

3.1 Conceptualising caregiving

This research was driven by curiosity to learn more about the role carers have had in the lived experience paradigm, to learn how and indeed if mental health carers consider their identity and experiences as something that grants knowledge, power and authority. When you examine the presence of carers in across academia, policy making and wider society the awareness has been persistently growing. However, prior to the 1950s, caring had received little to no attention as it was simply regarded as something that people preformed as a part of life. The 1950s and 1960s were dominated by the functionalist understanding of family life, meaning caring was not considered until the emergent of feminist thinking.

With the conceptualisation of community care in the 1970s (Twigg and Atkin, 1994), feminists began to explore normative assumptions about the roles of men, women, and others in front and back stages. Regarding caring and what was involved, this examination illustrated how the 'burden' of informal care fell predominantly on women and that that material costs involved in caring both created and maintained inequalities between men and women (Baldwin and Twigg, 1991).

Carers activism starting in the 1960s aimed to force the acknowledgment of the unpaid labour that was undertaken by families in private, arguing that caring as unpaid citizens' work benefitted not only individuals but also wider society (Fine and Glendinning, 2005). This idea has been evidenced across caregiver literature with evidence illustrating that unpaid care work saves the economy £162 billion annually (Petrillo and Bennett, 2023). The acknowledgement of caring as citizens' work led to increased power from the state though legislation and policy defining the rights, responsibilities, and protections of individuals who are labelled as carer by the state as defined most recently by the Care Act (2014).

Since then, caring has been conceptualised differently across a range of academic disciplines, government ministers and departments, third sector organisations and by carers themselves. The term 'carer', 'informal carer' or 'caregiver' is frequently used in health and social care research and policy making. It aims to describe a partner, family member, parent, or friend who provides unpaid or informal support for an individual living with a long term physical or mental health condition (Staley et al, 2021, p3). Carers, thus, are a heterogenous population (Leslie et al, 2019) with significant variation including those who may reject or do not realise they can define themselves as a 'carer' or those who do not find the label helpful. For this reason, the term is heavily criticized (Henderson, 2001, Simpson & Repper, 2011, Molyneaux et al, 2011), although a suitable alternative has not yet been proposed.

3.1.1 Policy Understandings of caregiving

The notion of caregivers/carers in UK policy literature separates caring into public and private activities. Discourses on caring mostly focus on the ‘carer’ over the person being supported, with the ‘carer’ being assumed as a white, female, family member who is not working. Twigg (1989) suggested the three ideal types of relationships with carers in social care contexts: (1) carers as resources; (2) carers as co-workers; (3) carers as co-clients. Carers, in policy contexts, are deemed a resource as opposed to an individual with rights.

Importantly for this piece of work, Twigg’s (1989) first conceptualisation of carer relationships; carers as resources. Within mental health services, service users report their carer not being involved as much as they would like within the formal care process; with carers echoing these grievances when it comes to communication, information sharing, and decision making (Gray et al, 2010).

Carers being a resource is evidenced by the taken-for-granted nature of caregiving in UK service design and policy making. This is particularly the case in mental health care where there is an assumption a carer will be present to support someone living in the community after the deinstitutionalisation of service users through the 80s’ (WHO, 2013).

Diary Extract 2

Is that how I was viewed? As a resource? Not a child, a secondary school student? A dancer? But a resource. To be poured from, when the system did not want to pour. I was 11 and deemed competent enough to not need safeguarding? I was 12 was flattered that people around me considered me grown up? As if the adultification of Black children combined with being a carer made it easier for those around me to see me as a resource. Old enough and wise enough to save us time. Save us money.

In this relationship the unpaid carer sector or ‘citizens’ work’ is viewed as existing before the establishment of formal care services, with the latter responding primarily to deficiencies in the former. Carers as co-workers involves state care agencies and social care sector acting and working in collaboration with informal carers as part of their system. In this type of relationship, kin and friendship relations are ‘semi professionalised and brought into the orbit of the formal system’ (Twigg, 1989, p. 58). Carers as co-clients illustrates the ways in which state agencies support informal caregivers, particularly those involved in highly demanding caregiving activities.

3.1.2 Medical and health services definition of (unpaid) caring

Within biomedical and health services research caregiving is cast as constituting a burden, stressor or strain to maintain the wellness of others (Garand et al, 2005; Sadler and McKevitt, 2013). Caregiver burden is understood by The Merriam-Webster Dictionary (2001) definition of caregiver is “A person who provides direct care as for children or the chronically ill.” “Burden” is defined in the same source as, “Bearing of a load” or “Something that is oppressive or worrisome.” Therefore, caregiver burden could be stated as the oppressive or worrisome load borne by people providing direct care for the chronically ill.

Otherwise known as caregiver stress or strain, carer burden is the dominant understanding maintained within biomedical and health service research; with most focusing on the idea of observable versus perceived costs in relation to the commonly accepted difference between subjective and objective types of caregiver burden (Liu, Heffernan & Tan, 2020). Objective burden is the observable, concrete, tangible cost to the caregiver resulting from the loved one’s illness (Jones, 1996). Subjective burden refers to the positive or negative feelings that may be experienced when giving care (ibid). Subjective burden may also be defined as the person’s appraisals of the situation (Maurin & Boyd, 1990). Research has indicated that caregivers who report a larger amount of subjective burden are at higher risk for negative health sequelae such as depression, and that this subjective aspect of burden is important in predicting outcomes (Given et al., 1992; Weitzner et al, 1999).

Diary Extract 2.5

You’d think that I’d related to idea of burden. That an upbringing defined by caring for someone intensely suicidal, with increasingly severe episodes of self-harm, and alters would be burdensome. And in some ways, it was. Yes, I was depressed, anxious, and self-harmed as a teenager and young adult. Yes, I missed out on educational, social, and employment opportunities extended to my similar counter, parts due to caring. But burden? Like a weight? A cargo? Or like an inconvenience. Am I saddled with this? Obligated?

Within mental health care, carer burden is understood as the personal costs that caregiving has on the carer (Naughton-Doe et al, 2022) with the juggling of responsibilities putting a strain on a carer’s personal well-being, work-life balance, and interpersonal relationships. Additionally, the emotional exertion involved in this role can lead to both tangible and intangible challenges, such as decreased earnings, diminished physical and mental well-being, and a decrease in overall life satisfaction (Petrillo & Bennet 2023; Stuart et al, 2020).

3.1.3 Sociological interpretations of caregiving

Outside of policy and health/social services literature, the concept of a caregiver being separated from family or kinship is unusual. Particularly in the global south where caring for the sick and disabled is viewed as a part of life, as opposed to extra labour, kinship caring conceptualisations are more prevalent. Anthropological studies on caring specifically are relatively few, but ethnographic accounts of suffering and illness have explored the meanings of caring for an ageing, disabled or sick relative and the embeddedness of caring practices in kinship and other social networks. This body of literature is concerned with exploring the social and cultural meanings pertaining to caring and the implications the act of caring for ageing individuals or those with long-term conditions has on the individual, family and the wider community.

The sociological contribution to understanding the concept of carer tends to err towards deconstructing the assumed notions surrounded caring (Salder and McKevitt, 2013). Rather than the medical or policy understanding, sociological understandings of carer ask wider questions; in this piece of work these questions focus on policy literature and power. Most of the early sociological work into caring came from a feminist perspective – with 1970s and 1980s feminist thinkers challenging the assumption that caring is a natural pursuit for women (Finch, 1990). Critiques of feminist thinking tend to highlight the amount of caring done by men.

Some take a Foucauldian understanding towards caring, arguing that that the category of carer is also a site of power (Winch, 2006); with carers acting as both the surveyor, and under surveillance by the community, family, and medical field for example. Through discursive analysis of carers portrayals in policy and evidence-based practice, Heaton (1999) traces the changing discourses shaping the growing visibility of the category of the ‘carer’ in UK policy documents, arguing that this has arisen from the ‘devolution and extension’ (p. 773) of the medical gaze focusing on the surveillance of populations from hospital to community care.

Attempt #3

I was 12 and was desperately attempting to use the internet to understand how to fit a lock on a door. Not in the 'fun teenage, don't go in my room mum', kinda way. In the 'oh my goodness the police have broken down the door to get my sister in a mental health crisis' way. I was 12 the first time I felt trapped by caring for someone. That I couldn't escape whatever this metaphorical prison I was building for myself by being reliable, by proving to services I could do it alone, so they stopped helping. I was 14 when I considered myself both a carer and a custodian having never consented to being either for my sister.

She felt I was her prison warden, making her take medication, letting the police into the house, calling the crisis team when I couldn't cope. I felt she was my monarch and I her ever faith and devoted servant. Together we were building a fragile castle, both sitting on thrones of our own making.

This thesis adopts a sociological understanding of caring and caregivers; attempting to critically deconstruct the notion of the 'carer' as an assumed subject; instead drawing on sociological concepts of identity, interaction and knowledge possession. Past sociologists such as Allen (2000) examined how carers negotiated care on hospital wards, revealing the range of relationships and interactions that carers had. Allen developed the concept of the 'expert carer' who had long-standing caring ties and experiential knowledge of the patient. I will be drawing on this idea in the following literature review.

3.2 Mapping mental health carer involvement in research and policy making

Our current constructions of carer are limited to traditional academic fields and knowledge types and there are very few 'carer led' definitions and conceptualisations of caregiving. Thus, the question for this literature review became one of identifying where carer led working in mental health is happening. For this reason, I turned to lived experience, co-production and Patient Public Involvement literature, as a space where centring carer knowledge may be happening.

Actively involving patients and the public in research is increasingly recognized as necessary to ensure outcomes are relevant and beneficial to the people most likely to be affected by them. This is reflected by increasing awareness of the role of Patient and Public Involvement (PPI) in research. PPI is usually defined as research 'with' or 'by' members of the public rather than 'to', 'about' or 'for' them (Carroll et al, 2022). This definition was originally developed by the advisory group INVOLVE but more recently the NIHR definition of PPI has moved away from separating 'patients' and the 'public', now referring to PPI as public involvement in research (NIHR, 2021).

Patient and public involvement (PPI) has long been argued to improve the way research is designed, undertaken, communicated and adopted by policymakers (Brett et al, 2014); with the aim of PPI being to democratise healthcare and challenge the dominant authority within healthcare decision-making. The emphasis on "partnership and collaboration in the research process between researchers and those affected by the research," (Macaulay et al, 2011, p46) is what underpins PPI work in the UK mental health system.

Attempt #18

I was 14 when I first heard the expression 'we can't help you if you don't help us.' I was sat in a ward round, my sister an inpatient in an out of area place a 5-hour train journey from our parents' house. I'd taken the train, feeling a sense of smug satisfaction that I'd done it alone.

I was flattered when her mental health nurse asked my opinion on should be allowed in her. It felt good being treated like an adult by her psychiatrist who asked me her responses to different medications. I held the perceived faith these adults had place in me like a prize compliment. It didn't matter I was child they wanted ***my*** *thoughts on how to treat my sister. What would help, what their next steps should be. I was 23 when I reflected, on the adultification I was undergoing by every person who was over impressed by my ability do it all alone. I was 24 when I considered dark sides of shared decision making and co-production. I can appreciate the differences between co-producing care and co-producing knowledge.*

Co-production has been viewed as an umbrella term (Verschuere, Brandsen & Pestoff, 2012) for the varying PPI and involvement work in the mental health field. It covers a wide range of terms and 'co'-words (Bovaird & Loeffler 2013) which tend to be ambiguous in definition, being applied inconsistently to a range of contexts, activities, and actors (Nabatchi et al, 2017). This inconsistency has led to co-production being deemed slippery and a woolly or muddled concept (Osborne et al, 2016; Nabatchi et al, 2017).

The practice of Patient and Public Involvement and the subsequent evidence base is still emerging with the reporting of quality of and impact varying in consistency (Staniszewska et al, 2012). Given there is not one set definition of PPI (Brett et al, 2014), understanding of the goals and value of PPI vary depending on the researchers' and policy makers' individual and system-wide understanding of its impact; whether it lies in the technical process to improve the effectiveness, accountability, and feasibility of research, or the importance of democratic rights and empowerment, or something as simple as to challenge what constitutes evidence (Boylan et al, 2019).

Researchers are increasingly being held to account to involve non-researcher contributors in their research and to provide accurate reporting of the nature of this involvement (Price, Schroter, Snow et al 2018; Locock et al, 2017). As a result, research teams increasingly structure the research process. To be inclusive of various patient and public involvement strategies, such as advisory, expert or stakeholder meetings, in order to ensure the inclusion of alternative perspectives within the design, production and dissemination of research.

Whilst carers are included in mental health research and policy making involvement activities, it is rare that carers' views are differentiated from service users; "it is easy to assume that the involvement of carers in research follows exactly the same course as involvement of service users and that the same practices apply to all groups," (Davies and Nolan, 2003 p.3). Simpson & Repper (2011) highlighted the ways in which carers hold different motivations, barriers, and challenges to getting involved in mental health research and policy work. Thus, it is important to learn and identify how mental health carers can be optimally involved.

There are sizable amounts of literature detailing the benefits and disadvantages of service user involvement in research, policy making and practice design (Wallcraft et al. 2003, Tait and Lester 2005, Lewis 2009). But there is little to no literature discussing inclusion of carers in research, practice and policy design. In fact, it is important to note that, in the vast majority of government policy, academia, and practice guidelines when discussing experts by experience and experiential knowledge, reference is made almost exclusively to the service user – or person with direct experience of mental distress – and very rarely refers to the carer.

3.2.1 Aims of the literature review

The aim of this scoping review was to explore mental health carers' knowledge as opposed to lived experience, being used in academic research. This was investigated through the presence of mental health carer involvement in co-production and PPI activities in UK mental health research and policy making activities. This aim was generated through conversation with the critical friends on the study who highlighted this body of literature as a space where carer knowledge may be, not only identified, but drawn on specifically. Thus, the aim of this scoping review was not to consider studies done *on mental health carers*, but to consider studies and policies that have been designed and driven *by and with* mental health carer knowledge at the centre.

The objectives of this scoping review are as follows:

i. To understand the range of mental health research and policy that carers as co-producers are present in

ii. To make clear where and how mental health carer knowledge is present in research and policy making in the mental health field

iii. To understand how mental health carers as co-producers are being reported on in academic research and policy making

iv. What co-created, co-produced or co-designed approaches in mental health care have been inclusive of caregivers and is described in the literature

Diary Extract 4

I can't be the first person asking these questions, right? I mean lived experience and involvement stuff in mental health has been going on for ages. I took part in that one study with Nic but then she didn't report my involvement? Everyone says being a carer counts, is welcome, but are we? We are in social care (ish) but in mental health?

3.2.2 Methods

The aim of the review was not to produce any critically appraised evidence on mental health carers' involvement, but to map out the ways in which mental health carers are involved in UK mental health policy making and research.

This review was conducted according to the Joanna Briggs Institute (JBI) guidance for conducting scoping reviews (Tricco et al, 2018) This framework builds on the methodology outlined by Arksey and O'Malley (2005) and Levac et al (2010) who state that scoping reviews intend to provide in-depth coverage of available literature, identifying four common reasons why a scoping review may be undertaken.

According to this framework, thus, there are six stages to conducting a scoping review:

i. Identifying the research question

ii. Identifying relevant studies

iii. Selecting studies

iv. Charting the data

v. Collating, summarising and reporting the results

vi. Consulting with relevant stakeholders

To be included in the review, relevant articles and policy documents needed to be based in the mental health or mental health social care fields, explicitly report on mental health carers presence in PPI or co-production in the study, be based in the UK and published post 2013. Commentaries, calls for papers, book reviews, presentation transcripts, and thesis and things not written in English were excluded.

3.2.3 Search strategy and extraction

Scientific journal articles were obtained for this review by using the Medline (PubMed), PsycINFO, CINAHL, MEDLINE, Cochrane Library and Social Work Abstracts/Social Services Abstracts. The search terms used are detailed below and were chosen from reviewing common terms used in studies identified through the preliminary literature search. Search terms covered four categories which were combined using Boolean operators. Following a search in two databases, additional criteria were applied to filter out physical illnesses, ages, and settings such as nursing homes. The search took place in 2021 and was updated in 2023. The search was limited to academic articles and local and nation policy documents, written in English published after 2013.

A staged strategy of reviewing the search findings was used, where initially the duplications were removed, followed by screening titles for relevance. The abstracts of the articles left from the title screen were reviewed, and the full texts were read of those which remained.

Search Strategy: Exp PPI/or exp patient participation/ or exp public participation/ or exp user participation/ or lay participation/ or exp citizen participation/ or exp community participation/ or exp patient engagement/ or exp public engagement/ or exp user engagement/ or exp lay engagement/ or exp citizen engagement/ or exp community engagement/ or exp consumer engagement/ or exp patient involvement/ or exp public involvement/ or exp user involvement/ or exp lay involvement/ or exp citizen involvement/ or exp community involvement/ or exp consumer involvement/ or exp community involvement And Exp Caregiving/ or exp Family Members/ or exp Caregivers/ or exp Family/ or Partner/ or Friend And Exp Mental Health/ or exp Mental Illness

Table 4 Search strategy

The process for selecting articles is outlined in the PRISMA-flow diagram (Figure 1) The records discovered during the database searches were imported into Mendeley and any duplicates were eliminated. A title and abstract screening were conducted, with any discrepancies being included in the full text review. A full text screening followed this, with the screening and selection of studies conducted in conformity with JHI guidelines for performing scoping reviews.

The data extraction was done using an extraction form developed in accordance with the JBI guidelines and the study protocol. The following information was extracted for each included study:

i. Authors
ii. Year
iii. Context of study
iv. Research methods
v. PPI contributors

vi. PPI rationale
vii. PPI methods
viii. PPI format

A narrative synthesis of the findings was conducted according to the guidelines set out by Popay et al (2006). No quality assessment was conducted. To explore patterns and contrasting findings, and further explore the research question, studies were tabulated according to their highest level of involvement, using Sweeney & Morgan's (2009) framework, and the differences in themes were compared. A sub-group analysis of those that primarily used participatory methodology was also conducted to investigate any differences in reporting for those using more 'authentic' coproduction methods. As the review made known the commonality of mental health carers involvement in research, studies were categorized by whether their reports were co-authored by carers, their date of publication, and whether PPI was reported significantly or separately.

3.2.4 Results

A total of 788 studies were identified through database searching. 191 duplicates were removed prior to the title and abstract screening. The title and abstract screening eliminated 289 studies that did not meet the inclusion criteria. After this process, 316 studies remained for full-text review. After the full-text screening, 8 studies were included in the final review (Figure 3). Overall, 93 studies used PPI or did co-production but failed to detail if mental health carers were included among the co-producers. 54 studies were not based in the UK; of these the majority came from Australia, Canada, or Italy. It is noted the Australian papers had carer co-producers often.

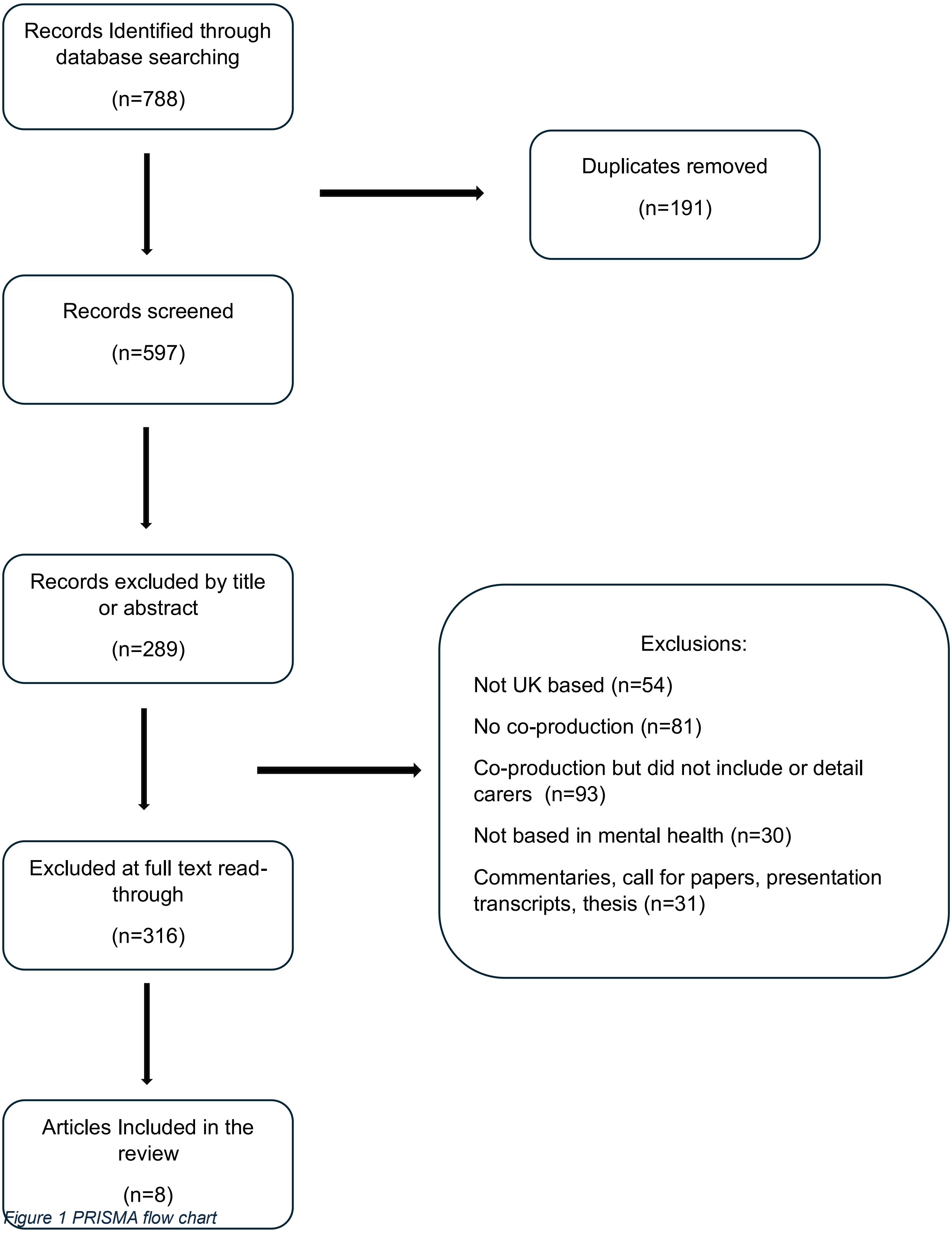


Figure 1 PRISMA flow chart

Researchers	Title	Aims	Methods	PPI Contributors	Rationale for PPI	Methods for PPI
Lobban et al, 2020	IMPlementation of An online Relatives' Toolkit for psychosis or bipolar (IMPART study): iterative multiple case study to identify key factors impacting on staff uptake and use	The first implementation study of a digital health intervention: Relatives Education And Coping Toolkit (REACT), into routine mental healthcare. Our main aim was to identify critical factors affecting staff uptake and use of this online self-management tool for relatives of people with psychosis or bipolar.	A mixed-methods, theory-driven (Normalisation Process Theory), iterative multiple case study approach using qualitative analysis of interviews with staff and quantitative reporting of uptake.	Carers as co-researchers and members of the steering group.	As part of a long-term national strategy to co-develop integrated technology-enabled mental healthcare. NICE recommends relatives be given carer-focused education which ideally should be co-produced	Researcher reflective diaries, developing versions of an implementation plan for the toolkit, Co-facilitated the workshop, analysed data, contributed to the final report.
Raffay, Wood & Todd (2016)	Service user views of spiritual and pastoral care (chaplaincy) in NHS mental health services: a co-produced constructivist	This study shows mental health service users are keen to have spiritual and religious elements to their care. Many regard this as essential to the	A series of interviews were conducted with service users across directorates of a large NHS mental health Trust. Their views on the quality of SPC services and desired changes were elicited.	The research team comprising service users, carers, and staff, explored what service users value	Toward making services truly patient led everything. To keep within the involve recommendations of doing research	Patient and public involvement panel that had carers on. Writing the interview schedule, piloting interviews, deciding which service user groups to target, and

	grounded theory investigation	healing process. NHS services should consider a bio-psycho-social-spiritual model in their aim to provide holistic, patient centred care to their patients	Grounded theory was used with a constant comparative approach to the interviews and analysis.	in their spiritual and pastoral care and what changes they want.		insights for the analysis
Kara (2016)	The value of carers in mental health research	The purpose of this paper is to assess the impact of a mental health carers' research reference group on mental health research in the Heart of England region. The main aim of the evaluation was to assess the impact of the group's work, and to identify any changes that could be made to improve the group's operations. A subsidiary aim	The methodology was a co-produced participatory evaluation, and the research was co-produced by the group. The design involved a literature review of carers' involvement in UK mental health research, and collection of secondary data (group records) and primary data from researchers, group members, and facilitators. Analysis was initially thematic, then synthesised.	Mental health carers are the core research team – for a participatory evaluation of a carers network. A mental health carer acted as the evaluation co-ordinator	Carers can not only offer effective support to the research of others, but also conduct useful research of their own. This indicates that there is scope for carers to make a much wider contribution than at present to mental health research, mental health services, and society as a whole.	The evaluation co-ordinator drafted the research design which was discussed, amended, and approved by the group. The evaluation co-ordinator was given responsibility for collecting and analysing data and drafting the evaluation report which, again, was discussed, amended, and approved by the group. All group members were responsible for disseminating the research.

		was to co-produce the evaluation.				
Gault, Pelle & Chambers (2019)	Co-production for service improvement: Developing a training programme for mental health professionals to enhance medication adherence in Black, Asian and Minority Ethnic Service Users	To identify perceptions of factors enabling or disabling medication adherence. To achieve consensus on content and delivery of an educational intervention for mental health-care professionals.	Using individual interviews and a consensus workshop with carers and service users (SUs treated under the 1983 Mental Health Act 1983/revised 2007 for England and Wales), the experience of taking prescribed mental health medication and perspectives on adherence were explored.	5 carers; 2 male, 3 female 2 Black Caribbean, 2 Black African, 1 Asian	Lived experience can provide a nuance perspective to a complex topic – with a recommendation (supported by evidence of effectiveness) is the use of co-production and "SUs as experts in shaping services".	A consensus workshop with carers involved
Grundy, Walker, Meade, Fraser, Cree, Bee, Lovell, Callaghan (2017)	Evaluation of a co-delivered training package for community mental health professionals on service user- and carer-involved care planning	To investigate the acceptability of a co-delivered, two-day training intervention on service user- and carer-involved care planning	Community mental health professionals completed the EQUIP training and training acceptability scale with follow up data collective through mixed methods	1 carer delivered the training and facilitating group work	To increase the meaningfulness and value of the training	Service user and carer advisory group, as co-applicants on the grant,
Renwick, McWilliams, Schaff,	Stakeholder identified research	To gain consensus on top priorities for research into early	A modified nominal group technique to gain consensus on	1 male carer in stakeholder	Actively involving users (clinicians, service users and	Stakeholder workshop,

Russell, Ramsdale, Morris (2022)	priorities for early intervention in psychosis	intervention in psychosis through a robust, democratic process for prioritization enlisting the views of key stakeholders including users, carers and healthcare professionals.	unanswered questions that were obtained by survey and ranked at successive stages by a steering group comprising users, carer representatives and clinicians from relevant disciplines and stakeholder bodies.	workshop and in the steering group	carers) is now a key criterion for commissioning research from the National Institute for Health Research (NIHR)	
Fraser, Grundy, Meade, Callaghan, Lovell (2017)	EQUIP training the trainers: an evaluation of a training programme for service users and carers involved in training mental health professionals in user-involved care planning	To obtain participants' views on the suitability and acceptability of a training programme that aimed to prepare service users and carers to co-deliver training to health professionals	Semi-structured interviews with nine service users and carers attending the training programme. Transcripts were analysed using inductive thematic analysis.	Four carers (three female; one male) delivering and evaluating the training programme. 8 carers on an advisory capacity	The EQUIP programme was developed to build on policy initiatives and guidelines which place service user choice and involvement in their own care planning as a central principle for improving quality of care and enhancing recovery	EQUIP Service User Carer Advisory Group (SUCAG), one carer on the grant application
Berzins, Baker, Brown,	A cross-sectional survey of mental health	This study aimed to identify safety issues as	A cross-sectional online survey was distributed via social	Not Stated	Not Stated	Carers acting as critical friends and providing feedback on

Lawton (2018)	service users', carers' and professionals' priorities for patient safety in the United Kingdom	described by people in the United Kingdom identifying as mental health service users, carers and professionals.	media. Identified safety issues were mapped onto the Yorkshire Contributory Factors Framework (YCFF) which categorizes factors that contribute to patient safety incidents in general hospital settings. Service user and carer responses were described separately from professional responses using descriptive statistics.			survey questions, feedback on study design and recruitment

Table 5 Data extraction results

3.2.5 Study aims

The studies included in the review had a variety of aims; with two distinct categories (1) studies about mental health carers involvement; (2) studies that included mental health carers in their co-production. Studies which focused on something related to carers specifically included Lobban et al (2020) who were investigating uptake issues in a digital support intervention for relatives of people living with psychosis or bipolar disorder and Kara (2016) whose study was carer-led and focused on assessing the impact of a mental health carers research reference group.

Studies which involved carers but were not focussed included: Renwick et al, (2022) who aimed to gain consensus of research priorities around psychosis, Berzins et al (2018) who aimed to identify safety issues as described by a range of mental health stakeholders, and Gault, Pelle & Chambers (2019) who looked at adherence to medication for BAME mental health service users. All these studies did further PPI work which carers were involved in, but their opinions were not centred.

The studies by Grundy et al (2017) and Fraser et al (2017) were both drawing on the same data set – the EQUIP training study which co-designed and delivered a training programme for mental health professionals to improve user-involvement in care planning. Each study reported on different aspects of this programme with Grundy et al (2017) reporting on the evaluation of the training programme itself and Fraser et al (2017) reporting the results of the subsequent evaluation in the ‘training the trainer’ section of the programme.

Diary Entry 22

It seems like studies which involved carers rather than just investigating their experiences are limited… obvious thought Cassie. But also why are they so lacking? Are carers just not respected as knowing? Or they just further back in the journey for respect from classic knowers? Are we actually just a group of idiots? Nope… well? Maybe me? I’m an idiot.

The wide range of aims and objectives in the studies illustrates the breadth and complexity of carer knowledge in the mental health system. That being said, the lack of overall studies which involved cares speaks to how caregiving literature is yet to differentiate between investigating carers lived experience and positioning carers to do lived experience led research. Consulting multiple carers, and seeking diversity of experiences, was recommended; “as there is not a single view held by carers but multiple perspectives” (Kara, 2016, p89).

3.2.6 Number of carers

The number of carers doing PPI in each study varied but was lacking in the reporting – with studies often saying they had carers involved, with little extra details. Three studies in the review stated the number of mental health carers that took part in involvement activities in their study: Renwick et al (2022) had 1 male carer, Fraser et al (2017) had 4 carers involved in the delivering and evaluation of the programme, and 8 carers on board in advisory capacities, and Gault, Pelle & Chambers (2019) had 5 carers, 2 male and 3 female.

The remaining 5 studies did not mention the number of carers involved as co-producers in the manuscripts; instead mentioning carers as co-producers or part of the research team in overarching statements such as this one from Raffay, Wood & Todd (2016):

“In this research, the research team comprising service users, carers, and staff, explored what service users value in their spiritual and pastoral care and what changes they want.” (p.2)

During the full text read through for the review it was noted the lack of manuscripts – both included and not included in this review – which failed to detail any numbers of co-producers/people doing PPI.

3.2.7 Format of inclusion

Findings from this review further illustrate that, where carers are involved, it is not in any novel or caregiver specific methods; tending to stick with stakeholder, expert, or advisory panels, or as co-researchers/deliverers. The language used in discussion of carer involvement tended to err towards PPI rather than using 'co-words.' In the same way that carers are well-placed to understand the needs and preferences of participants, researchers achieved convenient involvement by designing this with carers themselves, either through consultations prior to the project or allowing the group to determine times, location, length of meetings (Garner & Fauchner, 2014, Watson & Fox, 2018). Because of the variety in caring role requirements, "no one size fits all," in terms of the best means of involvement, and therefore offering multiple ways carers can contribute to research may be the "optimum strategy" (Banfield et al, 2018, p1226).

Diary Extract #76

Are advisory groups a good thing anyway? Obviously they are as the ensure the lived experience voice is present blahh blah. But also…. But also are we not keeping their knowledge and involvement in formats which maintain academic oppressive practice? But peer research also won't fix that issue because its forces people with lived experience to position it as something useful for 'norm' or 'traditional knowledge.' Why am I scrambling to try illustrate validity in carers experiences within our current system when the system is violent and benefits from staying that way?

Some studies invited carers to do some of the writing up and dissemination of data – something rarely seen in the literature (Kara, 2013). Mental health carers as co-authors in the academic writing up was present in Lobban et al (2020) and Kara (2016). Where innovative involvements methods were present, it was in the carer specific-led research done by Kara (2016) who had carers leading every part of the study, including being the evaluation co-ordinator and placing responsibility with each carer in the research team to disseminate data through their chosen means. Lobban et al (2020) encouraged carer researchers in keeping researcher diaries which provided valuable data for the reflection – something unique to their piece of work. Further, they invited carers and carer researchers to be involved in the development and implementation plan of the digital intervention, to co-facilitate workshops, analyse data and contribute to the final write ups – indeed one of the authors of the paper included in the review is a mental health carer.

3.2.8 Rationale for inclusion

It was expected that the rationale for including carers in PPI work would reflect the national picture emerging for doing inclusion i.e. the increased emphasis on "partnership and collaboration in the research process between researchers and those affected by the research," (Macaulay et al, 2011, p46.) to improve the research process, outcomes, and validity, as well as empowering an under-represented and underserved group (Lammers & Happell, 2004,).

In actuality, the reasons for doing PPI inclusive of carers varied within the literature. Studies which appeared to engage in power and political discourses tended to be motivated to do PPI and/or co-production work for human rights reasons, ensuring no decisions are made without the inclusion of people who are impacted by the phenomena. Kara (2016) argues for carers as effective stakeholders in supporting research and argues for that carers indicate a capacity to ‘make much wider contributions than at present to mental health research, mental health services, and society as a whole.’

Some of the studies involved in the review did PPI work as a way of gaining the lived experience perspective to a complex topic.) included 5 carers in their consensus workshop on examining medication adherence for BAME mental health service users. They refer to having service users present as experts to shape the services they interact with and having carers present to provide different perspectives on the topic. Both studies drawing on the EQUIP data allude to, similarly, centring the lived experience voice as imperative to the topic being studied – in this case, improving quality of user and carer involvement in care planning.

Diary Extract #78

I kinda think and stay with me here, maybe people should be included cause it is simply the right thing to do? What a hot take, Cassie. I guess what I mean is, if doing PPI is now essential for funding and in some cases publishing then are people doing it because it is the right thing? Or because it is necessary for their careers? Am I being harsh assuming most researchers don’t actually care or maybe it is more they have so many things to care about? But then that isn’t good enough.

Alternatively, now the NIHR have mandated PPI involvement in projects to some extent by 2025 (2015) the rationale for doing inclusion work in some of the papers presented in this review was around necessity for receiving funding. For example, Renwick et al (2022) write that ‘actively involving users (clinicians, service users and carers) is now a key criterion for commissioning research from the National Institute for Health Research (NIHR)’ (p.2961). Similarly, Raffay, Woof & Todd (2016) noted that their reasons for having a patient public involvement panel was to keep within the involvement recommendations of doing research. This finding correlates with the work of Price, Schroter and Snow (2018) who, in their review of PPI reporting in BMJ, found that there was an increased proportion of papers documenting PPI activity subsequent to the implementation of a policy mandating the inclusion of this information. However, it is important to note that the level of reporting PPI remained low both prior to and following the implementation of said policy.

3.2.9 Reporting

This review of 8 papers illustrates the frequency of reporting of mental health carers involvement in UK mental health research and policy. The majority of included papers demonstrate that reporting of carer involvement is patchy in terms of its reporting, with 2 studies reporting carers were involved but without detailing the numbers of involvement activities they took part in. This inconsistency in reporting has been previously highlighted, showing that PPI is hampered both by inconsistency in terminology and in consensus on reporting methods (Price et al, 2017).

Only Gault, Pelle and Chambers (2019) reported in detail the carers’ ages, ethnicities and genders, including 2 Black Caribbean, 2 Black African, and 1 Asian mental health carer taking part in their study. Fraser et al (2017) reported gender differences in their sample of carers doing PPI in the study. All other studies in the review only reported the number of carers involved. This additional information provides more validity and depth to the reporting of the involvement itself, as well as the applicability of the results of the study.

In terms of reporting the involvement activities, the majority of papers included in the review included this information in the methods section or a sub methods section of the manuscripts, with Renwick et al (2022) having a section entitled Steering Group Initiation and Survey Development where they detailed who was in their steering group and the scope of their involvement. Where doing co-production was a direct aim of the papers, however, there tended to be more detailed reporting of what took place, at what points through the study and who was involved, often with its own dedicated section within the manuscript.

3.2.10 Acknowledgements and thanks

Of the papers included in the full text read through, a number included references and thanks to PPI contributors, despite not mentioning them throughout the paper itself. These papers could not be included in the review as they did not mention any carer involvement in the main text of the study. Alternatively, and additionally, the full text read through showed a number of papers which mentioned PPI contributors in the main text but then failed to give them specific acknowledgment later in the paper. This was common in manuscripts where organisations were mentioned as collaborators in the acknowledgements while individual collaborators were not.

Diary Extract #80

Does being in the acknowledgements count for anything? Maybe young people who could use it for their CV or university application but otherwise? I always thought acknowledgements were just were academics had to thank random people to stop rifts appearing?

3.3 Discussion

The importance of involving mental health carers in research and policy making has been recognised in the UK (Kara, 2016) but little emphasis has been placed on why and how. Thus, this review may give an indication of the current practises and types of topics that carers are being invited to contribute to in the mental health space. This knowledge may also provide an insight into the impact of PPI with mental health carers and how it is commonly reported. Previous research scoping PPI in research has found that 51% of the 182 studies included in their review included some sort of PPI (Mathie et al, 2014) – although notably this study was not limited to the mental health field. There are a number of studies that I personally have been involved in as a carer expert which are not in the review and upon text searching did not report the involvement either not in enough detail to research the review criteria or not at all.

Due to the scarcity of literature which specifically names mental health carers as being involved in research, there were relatively few publications in this review. There is substantial variation in the quality and content of reported PPI in the literature, with limited methodological guidance for ways to initiate, sustain or report public involvement in research (Concannon et al, 2014). Analysis revealed, however, that a higher proportion of papers reported PPI including carers in more recent years – it could be argued this is due to PPI being mandated both in funding applications in the UK and in some journals reporting such as *BMJ* who added a requirement to report PPI involvement in publication (Price et al, 2018).

The absence of information about PPI in research papers is not solely due to a lack of reporting requirements but a lack of PPI activity in practice or unwillingness to report unsuccessful PPI. Indeed, Tarpey & Bite (2014), in their comparative analysis of PPI done for NIHR Involve, found that the rate of planned PPI in research submitted to the UK's NRES was 78% in 2012, but often research is not always conducted as planned. Therefore, it is vital to evaluate the extent to which planned PPI gets implemented in practice, versus when it is planned and fails to be impactfully implemented.

The review conducted finds that little attention was reportedly paid to figuring out the best methods of facilitating involvement with mental health carers. Early work by Rower and

Frewer (2005) suggested that minimal attention has been given to assessing the effectiveness of different methodologies that engage experts and stakeholders in policy and research processes. Their research goes on to argue that it is assumed the methods of involvement being used are ideal and/or fit for purpose, when there is little evidence to show this. This review shows similar evidence around mental health carers' engagement in research and policymaking as experts, with no evidence available around best practice methods for involvement with mental health carers. In an ideal scenario, this review provides the basis for a potential framework for determining the most suitable methods to address specific types of policy questions when working with mental health carers. Subsequently, it would be possible to establish recommendations and guidelines pertaining to the implementation of stakeholder involvement exercises.

The lack of studies in this review which mental health carers knowledge as something of individual importance – rather than as important among other stakeholders – speaks to the lack of understanding of a carers as a social group, and caregiving as knowledge granting experience. The lack of theoretical and academic understanding of carer knowledge is reflected in the PPI and co-production literature, which shows carers as an additional extra rather than a core component of knowledge making within mental health spaces. Mental health service users, survivor research, and service user research has an established academic prowess within the PPI space, however mental health carers are lacking in this meaning, despite being a unique group, often lumped into 'public' within involvement.

The studies in the review highlighted that building enduring, trust-based relationships with the individual's providing care was identified as a crucial factor in fostering effective PPI. These relationships offer benefits such as enhanced transparency and open communication among carers and mutual learning (Lobban et al, 2020; Banfield et al, 2018).

This review recognises that many studies rely on analysing existing datasets or linking data from different sources. As a result, it is understood that that it may be more difficult to directly involve mental health carers in the research process for these types of studies. However, I strongly believe that there is still a potential for incorporating patient and public involvement (PPI) even in these circumstances.

3.3.1 Where is the policy?

The most comprehensive policies promoting carer involvement in service user care and policy making have been found in the United Kingdom (Javed & Herman, 2017; Buckner & Yeandle, 2015). The UK Care Act 2014 stated that all carers are entitled to an assessment of their support needs with eligible needs met, although limited funding has prevented translation into practice (Fernandez et al., 2020). The National Institute for Health and Care Excellence (NICE) (2020) providing extensive guidance on ways in which services should be identifying, working with mental health carers in patient care. This includes offering them training, supporting and a wide range of information. In mapping this review the range of policies and statutory guidelines were examined.

Guidelines from both the National Institute for Health and Care Excellence (NICE) and the Social Care Institute for Excellence (SCIE) were read though were they pertained to mental health carers. However, none of the guidelines reported any involvement in their documents. Both institutions have web pages detailing the ways in which their guidelines are co-produced, including interacting with third sector stakeholders, academics, policymakers, and people with lived experience, but none of this is detailed within the actual guidelines documents. I, personally, have taken part in the design groups for NICE's updated guidelines around suicide and self-harm as a lived experience expert, but that involvement is not reported. Even further evidence is the work of Harding et al (2010) who examined service users' perceptions of being involved in the NICE guideline process and who found that service users viewed their 'expertise' as not necessarily idiosyncratic or narrow (p.8) but a basis for critiquing what is useful and constructs as appropriate 'health goals.'

Diary Extract 88

Is the issue actually in reporting involvement? Is it not reported because people do not want to be associated with policy documents where they feel their lived experience is not accurately reflected and listened to? Or is their involvement not being reported because the writers are not interested and don't see the value? Would reporting guidelines be helpful? Or would the writers inevitably just fill in what they need to, to get the work published? Does there need to be some sort of lived experience impact assessment asking how has lived experience shaped this document? Kinda like an equity impact assessment?

No that's a bad idea.

The only policy which directly stated in the document the ways mental health carers were involved within its design was the Triangle of Care (Worthington et al, 2013) detailed below.

3.3.2 Triangle of Care

The Triangle of Care is a '4-stage' policy. It was a collaborative piece of work between stakeholders in mental health caregiving and provides a set of guidelines and standards toward the aim of helping services move into a carer-inclusive culture where communication, shared decision-making and confidentiality are all agreed between the caregiver, the professional and the service user. This policy launched in 2013 and is a co-produced piece of work between Carers Trust (charity), the National Mental Health Development Unit, and mental health carer 'experts by experience' (p.3). The policy was developed as a best practice guide for use in acute mental health care unit but was expanded for use in all secondary mental health care services. The policy comes with the Triangle of Care Self-Assessment Tool – an audit survey designed to assess how well, if, and where the policy intervention is working to a satisfactory condition.

The Triangle of Care was generated for use by mental health services to illustrate how to effectively collaborate with and integrate the carer and the patient into mental health care. The policy self-describes as 'a therapeutic alliance between service user, staff member and carer' (Worthington et al, 2013, p.3). Its target audience includes mental health care services, carers involvement services, and commissioning groups. The Triangle of Care dictates that everyone in the care process should be valued the same - that experiential knowledge should be drawn upon as equally as the knowledge of the practitioners and the service user.

The 6 principles of the Triangle of Care are as follows:

(i) Carers and their essential role are identified at first contact or as soon as possible afterwards

(ii) Staff are carer-aware and trained in carer engagement strategies

(iii) Policy and practice protocols re: confidentiality and sharing information are in place

(iv) Defined post(s) responsible for carers are in place

(v) A carer introduction to the service and staff is available, with a relevant range of information across the care pathway

(vi) A range of carer support is available

3.4 Gaps in the literature

Despite the existence of the Triangle of Care (2013) proving a policy foundation for the importance of carer involvement, this has not translated into healthcare practice (Clibbens et al, 2019) or research, policymaking, and service design/improvement practice. Carers are systematically excluded from a wide range of care decisions including admission (Wyder et al, 2018), therapeutic engagement (McAllister et al, 2021); therapeutic leave and discharge planning (Barlow and Dickens, 2018; Petkari et al, 2021).

What is more, as evidenced in this review, carer participation in involvement activities for research, policy making, service design/improvement is limited despite ongoing emphasis of its significance. Carer involvement in staff education in health and social care is common.

This review revealed three key findings where the academic literature are lacking:

(i) Lack of theoretical, epistemological, and methodological foundations to carer experience – carers are lacking in theoretical and epistemological foundations which situate their knowledge and themselves as knowers. Instead, carers knowledge is forced to mutate itself to fit service user lived experienced epistemologies despite significant differences. When compared to other more established lived experience literatures, such as mental health service user/survivor literature. Little effort has been made to investigate and understand mental health carer experiences as foundation for knowledge. This gap shaped the thesis questions and direction the most.

(ii) Lack of carer specific methods for doing involvement - this literature review lacked any innovative methods for doing involvement work with carers specifically, sticking to classic methods such as advisory boards and in rare cases peer researchers. It hypothesised the lack of carer specific guidance and methods for doing involvement and platforming carer knowledge is due to the lack of a foundational understanding of why carer involvement is important and can make significant contributions to mental health research and policy making.

(iii) Minimal understanding of what contributes to mental health carers knowledge and expertise and how holding that knowledge influences their contact with different social worlds.

This study explores mental health carers' identity formation and its interplay with caregiving tasks and knowledge formation from the perspectives of the carers themselves. This exploration was guided by a constructivist grounded theory approach (Charmaz, 2005, 2006) which suggests that the aims of the study continued to evolve and change as meaning was generated through the data gathering process.

Drawing on the literature review, the self-interviews from the autoethnographic part of this work, and conversations with the critical friends, the aims and objectives of this research project were narrowed down to the following:

To qualitatively investigate mental health carers conceptualisation the role within their wider sense of self and make sense of the knowledge making processes to understand their space within lived experience paradigms.

i. To investigate how mental health carers make sense of what constitutes their caring role and its place within their sense of self
ii. To understand the role being a carer plays on mental health carers knowledge.

iii. To learn how and in what spaces mental health carers currently do and would like to apply their knowledge.

Interlude 3

Take, for instance, you

Take, for instance, me

Take, for instance, the word instantly

And before you it was used to describe porridge and soups and coffee

And before this it was used to illustrate a love at first sight

But now they use it to sum up your life

They tell me you died

Instantly

4 Study design or Is this a story worth telling?

Attempt #27

By the time I was 15 I considered myself expert in this. Call ambulance, text care coordinator, text parents, look up what coursework was nearest due and prioritise getting it done, cancel on my friends for whatever sketchy alcohol consumption in woodland was occurring. I was 15 and holding vomit covered pills in my bare hands. It's easier for doctors to treat an overdose patient if they know the medication, and somewhere on the surface of my brain I knew this. So, I scooped up the vomit covered pills shoving them under the faces of disgusted paramedics. Begging them to save her. Somewhere deeper down I knew they couldn't identify anything from these pills. But if I brought them then I did my job. I was a good carer.

The aim of this chapter is to provide an overview of the empirical methods employed within the study. The data gathering was multi-method using a range of qualitative methods (constructivist interviews, cognitive interviews, participant observations). The datasets consist of 40 constructivist interviews, and 120 hours of cognitive interview/observational data. Each data set was initially analysed thematically before integrative analysis was done. The overall aim was to learn how mental health carers make sense their experiences and its' influence on how they connections to different social worlds and view the experience as knowledge. Each method was chosen to explore set of objectives as seen in the table below:

Constructivist Interviews	Objectives: to investigate how mental health carers make sense of what constitutes their caring role and its place within their sense of self.
Cognitive Interviews/Observation	Objectives: to understand the role being a carer plays on mental health carers knowledge. To learn how and in what spaces mental health carers currently do and would like to apply their knowledge.

Table 6 Aims and objectives of each phase of empirical data gathering

4.1 Constructivist Interviewing

The first form of data collection used in this study was in-depth constructivist interviews with people who identified as *'supporting someone with their mental health.'* Interviews were conducted in line with grounded theory's recommendation of 'theoretical sampling' (Glaser, 1992). Charmaz (2001) notes that "in- depth qualitative interviewing fits grounded theory methods particularly well" (p. 676). Charmaz (2001) further indicates that:

The interview can elicit views of this person's subjective world. The interviewer sketches the outline of these views by delineating the topics and drafting the questions. Interviewing is a flexible, emergent technique; ideas and issues emerge during the interview, and the interviewer can then immediately pursue these leads (p. 676).

In constructivist interviewing, the interviewee is centred in the entire interview process. Constructivist interviewing acknowledges the interview to be a meaning-making experience for all involved and a place for knowledge production through the active collaboration of the interviewer and interviewee (Hiller and DiLuzio 2004, p3). This interview method is defined by the establishment of a 'human-to-human relation with the respondent and the desire to understand rather than explain' (Fontana and Frey 2005, p706).

Constructivist interviewing was selected over interviewing styles such as Interpretative Phenomenology for a range of reasons including the focus on interviewees ability to hold multiple realities and constructing shared meanings (Burns et al, 2022). Further, constructivist interviewing places emphasis on the interviewee being proactive in the interpretation of the phenomena investigated and the researcher must rely upon their interpretation (Creswell 2003, p.8). This is intimately related to what Denzin and Lincoln (2005) describe as constructivism's subjectivist epistemology, in the sense that knower and respondent are co-creators of understandings (Denzin and Lincoln 2005). Given this piece of work is drawing on autoethnographical approaches and my lived experience, constructivist interviews as a space meaning making led by the interviewees seemed ideal. What's more a constructivist approach is very well-suited as a method for change in social justice research especially where the researcher's interaction with interviewees is a necessary ingredient for deriving innovative understandings and theories (Miller, 2016).

It has been conventionally expected for interviewers to exercise caution when formulating questions, ensuring their neutrality and lack of direction. This serves to prevent any potential bias or influence from interfering with the interview process (Gubrium and Holstein 2003, p31). As a result, interviewers have been required to maintain a certain level of objectivity and refrain from injecting their personal perspectives into these interactions.

The interview, however, is not an unproblematic, neutral tool, but an unequal, unbalanced, asymmetric experience that sees the interview itself, interviewer, and interviewee as historically and contextually placed as the one who gains as well as the one who "holds" the knowledge to bring together both the conscious and unconscious motives, desires, feelings, and biases of both parties taking part. Researchers are urged to be reflexive about what the interview accomplishes as well as how the interview is accomplished, and therefore the way that text is created. As mentioned in chapter 3 on reflexivity, reflection, and researcher positioning, I have identified how, during the research process, I acted in a reflexive manner.

During the interviews, interviewees were able to freely discuss and reflect on their individual situations. Interviews were conducted to be "active interactions between two (or more) people leading to negotiated, contextually based results" (Fontana & Frey, 2000, p. 646). Interviews flowed according to the thought processes of the participants and were not always dictated by the semi-structured or 'aide memoire' interview guide with my position as an insider to 'communicate with people to create stories" (Nunkoosing 2005, p698). In grounded theory, constructivist interviewers are considered "part of the world we study and the data we collect… [and that] … we construct our grounded theories through our past and present involvements and interactions with people, perspectives, and research practices" (Charmaz 2006, p10).

4.1.1 The sample

Sandelowski (1995) recommends that qualitative sample sizes are large enough to allow the unfolding of a 'new and richly textured understanding' of the phenomenon under study, but small enough so that the 'deep, case-oriented analysis' (p. 183) of qualitative data is not precluded. 25 interviews were the aim of the recruitment as it was suspected a wide enough range of carers in terms of caring relationship and diagnosis of the care recipient being a mixed between common mental disorders like depression and anxiety, and severe mental illnesses like schizophrenia and depersonalisation disorder. Ritchie et al (2003) suggest that studies employing individual interviews conduct no more than 50 interviews so that researchers are able to manage the complexity of the analytic task. For this reason, when 40 interviewees had been interviewed recruited was cut off to ensure the dataset did not become so big it was unwieldily.

The interviews typically lasted 1 to 1.5 hours on Zoom or MS Teams and were recorded and transcribed (Bryman and Becker, 2012) before the recording was deleted and any identifiable information removed. This information included but was not limited to names, locations, medications, dates and media appearances. Interviewees received an information sheet prior to the study. If they had any questions, these were answered via email or in a 1:1 conversation with the researcher. Written consent was gained before the interviews took place and verbal consent was gained before and after the recording was started. In the first phase of the study, 40 interviews occurred with 32 completed data sets being generated. Data sets were considered complete if the interviewee answered all of the questions and/or did not end the interview early. Interviewees were compensated £25 in the form of bank transfer, charity donation, or vouchers. These options were given to provide as much choice as possible.

Demographic	Type	# of participants
Gender	Woman (inc: trans)	19
	Man (inc: trans)	13
	Non-Binary	5
	Other	3
Age	18-24	6
	25-35	14
	36-46	11
	47-60	5
	60+	4
Care recipient identity	Parent	14
	Child	5
	Sibling	6
	Partner	11
	Grandparent	2
	Friend	1
	Neighbour	1
Geographic Location	London	6
	Southeast	5
	Southwest	5
	Midlands	9
	Northeast	8
	Northwest	2
	Scotland	2
	Wales	2
Ethnicity	Asian or Asian British	7
	Black, Black British, Caribbean or African	3
	Mixed or multiple ethnic groups	5
	White	23
	Other (inc Arab)	2
Sexuality (Trans + intersex included in gender section)	Lesbian	7
	Gay	4
	Bi/pansexual	9
	Queer/Questioning	5
	Asexual spectrum	2
	Other	2

Disability	Long term heath condition	4
	Cognitive or neurodivergence	7
	Sensory	3
	Mental illness	11
	Physical or mobility	3

Table 7 Demographic information of constructivist interviewees

4.1.2 The pilot study

Kim (2010) argued for numerous benefits of pilot studies within qualitative research: they allow the researcher to make adjustments for the final study and to gauge the feasibility of the research design, and aid Early Career Researchers in learning vital skills for conducting interviews and analysing data. For this reason, and at the recommendation of the ethics board, a set of three pilot interviews were completed in this research study to ensure the narrative interviewing approach would be effective in achieving the aims of the project and to determine the directions that conversations were likely to head in. The pilots also allowed more practical components of the interviews to be explored, such as estimating the potential length and ways to plan for and mitigate risks of harm.

Sampson (2004) argues that pilot studies in qualitative research are often used in a haphazard way, leading to their benefits being undermined or overlooked. For this reason, particular emphasis was placed on using the pilot study to learn and trial the techniques of narrative interviewing to ensure they were fit for purpose. Furthermore, each pilot interview was conducted to trial and practice specific anxieties I held about the research process; for example, to ensure that the interviewees stayed psychologically safe and that I could trial bias-free language usage as well as to experiment with ways of drawing interviewees into telling longer, detailed stories. I used a research diary heavily during this time to make records of interviewees' reactions to questions and their reactions beyond verbal communication. These learnings were taken into the further design of the narrative interviewing.

Overall, the objective of the pilot studies was to identify any pitfalls in the topic guide and trial and refine the technique of weaving personal lived experiences into a storytelling style interview (Flood-Grady & Koenig Kellas, 2015), as opposed to investigating the topic itself. Constructivist interviews are theoretically positioned to criticise the question-response schema of classic interviews. Through the pilot interviewing experience, leading questions were designed and refined, with input from the critical friends on the project, to help interviewees get into the right mindset for storytelling.

The piloting of the constructivist interviews took place on Zoom in April 2021 with four interviewees. The interviews lasted between 45 minutes and 1.5 hours, with people recruited form my personal network and were purposely sampled due to all having different caring relationships – parent, partner, child, friend. Beyond investigating the objectives aforementioned, the piloting allows for the small sale trial of analysis including narrative sense-making techniques alongside constructivist grounded theory building and coding techniques within the framing of identity, much as McAdams (1993) proposed it is through the organisation of life events into a coherent story that identity is constructed. Lastly, the piloting aided me in learning how to minimise bias in the wording of questions and how to be more transparent about knowledge claims I am making from my own lived experience during the interviews, and in the surrounding observational notes being made, and how to autoethnographically reflect upon them.

Interviewee initials	SW	WL	HD	DFE
Gender	Female	Female	Male	Non-Binary
Geographical Location	Nottingham	Manchester	Kent	Kent
Caring Recipient	Parent	Child	Partner	Friend

Table 8 Demographic information of pilot study interviewees

4.2 Participant observation via cognitive interviewing

Participant observation is widely used in ethnographic qualitative research. It sees the researcher actively participating in the communities they are researching (Creswell, 2013). During a participant observation the research is not a distant and objective observer but, through fieldwork, an active participant in the lives of the culture-sharing group being studied (ibid). In addition, the research setting is the study informant's daily lives, not an objective setting separate from the lives of the participants. Due to my personal involvement in this study through the utilization of autoethnography, I was truly an 'insider' and complete member of the culture of caregiving I was studying due to my extensive personal caregiving experience (Tannenbaum & Spradley, 1980).

Observation of participants can be a valuable data collection tool in educational research as it enables the researcher to learn about participants' actions and the meanings, they attach to them by observing them as they occur (Marshall & Rossman, 1989). Therefore, I undertook observation of my participants to confirm and learn from interview data and investigate any disparities between the actions undertaken by the participants and the meanings they attributed to that situation in previously undertaken constructivist interviews. O'Donoghue (2007) advises that grounded theory researchers should try to note which actions seem to be inconsistent with participants' stated perspectives and to investigate the reasons for these inconsistencies by "engaging them in further 'conversations' to unearth nuances to perspectives which have been misunderstood" (p. 91).

Participant observation provides a different perspective and thus, different data than obtained from the constructivist interviews. The aim of the participant observations was around learning what carers constituted their knowledge and how it was presented and drawn in social change situations. For this reason, the observations were not about witnessing care and caring. Over the course of many years doing mental health caring, I have been in and observed others in various 'natural environments' and I was able to shape this research around that experience (see section 2.1 for more information on the autoethnographic approach).

The participant observations took the form of cognitive interviewing (see section 4.2.1). The method was a mixture of participation, observation, and interviewing (Delamont, 2004) via cognitive interviewing, where the purpose was to observe how participants interact with the project in front of them, as well as me the researcher and me the mental health carer (Atkinson and Hammersley, 1994). Participant observation is a deep investigation of social life and life experience. This process entails becoming involved in the social world of the specific community in order to see and experience how life activities are practised (Lincoln & Denzin, 2003; Lofland et al, 2006).

During the course of the study many opportunities for the researcher to become 'participant as observer' presented themselves, theoretical memos were written soon after the observation period when such opportunities revealed insight into the research area. This fits with Glaser’s (1978) recommendation that the researcher should record all promising ideas as they happen as memos. As noted, often these observations led to further ‘member checking’ to confirm promising theoretical directions in the research. I took note of the positive aspects of providing care they discussed in the face of knowledge sharing about things that presented as negative.

All observation participants were offered a preliminary meeting, provided with a copy of the information sheet and consent form and offered the opportunity to ask questions. They were invited to consult the information sheet with their families, and contact the researcher with any questions, before returning their consent form at the first cognitive interview session.

Constructivist interviews were carried out as part of the observation session which provided freedom for mental health carers to discuss, express, and co-create their understanding of their lived experience outside of the traditional structures of cognitive interviewing. The aim of the follow-up interviews was to learn from mental health carers with experience of involvement activities what motivated them to share their lived experience knowledge with external bodies such as policymakers and academics. The follow-up interviews involved discussions about mental health caregivers’ experiences of involvement activities in mental health academia, policymaking, and service design spaces hosted by local and national government, local and national NHS bodies, charities, and universities.

The discussions were guided by the interviewees’ desire, ability, and willingness to share how they conceptualised the knowledge they had gained through live experience, and if and how they considered and used it in research and policymaking spaces. These interviews were not guided by a topic or interview guide; instead, an unstructured conversation was held, with the questionnaire from the cognitive interview serving as an anchor for the interview.

In particular, it is vital to note that, in the follow-up interviews, the interviewer is not a neutral tool for gathering this data. I tirelessly contributed to the research diary I kept and frequently engaged in reflection activities to identify my emotions and my experiences and separate them from those being expressed by the interviewees.

Observations took place via Zoom or MS Teams and lasted around 2.5 hours with written and verbal consent gained before each observation and done following Norman et al’s (2006) ‘cyclical consent process’ which takes into account alternative methods of communication that participants used to suggest or withdraw their agreement to participation, including physical gestures suggesting agreement, the avoidance of discussions about the research and comments and non-verbal gestures during observation sessions.

4.2.1 Cognitive interviewing

Cognitive interviewing was developed in response to issues around non-response and non-completion of questionnaire questions, which lead to incomplete data sets (Drennan 2003). Cognitive interviewing emerged as one of the most prominent methods for learning, identifying, and adapting survey questionnaires (Beatty and Willis, 2007). It is a popular technique in medicine, education, and health (Willis & Arinto 2013). It uses qualitative methods to investigate where and how survey methods achieved their desired outcomes.

The background theory of cognitive interviewing was first detailed by Tourangeau (1984) and has since been adapted multiple authors including by Willis (1999, 2004). It is briefly detailed below:

(i) Comprehension of the question and survey

  a. *Attention:* How much attention is paid to the instructions of the questionnaire?
  b. *Question intent:* What does the respondent believe the question is asking?
  c. *Meaning of terms:* How do respondents interpret the specific words and phrases in the question?

(ii) Retrieval from memory of relevant information

  d. *Recallability of information:* What type of information does the respondent need to effectively answer the question?
  e. *Recall strategy:* What type of strategies are used to retrieve information? For example, does the respondent tend to count events by recalling each one individually, or do they use an estimation strategy?

(iii) Decision and judgment processes

  f. *Motivation:* Does the respondent devote enough mental effort to the question?
  g. *Sensitivity and social desirability:* Does the respondent want to tell the truth or are they seeking to present themselves as “better”?
  h. *Importance and completeness:* Respondents may evaluate the completeness the recalled information or knowledge, making inferences about any gaps in what is retrieved from long-term memory.

(iv) Response processes

  i. *Mapping the response*: Can the respondent match their internally generated answer to the responses available in the survey questions?
  j. *Editing:* Respondents may ‘‘edit’’ their answer to see if it is consistent with how they answered other questions.

Examining whether respondents’ interpretations of self-reported items are consistent with the intended meanings of the survey design is vital for judging whether survey results provide valid interpretations. Studying survey response processes (as an aspect of validity) includes the empirical investigation of (a) the processes, strategies, and knowledge that underlie an item and/or task, and (b) whether the connotations and interpretations of these items or scale responses remain the same across persons, groups, and contexts (Willis, 1999).

For survey questions that are non-trivial, the question-answering process may be complex and involve a number of cognitive steps. Some of these processes may be “conscious”, but some will be automatic – meaning the respondent may not be aware of the processes they went through to gain that answer (Willis, 1999). The cognitive processes used to answer survey questions are dependent on the type and style of question being asked.

Autobiographical questions place a substantial burden on retrieval processes; asking questions that are sensitive (for example, “Have you engaged in self-harm behaviours?”), places more demands on the respondent’s decision processes. Researchers who utilise cognitive interviewing techniques must recognise that they cannot know, in an absolute sense, what transpires in a respondent’s mind as they answer a survey question. Rather, a cognitive interviewer’s goal is to prompt the interviewee to reveal the social and cognitive processes they go through (Willis, 1999) and to co-create understanding of the survey. Within a constructivist paradigm, such as is being applied in this research study, cognitive interviewing therefore fits well, as it centres the interviewee's understanding and meaning-making (Hiller and DiLuzio, 2004), and acknowledges that the interview itself is a meaning-making exercise conducted through collaboration between the interviewer, interviewee, and the survey being evaluated.

Cognitive interviewing is conducted using a range of processes. Firstly, think-aloud interviewing is a technique that involves survey respondents verbalising their responses to and opinions of the survey as they complete it. Both in the literature and in this study, think-aloud interviewing is acknowledged to be a difficult activity which adults tend to struggle with (Willis, 2005). For this reason, all the carers who took part in this phase of the study received an introductory session on cognitive interviewing delivered by the researcher and were offered the space to provide feedback on the experience after each session and to comment on how it could be made easier for me. In the think-aloud interviewing process, the researcher's role is more supportive – being primarily that of an observer and a data collector as opposed to an active co-creator of meaning. The interviewer is there to encourage the respondent to keep talking and to record "cognitive protocol" for after analysis (Willis & Arinto 2013).

The second procedure is commonly referred to as verbal probing. During this approach, the interviewer employs targeted and specific questions to elicit precise information regarding the respondents' thoughts, rather than relying solely on their spontaneous reporting. Verbal probing is frequently employed to acquire a deeper understanding of certain cognitive processes related to answering survey questions, such as comprehension or retrieval, which may vary depending on the given context (Willis et al, 2005). In this study, verbal probing was applied at points when interviewees struggled to express the thinking processes they went through when answering questions; often, this took the form of the interviewee being asked to repeat the last thing they said and me, the researcher, pointing out what presented as significant in that sentence for the interviewee.

Verbal probes are developed concurrently or retrospectively in two categories: (a) *scripted probes*, which are developed prior to the interview and often based on expected questions in the survey that have been pre-identified as lacking clarity. Within this project, scripted probes were given to each interviewee and included questions such as "What does the term 'regularly' mean to you in this instance?" or "What did you envision when considering what respectful staff would look like?"; and (b) *spontaneous probes*, which are thought up during the interview off the back of the cognitive process done by the interviewee.

There are two generalised approaches to probing questions: (a) concurrent probing, and (b) retrospective probing. As one would expect, concurrent probing refers to an exchange characterised by the interviewer asking the survey question, receiving an answer, and then asking a probing question, which in turn gets answered. The cycle continues until, together, the interviewer and respondent have figured out the respondent's reflections and understanding of the question (Willis, 1999). In retrospective probing, the respondent is asked any probing questions after the entire interview has ended – sometimes in a separate session, referred to as a debriefing session. Overall, concurrent probing is more frequently used, likely because the information being asked about is still "fresh" in the interviewee's mind. When planning for cognitive interviews, it can feel more feasible to wait and to debrief the interviewee by probing after the questions have been administered (in order to avoid the potential for bias mentioned above). However, there is then a considerable danger that interviewees cannot accurately recall their thinking and instead fabricate an explanation (Willis, 1999).

Within this study, the choice of concurrent or retrospective probing was determined in conversation between the interviewee and interviewer. Some mental health carers flourished in their ability to interact with the questionnaire themselves – often filling it in, making notes on their thinking processes, and passing this information along. In this instance, a retrospective probing session occurred, with the interviewee talking me through their experience of filling in this questionnaire. Other mental health carers in the study thrived on talking through the questions and being probed at that precise moment. Invariably, there was a mix of concurrent and retrospective probing in all the cognitive interviews conducted.

A *hybrid model* of cognitive interviewing is one that blurs the boundaries between the two techniques detailed above, as well as between the roles played by the researcher in each technique. Within this study, a hybrid approach was used to allow interviewees a flexible, dynamic experience. Given that the interviewees took part in five cognitive interviews, it was deemed important to ensure that they were not at risk of repeating themselves and disengaging from the study (Willis, 2005; Beatty & Willis, 2007). Five interviews appeared to be the number at which no significant "new" points about the questionnaire were expected to arrive, i.e., saturation of the data was reached. Further, the first interview served as a space for the interviewees to learn the cognitive interviewing method, while the last interview served as a cognitive interview and a feedback session on the method.

4.2.2 Questionnaire section

The participant observation aspect of this study simulated an 'involvement activity' with the aim of learning with mental health carers what their knowledge is and what motivates them drawing on it for social change. Given cognitive interviewing was the simulated activity of choice a questionnaire needed to be selected. As mentioned prior (see chapter 3) the Triangle of Care is a set of policy and guidelines, which set out principles of good practice for mental health and secondary mental health services and inpatient care pathways to work with mental health carers. The Triangle of Care is, supposedly, a co-produced piece of work between clinicians and professional staff from Avon and Wiltshire Mental Health Trust and mental health carers from the local area. The policy argues for better recognition of carers as key partners in mental health care, with the Triangle of Care being an "investment in safety, quality, and continuity of care at relatively little financial cost" (Martin, 2019 p.3).

The aim of the evaluation is to assess how each service is working to the 6 core goals of the Triangle of Care in an equal and reciprocal alliance between clinician, service user, and carer to ensure the best outcomes for the service user. There is a range of self-assessment tools available for this process, including The Triangle of Care Self-Assessment Tool and the Triangle of Care Carer Feedback Questionnaire. The latter is the chosen questionnaire for the cognitive interviewing process in this thesis.

There were several reasons for selecting the Triangle of Care Carer Feedback Questionnaire for this study, primarily being that the questionnaire had previous been 'co-produced' by mental health carers. This was useful as it provided a format for perceiving the extent to which mental health carers are already involved in mental health service improvement/policymaking and how successful their involvement has been in producing a usable and useful questionnaire. Beyond this, given that the objective of the cognitive interviews was to examine ways in which mental health carers drew on their experiences during an involvement activity – in this case, the design of an audit task – having a pre-made activity was a pragmatic decision. The Triangle of Care Carer Feedback Questionnaire was a readily available, structured tool, which asked carers to reflect and draw on their experiences. It acted both as a basis for observations of mental health carers drawing on their knowledge, and as a springboard for further conversation on the topic during the follow-up interviews.

You can find a copy of the original question in appendix 11.6.

4.2.3 Observation sample

The observational data was gathered doing a simulated involvement activity. The participants for this simulated activity were 7 mental health carers who took part in the activity 5 times over 6 months [see below]. Each of these cares was recruited via social media and all had to have had prior experience of patient public involvement – whether on an advisory board, as a peer researcher, or in a policy setting such as for a CCG/ICB.

Selection of participants was in line with traditional grounded theory's use of the 'constant comparative method' that seeks to compare different people's views, situations, actions, accounts and experiences (Charmaz, 2000). With this in mind, 'purposive sampling' was undertaken to determine selection of participants or cases for inclusion in the study. 'Purposive sampling' is defined by Punch (2005) as "sampling in a deliberate way, with some purpose or focus in mind" (p. 187). Selection of participants was determined by the need to capture a broad range of experiences and perspectives of the phenomena of how mental health carers make sense of their experiences and share them in an effort to make social and/or systems change. This diversity included a range of care recipients with different diagnosis, living in different locations around the country, and receiving different care packages. For the carers themselves a diversity in age, gender, ethnicity, sexuality, and disability was deliberately sought out.

Demographic	Type	# Participants
Gender	Woman (inc: trans)	4
	Man (inc: trans)	2
	Non-Binary	1
	Other	0
Age	18-24	2
	25-35	3
	36-46	1
	47-60	0
	60+	1
Carer recipient identity	Parent	3
	Partner	2
	Sibling	2
	Child	1
Geographic location	London	1
	Southeast	1
	Southwest	1
	Midlands	1
	Northeast	0
	Northwest	2
	Scotland	1
	Wales	0
Sexuality	Lesbian	1
	Gay	0
	Bi/pansexual	1

(Trans + intersex included in gender section)	Queer/Questioning	1
	Asexual Spectrum	1
	Other	0
Ethnicity	Asian or Asian British	1
	Black, Black British, Caribbean or African	1
	Mixed or multiple ethnic groups	1
	White	4
	Other (inc Arab)	0
Disability	Long term heath condition	1
	Cognitive or neurodivergence	1
	Sensory	0
	Mental illness	2
	Physical or mobility	1

Table 9 Demographic information of observation participants

Type of Cognitive Probe	Definition	Example from Data
Comprehension/Interpretation	Paying attention to instructions and questions, making sense of the question, determining what information is being asked, and making connections between key terms in the question and relevant concepts (Tourangeau et al., 2000).	*"What does a range of carer support mean to you?"* *"What does 'the staff offered you an opportunity for a conversation' mean to you?"* *"How would you interpret the following question: Did staff from the ward or team offer you the opportunity to have a conversation?"*
Paraphrasing	Paraphrasing is a technique that asks interviewees to re-design questions in light of the answer they are intending to give.	*"Can you re-phrase this question to better fit what you would answer?"* *"How would you phrase this question to ensure it was asking about your specific knowledge in relation to medication?"*
Confidence Judgement	Confidence judgements are designed to question the recall of the interviewee and ensure they are not creating artificiality.	*"How sure are you that you received a formal appointment to hear your history?"* *"You agreed that you were regularly updated on the care plan – can you tell me how you're sure it was regular?"*
Recall probe	A recall probe aims to learn the extent to which an interviewee remembers details. These probes are often repeated within and between interviews to see how the interviewees alter answers based on slightly different contexts.	*"How do you remember being informed about confidentiality?"* *"Can you recall the ways in which medication was explained to you? Would that answer fit within this question?"* *"Do you remember who offered you information about a carer's assessment?"*
Specific probe	Specific probes involve immediate reflection on the topic of a question. These tend to be concurrent probes rather than retrospective.	*"Do you recall being introduced to the carer lead on [specific] ward?"* *"Why do you think consent is important for discharge?""* *"What do you think is meant by question 12 – have you been told about carers' service?"*
General probes	Asking wider questions about the interviewee's journey to their answer, as opposed to the literal content of the answer.	*"How did you arrive at that answer?"* "*You answered that quickly – did the answer come to you easily?"* *"How relevant does the last standard in the questionnaire feel to your experience?"*

Table 10 Examples of cognitive interviewing techniques

4.2.4 The Sequence of Cognitive Interviewing/Observation Activities

Given that the questionnaire used in this study was not one designed by the research group, but a readily available questionnaire, it is difficult to situate the cognitive interviewing process within the wider survey design process. For the purposes of this study, that is acceptable, since the cognitive interviewing in this instance served as a vehicle for conversation in order to learn about how carers are involved in policymaking activities, and the TOCSAQ was an accessible and popular example of how carers have been involved.

Taking this into account, therefore, the sequence of cognitive interview activities for this thesis is as follows:

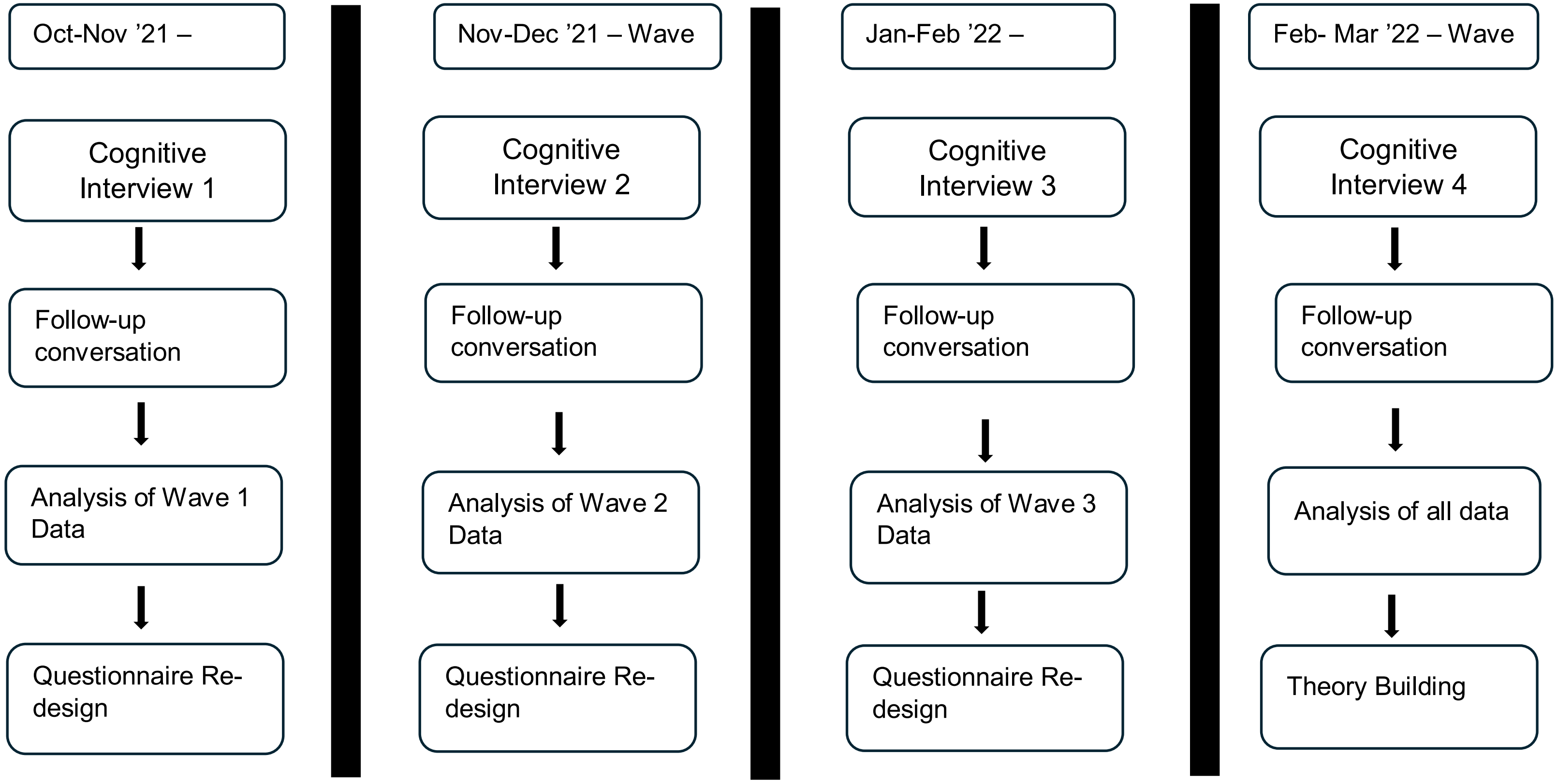


Figure 2 Table illustrating observation/cognitive interview process

4.2.5 Processing data from the observations

Modifications were made to the questionnaire in between each round of cognitive interviewing. That process looked like a report for each cognitive interview was written up in order to maintain the “case history” integrity of each interviewee’s ideas and meanings. After each monthly set of seven interviews was completed, a larger report was produced which compiled the range of results from all interviews in that month; this data informed the adaptation of the questionnaire for the next round of cognitive interviews.

In certain instances, when drafting cognitive interview reports or creating comprehensive reports that consolidate all the interview data, there can be advantages to gathering precise respondent answers to particular questions (Willis, 1999). In the case of this doctoral work, it was most useful to report verbatim the interviewees’ words when they were offering alternative questions or rephrasing specific questions. An extract from one post-interview report is detailed below:

> **Standard 1 - Carers and their essential role are identified at first contact or as soon as possible afterwards.**
>
> *Comments:*
>
> *DRA-69910552 struggled with answering these questions. They objected to the phrasing of the standard suggesting that – if the service is not providing daily support – then it should have an awareness of the person who is doing that role. They suggested this phrasing lacked the urgency that is required.*
>
> *They agreed with the statement that the carer role is essential but questioned which statutory services were considered to be first contact, reflecting on their very first contact with mental health services and how they had been ignored or deemed an unimportant presence.*

The final annotated questionnaire then becomes the main section of a cognitive interviewing outcome report, which is prefaced with a description of the specific purposes of testing, the nature of the participant population, a description of recruitment methods used, the number of participants tested, the number of interviewers used, and a description of specific procedures used during the interviews. The “protocol”, consisting of the tested questionnaire, along with scripted probes, can also be included as an appendix (in which case the main report may only contain those questions for which interviewers had specific comments).

In this study, post-interview activities are where the co-creation of meaning and concepts took place, with the researcher inserting themselves more firmly into the study. Given that this study is based within a constructivist theory, which views meaning-making as a shared experience between the interviewer and interviewee (Hiller and DiLuzio 2004, p3), the post-interview activities included taking the completed questionnaire and identifying priorities for the revised versions, any topics that should be included, and experiences that the mental health carers had which they considered important but did not fit into any specific categories in the questionnaire. It also provided space for mental health carers to reflect on the cognitive interviewing process itself.

After these activities, the revision of the questionnaire took place, drawing on the range of data from across the cognitive interviews, the completed questionnaires, and the follow-up activities. Given that a set of cognitive interviews typically generates common themes and key points where interpretation differs from the desired interpretation (Willis and Artino, 2013), it was essential in the redrafting of the survey questions to focus on the questions that caused the most confusion and saw the widest variety of interpretations. The naming of each standard of the TOCSAQ was also considered in depth by all interviewees, who responded with similar levels of dislike, distrust, and desire to reword. See the example below:

Standard 2: Staff are "carer aware" and trained in carer engagement strategies.

> *"Should this not read something like staff should be proactive in working with carers? I mean what does carer aware even mean?" – FR*
>
> *"Carer aware? I am sure they are aware carers exist, that doesn't mean they could look at you and know?" - JA*
>
> *"To me this implies that the staff should be psychic. You! Carer! I am aware of you cause I read your mind. Carer aware… it's such an NHS buzzword" - BC*

When a common message was observed in the feedback, similar verbal probes were used to re-phrase the standard in question. Then, these re-phrased elements were combined to create a new suggested standard to be assessed in the next round of interviews.

Willis (1999 p.30) states that, "*[a]s a general rule, it is beneficial if everyone who is actively involved in the questionnaire design process, including clients, participate in cognitive testing, even if simply as an observer."* Within this particular study, therefore, because it was not focused on designing the questionnaire explicitly, but on using it as a vehicle for conversations about mental health carers' inclusion in policy design, the rounds of interviews were continued until the majority of interviewees judged the questionnaire to be a space where they could effectively share their lived experience with statutory mental health services.

4.3 Data Analysis

Diary Extract #56

Is this a viable way of understanding people's experiences and my own? Am I not interpreting peoples stories they way that suits me and moving them away from their true meaning? Who am I to decide peoples personal truths?

Grounded theory is not a linear process. Rather, the approach is concurrent, iterative, and integrative as data collection, analysis, and conceptual theorising occur simultaneously and from the beginning of the research process. This process continues throughout until the theory is developed. In the study being detailed, through the data collection and analysis, theoretical possibilities within emerged within the data. Some of this process is difficult to document in a form that fully captures its complexity and the abstract nature of parts of the work.

In a constructivist grounded theory, data are narrative reconstructions of experience – not the original experience themselves (Charmaz, 2000). Different sources of data were used in forming this grounded theory, including the interviews and associated writing done by interviewees, my own observations and research diary, and my personal lived experience knowledge; and, as is consistent with grounded theory, relevant literature, including reports, records, and reflections. Analysis began with coding.

As described by Charmaz (2006) coding of the data was undertaken in two phases – initial coding and focused coding. While a detailed explanation of the steps between major phases of coding and analysis is rarely outlined (Chen and Boore, 2009, p.7) the following sections outline the process used in this research, drawing on thematic analysis of commonly occurring concepts. The development of concepts and theoretical frameworks consisted of multiple phases:

i. Creating and refining the research and data collection questions
ii. Data collection and initial coding
iii. Beginner memos which raised codes into cautious categories
iv. Further data collection and focused coding
v. Advanced memos redefining conceptual categories; adopting specific categories as theoretical concepts whilst holding others as themes
vi. Sorting memos
vii. Integrating memos and mapping concepts

4.3.1 Open coding

The initial form of analysis in this study was open coding. Coding is seen as “the pivotal link between collecting data and developing an emergent theory to explain the data” (Charmaz, 1995, p. 37). Charmaz (2006) indicates that there are two main phases in coding:

i. an initial phase involving naming each word, line, or segment of data followed by
ii. a focused, selective phase that uses the most significant or frequent initial codes to sort, synthesize, integrate, and organize large amounts of data (p. 46).

As recommended by Charmaz (2006) I initially conducted line-by-line open coding to start the chain of theory development whereby actions or events were interpreted into open codes. These initial open codes served to break open the data into categories, helped to expose processes and kept the analysis grounded in the data (Charmaz, 2006). The initial codes primarily were gerunds (words ending in *ing* that reflected a process); interviewees were often invited to conceptualise or identify what they assumed were the most significant parts of their story and label them with a code too. Starting with words and actions often helped mental health carers to see the fluidity of their role and provided a way of looking at their experiences within their personal perspective.

I further adhered to suggestions by Charmaz (2006) to “code the data as actions” to curb the researcher’s tendency “to make conceptual leaps and to adopt extant theories before we have done the necessary analytic work” (p. 48). Charmaz (2006) writes that line-by- line coding reduces the likelihood that the researcher will “merely superimpose their preconceived notions on the data” (p. 51) and risk importing alien professional language used to describe the phenomenon. The codes used in the initial analysis of the data were as close to the data as possible – using the language of mental health carers.

4.3.2 Focused/selective coding

I then undertook the next, more focused, selective phase of coding where sorting, synthesizing, integrating and organizing large amounts of data occurred (Charmaz, 2006). This coding was undertaken to sort data to a higher level of abstraction and to “check on the fit between emerging theoretical framework and the empirical reality it explains” (Charmaz, 2000, p. 516). Charmaz (2006) explains that “focused coding requires decisions about which initial codes make the most analytic sense to categorize your data incisively and completely” (pp. 57-58).

Bryant (2009) argues that grounded theorists utilise a mix of inductive and deductive reasoning during this coding process with the innovative component of grounded theory conceptualising arising from abduction, developing new hypothesis from careful comparison of the data. During selective coding the other categories are not ignored, rather their relationship with the core category is understood and explained (Glaser,1978). This focus on the core category and its relationship with other categories will in time allow emergence of the theory and theoretical saturation. At this stage the theory can be modelled and understood via theoretical coding.

In the process of focused coding, I journeyed through the interviews, stories, and my observational notes to examine interviewees' interpretations of their experiences in tandem with what the initial coding process picked up. For example – when considering the initial code of "*agonising",* I looked at all the sources of the data that illustrated agony, pain or hurt to see how it was spoken about. I compared what each interviewee said about the experience of their caring role being agonising to help me refine and separate the code. I was led to look at the causes of this hurt, the effect of them hurting, and the ways in which carers actively responded to this hurt or agony, as well as the strategies they used to make sense of this hurt. I went on to understand "hurting" as a category which formed a facet of the learning process that carers go through.

A category is a theme or variable that aims to make sense of what the participant has said. It is interpreted in light of the situation, other interviews, and the emerging theory. Categories clarify ideas, events, or processes in the data (Charmaz 2006, p91). The early categories were considered provisional because, in keeping with the grounded theory method, it was important to remain open to further analytic possibilities. Ongoing comparative analysis and conceptualisation resulted in some changes in the initial coding, for example, the early code of "*not fitting in"* was further developed to *"caring as female work,"* part of the category called *"rejecting carer identity".* This was in recognition that part of the process of making sense of the self within the caring role required carers to make sense of their personal identity in relation to how they understood caring as something external.

4.3.3 Theorising

Theoretical codes explain how open and selective codes interrelate (Holton, 2007). This is a central component of theoretical development as it fully answers the question posed of the data from the outset, what is going on? By explaining the relationship between all of the categories with each other and the core category a model of what the data is telling us can be produced. This modelling is in effect the production of conceptual understandings that link and integrate the theoretical framework produced. Glaser (1978, 2005) describes a theoretical code as a means of re-ordering and explaining the disparate substantive codes.

During constant comparison of open and selective coding memos will be produced considering substantive categories and the interaction of the codes, categories and their properties. These memos must be sorted and different theoretical codes applied to the developing theoretical understanding. Theoretical sampling is the process whereby purposive sampling is undertaken in response to ongoing constant comparative analysis, tailoring the sampling to address the emerging questions (Glaser & Strauss, 1967; Glaser, 1978). The initial coding and categories produced direct the researcher to the next participants and data. This process allows development of the greatest possible understanding of the emergent categories and their properties (Glaser, 1978).

This active sampling allows comparisons to be made with existing theoretical concepts arising from the data and helps delimit the scope of the research (Holton, 2007). This process works alongside constant comparison to identify and develop the core category allowing supporting categories to be identified and the properties of these categories to be differentiated. Theoretical sampling allows the researcher to be guided by the data to the next set of data allowing them to identify similarities and differences in the data.

The aim of constant comparison and theoretical sampling in classic grounded theory is to develop a core category. The need to control the research scope by delimiting the research is explicitly and repeatedly referred to by Glaser (1978, 1992). The core category is not simply a centre piece that the other categories relate to. It is a frame that allows research to remain ordered and controlled. The core category when developed will be relevant to all the data and all others categories will relate to it. As such the core category is the highest-level theoretical construct in any given theory. It is derived from constant comparison of all data and while relating to all of the categories it does not account for all the relationships between categories (Glaser, 1978).

Data and analysis relating to the core category will take longer than others to attain saturation. This category will be more enduringly pertinent with more data referring to it than any other. It will in itself be a component of the substantive area/main concern of the study and as such it will relate to all the other categories in a range of ways. The core category will often, but not always be a basic social process which is identifiable by the presence of discernible stages of development over time (Glaser, 1978).

The process of constant comparison involved comparing incidents to other incidents to establish consistencies and differences in conditions that could be identified. It also involved comparing developing concepts to more incidents for the purpose of "theoretical elaboration, saturation, and compression or streamlining of concepts" (Holton 2007, p278). Associated with this process was memo writing, and I wrote a number of memos stored in the research diary about my interpretations and analysis throughout the process.

Analysis of the data showed that mental health carers often talked at length about their role in "harm" whilst supporting the person in their lives. One carer said:

> *"I'd say the most important is stopping her when she wants to hurt herself. You know, making sure she hasn't snuck something into the house to harm herself. Making sure her friends' parents don't leave things [things?] yeah like paracetamol or scissors or something lying around"*

Whilst the idea of preventing self-harm after an episode or release was a common idea expressed by a large number of mental health carers spoken to, the analysis and comparison data revealed another view about harm that was expressed by different mental health carers. These carers detailed how their role in harm was not preventative but involved being present at crucial times such as the follow-up wound care. According to these mental health carers, their role in harm was less about prevention and something closer to post-harm management.

The coding process forced me to consider the data in new ways; for example, my own understandings around harm and self-harm were challenged and I had previously assumed my own expertise on the topic, and so I was made to look at what was (seemingly) familiar in a new light. Another example of this was mental health carers' immediate recourse to external information. In stories about learning about diagnosis of the person they supported, a few carers talked at length about seeking out information online rather than asking the service user or any of the service user's clinical team. When I questioned why, I expected a response about clinicians being unavailable, but instead heard about how the carers had not even considered asking clinicians to be an option due to previous experiences of being disregarded by them. This notion of being disregarded by those in power became present in two places across the data: (1) self-motivated learning as a caregiving task and (2) being disregarded by services as a motivator for considering one's personal expertise.

In this study, therefore, theorising was about my engaging with people who supported someone living with mental ill health or mental distress; listening to them, talking with them, and learning their stories through words and actions, as well as observing them as they engaged in this process of storytelling. It is from these interactions within their empirical worlds that I was able to gain understanding. Interacting with the data, analysing it, and studying how mental health carers constructed meanings and actions, led to theorising.

4.3.4 Memoing

Memos are “written records of analysis related to the formulation of theory” (Strauss & Corbin, 1990, p. 197). According to Charmaz (2000), “memo writing is the intermediate step between coding and the first draft of the completed analysis” (p. 517). Memo writing occurs throughout the analytic process whereby memos elaborate processes, assumptions, and actions that are subsumed under codes (Charmaz, 2000). As suggested by Charmaz (2006) I found that writing successive memos, ranging from concrete to theoretical, throughout the research process kept me involved in the analysis and helped to increase the level of abstraction of my ideas and focus of my research.

Writing memos also allowed constant engagement in Glaser and Stauss’s (1967) recommended “constant comparative method” (pp. 101-115). I was able to “compare incidents indicated by each category, integrate categories by comparing them and delineating their relationships, delimit the scope and range of the emerging theory by comparing categories with concepts and write the theory” (Charmaz, 2006, p. 84). As suggested in the constructivist grounded theory method (Charmaz, 2000), I attempted to use action codes throughout my memo writing to enable me to focus on interrelated processes rather than static isolated topics. Memos were referenced, filed and were easily retrievable for sorting and cross-referencing with all the other data in the study.

4.4 Autoethnographic data analysis

The analysis of the autoethnographic data (self-interview data, research diary data) was guided by Cooper and Liyea (2022) who argue for the ‘balcony’ and on the ‘dance floor’ skills for navigating autoethnographic data. This method involved co-locating myself as both reader and participant of each story in the self-interviews to understand how it flowed as a story, what the key message of each story was, and how I related to it as both reader and author.

Fetterman (2020) observes that “analysis in ethnography is as much a test of the ethnographer as it is a test of the data” (p. 100) – this idea is even more true in autoethnography since there is an even tighter connection between the researcher and the data. Clearly, as a form of ethnographic research, autoethnography can benefit from data analysis methods rooted in ethnography. Autoethnography shares with ethnography:

i. Focus on culture
ii. Focus on context
iii. Focus on both individual and societal issues/events
iv. Emphasis on holistic analysis

As data was analysed, I drew on ethnographic techniques including: triangulation, pattern recognition, key events, content analysis, crystallization, and various types of visual representations (Fetterman, 2020). I engaged first in emotion coding, considering the emotions recalled and experience by myself and others in my story. Moving on to descriptive coding and open coding which I kept opened ended through the research diary and self-interviews as the study progressed. (Saldaña, 2016). Coding up each self-interviews better equipped me to describe my experiences, capturing the meaning-making through my own words and emotions, and being open to all aspects of my experience relevant to the study. The process of triangulating involved examining internal thoughts and external behaviours and their consistency across the same and common stories, as well as between current memories and past notes. Considering descriptive facts around my experiences of mental health caring with the visceral emotions felt and considering their 'appropriateness'.

As the iterative research process of autoethnography unfolds (Emerson, Fretz, & Shaw, 2011), crystallisation allowed me to take personal snapshots over time as memories, perceptions, and known facts may morph and change. With these techniques and more, I found the blending of multiple analytical approaches generated more validity, depth, and richness in the autoethnographic research findings and the other data in the study.

4.4.1 Synthesizing results

This study generated multiple forms of data which utilised different data analysis approaches including coding, chronological analysis, cognitive interview analysis and thematic analysis. To synthesize these results, I layered the themes arising out of your thematic analysis over the autobiographical timeline, which may provide deeper insights into how my personal story aligns with the broader cultural and political context and the context of the different data types. The interludes or poem (Instantly) written throughout this brings together the key themes identified through the data – an arts-based technique for synthesising autobiographical data suggested by McNiff, 1998 with Rolling (2013) adding that an arts-based technique can prompt recall and help refine meanings further.

4.4.2 Trustworthiness

Lincoln and Guba's (1985) four criteria of trustworthiness - credibility, transferability, dependability and confirmability - were deemed appropriate when evaluating this type of qualitative study rather than such positivist criteria as validity and reliability. The question of trustworthiness essentially asks: "To what extent can we place confidence in the outcome of the study?" (Maykut & Morehouse, 1994, p. 145)

4.4.3 Credibility and transferability

To ensure credibility of the data, Lincoln and Guba (1985) recommend prolonged and persistent engagement with the research area and use of research methods that ensure "credible findings and interpretations will be produced" (p. 301). I have had both formal and informal engagement with the research area over an 11-year period as evidenced by the autoethnographic elements of this study. I also used the constructivist grounded theory method to conduct my research that routinely employs the technique of 'member checking' to improve the credibility of the study and to confirm that the theory "makes sense to the participants" (Charmaz, 2006, p. 183). Transcribed interviews were subjected to 'member checking' with participants and were triangulated against findings from participant observation. Sustained attempts were made to involve the participants in confirming the credibility of the emerging theory as evidenced by the use of theoretical sampling and successive tabular representations of the tentative theory during 'member checking'.

4.4.4 Confirmability and dependability

According to Flick (2006), dependability refers to the consistency of research findings and is checked through a process of auditing. Lincoln and Guba (1985) advise that the development of an 'audit trail' is a major component in the dependability and credibility of the study (Lincoln & Guba, 1985). Acting upon this advice, I created an 'audit trail' to provide transparency of process and thereby, increase the trustworthiness of the outcomes of the study.

According to Lincoln and Guba (1985) confirmability refers to “the extent to which the data and interpretations of the study are grounded in events rather than the inquirer’s personal constructions” (p. 324). The major strategies adopted to ensure confirmability were in providing an audit trail that would reveal to another that the findings were firmly grounded in the data. Apparent in the audit trail is careful, line-by-line open coding of interviewees’ data followed by formulation of categories and concepts that fit the data and have explanatory power. As researcher, I attempted to adopt a symbolic interactionist perspective located within the interpretivist paradigm to ensure that interviewees could have their own stories heard as reliably as possible. I also ‘bracketed’ my own understandings of the research area through an initial self-interview so that I did not unduly privilege my own rendition of the research area.

4.4.5 Ethical considerations

I was conscious of a range of ethical issues and considerations when working with mental health carers to generate knowledge. Ethical approval was secured from the London School of Economics and Political Science Research Ethics Committee before any data gathering began, but post contact with the critical friends and the beginnings of the autoethnographic process.

The underlying principles to my ethical approach were developed with the critical friends in the study and drawing upon the work of Faulkner (2004). To this end, clarity and transparency were paramount in my approach – including ensuring holding a clear and open approach towards all people involved in the study including interviewees.

Empowerment was another underlying principle in my approach; defined with in tandem with the critical friends as enabling individuals to address their lack of power and to cultivate both personal power and political power. Within the data gathering I was conscious to positioning the interviewees as the authority on mental health caring. To aid this I attended a range of training to increase my competency as researcher, including SRA introductions to cognitive interviewing, narrative methods, and types of analysis.

I was conscious of asking carers to repeat traumas and was vigilant to any distress caused by participation in the research. All interviewees were offered post study peer support offered from a third-party charity called Survivors Voices who specialised in providing 1:1 peer support for mental health service users and their carers. Interviewees were also provided with a debrief sheet detailing third sector support agencies they could contact if they were in distress.

Through a rigorous application of coding protocols and data storage methods, I was able to ensure that all data was securely stored but was accessible and readily retrievable for analysis and theory development. Data were stored in hard and soft copy form and back up files were made of electronic data. Interview recordings, transcriptions, participant observation memos and all personal documentary sources of data were coded and filed in a locked cabinet as promised in the initial permission letter to participants to ensure anonymity of participants’ details.

Data provided by the participants was used solely for the proposed research and was always securely stored to ensure privacy. All identifying details were removed from data used in the study and participants were assured that their identity would remain permanently confidential. Prior to the study commencing, participants signed a consent form to indicate they agreed to be involved in the study. They were provided with transcripts of their interviews and diagrams of the analytic directions in the analysis for member checking and verification. They were assured that any portion of the interviews could be withdrawn at any time during the study if they deemed it too sensitive or inaccurate for inclusion in the study.

Interlude 4

They said it as if I should feel some small quantity of comfort from the fact that you are dead,
That this is what you wanted,
That this final time was the last time,
That you said no long goodbyes or last words
Just gone
The fact is though,
You're a different kind of gone all together.
Gone like those promises we made for your wedding,
And those tattoos that would last forever,
Gone like the promises I muttered into my palms as I listened to your screaming.
Goner like my dreaming.
Gone as in never coming back.
Gone as in mum and dad sold our old house because they couldn't bare to step into your bedroom.
Gone like that.
But they tell me you died instantly.

5 Theory Building on Carer Identity or Sorry, you guys know who you are?

Attempt #21

At 14 I was sitting in my sister's ward rounds regularly, being asked where my parents were, being asked why I was crying, being asked why I was making everything about me. I was 14 and learned that for my sister to be cared for I had to swallow my emotions. Provide concise answers to questions no one bothered to check I understood. I learned to swallow my emotions. Swallow my identity. My sense of self within this thing called caring.

At 14 I was starting my GCSE's I was given the identity of good student despite bad attendance. I was a dancer – attending lessons on Mondays and Wednesdays paid for by the council to give me 'normality.' I was given the identity of friend, best friend, and rubbish girlfriend.

This chapter and subsequent three chapters develop an emergent theory generated from the central research question. The social process generated through the constructivist grounded theory method can best be described as "a series of evolving sequences of action/interaction that occur over time and space, changing or sometimes remaining the same in response to the situation or context" (Strauss & Corbin, 1998, p. 46). Within the context of this study mental health carers made sense of their identity and knowledge over time with the theory generated illustrating that mental health carers go through a sense making social process around their experiential knowledge; processes: (1) identity work; (2) knowledge processing; and (3) knowledge sharing.

The three stages, while sequential, are also at times indistinct and iterative, where mental health carers may experience two sub-stages at once or revisit a stage depending upon the conditions operating in their lives at the time. This chapter will discuss the first part of this social processing – identity work and its influence over different social worlds.

You can find these results written up into a paper in appendix 10.11.

5.1 What constitutes a mental health carer identity?

The constructivist interviews generate a range of findings relating to the concept of personal identity. While current research focuses on the social and relation roles of caregiving and how it can cause identity disruption (Montgomery & Kosloshi, 2012), the data in this thesis revealed how mental health cares formulated the different variables that made up carer identity, as well as, how the changing nature of identity work performed in relation to their contact with different social worlds.

Caring as *action* is assumed to be animated and unpinned be caring *emotion,* whether the emotion arise from the moral disposition of the carer themselves or from the specificities of the carer's relationship with the care recipient. Care encompasses both physical acts of rendering assistance ('caring for') and internal feelings of concern or commitment ('caring about') (Bowlby 2012). With caring identities melding both action and sentiment with sense of self and access to social worlds.

5.1.1 Trying to make sense of this experience called caring

A key theme which emerged during the interviews for all mental health carers was a need or desire to make sense of their experience of supporting someone with their mental health. To illuminate how the role or factor of 'mental illness' influenced their relationships with the care recipient and what about the concept of 'mental illness' constituted as care. The interviewees recalled noticing various changes over the length of their caring relationship, noting how the role ‘mental illness’ played in their relationship was not always clear or transparent.

“For a long time I didn’t, I well I guess I did know something was wrong with them, but I didn’t know if it was my place to say something”

“In retrospect, mental illness was always a key part of us, now that, that [mental illness] is clear I consider myself carer”

Making sense of mental health caregiving also involved the constant questioning and conceptualising of the personal relationship between the interviewees and the care recipients. While some carers felt secure in their relationship with the person -this was particularly evident in parent to child relationships – others found their conceptualisation of the relationship differed sometimes identifying as a carer, other times as a partner.

“Oh, I’m always his mum. Mum first, carer second”

“She is my daughter before any anorexia or caring or whatever. She is my child”

Some mental health carers talked about finding safety in keeping the relationship and the caring identity separate. Describing how common stereotypes around caregiving being a problem or drain on the relationship causing damage to the care recipients mental health. For this reason interviewees spoke about rejecting cultural norms around caregiving as it did not reflect or pertain to their caregiving experience – including concepts around caregiver burden (Jones, 1996) and carer identity disturbance (Montgomery and Kosloski, 2012).

“I’d never call myself a carer in front of [care recipient name]”

When asked what constitutes being a carer, interviewees in the study talked at length about three distinct social processes; (1) caregiving tasks; (2) sense of self and personal growth; (3) relationship with the care recipient.

5.1.2 Caregiving tasks

With the change in delivery of mental healthcare from hospital-based settings to community-based settings, day-to-day care needs are being dealt with primarily in the home, by unpaid carers – friends, families and neighbours. Mental health carers play a significant role in supporting and managing people with mental illness to live and thrive within their community.

Caregiving tasks for someone living with mental distress or illness have been described at length by past researchers; with common frameworks for understanding caregiving tasks being based in the Activities of Daily Living Scale. Activities of Daily Living (ADLs) are basic self-care routine activities that people tend to do daily without assistance (Baruah, Sarma, 2016). These include fundamental skills typically needed to manage basic physical needs such as grooming/personal hygiene, dressing, transferring/ambulating, toileting/continence, and eating. Basic ADLS are categorised separately from Instrumental Activities of Daily Living (IADLS) which include more complex activities around community belonging such as managing finances, childcare, or medication (Spector & Fleishman, 1998).

Capacity to complete ADLs and IADLs is judged based on independence; with the inability to complete ADLs independently correlating to poor quality of life outcomes (Millan-Calenti et al, 2010). Within mental health service users, the capacity to do ADLs and IADLs is closely linked to cognitive impairment over motor or perceptual issues. Further, for mental health service users is the importance of ability to complete the tasks versus awareness that the task needs competition, which can fluctuate depending on the individual’s symptomology.

For people with mental illness, the ADL/IADL scale is a somewhat poor reflection of judging where and how symptoms reflect the extent of disability.

Interviewees labelled a range of day-to-day tasks they considered tied to their role as carer, conceptualising both the impact these tasks had on their life and on their desire to identify as a mental health carer. These tasks invariably fell into one of 6 categories: (1) education, learning and information getting; (2) the role of harm; (3) relationship management; (4) maintaining the day-today; (5) Emotion work; and (6) ADL/IADLs.

5.1.3 Education, Learning and Information Getting

Interviewees all identified education as a primary task involved in supporting their care recipient. The majority of interviews described a journey around information seeking, linking the perceived 'severity' of information seeking and frequency with the extent to which they related to the carer identity.

Seeking out information around diagnosis and symptoms, the mental health system, and the surrounding third sector and non-statutory support tended to be the moment the majority of interviewees label themselves as a carer. Having to seek out knowledge around navigating the mental health system forced interviewees to face the reality of their situation

'I just remember sitting there wondering why she was even in hospital. I was told a diagnosis and nothing else'

'No one like… taught us how to deal with her attacks or what causes them we just had to figure it out together. Now preventing them is wrapped up in my daily life'

While information seeking around the wider support systems e.g. the welfare system, carers assessments, and

'There's like, the things you need to say on PIP forms to be successful, it took ages to figure that out. In the end I like asked our friends who were successful"

"Oh my god it was like trying to understand tax credits again. If she was on UC [universal credit] it matter cause I was on UC and we were in the same household. But I was working and she wasn't. Honestly it still sends me in a tizzy"

Interviewees drew attention to the importance of learning the right language

"I can't not identify as a carer with this vocabulary [laughs]"

'google*, google, google, they talk like you aren't there. I'm desperately trying to figure out what they are saying so when it's my turn [to speak] I don't seem dumb'*

Some interviewees mentioned specific skills they had learned to support their caring such as first aid and advocacy.

"I ended up paying for a first aid course to due to the erm, the self-harm stuff"

Attempt #30

It took a lot of hospitalisations before I could say I understood how it worked and what they were all saying. Mental health nurses and psychologists and psychiatrist words flew over my 16-year-old head as I grasps desperately at the ones I understood. Given this language I *could google to build a skeleton army of words that I would use to fight my cause. My sisters rights. It's a contradiction I know bouncing between feeling like an expert, that I've got this, and having no idea what anyone is saying or how I was expected to keep up. Psychiatrists call it Black and White thinking. I call it coping.*

5.1.4 The Role of Harm

The theme the role of harm became transparent quickly when discussing caregiving tasks with interviewees. While some tasks were conceptualised as 'dealing with harm' in terms of dealing with the outcomes of harmed already caused whether physical harm:

> *"She has a bunch of erm unconscious self-harming habits I'm on alert for… yeah like pulling out her hair. She picks at her nails till they bleed too"*

> *"He has this habit getting drunk picking fights with people. I think its cause he feels he deserves the hurt. But the why doesn't matter really, it's the managing broken arms, the concussions that impact me most"*

or emotional harm:

> *"The thing I probably do most is like suicide watch. I'm constantly on edge trying to make sure he is safe"*

> *"Trying to help [care recipient] regulate post [autistic] shutdown. Trying to get through the 5 f's to bring her back to me"*

'Protection from harm' was the other way harm was conceptualised by interviews. This theme spoke to their experiences trying to prevent or minimise harm being cause to the care recipient from external parities such as the police or mental health services, or trying to prevent the care recipient causing harm to themselves:

> *"She has a bunch of erm unconscious self-harming habits I'm on alert for… yeah like pulling out her hair. She picks at her nails till they bleed too"*

> *"Obviously there was all the stuff you do… like cupboards with cleaning stuff in, hiding meds she could use, hiding all the knives, my god. Telling her friends parents when she went over too. That was a big one"*

> *"…desperately trying to keep the police away when our stupid neighbours called for a welfare check. I keep explaining the police do more harm than good"*

The carer protecting themselves from harm from the care recipient, and protecting physical spaces from damage such as buildings and objects.

> *"Keeping the kids and myself safe when he has his episodes. One time he [pauses] well anyway he has hurt me in the past."*

> *"Sometimes it feels like her anger is just this random switch. One minute its find the next she is smashing up our kitchen. I've taken to just replacing things with the cheapest ones cause I know it'll be broken"*

Hospitalisation #6

I was 17 the first time I truly considered the danger that came with caring for my sister. It had been years of her hurting me that I made sense of through punishment and failure. But there were times when the pain felt unwarranted. Her anger was like this avalanche letting go of its *snow me the ever-constant snowdrop flower, crushed under its weight only to pop up again as the snow melted.*

I was 17 when she landed me in an overnight hospital bed. Lying through my teeth to who had caused the harm, did the police need to come, did I want to press charges, did I remember who. Being told I didn't deserve this by external people with my internal monologue saying they'll take her if I said anything. I was 17 when I thought, maybe I can't do this.

5.1.5 Relationship Management

Relationship management referred to two distinct caregiving tasks; (1) managing the relationship between the carer and care recipient, and (2) managing the care recipients' external relationships. Interviewees spoke particularly about how managing relationships was a key aspect of building and accessing different social worlds and spaces, and how the caring role influenced it significantly.

"Having to like step in to help her figure out relationships or like do relationships for her is the place I feel most powerful"

Where someone without a caring role may view a cornershop as just that, a place to pick up a newspaper and as snack, one carer spoke at length about how the relationship with the person that own the cornershop was vital for supporting their care recipient

"When he dissociated really badly, he'd walk to the shop at the end of the road and just take stuff. [owner] had my number and would text me he was there and note down what he'd taken so I could pay him back at a later date. He could have called the police. [care recipient] was stealing but [shop keeper] he was so [pause] kind about it. Its those relationships that made it easier"

Multiple interviewees describe a middle man style relationship between the care recipient and a formal support service such as mental health services and education or workplace settings:

"I'm definitely used as a scapegoat by [care recipient] when they er don't want to talk to their care coordinator"

"When he is an inpatient… yeah he relies on me to get the stuff he wants passed staff'"

"I have his line managers number and often update him when [care recipient] is having a rough time"

Lastly in relationship management, interviewees talked about their personal relationship with the care recipient, including managing expectations around the support they were able to provide. For the carers who were supporting a romantic partner, they talk about the role of sex in relationship maintenance.

5.1.6 Maintaining the Day-to-Day

Maintaining the day-to-day involved caregiving tasks which interviewees identified as routine. Tasks which became habitual and therefore were rarely recognised as a 'caring' activity until the questioned by myself.

"I have a habit of waking up 25 minutes earlier than her so I can have the kettle boiling. Its sort of nothing but like it sets her up to have a better day"

"I appreciate that my day looks different to others who don't have a partner with bipolar. But like I'm not a bipolars boyfriend. Yes my day must look different but I don't really know how"

This ritualisation of the day spoke to the embedded nature that caring can become over time, influence carers social worlds and their interactions and movements within and between them on a micro social level.

"I make sure to set aside like 15 minutes when [care recipient] gets back from work, to like talk it out or else he gets anxious"

"I remind mum a lot, and help her get back into cooking and like talking to my little brothers"

Covert activities such as wellbeing check-ins were easy to conceptualise as a completely normal aspect of their relationship, only made different or special by the presence of mental ill health.

"I know I'm not suppose to but I check where [care recipient] is on snapchat maps. I can see where she is and if she's moved all day"

"Oh yeah I have an hourly water reminder which er also is my check-in on [care recipient] reminder"

Attempt #40
I always remember this attempt. It sticks to my lungs making my breathing heavier every time I talk about it. I was 18 and she had just been admitted after 70 hours in section 136 suite. Nothing unusual. What was unusual was the blame being so acutely placed on me not ensuring the day to day. I hadn't checked in when I said I would, I was late to arrive to see her, I hadn't picked up the right things from the train station, and hadn't washed my hands properly before touching her.

I was 18 and I'd spent a lot of the time caring for her blaming myself and being told otherwise. But this time it was agreed it was my fault. Because I hadn't done my job properly. Because I hadn't 'managed the day to day' properly.

5.1.7 Emotion Work

Emotion work, unsurprisingly, encompasses the majority of tasks which mental health carers identified were key to them making sense of their caring role and its influence on their identity. The one caring task every interviewee spoke to was the idea of cheerleading or encouraging the care recipient to do daily tasks.

*"Its just a lot of motivating them to do normal sh*t. Brushing their teeth before bed, taking at least two showers a week"*

"…aye, pestering her until she actually moves"

"remindin' him of responsibilities and that. He can't be in bed cause the kids need him. I need him"

Another caregiving task labelled by the interview sample was around the role of providing friendship or companionship for the care recipient. This task was somewhat difficult to conceptualise the 'line' where standard companionship in relationships began and where it was considered 'extra.'

"Friendship I guess. Not welfare checking in but wellbeing checking in you know what I mean?"

"I might be a bit old but I'd call it companionship. Something extra that was needed outside of our usual marriage"

Emotion work also presented with caring tasks around symptomology, in particular post suicide crisis, and anxiety/panic attacks. Emotion work related to symptoms appeared to have significant influence over the interviewees sense of self and ability to move within social worlds, often describing emotion work as disruptive or an 'extra' within their relationship with the care recipient.

"I'd say I feel most like a carer post an episode. You know, I mean you do know haha, its hours and ages to bring her back, then making sure the protector won't come back. Making her feel safe"

"I just felt like an emotional punching bag 24/7 to be honest, but particularly when she was angry… I had to leave work early, skip social events and all that."

"During like when things are really bad [suicidal ideation and attempts] it was like the world stopped moving. I was doing everything. Running the house, working, and somehow providing emotional support. Making she [care recipient] actually attended appointments, making the house safe [jokes about specific attempt using power tools]"

Attempt #48

At 21 she was juggling knives. Praying for that whisp of wind that was going to blow her off the edge. And I? I was desperately trying to prevent that. Hourly check-ins, thrice weekly visits to the ward she was on, skipping lectures, missing essay deadlines. Trying desperate to write a dissertation, in between working to pay rent and trying to make her safe in a space that was not her own, surrounded by people she did not know. It's no wonder, really, she drank the cleaning bleach. It is still a wonder that I didn't.

5.1.8 ADLs/IADLs

Lastly, interviewees who supported people with significant levels of need described how at times their caregiving tasks involved supporting people with activities of daily living such as helping the person shower, or take care of their personal hygiene such as clipping their nails. While these caring tasks were rarer in the data set, they tended to be present where the care recipient experienced support needs related to severe mental illness diagnosis such as psychosis or anorexia, or where the care recipient had co-occurring physical health conditions such as diabetes.

"He is diabetic and has foot problems, so I often check on his feet. I er clip his toes nails that sort of thing"

Of all the ADL/IADL's labelled in the framework, the most common ones discussed in the data set were: Support with personal hygiene:

"Sometimes he needs help shaving so I do that"

"This is gonna be gross… there are times I take out her tampon cause she just doesn't"

"Brushing her hair maybe? I do it cause she finds it soothing mostly"

Support with food and eating:

"Sometimes its' just like making sure she eats nutritional foods. But to do that I have to make them for her"

"I take her food and watch her eat"

"We do food shopping together a lot. It gets her out the house and all and it encourages her to choose meals she actually wants"

Support with child or animal care:

"When she is sick it is always on me to walk our dog, and I don't mind but I also work a lot more"

"His kids are adults but when they need help and he's had an episode it falls to me. They are like my step kids but not"

"When [child] was a newborn I picked up lots of night feedings cause she just didn't cope with the lack of sleep"

Support with finances:

"Oh I do all our finances cause money is a big trigger for him… it works for us given the big G [gambling]"

"Obviously they have history of mad spending during episodes, so I manage their money… yeah I take their card off them"

Themes	**Sub-themes**	**Codes**
THEME 1. Education, Learning and Information getting	Learning the Language	*'When she had her breakdown, I had zero idea what was going on. It was hours in the library back then *laughs* these days its google. Like the acronyms change all the time. Like these days they are ICP… that wasn't a thing a few years ago'*
		'I was like a kid, so it was… you know… not understanding what they were saying and not feeling able to ask, these days the language they use is the language I use'
	Learning the mental illness – diagnosis & symptoms	*'I just remember sitting there wondering why she was even in hospital. I was told a diagnosis and nothing else'*
		'I keep a mental binder of medications, which she has taken, which she hasn't how she responded. But it took a long time to learn.'
		'No one like… taught us how to deal with her attacks or what causes them we just had to figure it out together. Now preventing them is wrapped up in my daily life'
	Learning the social support system	*'I remember reading about a carers assessment and thinking wait can I have this? When I floated it with her CC [care coordinator] she laughed. You've gotta learn to advocate for yourself too, ya know'*
		'There's like, the things you need to say on PIP forms to be successful, it took ages to figure that out. In the end I like asked our friends who were successful'
	Learning specific skills	*'I ended up paying for a first aid course to due to the erm, the self-harm stuff'*
		*'It's hard to say what exactly I've learned. So much of *pause* it [caring] is just day to day stuff. Like making her a cup of tea in the morning. Normal in a relationship sure, but in mine its vital to the day going smoothy'*
	Learning the mental health system	*' google, google, google, they talk like you aren't there. I'm desperately trying to figure out what they are saying so when it's my turn [to speak] I don't seem dumb'*
	Information providers	*'I guess I got most of information from peer support networks, accessing the survivor movement too'*
		'Oh Twitter, definitely Twitter and a Facebook group'
		'I just went directly to the CCG [clinical commissioning group] to ask about how the system worked'
THEME 2. The role of Harm	Protection From Harm	*'Obviously there was all the stuff you do… like cupboards with cleaning stuff in, hiding meds she could use, hiding all the knives, my god. Telling her friends parents when she went over too. That was a big one'*

		‘The thing I probably do most is like suicide watch. I’m constantly on edge trying to make sure he I safe’
		‘It might be weird but like often I take her passport and keep it with me… yeah I’m worried in mania she’d vanish’
		‘There’s a lot of managing triggers, I mean my dad he erm disassociates a lot, so trying to
		‘There’s well an element of protecting myself… like from violence but also psychologically’
	Physical Harm	_‘She has a bunch of erm unconscious self-harming habits I’m on alert for… yeah like pulling out her hair. She picks at her nails till they bleed too’_
		‘Obviously there was all the stuff you do… like cupboards with cleaning stuff in, hiding meds she could use, hiding all the knives, my god. Telling her friends parents when she went over too. That was a big one’
		‘… it feels wrong, but I provide them with clean stuff to self-harm. Their psych told me to minimise infection’
		‘Checking for self-harm he is desperately trying to hide. Like sometimes he cuts the soles of his feet, so I end up checking the floor for blood everyday when I get home’
	Emotional/Mental Harm	_‘The thing I probably do most is like suicide watch. I’m constantly on edge trying to make sure he I safe’_
		‘Part of the daily *arm gesture* is just being a buffer between her and the things that cause her stress’
		‘When in crisis its… I have to like report illegal behaviors. Not drugs use but like theft, violence against my brothers’
THEME 3. Relationship Management	Between the service user and services	_‘Sometimes it feels like both_
		‘I’m definitely used as a scapegoat by [care recipient] when they er don’t want to talk to their care coordinator’
		‘When he is an inpatient… yeah he relies on me to get the stuff he wants passed staff’
		‘In the pandemic it was lots of zooms with her care team. Erm ward rounds, cpa that sort of thing’
	Damage Control where relationships go wrong	_‘I’ve stepped in when they have picked fights at work for sure doing my best to make sure they aren’t fired [cries]’_
		‘This’ll probably seem like overstepping but I have messaged [care recipients] boyfriend to make sure he knows what is happening’

		'Young people know what is best for young people' – having the opportunity to give my unique input
	Within educational and work settings	*'When she moved to uni, I ended up contacting disabilities services for her to get what she needed'*
		'I have his line managers number and often update him when [care recipient] is having a rough time'
	General Public and Public acceptable behaviors	*'Sometimes with[care recipient] its reminding him not to shout in the street. He's a big guy, I worry what would happen if he yells too loud or at someone'*
		'this'll sound silly but begging him not to fight cops?'
	Inter-personal/within the relationship between the carer and the care recipient	*'Is swallowing what I want to say until they are better a task?'*
		'For sure I am the peacemaker in our relationship, after he has violent outbursts its always up to me to make amends'
		'This might be off but I always set our schedule as a couple? Like making sure dates are in. He'd never do that but I know he misses it when its not there'
THEME 4. Maintaining the day-to-day	Ritualization of the day	*'I make sure to set aside like 15 minutes when [care recipient] gets back from work, to like talk it out or else he gets anxious'*
		'Oh particularly when it comes to food, we follow the plan. The plan's on the fridge [husband] sometimes deviates from the plan and she [care recipient] doesn't cope'
		'Keeping time promises for sure. If I say I'll be back at home by 5 then getting back by 5 or else'
	(Re)introduction of responsibilities	*'I remind mum a lot, and help her get back into cooking and like talking to my little brothers'*
		'When mum comes home again… yeah I like slowly stop doing things and she picks them up'
	Wellbeing Check ins – both overt and subtle	*'Oh yeah I have an hourly water reminder which er also is my check-in on [care recipient] reminder'*
		'I know I'm not suppose to but I check where [care recipient] is on snapchat maps. I can see where she is and if she's moved all day'
		'I have alarms through the night so I can wake up and check in when he is on nights'
THEME 5. Emotion Work	Cheerleading + encouragement	*'I call myself her little cheerleader…. Cheering her on to do things that feel massive'*
		*'Its just a lot of motivating them to do normal sh*t. Brushing their teeth before bed, taking at least two showers a week'*

	Companionship + providing friendship	‘I might be a bit old but I’d call it companionship’
		‘Friendship I guess. Not welfare checking in but wellbeing checking in you know what I mean?
		‘Honestly most of the time its just being his friend. He’s lonely you know’
	Post Crisis Support	‘The biggest thing post crisis is probably *pause* making sure they don’t just isolate themselves and push me away’
		‘I’d say I feel most like a carer post an episode. You know, I mean you do know haha, its hours and ages to bring her back, then making sure the protector won’t come back. Making her feel safe’
	Supporting Decision Making	‘Sometimes she’ll come to around hospital decisions? Her CPN will have said she should go in and we talk about if voluntary or not, I wouldn’t consider it a ‘task’ as much as making life decisions with my partner
	Symptom based emotional support	‘I do a lot of body-doubling to make sure she actually works’
		‘I just felt like an emotional punching bag 24/7 to be honest, but particularly when she was angry’
		‘The thing I probably do most is around sleep, making sure she actually goes to bed. Good sleep hygiene that sort of thing, ya know.’
THEME 6 ADL/IADL Activities	Support with Personal Hygiene	‘Sometimes he needs help shaving so I do that’
		‘He is diabetic and has foot problems, so I often check on his feet. I er clip his toes nails that sort of thing’
	Food and Eating Management	‘Sometimes its just like making sure she eats nutritional foods’
		‘I take her food and watch her eat it’
	Childcare and Animal Care support	‘When she is sick it is always on me to walk our dog, and I don’t mind but I also work a lot more’
		‘I always end up picking up the kids to and from school, sort their food, all sorts really’
	Support with Finances	‘Oh I do all our finances cause money is a big trigger for him’

Table 11 Quotes illustrating caregiving task themes

5.2 The complex landscape of carer identities

5.2.1 Sense of control

The central theme revealed in interviews with mental health carers was about the sense of control they felt over the experience of caring and their subsequent emotions around the identity and its impacts on themselves and their different social worlds. How mental health carers come to decisions about their identity within the role was a complex multifaceted process with no one end point. The theme sense of control illustrated the impact of ‘choice’ for mental health carers.

Carers in over 20 interviews, built narratives around how their lack of control over the care role was key in the roles influence over their identity. Describing an experience shaped by originally unwanted responsibility, forced adaption and resilience, and increased negative emotion associated with both the care recipient and the caregiving role. Caregivers who report lack of choice about caregiving experience higher emotional stress, reduced psychological and physical health, and lower life satisfaction than individuals who feel they have choice in caregiving (Schulz et al, 2012).

“Its not like I chose all this, if anything I was pushed into this position by services being reliant on me. I love [care recipient] but that can be really difficult”

“I’d say being a carer was like an inevitable downward spiral. In that I’m a woman its expected of me way, but in that I need something to make sense of my self ah caring is right there way”

“Its not like I like being a carer. I didn’t choose it. I wanted to be a normal kid. But here we are”

Analysis of this data and further conversation with interviewees and critical friends revealed how mental health carers who spoke about limited control over the role where most likely to experience a loss of a wider sense of self – a common finding among studies which examine carer identity. Loss of sense of self or role engulfment is described by Eifert et al (2015) as an experience where caring responsibilities begin to consume the carer, leaving little time for other activities and behaviours which previously gave the carer meaning.

Mental health carers who spoke to having more control over the caring role, the activities within it, and felt the caring role had minimal influence over their social worlds, made reference to the fact carer was not a permanent part in their sense of self.

“It works for the time being. Being a carer, I mean. But what if they get better?”

“Before anything else I am her mum. Carer or not I’m mum”

This theme has gone on to be understood through an achieved or ascribe lens as generated by Hughes (1945) who describes how people hold a range of identities which fall into one of two categories depending on both the degree of influence it holds over the persons day to day, and the perceived status that identity holds in their sense of self.

Attempt #22

I was 14 by the time I had adapted to the word carer being dangled under my nose like the key to understanding this situation I found myself in. The word said quietly by teachers and school administrators to explain my attendance record. Said to my face by GPs, mental health nurses, and IMHAs [independent mental health advocates]*. No one thought to tell me they were talking about me. How could they be talking about me, I wasn’t caring. I was just doing what I was told.*

5.2.2 Achieve or ascribed?

There was a distinction in every narrative built with mental health carers around if their felt the identity for 'carer' was something they had achieved or something that was ascribed. In this instance, ascribed refers to caring identities which felt permanent, non-moving or changing and etched deeply into the interviewees way of understanding themselves and their social world. Similar to identities like gender, sexuality, and race, interviewees viewed carer as a permanent facet of themselves and a regulating force for how they interacted with the social world.

In this instance the term achieved describes mental health carers who felt their caring identity was something they had earned or perceived their caring identity as something they held a sense of control over. To this end achieved mental health caring identities rival those of jobs such as barista therapist, or judge, or identities such as mum where the individual has 'worked' to earn the identity. Mental health caring to this group was viewed as in motion, having a fluctuating level of influence over people's social words and ability to interact within and between them.

5.3 Mental health carer identities

Through the data gathering process, interviewees invariably fell into one of four carer identities that become present. I describe four categories (which are not mutually exclusive); (1) The fluid mental health carer; (2) the labelled mental health carer; (3) embracing the mental health carer identity; (4) rejecting the mental health carer identity. Each of these identities made sense of their caring role as achieved or ascribed, through a range of interpersonal and external factors which influenced their sense of self and sense making around the caring role.

5.3.1 Fluid mental health carer

The most common construction of mental health carer identities presented itself as fluid; with interviewees describing an identity that is flexible to a range of externa variables. The experience of caregiving was not static, neither viewed in a positive or negative light but something that grew and changed as the relationship did. Fluid mental health carers tended to view their role as something achieved – holding a sense of control over the identity and their connection with it.

Fluid mental health carers were defined by the fluctuating nature of the symptoms of the care recipient. Often speaking about feeling more like a carer or identifying more as a carer when the person was experiencing a time of acute mental distress, requiring higher support needs.

> *"Maybe when she starts using again, I feel more like a carer. Specially cause I get more anxious"*

> *"It only really bothers when they're in crisis which happens the same time each year so these days its easy to plan for you know"*

Fluid mental health carers also made sense of their identity through 'the perks' that came with caregiver identities. Perks tended to be viewed as small everyday benefits that almost acted like a 'payment' who caregiving including skipping queues, free companion tickets at events or days out such as the theatre of theme parks, and a level of respected or authority granted to the in medical settings.

> *"Calling myself his carer helped. The nurses would actually engage me conversation way more than when I was his wife …. it makes me feel good"*

"When school found out I was a young carer, suddenly I was allowed my phone in the classroom. I got extra time in exams. It was a sweet deal given [care recipient] was mostly fine. I just didn't tell them that"

Some mental health carers described the ability to hide behind or using the identity as a weapon to get a specific outcome. They may not reflect on the identity as an important or dominant facet of themselves, and the caring role may hold minimal significance over their access to different social worlds, but it can act as a vehicle to getting a specific need met.

"This'll sound bad but like, I can hide behind being a carer sometimes. It gets me out of responsibilities at work. I know it's bad."

"Oh we definitely include that I'm their carer on anything benefits/DWP related. Especially like when applying for PIP. it feels like it's in every line cause we are that desperate for support"

Overall, interviewees who fit into a fluid narrative had the least attachment to the identity of carer. It held minimal influence over their sense of self, understanding, and interactions with the social world. Describing a social world where care was an ongoing constantly changing variable which at times was dominant but otherwise held minimal influence.

5.3.2 The labelled mental health carer

The second conceptualisation of a mental health caring identity was an identity as determined by an external party. Interviewees who most closely aligned to this identity outsourced the decision making around it to people they perceived to have more authority than them – this was often clinicians, local government agencies, in some cases the third sector and academics. Labelled mental health carers created a narrative around a lack of choice in caring activities while simultaneous deferring the sense making of their experience to someone. Describing an ascribed identity around caring, they held contradictions around feeling in control and completely out of control of being a carer.

"I'm not a carer am I. [pause] am I? I know our relationship isn't like my friends but

"Its not like she is dependant on me all the time you know, just when things are bad…. [laughs] she could not hold down a job without me for love or money"

The theme desire for permission was paramount in labelled carers conceptualisation of caring within their personal identity. They viewed caring or being a carer as something that held specific standards or requirements such as: types of caring activity – particularly around ADLs being needed to be a carers; hours you needed to be doing to support someone; or it had to have a detrimental impact on personal wellbeing.

*"nah I sure as sh*t didn't considered me a carer till the GP says I was one for [care recipient]. Caring's helping someone shower, sh*t, shave. Not this"*

"I always considered caring as a like, oh they are dying thing, ya know. Its not like he was ever dying, so ya know"

Labelled mental health carers described times where another party considered them a carer and thus a personal journey commenced to understand how the role of carer was folded into their personal identity and the impact it had on their access to and interactions within the social world.

> *"I was given a pamplet on it [carers allowance] actually. It was the least important once at the time given [care recipient] was getting 13 stitches but it came home with me… it got me thinking I don't wanna claim this I'm not a carer but it was given to me by people that know"*

Interwoven with the desire for permission theme was experiences of imposter syndrome, with interviewees highlighting concerns around taking up spaces and resources they should not. Implying that there are 'real' carers and they were somewhat faking or masquerading as one. Interviewees describe narratives around not feeling like a real carer, as if their caregiving tasks didn't count or match up to societies expectation; often describing having an *'easy ride compared to real carers.'*

> *"I went to a carers group hosted by the GP…. I definitely shouldn't of gone. Nah there were actual carers for people with like ALS"*

> *"Tories and all that… there's limited resource given all the cuts. Who am I to take up space for carers when there basically isn't any"*

Attempt #29

Sometimes being labelled was easier – I felt most like a carer when I wasn't with my sister. I was surrounded by people who decided I was a carer and they were people in authority so who was I to argue. Psychiatrist, psychologists, mental health nurses all looking at me as her carer. Not a person. Not a teenager. A carer.

5.3.3 Embracing the mental health carer identity

Interviewees that built a narrative describing the embracing of a carer identity tended to be those where caregiving was not an established expectation in the relationship – such as children supporting grandparents and supporting a sibling. They described narratives built on either a sense of pride or loss of the sense of self or personal identity.

Interviewees whose narrative revolved around a sense of pride understood their caregiving relationship as something achieved, that they had made an active effort to become 'good' at. They described mental health caring as an important facet of their sense of self, where they derive personal value. Further, they understand mental health caring as playing a positive role in their connections with the social world; understanding caring as a foundation for skills and attributes which are useful in other parts of life.

> *"Caring is part of who I am, I am a warrior. I am resilient. I've bounced back after so much negativity"*

> *"It [caring] is something I have been working on and improved at. Therefore it feels like something I've achieved and am proud of"*

Interviewees whose narrative revolved around a loss of sense of personal identity describe a caregiving experience as intense, overwhelming and all encompassing. Something ascribed to them that they had no control over, interviewees talked about slipping into the role of carer, in some cases without noticing, the significant disruption it had on their life trajectories, and the feeling that the only way out is death. Interviewees understood caring as the epicentre of their social world, having control over how, when, and indeed if they interacted with wider society.

> *"Back before my revelation, being a carer was all I was. I lost everything about myself except caring for [care recipient"*

5.3.4 Rejecting the mental health carer identity

Lastly, mental health carers who rejected the identity of carer were somewhat common in the study. Interviewees built narratives that centred either the normalisation of their relationship with the person or were built up external criticism or pressure that led to them rejecting the identity. Interviewees conceptualised caring not as something they had control over but as something that was not inherently special, different, or worthy of study.

Some interviewees spoke at length about the criticism they had received for identifying as a carer – both from external parties and from the care recipient. External pressure tended to come from those they considered to be in authority such as teachers at school, local government, and mental health services themselves. These interviewees made deliberate efforts to not let their experience supporting someone with mental illness impact their interpretation and connection to their personal social worlds.

"When I talked about caring it was just reams of advice from people that have no idea. And wouldn't acknowledge they had no idea. They'd talk like I was doing everything wrong but like [recipient name] is my parent. I know. So these days I just swallow it"

While internal pressure was both an internalised social process and pressure from the care recipient to not identify that way. Interviewees described how the two way nature of a caregiving relationship meant that if they shaped their identity around caring it forced the care recipient to reshape their sense of self around requiring support – explaining how this tended to cause distress for the care recipient.

"When I floated the fact, I was a carer she just got super upset about it so I didn't bring it up again or like, identified that way. I mean I think it made her question her mortality, but also her motherhood-ness. Like if I'm supporting her then what is she doing for me"

"She really didn't like when I referred to myself as her carer. Reckon it made her feel inept even tho' it was never like that for me"

"I wanted to make space for this part [caregiving tasks] of our relationship that was becoming more and more evident. But he just wasn't open to it. It made him question things about himself that he hadn't and he started getting even worse so I dropped it"

Self-harm #30

Like my self-harm, caring for my sister came with criticism. The self-harm helped me make sense of what was happening, making evident the punishment I clearly deserved for failing my sister. The criticism on my ability to care, me taking on a carer identity, and my desire for all the caring to stop cemented the need to punish. To taking a 400°C hair straightener to my arm to watch the skin, through to flesh, to through bone melt away. I wasn't a good enough carer, I was selfish for wanting not be a carer, I was selfish for wanting to be one.

A final theme that became evident for interviewees who rejected the carer identity was around the idea of gendered work. These interviewees' built narratives laced with feminist theory around rejecting societal conceptualisations around caring and caregiving choosing to interpret care through a social collective lens rather than an individualised experience specifically for woman.

"I feel like a carer because I am socialised to do so, not because I actually identify that way"

Themes	**Sub-themes**	**Codes**
THEME 1 Fluid Mental Health Carer	Symptomology based fluctuation	*'Oh I definitely feel more like a carer when crisis is happening for sure or when theres a change in meds'*
		'Maybe when she starts using again, I feel more like a carer. Specially cause I get more anxious'
		*'Obviously when sh*t is really bad, like he can't be alone' – they feel more like a carer*
		'When mum is in hospital or on her way to being in hospital I'm called a carer a lot more? Like the social workers and the doctors call me one, so then I feel like one'
	'The Perks'	*'I got earlier access to the [covid-19] vaccine cause I'm their 'carer', that was cool. Ohh and skipping queues at theme parks'*
		'I guess a perk is getting extensions at uni. I can just tell me ac [academic coordinator] that something has happened and can't meet a deadline without having to provide evidence'
		'My line manager is really good, she lets me be flexible when things are bad'
	Wielding the identity as a weapon	*'I probably identify most when playing the game' – using the identity to give legitimacy to themselves while trying to gain specific things from statutory services*
		'Oh we definitely include that I'm their carer on anything benefits/DWP related. Especially like when applying for PIP. it feels like it's in every line cause we are that desperate for support'
		'This'll sound bad but like, I can hide behind being a carer sometimes. It gets me out of responsibilities at work. I know it's bad.'
THEME 2 Labelled Mental Health Carer	Desire for permission	*'well, do you think I'm allowed to call myself a carer' – seeking validation from those perceived to have more power*
		'I have definitely been labelled a carer by the system, I mean, they [they system] need by help to function'
		'Don't you need like, the government to say you're a carer?'
	Imposter Syndrome/Shame	*'Sometimes I think about going to carers groups, but I don't think I belong there'*
		'I'm not a carer because no one has told me so? I thought you were declared it by a GP or the DWP or something'
		'It sort of depends on the audience, when I'm already labelled as a carer its cool. But I'd never introduce myself as one'

		'Duty of care' – feeling emotionally supported when discussing sensitive topics
THEME 3. Embracing the Mental Health Carer Identity	Sense of Pride	*'Caring is part of who I am, I am a warrior'*
		'My identity is structured around my role as a sister and everything that entails'
		'Just being there for [care recipient] is what our relationship is based on, when they got worse it was natural to step up'
		'It [caring] is something I have been working on and improved at. Therefore it feels like something I've achieved and am proud of'
	Losing sense of self	*'Back before my revelation, being a carer was all I was. I lost everything about myself except caring for [care recipeint]'*
		'The first time she started using severely and she was turned away from services, then I… [cries] … I was barely me anymore, she was barely herself'
		'I moved across the country, rent this tiny studio all to be closer to her when she needs me, I left my friends, my job, my other kids'
THEME 4. Rejecting the Mental Health Carer Identity	Externally pressure	*'When I floated the fact, I was a carer she just got super upset about it so I didn't bring it up again or like, identified that way'*
		'I bought it up at school one time, to like my form teacher and he was, well, not very good about it. He said I couldn't be a carer cause I didn't help [care recipeint] with like, intimate stuff. And I guess that really stuck with me, so I refused all help'
	Criticism	*'I feel more like an undercover agent than a carer' – to avoid questions and not risk outing the person they support as mentally ill*
		'It's [caring] is merely a facet of our relationship, who are you to decide if it is special'
		'I don't identify as a carer cause it just leads to criticism and unsolicited advice from my friends. I know they mean well but'
	Gendered work	*'I feel like a carer because I am socialised to do so, not because I actually identify that way'*
		'Obviously the gendered aspect is important. Am I carer or am I just female and take up this role cause I'm female?'

Table 12 Quotes illustrating identity themes

Interlude 5

The fact is though,

You’re a different kind of gone all together.

Gone like those promises we made for your wedding,

And those tattoos that would last forever,

Gone like the promises I muttered into my palms as I listened to your screaming.

Goner like my dreaming.

Gone as in never coming back.

Gone as in mum and dad sold our old house because they couldn’t bare to step into your bedroom.

Gone like that.

But they tell me you died instantly

6 Theory building on carer learning types or OMG I saw that tweet too

Abuse # 9

My sister had this habit of rolling the knots in my shoulders like weird little stress balls. The pain, if memory serves, was excruciating. But somehow it made more sense she hurt me than hurt herself. If she hurt herself, I was failure. If she hurt me, then I didn't have to punish myself. If she hurts me then it's a better form of harm reduction than if she hurts herself. I was 19 years old when I tried to explain this to someone for the first time, think it was a good tip. If they hurt you then you won't get in trouble. Maybe others could learn from my experiences just as I have learned from theirs.

It took me until 25 to realise how ridiculous that is. Not learning from each other but the expectation I had to hurt for my 'job' to be done. I learned from other carers this wasn't some universal experience I had told myself it was. I learned from other carers it didn't have to be as hard as I found it.

Theorising how mental health carers fit into a lived experience paradigm means considering in what ways mental health carers formulate their lived experience knowledge. Given the current discussion highlighting that the foundation for experience knowledge is identity, caregiving tasks, and how they impact individual social worlds, the next step in the analysis is to consider what about these experiences constitute knowledge and how that knowledge is formed.

The epistemic processes involved in knowledge formation include a focus on attitude formation and change, impression formation, judgment under uncertainty and causal attribution. Traditionally, such endeavours' have highlighted localized issues *specific* to a given domain of knowledge (see Kruglanski & Orehek, 2007). Knowledge is created in the spiral that goes through seemingly antithetical concepts such as order and chaos, micro and macro, part and whole, mind and body, tacit and explicit, self and other, deduction and induction, and creativity and efficiency. The key to understanding the knowledge-creating process is dialectic thinking and acting, which transcends and synthesizes such contradictions (Nonaka & Toyama, 2003).

The data in the study revealed how mental health carers undergo a range of self-motivated and externally motivated knowledge formation processes through their experience supporting someone living with mental ill health and distress. This knowledge is frequently drawn on by mental health clinicians and services – whether during decision making, care planning or discharge to name examples given by interviewees. The aim of this chapter is to illustrate the types of knowledge production, consolidation, and application that interviewees identified during the data gathering. This carer knowledge is understood through a critical theory lens - with critical theory existing as a new space for non-classical forms of knowledge and knowing to be made present and given authority (Pickersgill, 2012b).

Some mental health carers in the study identified the importance of recognition from non-group members for their knowledge to be 'valid'. Normally this came from people in authority e.g. clinicians, but it was also highlight that it was important for some carers that the care recipient understood or accepted their interpretation or knowledge about something.

6.1 Knowledge formation, experiential learning theory & carers

Knowledge itself is a contextually situated reality, often viewed from a certain angle. This knowledge will be viewed different depending on the rang of contexts and angles one chooses to view it. Knowledge creation is explicitly tied to the social contexts of the creator; with social, cultural, historical and, important for this thesis, interpersonal experiences placing knowledge within an individual context (Karpov, 2003). The contexts which an individual knowledge creator lives in gives them the epistemic basis for interpreting information and creating meanings (Kruglanski et al, 2010). In other words, in knowledge creation, one tries to see the entire picture of reality by interacting with those who see the reality from other angles, that is, sharing their contexts.

Knowledge is created through such interactions between human agency and social structures. Our actions and interactions with the environment create and enlarge knowledge through the conversion process of tacit and explicit knowledge (Nonaka & Toyama, 2003; Nonaka & Takeuchi, 1995; Li & Gao 2003). Giddens (1987) argues that we enact our actions with two main levels of consciousness: practical consciousness and discursive consciousness in our daily lives. While the discursive consciousness gives us our rationalisations for actions and refers to more conscious and therefore more explicitly theoretical knowing, practical consciousness refers to the level of our lives that we do not really think about or theorise. In that sense, tacit knowledge is produced by our practical consciousness and explicit knowledge is produced by our discursive consciousness (ibid).

Hospitalisation #13

I reflected in this hospital bed if I knew how I'd got there. One a conscious level I did? My sister was having what doctors call an episode of mania. The high was not spend money we didn't have or having crazy sex. Nope this time the high was feeling invincible, unstoppable, an unending buzz beneath her skin that the something better was right there. She didn't have a drivers license when she crashed the car. Somewhere I knew that but I didn't stop her. Didn't know how.

I'd been given the idea of mania as the way to theorise this experience, as a way of providing an explanation layered with the unspoken justification for her actions. I knew back then as I know now it had to be something more than that, but I didn't theorise what because I didn't know how. Or if it was worth it.

Knowledge creation starts with socialization, which is the process of converting new tacit knowledge through shared experiences in day-to-day social interaction (Nonaka, Takeuchi, 1995). Since tacit knowledge is difficult to formalise and often time- and space-specific, tacit knowledge can be acquired only through shared direct experience, such as spending time together or living in the same environment, typically mental health carers are acquiring tacit knowledge through hands on experience such as dealing with an episode of self-harm or ensuring a meal plan comes together. Carers can share this tacit knowledge with others in the care recipients support network or other carers by empathizing with them through shared experience.

The continuous ever-changing nature of providing support for someone with a mental illness requires carers to view and understand their tasks as a part of the entire process of support. By 'indwelling' or 'living in' the world, individuals accumulate and share tacit knowledge about the world that surrounds them. For example, mental health carers can accumulate the tacit knowledge about mental illness through their experiences with mental illness, whether their own or through the person they support. Here, carers embrace contradictions rather than confront them enabling them, as actors, to absorb knowledge in their social environment through action and perception.

6.1.1 Experiential learning theory

Experiential learning, or active learning, interactive learning, or “learning by doing” has resulted in positive outcomes (Morris, 2020). It is commonly understood as a part of formal education process such as when students take an active role in the learning process the student’s learning is optimized (Smart & Csapo, 2007). However, experiential learning can also occur outside formal education settings, including in everyday life situations. Experiential learning theory defines the learning process as “the process whereby knowledge is created through the transformation of experience. Knowledge results from the combination of grasping and transforming experience” (Kolb, 1984, p.41). Kolb defines the experiential learning model as a cyclical process of learning experiences; where effective learning only occurs when the learner goes through the entire cycle. The four-stage learning model describes two differing dimensions of grasping experience: (1) concrete experience (CE) and (2) abstract conceptualization (AC). Followed by two opposite dimensions of transforming experience: (1) reflective observation (RO) and (2) active experimentation (AE).

Experiential Learning Theory has been further refined and elaborated by Kolb and colleagues with Kolb (2015) reiterating:

a four-stage cycle involving four adaptive learning modes (p. 66) … [where] Learning arises from the resolution of creative tension among these four learning modes. This process is portrayed as an idealized learning cycle or spiral where the learner “touches all the bases” – experiencing (CE), reflecting (RO), thinking (AC), and acting (AE) – in a recursive process that is sensitive to the learning situation and what is being learned. (p. 51)

Kolb (2015) asserts that knowledge results from a combination of acquiring experience (through concrete experience and/or abstract conceptualization) and transforming experience (through reflective observation and/or active experimentation). Experiential learning theory, therefore, views learning as a cyclical process in which learners directly experience a phenomenon, reflect on that experience, develop a conceptual framework to integrate their experience with prior knowledge, and then engage in experimentation which begins the cycle again (Kolb 1984; Mcleod, 2024).

Experiential learning refers to the learning that arises from life experiences as opposed to didactic forms of learning. It is a sense making process of active engagement between the inner world of the person and the external worlds and environments (Beard and Wilson, 2013 p.4). The success of experiential leaning in achieving various learning outcomes is frequently attributed to the fact that it supports a wide variety of learning styles and use skills/knowledge. Experiential learning theory has been applied across a range of fields including education, medicine, and psychology (Kolb, 2015); it is intended to be a holistic learning process that merges experience, perception, cognition, and behaviour (McCarthy, 2010).

Self-harm #44

*It was the day after my GCSE results that I first burned by bone with hair straighteners. My sister was an inpatient, my parents were working, and I had got into sixth form no problem. But that was not enough. I had 5 A*s a bunch of A’s and B’s and one lonely C in math. I remember wishing I’d been able to sit some kind of exam to prove my caring. Show the things I had learned from my time with my sister. Some way of proving Have that grade to show why the rest of my grades were terrible compared to others in my life.*

6.2 Mental health carer learning types

The observational and cognitive interviewing data revealed five ‘learning types’ where mental health carers illustrated conscious and unconscious forms of knowing about their role. The mental health carers in the study outlined five types of learning they underwent and continue to undergo to supplement their lived experience of supporting someone with a mental illness. Drawing on their lived experience, the mental health carers in the study spoke at length about the different methods of learning, motivations for it, and key milestones where learning occurred. The five types of learning identified were:

i. Pre-diagnosis Learning
ii. Collective Learning
iii. Action Learning
iv. Self-directive Learning
v. Formal Learning

6.2.1 Pre-diagnosis learning

The majority of individuals started to learn about the condition the person they supported presented with prior diagnosis or statutory service involvement; becoming aware that the person was presenting with mental illness symptoms and seeking out knowledge in advance of statutory help. This learning tended to be done in online forums, social media, and through personal connections. A number of individuals in the study spoke about how they supported someone for a significant length of time while before they received a formal diagnosis. During this time, they focused their learning on the symptoms and condition being experienced, rather than wider support options. For mental health carers supporting someone who had a diagnosis but had not disclosed it yet, their pre-diagnosis learning was done more often with the care recipient – together learning how to manage the persons mental health without labelling it as such. This was particularly true for children supporting their parents and vice versa.

Pre-diagnosis learning also took the shape of mental health carers changing and learning habits and patterns to fit the care recipient before they had even conceptualised mental health as part of the persons sense of self and as a part of their personal relationship.

Attempt #5

I might have been too young, but it took a very long time to consider how my sister functioned, her behaviours and actions, were related to mental illness… I had started learning and altering how I was behaving, changing my habits to make her feel safe, less lonely, less angry. By this attempted she was being investigated for any number of mental illness and physical illnesses, but I wasn’t privy to those conversations yet.

During this pre-diagnosis learning period mental health carers described primarily investigating the symptoms and condition but some also sought out where support from external agencies was needed or indeed possible. These agencies included schools, workplaces, statutory mental health services and the welfare support system. Often the context of the support seeking was not for their own personal support, but to see what was available for the person they are supporting.

“I think I’d tried to get him to go to the GP about it long before he did. Before he even knew anything was really wrong”

Experiential learning theory views knowledge as something situated within context: emphasising the time, place, and motivations for learning (Morris, 2018). Experiential learning occurs at specified times or milestones (Smith and Segbers, 2018) and in interactions with specific people (Harper, 2018; Morris, 2018). For mental health carers engaging in pre-diagnosis learning, the surrounding context to motivate their learning is based off the interactions with the person they are supporting. Whether through a definite conversation, or through more abstract contact with them.

“Before [care recipient] told me about their diagnosis I’d already googled so much. I think my first stop was probably MIND [charity] or maybe Rethink [charity]. It was obvious something was going… she wasn’t eating, she was barely sleeping”

“We didn’t seek help from services until [care recipient] maybe third breakdown? Not really for any reason except we didn’t think it applied to us? Mental illness is hearing voices not… this”

Experiential learning theory also states that the ‘place’ where learning occurs has significant sociocultural, historical, and personal meanings (Pipitone, 2018; Harper, 2018). For mental health carers engaging with the ‘place’ in pre-diagnosis learning is important as it allows them to mould their thinking to be more critical of basic societal norms, and the power structures (Deringer, 2017) which remain dominant in the mental health field. In pre-diagnosis learning mental health carers developed their own understanding of mental ill health, drawing on the experiences of the person they supported, their wide politics, and the context of the person they supported symptoms.

“Oh I wanted to learn everything. I think my ADHD hyper fixated on their symptoms and I trawled for any info of how I could support them. It took awhile to realise it was mental illness and not just being trans in a heteronormative society”

Interviewees also spoke about the unconscious learning and adaptions they had made to their behaviour, they only realised later into their caring relationship.

“I’m not really sure when I learned to do it, but like waking up with that cup of tea ready just made the day easier so I would do it”

“There’s a lot of little things I picked up before they were diagnosed with PTSD. The usual stuff like not making loud noises but smaller things like when to squeeze their hand during a panic attack. Oh or on panic attacks recognising when they wanted to not be touched at all and just coached through breathing. I learn that long before [mental health nurse] told me about ground techniques”

6.2.2 Collective learning

Community learning or collective learning, as named by the interviewees, was identified as a frequent way of learning. Taking place primarily in digital spaces, collective learning saw mental health carers learning from each other’s experiences mostly on issues or challenges with statutory services. It was identified that collective learning occurred on social media, at carers support groups put on by charities or statutory services, and during research or policy involvement activities.

‘Doing stuff like this [interviewer: like this interview?] yeah, it’s a good way to learn from others. And being involved in studies is a way to meet others who also have rubbish experiences with the system’

Interviewees discussed how collective learning processes existed as a means of knowledge exchange – learning from each other’s stories, errors, and successes. This is common within established communities of practice such as social workers who use story telling among other narrative methods as a means of tacit knowledge exchange which ensures the justification of practice which sits outside of tradition or formal education (Gola, 2009). The majority of interviewees placed emphasis on the importance of finding community, meeting other carers or people with similar experiences as a place for learning.

"I'm at a point now where if some new goes wrong with [name] I can ask the twitterverse and someone while chat me through it"

"Yeah, yeah we met at a [charity name] event for young carers. Ages ago now. He has guided me through so much stuff"

Within Experiential Learning Theory community learning or community engagement is a central process (Deringer, 2017); with Fifolt et al (2017) arguing that the role of experiential learning is to bring a community together. For mental health carers, this means that engaging in community learning as a collaborative process helps them establish their learning as knowledge. Within collective learning among mental health carers, this presents itself as carers forming mentor/mentee relationships in virtual spaces. With a carer who has experienced a phenomenon taking the role of the educator to someone who is experiencing it for the first time – the leaner.

"Meeting [name] was the best. Yeah, yeah I realised, they gave me words to explain that I was carer, that this situation with mum was not normal. Yeah I learned a lot of them"

"We really need to platform more young voices in mental health caring. We can all learn from each other but god we need to hear some new people"

During discussions of the collective learning process interviewees identified common knowledge that mental health carers hold, establishing common realities to build their lived experience upon. Caron-Flinterman et al (2005) suggests that through the process of collective learning lived experiences often combine to become a collective pool of experiential knowledge. What's more, involving multiple carers, with opportunities to meet together, developed "informal support and information networks," (Kennedy et al, 2010, p9) to share knowledge about health conditions, caring strategies, and health conditions (Chadwick et al, 2010).

Attempt #34

I was 16 when I was finally dragged onto social media. Someone made me a Facebook account and I hated it. I made myself a Twitter account and at first it made me feel seen. I could tweet things about my sister, about how she was acting. It was a space for my distress, my loneliness, a space where I could talk about what I was experiencing without inviting the people around me to journey down the rabbit hole with me. I connected with other people who spent their time watching people in distress and at first it felt less lonely, then this impending sense of doom arrived, this responsibility to a community I don't know when I consented to being a member of. All lost and dependant one each other for advice to fight a system that invisible-ised us all.

6.2.3 Action learning

For some interviewees, particularly those supporting their adult children with mental illness or those supporting their partners, learning occurred through 'trial and error.' When asked they constructed this learning process as 'Action Learning' or 'Doing Learning' where, when working with the person they support, the developed ways of supporting them via action and feedback. Action learning was the only learning method which was entirely dependent on interactions with the person being supported, being led by the needs, wants, and desires of the care recipient.

Experiential Learning Theory views learning and action learning by this definition as purposeful, with the learner taking responsibility for finding solutions through an inquiry process relating to specific real-world problems (Morris, 2019). Action learning was most commonly present in for mental health carers in conversations about symptom management or caregiving tasks:

"When she was resistant to her meds [name] would start hiding them under her tongue so now I check out of habit even though she's been on these meds for god 8 years [laughs]"

"Ohh it was definitely a trial and error thing. Yeah like what her safe foods are in different moods. [name], husband, was rubbish at it. Never got the right brand of yoghurt for [Care recipient]"

What's more Kolb (1985) acknowledges that active experimentation, as part of experiential learning, utilises 'theories to make decisions and solve problems' (p.30). Across the data this presented as mental health carers trying to navigate learning habits and routines which function best for the person they support. In action learning, mental health carers assume collaborative responsibility for the learning process (Hou & Pereira, 2017) acknowledging that the care recipients needs are likely to fluctuate.

"Of its definitely with stuff like figuring out routines, what keeps them calm and like what works after an inpatient stay? Particularly within those first few days after. We've got a good thing going when they are discharged but it's taken until now"

Where the data illuminated the ways in which mental health carers underwent action learning with the wider mental health system as opposed to the care recipient it presented as the learner (carer) having a clear role, purpose and responsibilities in the done action and subsequent learning (Bialka & Havlik, 2016; Fifolt et al, 2018).

*"With services, god with services it was so much throwing sh*t around till it stuck. Endless phone calls, finding the person who would listen"*

"Oh in the end I just went to the ccg. Yeah? [laughs] just do it. Go straight to the top. It worked for me"

6.2.4 Self-directive learning

Every interviewee spoke at length about the individualised learning they have had to do to be able to perform their role as carer – if they identified it that way, or simply to support their loved one. They defined self-directive learning as filling in knowledge gaps or seeking out additional information to what was provided. Experiential learning theory encompasses the risk that is involved in learning; incorporating novel, challenging, and differing experiences (Davidson et al, 2017). Mental health caring is often unpredictable (Mackay & Pakenham, 2012) with carers constantly adapting, undergoing new experiences and subsequent learning.

"So, so, yeah much is just google. The constant acronyms? Initialism? Constantly googling looking at those cause they [clinical staff] chat like you're not there"

"Oh yeah I had to learn it all myself. Not even a leaflet on their diagnosis. All the new [experiences] yeah I have to do it [learning] all again"

Experiential learning is often an emotionally intense experience, particular with self-directive learning comes constant reflection and action on that reflection. Larsen (2017) finishes saying that experiential learning is a ‘highly charged, emotional experience’ (p.279). For mental health carers, self-directed learning seems to be their preferred type of learning, as they actively participate in it. However, they can find this activity challenging and draining. It is important to note that self-directed learning can be time-consuming and require substantial effort, particularly when there is a lack of support from others or knowledgeable leaders.

“I mean I had to learn the entire system, not just like when are visiting hours and what am I allowed to bring, but also what is a mental health OT what’s a care co-ordinator, all the way to what on earth is an SSRI”

“Sometimes I wish it was all laid out for me, no winding down reddit threads from 3 years ago praying its not out of date”

Self-directed learning was the most expansive learning method identified, with every carer speaking at length about the topics, knowledge sources, and motivators that led them to doing it; with the motivators for self-directive learning dictated by the needs and desires of the care recipient.

Abuse #11

After the 11th time I was hurt bad enough for it to make me stop I googled help. Let me end this story now by saying I didn’t do anything with it. But I did look. It was almost more distressing to see so vividly how my situation was ‘bad’ all the support numbers materialising in front of my eyes was such, made evident in a way I wasn’t ready for that in fact this was weird. I deleted the search history afterwards out of some strange shame. It felt like I was googling a way out, and I hadn’t earned that way out yet.

6.2.5 Formal learning

A few (n=8; 3.2%) interviewees spoke about formalised learning experiences; including attending courses at recovery colleges or local carer centres, in school, attending training at a local pharmacy, and various one-off experiences with the person they support, their care coordinator or mental health staff member. Formal learning experiences were understood as traditional spaces for learning, often with a teacher, leader or facilitator.

“I was sent [by a social worker] on a course once about mental illness.”

“I went to a recovery college with [care recipient]. It was mostly for her but I found it helpful to see what she was learning and how I could fit in… it was like making a crisis plan”

There seemed to be no pattern in terms of who received a more formalised education about their caring role, however the formal learning experience that these interviewees identified tended to grant them an air of legitimacy in their role as a carer, given it had been acknowledged by a wider body and that their learning needs were attempting to have been met.

“I had like a 1:1 with his mental health nurse. I think cause I am a mental health nurse they saw me? But she gave me the full run down of the situation”

“My school did a PHSE session on young carers? If anything it made me feel even less like I counted as one”

Experiential learning theory discusses how learning experiences which have an instructor or are done with peers ensures deeper critical reflection (Asfeldt et al, 2018). Learning done in these spaces warrants the learner (carers) to critically reflect upon their assumed knowledge, allowing the carer a new level of self-awareness that comes with new or revised understandings (Hou & Pereira, 2017). For mental health carers, while they may not agree with the new knowledge they are equipped with in formal learning experiences, having the chance to reflect on their knowledge and it's beginnings in a space specifically designed for that purpose may have been beneficial.

"I went to one of the support groups things in [local mental health hospital]. What a waste of time, honestly I couldn't. The staff were so rude, I wanted to take over"

"I had support from a charity when I was in school… yeah I met other carers through that and it was nice. They, yeah, they weren't mental health but they gave me tips for managing school and stuff"

6.3 Mental health carer as a community of knowers

Considering both the data in the previous chapter about carers identity plays into their sense of self and contact with the social world and the data illustrated in this chapter around mental health carer ways of gathering, interpreting, and absorbing knowledge. Further this chapter illustrated how mental health carers co-learn with others. As we experience the world around us, we gather information, practice skills, and change attitudes with the meanings we attach to what we learn shaping our values, beliefs and subsequent actions. Merriam (2018) described aspects of adult education that became evident in mental health carers experiences. As a person grows, "his or her self-concept moves from that of a dependent personality toward one of a self-directing human being" (p. 85), much like carers moved beyond their first conceptualisation of the caregiving role to a complex interconnected set of self-narratives built with the carer recipient and solo.

For interviewees their self-image changed during this process as they came to term with their caring role. Throughout life, adults "accumulate a growing reservoir of experience, which is a rich resource for learning" (Merriam, 2018, p. 85); as interviewees became more attuned with themselves, their understandings of caregiving tasks, their identity, and how the care experience influenced their social worlds became deeper and more personalised. Interviewees social roles as a mental health carer, further, influenced their capacity and methods navigating different social spaces. The more problem-centred contexts mental health carers learning took place in, there was a stronger the motivation to find a solution or reach acceptance. The self-evident reasons behind carers learning had to do with the need for knowledge that would change the situation they found themselves in (Merriam, 2018).

What's more, as interviewees became more attune with how their caring role influence their sense and self and access to different social worlds, the more aware of the shared knowledge and understanding of the social world they shared with other mental health carers. This carer cultural knowledge starts with the collective component of cultural identity which involves an individual's psychological connection with a culture through the individual's personal endorsement of the culture's shared knowledge (Hong et al, 2007). It goes beyond the mere possession of knowledge about a culture. Rather, it is the alignment between an individual's personal characteristics and the culture's most central and widely shared knowledge. For example, mental health carers identification with a 'carer culture' could be dependent on the individual's personal agreement with the most important and widely shared values, beliefs, normative expectations and practices of the community. The more the individual personally endorses and enacts the shared cultural knowledge, the more the individual will identify with 'carer culture.' This may explain why some mental health carers who do less caring giving activities or those with limited interaction with statutory services are less likely to identify as carers or see their experiences as a source of knowledge.

Diary extract #46

What makes something culture anyway? Maybe this is my confused racialisation mixed-race-ness coming through but I've lived between cultures so long am I just projecting onto a space I feel like I can exist in? I guess I'm part of white culture given I'm in the UK but Black culture was always this illusive far away thing I didn't have permission to access? So, then carer culture? What would be the collective thing we all share? Just… distress?

Mental health carer learning was part of daily life, in a way that was less noticeable than going to class or reading or searching online for data; Interviewees had to understand how their caring role influenced their ability to engage in wider social worlds and spaces – whether employment, education, other relationships, or hobbies. According to Merriam (2018), "Learning in adulthood is often more than just adding information. It is also making sense of our experience" (p. 86).

Interlude 6

But they said you died, instantly?
They said it as if somewhere within you was the grace not to linger?
Like death pointed his finger at you and that was that?
Like there was no slow cause of death for us all to deal with?
They said is as if I should feel some sort of relief?
And I'm not saying I knew you better than most,
In fact, I am pretty sure I didn’t,
But I'm also pretty sure you'd rather be alive.
Just not haunted by the things that haunted you.
…
My heart is bending

7 Theory building on carer knowledge for social change or Is incremental social change enough for the mental health system?

Attempt #38

By number 38 I had begun to reconcile the black and white nature that came with being present in services. One day I was an expert whose opinion was valued and listened to, the next I was another risk factor to be considered. I'd had enough contact with those in power to know what they really thought, their inability to see past a scar covered, parentless, wildly teenager and see what I was. A young person, hurting.

Suicide attempt 38 was not anything special, it wasn't some monumental moment in my life. It wasn't triggered by anything significant it was just an attempt made out of a dark desperation that had always festered within her. I couldn't give the clinicians that asked me a reason – 'anything to go on' they had said. I had nothing. I still have nothing. Now, I'll always have nothing.

The observation and follow up conversation processes revealed more than just how carers have learned their knowledge and decision making around drawing on it. It also garnered information about how mental health carers position themselves as actors for social change and what they perceive is foundational to being an actor for social change. This chapter is reporting on findings which centre carers as social actors, in particular via co-production and involvement activities within mental health spaces.

Involvement of mental health service users and caregivers in service planning, monitoring, advocacy, research, and policy making activities has been promoted globally as a strategy for bolstering health, quality of life, and improving, particularly service users, mental health, self-esteem, and confidence (Omeni et al, 2014), Neech et al, 2018). While service users have experienced an increase in their involvement across all these aspects the UK mental health system (Omeni et al, 2014; Grundy et al, 2016), mental health carers have not had a similar experience. While individuals receiving services have witnessed a notable surge in their engagement in various facets of the UK mental health system (Jennings et al, 2018), mental health caregivers have not encountered a comparable level of involvement.

Experiential knowledge in mental health as dubbed mental health service users as experts by experience; starting thirty years ago with Beresford and Croft (1993) publishing their seminal book on citizen involvement in health and social care. Service user participation and involvement, with service users being labelled as experts by experience is implemented across different areas, such as the co-production of health and social services (Boyle & Harris, 2009; Needham & Carr,2009), research (Russo, 2012; Russo & Beresford, 2015) and social work education (Farrow & Fillingham, 2012; Robinson & Webber, 2013). In the field of mental health and social care, there is a demand for experts who have particular knowledge that is based on personal experience with mental health problems (Tokiko, 2016) but scholars have not undertaken as intensive an examination of the emergence of expertise by experience.

Examining mental health carers knowledge through a self-defined lens, where the focus is on alternate kinds of knowledge and knowing which differ from professional medicalised, academic or psychiatric understandings, (Freidson,1972) separates this piece of work from prior research on mental health carers which tends to focus on the 'burden' or 'stress' of care, often focusing on the physical aspects daily activities of caring and aspects of dealing with statutory bodies and institutions such as hospitals or social care - in the case of mental health this also includes the police (Albert and Simpson, 2015; Lavoie, 2018).

Interviewees spoke at length about the ways in which their knowledge had and had not been respected and taken account for within systems change and their experiences trying to be change makers. The data gathering and further interpretation from the study generated themes exploring the barriers and enablers mental health carers perceived to their knowledge and experiences being considered as equal and where relevant authoritative within the current mental health system.

Attempt #43

It was via ligature. Guitar strings from the ward guitar. Not an interesting of novel attempt. But in an NHS funded private bed. The after though, I was invited to feedback on ward safety, how can the ward be safer? Look at these harm blankets the trust invested in, we can wrap her up like a burrito and she can't get out. They said with glee? Like a modern straightjacket is some genius idea. Even more confusing other carers in the room seemed very pro. What? I still can't believe it.

7.1 Components of carer knowledge

While there is still a limited understanding of mental health carer knowledge, it is vital that those currently in power, such as researchers and policymakers have ways and means of listening and uplifting mental health carer voices (Kara, 2016). While I have argued for the importance of carer knowledge, we cannot divorce the fact it is situated within experiences of providing care, working with services, and experiences with mental health and mental illness. The carers of individuals with severe and enduring mental illness (SMI) shoulder a significant responsibility in providing care and support to their loved ones for extended periods of time (Rose et al, 2004), and therefore their expertise on the topic requires space and study.

There is a range of evidence available on the benefits of including mental health carers in statutory provided 'care' for people with mental illness. Whether it is in discussions on care planning (Cree et al, 2015), crisis planning (Brennan et al, 2016), or discharge (Petkari et al, 2021) for example. The concept of 'co-production of care' embodies a commitment to collaboratively and meaningfully work with both service users and carers. However, there has been limited effort thus far to co-produce services through the 'Triangle of Care' (Worthing et al, 2013), where carers contribute their own skills, resources, and expertise.

If traditional knowledge makers and knowers are valuing caregiver input (on their terms), it is imperative to consider both how mental health carer knowledge fits within our current lived experience paradigms and what constitutes the knowledge that traditional knowers are so keen to learn from. The analysis of the data, supplemented with conversations with the critical friends, and the self-interview data revealed a range identifiable or overt 'components' that make up carer knowledge.

7.1.1 Identity

The role of identity in carer knowledge needs to be considered from multiple perspectives. At a foundational level our class, gender, sexuality, disability, and how we are racialised are core sources of identity (Weber, 2010). Further the range of social determinants which are also considered as foundational mechanisms for knowing the self and relating to the social. With mental health carers drawing on experiences such as teenage pregnancy, menopause, extremely rural living, and being care leavers as examples of foundational social determinants which impact their identity perception.

Intersectionality attends to identity by placing it within a macrolevel analysis which ties individual experience to a person's membership to social groups, during a particular social, historical and cultural period (Wijeyesinghe & Jones 2014). An intersectional approach to knowing and identity forms a foundation for understanding connections between systems of power and privilege in which personal narratives related to identity develop, evolve, and are understood. Therefore, not only are the experiences of social groups complex and mutually consisted, so are the systems of power and privilege that strong shape person and group experience.

Self-harm #4

*I think I realised I was Black after the first time I hurt myself and the scars came in a darker brown than my skin. Not a sweet demure little pink – ew internalised racism there – but yeah. Turns out when you have myelinated skin it scars the same *shocked Pikachu meme*. I don't think I rolled my Blackness into my caring experience until much, much later. Thinking about how my treatment, my sisters treatment, was explicitly tied to the perceived deviance of our skin? I'm not sure what point I'm making. I guess just that even when given words like intersectionality or oppression its hard to actually draw those things into your understanding of yourself and an experience. Is that obvious?*

Considering the role of *social identities* (Tajfel, 1982) which are defined as the parts of an individual identity or self-concept that derives from their knowledge of their membership and subsequent value and emotion significance to that social group. Understanding mental health caring identities as socially constructed, means they do not stem from a natural state but as a result of a range of processes, including interaction with services, the joint identity built with the care recipient, and caring tasks.

Mental health carer identities were found to be constructed in relation to the care recipient through a series of negotiations between the carers personal sense of self, the care recipient, statutory services, and clinicians. Effective relationships contribute to a developing enactment of what a mental health carer does, rather than any prescribed or mandated definition. For mental health carers, the value they placed on the knowledge gained through caring related to their desire and/or capacity to identify as such. Those that were firm in their carer identity, were more likely to label their experiences both *of caring* and as *a carer* as a source of knowledge and knowing, as well as a reference for how they related to the social world. Viewing mental health caring identities as socially constructed makes the knowledge generated from them as socially situated, within history, culture, and society, as well as within personal identities and their intersectionality within our systems of power.

Considering the mental health caring identities generated through the data gathering in this thesis and the role of identity in critical perspectives to knowing the extent to which a person identifies with the label 'carer' impacts the extent to which they view their experiences as a form of knowledge. Those accepting of the identity were more likely to view their lived experience as something equipping them with a unique understanding and expertise of mental health and the mental health system. Those who rejected the identity of carer less likely to view their experiences of supporting some with mental illness a basis for knowledge, instead viewing it as a facet of their relationship with that care recipient. Those who rejected the identity tended to argue that their relationship with the care recipient was being labelled as 'special' by external bodies, such as local government or academia.

7.1.2 Ownership and sensemaking of story

The observational data revealed how mental health carers make sense of and reject ownership over the story of mental illness in their life. Where interviewees had time to create distance or separation from their lived experiences – whether physical distance, emotional distance, or time – they were more likely to have a less emotionally charged narrative about their lived experience. Interviewees hypothesised that having a less emotional connection to their lived experience positioned that knowing as easier to draw on and more valid. This speaks to the importance of emotions in the knowing process formation and having knowledge authority over an experience (Noorani, 2016). Where mental health carers highlighted the importance of emotional disconnection, it is likely this is due to needing to fit within our traditional knowledge making system which values objectivity over all.

"How are you meant to share a story anyway? I can't share mine without illustrating all the [pause] bad stuff [care recipient] did. But that doesn't make it less mine, just means I have to think about what is and isn't safe to share."

The mental health carers who felt they owned their lived experience and stories were more likely to have had time to reflect on their role within each story and interaction and their personal identity within their caring role. The observational data illustrated mental health carers process of sense making around specific stories – often concluding which parts of their story 'belonged to them' and which parts did not.

"Naturally there is lots of sides but I can only share the bits I was present for. My interpretation is way… way less favourable? Nice? Compassionate? To services than [care recipient]"

"Being able to let go of the can't complain, can't grumble rhetoric I had with both [care recipient] and services was a blessing in disguise… yeah the honesty made it [particular crisis] more mine or maybe as much mine?"

7.1.3 Capacities and the caring role within wider life

The role of cognitive, time, and space capacities in critical approaches to mental health carer knowledge involves reflecting first on the idea of personal capacity. Caregivers are often conceptualised to be lacking capacity – caregiver burden theorises how carers are so buried under their caring role they have no time for anything else (Jones 1996). Carer identity engulfment theory speaks to how the caring role becomes the cognitive dominance and carers lose capacity to conceptualise themselves in other ways (Eifert et al, 2015). The role of capacity, as considered through traditional knowledges, thus, focuses on carers lack of capacity rather than carers agency and decision making around building types of capacity into their daily lives, inclusive of their caring role. The role of capacity in carer knowledge was made evidence particularly through the observational data, where in conversation about changes to cognitive interview questions, participants would illustrate areas where they were equipped with or lacked different types of capacity.

"It's weird you use the word burden. I get what the research is showing but burden? Did you consider your sister a burden? I sure never thought of [care recipient] as one"

Cognitive capacity refers to how interviewees make space for their caring role within their wider selfdom. Different to identity, cognitive capacity as described by mental health carers in the study implies a level of agency to make decisions in their life i.e. holding cognitive space for decisions inclusive of caring not because or in spite of its presence in their social world.

Time capacities refer to how mental health carers manage their own and the care recipients time within different social spaces. Inclusive of the time caring activities may take, interviewees described the different ways their time was structured based on the care recipients needs and their person desires.

> *"During crisis time is an illusion. The days just meld into harm reduction and keeping him alive. Theres no work, no friends, no food shopping or fun…. Oh at other times its less overwhelming [pause] that?"*

> *"… these days its different. I mean I'm job hunting and don't really have to consider [care recipient] that much. Beyond like being nearby. I have all this space to just be"*

Diary Extract #61

I think time capacity is like when I went to dance classes and sometimes, I quit cause I said I didn't like it but really Ciera had done something insane. Kinda like what [observation participant] said… there has to be more than this? How do you make space for more than this? I never really did outside of interrailing.

Lastly, space capacity or proximity to the care recipient refers to both the physical proximity to the care recipient i.e. whether co-habiting, living in the same city, different cities or different countries and the ability to have physical separation in shared spaces such as the home.

> *"We were lucky enough to build a granny flat [laughs]. Its great [care recipient] gets a home that is entirely theirs and I get peace of mind. And no this still doesn't mean I think they are a burden!"*

7.1.4 Interactions with statutory services

Given mental health caring is performed in proximity with both the care recipient and often other caring bodies – whether mental health services, social care, or criminal justice to name a few – a critical theory approach to understanding mental health caring centres carers interpretations and interactions with statutory services as 'true' (see section 8.1.1 on social epistemology) and a space for learning and knowledge.

The data from the observations revealed how frequent contact with a statutory body such as mental health services or the welfare system was a significant factor in sense making around the caring role and knowledge generated from it. With interviewees describing both the content of interactions with statutory services and the impacts that, that contact had on their learning and understanding of their caring role.

> *"It was the police actually. Actually maybe they should be in the questionnaire but anyway, What was I, oh yeah erm the incompetence of the police really showed me how much I've got this. I know my sh*t when it comes to [care recipient] drunk in public"*

> *"… part of it for me was when her pharmacy checked with me about meds like I know anything about them? Well time to know about them."*

Having personal contact, or being in contact on behalf of the care recipient, or being in receipt of carers allowance (Gov.UK) seemed to grant mental health carers the confidence to claim knowledge. O'Reily et al (2020) describes parents deploying notions and normality and abnormality in order to get the desired outcome from statutory services, building on this, mental health carers who have undergone learning on how to 'play' the system and get their desired outcomes are more likely to identify with expertise. Further, carers who made an active decision to be present or to avoid statutory mental health services are more likely to identify themselves as experts. Carers with frequent contact, further, are likely to have reflected on that experience as expertise.

7.2 Carer knowledge within system change efforts

The emphasis on lived experience as a valuable source of knowledge has been shaped by self-help groups, mutual aid groups, patient activism, and the patient consumer movement (Epstein, 1995; Allsop et al, 2004; Hess, 2004). This importance of personal experience is not only recognized and driven by patient groups and third sector organizations, but also by government, policymaking bodies, and healthcare institutions (Martin, 2012). As a result, there is an increasing emphasis on capturing, comprehending, and utilizing patient and user experience to enhance healthcare services and policy.

Today, experience is widely recognised as a form of knowledge and expertise, as indicated by the pervasive use of terminology such as 'experiential knowledge', 'expert patient' and 'expert-by-experience' in policy documents and patient involvement initiatives (Greenhalgh, 2009; Toikko, 2016). However, there is little consensus on what experience(s) should be considered knowledge (Pols, 2014; Blume, 2017). Questions about whose lived experience is represented, how and by whom are often raised in relation to initiatives aimed at increasing public and patient participation (Horner, 2016 p.15-16). Moreover, it is widely recognised that knowledge and power hierarchies shape what and whose experiences are included in healthcare-related decision making, with professionals and those with officially recognised credentials playing a key role in consultative practices (O'Shea et al, 2019).

Considering how carer knowledge can be adapted for work within mental health services feels like a necessary contradiction for this piece of work. A contradiction because throughout this thesis process, I have heard from mental health carers, reflected with the critical friends, and through the self-interview and research diary processes, the importance of carer knowledge being considered unique, equal to other knowledge holders from different backgrounds and equipped with epistemological backing. That said, interviewees spoke at length about how their knowledge should be respected and taken for account within in mental health services, research and policy making, not just limited to their social worlds. The data gathering and further interpretation from the study generated 5 themes exploring the barriers and enablers mental health carers perceived to their knowledge and experiences being considered as equal and where relevant authoritative within the current mental health system.

7.2.1 Carers as equivalents not extras

This theme describes the experiences of mental health carers who had shared their experiences and knowledge in research and policy making activities. Interviewees described not being taken seriously, having their thoughts and opinions disregarded for other stakeholders present in the space. Interviewees go on to describe how they rarely saw their input reflected in anything created – whether academic report, policy document, or care plan.

> *"The whole am I meant to be in the room imposter syndrome kinda thing gets to me every time"*

> *"I mean doing this [participant observation] with you feels like the only time ever what I have said has been taken on board. I mean each questionnaire I can see what I have said and I get its simulated but like isn't that depressing"*

Interviewees spoke about how being treated as a lucky addition rather than an integral stakeholder in the mental health policy making space reflects how tokenised their involvement. Traditional hierarchical relations saw carers positioned as the least important stakeholder in the majority of mental health policy making spaces that interviewees found themselves in.

> *"One lady said to me: oh, how nice to have a carer along. But the meeting was about carers in ward rounds? Why was it nice I was there? Shouldn't it have been all carers?"*

One interviewee spoke about how they felt they had to mute or diminish their experiences when in policy making spaces less the professional stakeholders – in this instance researchers and NHS England employees – get anxious or defensive.

> *"I often feel that, if I speak like this – I mean you know me Cassie [researcher]. They get intimidated. They cling onto their power even more. It's a little cute if it wasn't so frustrating"*

Interviewees did highlight multiple involvement activities that have endeavoured to work towards creating equal partnerships – including carers. Working in ways that demonstrated professionals and clinicians value the expertise of carers and valued the carers themselves. This includes timely payments and non-monetary recognition such as additional opportunities related to the project, opportunities for growth, institutional support, and enough resources to feel heard and contribute to the extent that the interviewees desired without pressure. Participatory methods were also effective in subverting traditional power imbalances, "as knowledge produced from the project was owned by the participants," and avoided imposing researcher values (Williamson et al, 2020, case study, p4).

Diary extract #65
I think I'm at the end of my wick with involvement. Beyond just the usual suspects being at everything and I'm a usual suspect (ew) but how are we meant to hear diverse voices when the same people are always there. Diversity of experience for sure but also like just diversity. We keep hearing from the same Black folk and don't get me wrong [lived experience colleague] is a gem, a hero, but like there has to be others.

7.2.2 Carers draw on distinct and unique ways of navigating the mental health field

A prominent theme generated through discussions with carers on their experiences of involvement activities and spaces they draw knowledge for social change was that carers insights have significant potential to improve outcomes and steps toward equality in social change if carers are effectively equipped to speak out and those in power are willing to listen and learn (Morse et al, 2021; Kara 2016). Indeed, bypassing mental health carers unique experiences created easily avoidable barriers within research, policy, and the care process. Where the interviewees were given input into research and policy making activities as early as service users, they described being able to ensure the policy stayed relevant and reflect their priorities.

> *"I remember one time, she [policymaker] made, made this point about section 17 and I just thought she doesn't have a clue. She thinks they actually bother to call carers to tell us? Cause they [wards] don't"*

Interviewees further reflected on how their involvement increased how ethical research studies came across, and the breadth of policy making activities. They descried how as carers they were able to highlight potentially sensitive issues that had previously either not been considered, or other stakeholders were unable to verbalise effectively. Interviewees went on to describe how they believe their experiences could have been more effectively used and adapted across system change. It is hypothesised, therefore, that having epistemological backing to carer lived experience may provide an academic foundation for carer knowledge to be legitimised.

> *"Cause I approached it as a carer I was less tied up in all the politics so could say things without fear of pissing someone off or fear my treatment might be removed or something*

which obviously sucks for service users. If they actually respected literally any perspective except their own it might be different"

"It's not like service users, ya know. When I attend stuff 'as an autistic' the reception to what I say is so different even I notice [laughs]"

Interviewees describe their experiences of being involved in analysis and dissemination of data towards policy making in mental health. Discussing how their involvement often reframed taken for granted understandings about the mental health system from both the service users, professionals and clinicians and how they are ideally placed to interpret and translate a service users' narrative where there is obvious animosity between service users and clinicians.

"I've found myself a middle-man during the [charity] self-harm guidelines workshop. There was this… [tension?] yeah it was like heavy when [service user] bought up being discharged from hospital after presenting with self-harm. This clinician they just kept denying it happened"

"I blame the ADHD but my patter recognition is amazing so like, obviously service users and services want the same thing and they are saying the same things but just not getting the others side. I just get it and can say it. And being a carer I'm 'neutral' so"

7.2.3 Carers as change makers and motivators for change

Mental health carers as change makes and motivators for change was a significant theme which directly linked to the subsequent substantive theory generated from this thesis being the need for a critical theory of carer knowledge. Critical theory is primarily motivated by different knowledge's creating change for their communities (Kemmis, 2008), this theme is illustrating how mental health carers desire desperately to make change in their communities and with the care recipient.

"If they trusted me I'd make so many changes. Firstly, making care coordination actually do I mean anything. But they don't trust carers. We are a free resource nothing more"

"I just feel like me and [care recipient] could do it better. Let us plan everything and have services just play along for a bit. Can that be your next project?"

Multiple interviewees spoke about being peer researchers or carer researchers on projects done in policy making spaces. They describe their motivations as:

"*It felt like our family's experience could be of some help to other families in the future. I'm not sure now"*

"It was flattering to be asked for sure. Though who knows how much I impacted the study given I just like read stuff"

Due to the personal importance of the practical outcomes of research, when this was delayed or constrained, this was:

"frustrating waiting for results to be gathered and disseminated, especially when you feel so connected to the research subject. We realised that the speed at which we want to see the results of research shared with the wider public can be at odds with the work the research team has to do."

Carers support "*elevates respect for the project,"* and *"increased staff buy-in"* (Mitchell et al, 2020, p5). Mindfulness of carer involvement, by also collaborating with professionals and service providers during the research, was endorsed to enable research to lead to change (Walmsley & Mannan). Directly presenting to decision-makers was also highly effective; *"youth got up there to present, it was meaningful for the adult stakeholders who came to hear directly from them about their experiences,"* (Elliot, 2013, p13).

7.2.4 Building on existing competencies

For interviewees who used their lived experience to define their career direction, there was clear evidence that they used their experiences to enhance competencies; particularly among activists, researchers, and mental health clinicians who took part in this study. Although all interviewees were over the age 18, some spoke about how involvement activities had influenced their career paths – going into research or charity sectors primarily. What's more those who considered themselves 'good' at doing involvement activities describe it as a unique, specific skill set – being able to effectively, purposefully share lived experience towards policy making.

> *"I builded this network through various stuff. Then when I finished my A-levels I was able to reach out… mostly twitter to be honest. But I got my first grown up job that way [laughs]"*

Stepping into lived experience led work, whether in peer support, third sector, academic or policy making roles, mental health carers spoke to the insecurity that their knowledge was not 'valid' or the right type for the space. This again speaks to the lack of theoretical foundations around carer knowledge acting as a barrier for mental health carers knowledge to be effectively listened to, supported, and learned from.

> *"I've been in mental health spaces where I was definitely so not welcome. Some were activist space which I mean I get why they are gatekeeping but in academic spaces I mean it sucks. Maybe its imposter-y syndrome on me but like you could tell they didn't care about carers. Irony et al"*

> *"low key this is my career"*

Developing skills in research and advocacy was "capacity building, enabling parents to begin to lead change in their own localities…expand their collective power" (Walmsley & Mannan, 2009, p274). The groups formed for the research went *to raise the profile of caregiving issues in their community, and to initiate efforts to address those issues"*

7.2.5 Being controlled

This theme referred to actions and situations that limited the interviewees' ability to contribute and make their own decisions. This includes experiences such as being missed out of key communications, not invited to events or discussions, and when in policy making spaces not having accessible ways of contributing. The interviewees found themselves positioned without influence; but their presence increasing buy-in and success of projects.

> *"There was one I did with [local CCG]. I ended up emailing them about what happened cause I never heard from them after the first meeting. [What activity was it?] We were co-designing this leaflet for [ward] and when I looked at the leaflet they were all loud and proud about involving carers? But I wasn't involved. I was barely invited"*

The interviewees expressed how professionals seemed to avoid providing adequate information or information specific to carers, instead giving information they would provide to service users or the public. The consequence of this lack of information found carers being unable to provide fully informed opinions or in some cases consent to the policy making activities at all.

7.2.6 Feeling respected as a person

‘Feeling respected as a person’ refers to the importance of mutual trust and to be met with respect for who you are, not just a carer supporting a service user with the desired experience or diagnosis. Interviewees described experiences of feeling invisible or silenced as if their lived experience held less value. Particularly to health sciences researchers and policy makers who often needed some other specific facet of their identity or skill set as to afford the carers respect.

“Whenever I introduced myself as a mental health nurse they respect me so much more. I always reiterate I’m a carer first but… yeah they don’t talk to me after that”

“Since I started my PhD I do feel like they listen to me more. Like mum is really bad with [care recipient] and her team so it’s sort of fallen to me? And now I’m doing a PhD it feels like they respect me and don’t just ask for mum all the time”

Furthermore, the users needed to feel that they were trusted by staff to participate in and influence their care. When users and clinicians were able to listen to each other and to accept their different perspectives, they were able to acknowledge and understand each other. There was also a need for a sense of common struggle in the care relationship with the professional in order to develop a platform for change. The ability to work together towards common goals created a feeling of equality between users and clinicians

“When I was in a NICE guideline session the… host person skipped over me to ask [care recipient] everything. It’s like I was there for emotional support only not cause I had ideas’

‘Of for sure… like I feel like I have to prove myself so much more… yes! It leads me to overshare so much I wish I didn’t but I panic”

Diary Extract #73.5

Respect still tastes weird on my tongue. In my current mood I’d say those in power never respected me. If I was feeling more sympathetic maybe I’d say they respected me after I proved myself. I dunno.

Interlude 7

I keep re-reading the ending of your life expecting another chapter.

I keep expecting laughter.

I unexpected the success of this attempt so hard

8 years later part of me still

Believes I can make it not true.

You were the Gameboy advance, Pokemon training, anime protagonist of my youth

8 Substantive theory and discussion: Toward a critical theory of mental health carer sense making, knowledge, and its influences for social change

Self-harm #38

I was 16 when I spent 2 hours begging my teachers to let me have my phone during my GCSE exams. I imagine they thought I was needy, a phone addict back before all young people were overly attached to their phones. They said no naturally. I didn't have the words, the authority, I couldn't articulate myself in a way they would have understood. How do you explain to your examiners you aren't going to cheat, you're not anxious about your English lit exam. You're anxious something irreparable will happen and having access to your phone might prevent it. My sister died that day and my phone was in blazer pocket. Her suicide 'note' in the form of a text message waiting silently for me. Asking me to answer or this was it.

Spoiler alert this wasn't it. No this wasn't her final suicide attempt; she made many more. This wasn't the first one I carved into my skin either but it was the first one which landed me in hospital next to her. Tattoo ink now covering the stitch marks, the staples, and scars that hold the words I never figured out how to utter to my teachers.

The focus of this chapter is to illustrate the interpretation and theoretical renderings of the findings as presented in the prior three chapters. I will establish the relationship between the role of mental health caregiving and it influences on individuals' social worlds, before moving to illustrate how the caring role establishes a foundation for knowledge which can be used in research and policy making. Thus, the following substantive theory aims to provide a deeper understanding of this phenomenon which is gleaned from the perspective of mental health carers themselves.

The constructivist grounded theory approach taken in this work centred the realities of mental health carers as a community, co-learning the findings inclusive of my lived experience. The substantive theory generated is based on the analysis and interpretation mental health carers sense making around their experiences including then meanings, processes, and contexts they understand their role and knowledge. This part of the work also acknowledges prior theoretical works, locates this study within the relevant discourses, and positions the new substantive theory in relation to those theories – thereby showing where the work aligns with or extends relevant literatures and theories (Charmaz 2006, p.169).

"The contributions carers can make… are only beginning to be recognised" (Kara, 2016, p.86)

In this thesis, critical theory is understood as knowledge produced by marginalised groups to understand, develop, and change their situation. There is a narrow and elite view of knowledge, both in terms of the settings where knowledge developed and in terms of ontology which critical approaches aim to interrupt (Collins, 2004). Knowledge arises in the academy, its implied, and this is its natural home. Natural and prized. Proponents of critical theory seek primarily to support, uplift, and platform knowledge of oppressed people in our society; this could include disabled people, racialised folk, mad people, or multiply marginalised people (Creswell, 2009).

The studied phenomenon of this research was mental health carers sensemaking around their identity, caring role, and its impacts on their social worlds and social change. Analysis of data illustrated how mental health carers draw on their sense of self, their learning from their caregiving role, and interactions with the care recipient and external services as foundational knowledge making experience to motivate social change. Mental health carers undergo reflexive and doxastic practices in which they reflect on their lived experiences, sense of identity, and positioning within their daily lives, both internally and with the care recipient and through co-learning with peers.

The analysis of this experience generated a critical conceptualisation of mental health caring and the need for a critical conceptualisation, drawing from mental health carers lived experiences. This critical conceptualisation of mental health caring combines the social identity of carer, their relationship with the care recipient, the nature of care itself including the ‘action of caregiving’ in this thesis referred to as caregiving tasks, with the social domain in which the caring relationship is located in. Going on to illustrate how (1) a critical theory toward mental health caring is beneficial and (2) the importance of understanding mental health caring through a justice driven lens.

The findings from this thesis, therefore, exist primarily to advocate for 2 specific things; the value of understanding mental health carers experiences through a critical lens, and equipping mental health carers to conceptualise their caring role as a foundation for knowledge and their power for justice and social change within the wider mental health fields and caring communities (Josewski, 2017). Considering critical knowledge and ways of knowing from communities who are marginalised, not by western traditional forms of knowing, is the context for this chapter and the underpinnings of the substantive theory of this constructivist grounded theory.

8.1 Towards a critical theory of mental health caring

Reflecting on the perspectives provided by mental health carers in this thesis, psychiatrisation, individualism, and sanism are key for understand a critical social justice lens to mental health caring. Psychiatrisation represents a structural form of oppression and inequity that, alongside other forms of discrimination, systematically pathologizes, stigmatizes, and marginalizes individuals diagnosed with mental illness (Liegghio, 2013). While, sanism refers to the systemic forms of discrimination arising from dominant beliefs regarding rationality, normalcy, and mental health (Diamond, 2013; Perlin, 2003). For the carers in the study, sanism is closely intertwined within their lived of the care and the care recipient (Runswick-Cole et al, 2024) with sanist myths dominating the social discourse and practice so that ‘mentally ill’ people are constructed as ‘different’ and ‘less than’ other people; they are ‘dangerous and frightening’ and ‘incompetent’ (Perlin 1992, p.45-46). These myths were tangled within mental health carers understanding of the role, their sense of self, and their access to different social worlds. Mental health carers spoke about the secondary discrimination they experience around not being viewed as valid knowers and respected in the knowledge creation process.

In keeping with this characterisation of the types of mental health discrimination that position mental health caring as both serving as part of this oppression and of being oppressed, it is important to consider mental health carers inequities as they emerge from intersectional and post-colonial frameworks. Black and Indigenous feminists and intersectional scholars centred understandings of mental health and care in multiple and simultaneous intersections with social inequities, including racism, classism, and genderism (Collins, 2004; Hankivsky et al, 2012; hooks, 1989; The Care Collective, 2022).

Attempt #26

It was around this point I first questioned diagnosis. Not in the way I do now which is an intersectional deep dive into how diagnosis maintains class division, but within the psychiatric label. I was 15 and pondering if depression and anxiety were the right labels for my sisters' experience. They were the same labels I had and, well, its not like we experienced much of the same stuffy beyond self-harming. I asked her IMHA about it, not in a formalised lets challenge a diagnosis way, in a I'm 15 and this feels like a contradiction I'd like explaining. I remember this IMHA looking at me and saying stuck with depression and anxiety, its easier on all of us if its nothing more severely. Sanism… am I right.

Fundamentally, it is vital we recognise that expertise comes from individuals and communities in specific social, cultural, and economic environments, rather than the world being a blank slate in which value neutral technocratic solutions can be imposed (Steinvorth, 2008). And while steps forward have been made people from communities that are oppressed, with activists, with critical scholars, working tirelessly to give institutional legitimacy to critical knowledge, ways of knowing, and lived experience led theories, more steps need to be taken for all oppressed communities.

Some will argue effort is consistently made to listen and empower voices from lived experience perspectives in mental health research, policy making and service design. Lived experience is the topical term with many academics, ministerial policies, and third sector agents increasingly claiming they have included people with lived experience in their work and among their authorship (Holmes et al, 2020). With the *Lancet Commission on Global Mental Health* argues that "engagement of civil society with mental health should be increased, in particular of people with lived experience of mental disorders' and a recent Editorial in *Lancet Psychiatry* acknowledges that "global mental health" contains assumptions about knowledge and expertise that are inimical to the very populations it purportedly sets out to help (Patel *et al*., 2018). But, as discussed throughout this thesis, this effort has rarely been extended to mental health carers.

Critical theory informed by social justice, suggests that knowing is closely connected to conceptions of who human beings are (identity), how they view reality itself (connections to the social world), what they actually do (action) and what they might become (knowers) (McAdams & Cox, 2010). In the development of critical perspectives on mental health caring, this is an important point to note. The diversity of information that arose across the empirical work in this study is understood through the above lens. Mental health carer's identity, the various components that they interact within mental health caring role, and how these lead to mental health carers make sense of their caregiving as a key influence in their connection to the social world.

Based on this conceptualisation, I propose theorising toward a justice-driven critical theory understanding of mental health carers, which aims to make visible a mental health carer led conceptualisation of the experience of caring; positioning mental health carers as knowers, within a system where their knowledge base has little clinical, academic, or classically lived experiential backing. The substantive theory presented argues for mental health carers as community, who can and should be using their lived experience to generate knowledge. Mental health carers are knowers in their own right and adopting a critical lens allows for understanding mental health carers desire to be change makers – whether in policymaking, service design/improvement, or research spaces in the mental health field.

8.1.1 Critical theory led carer knowledge as a social epistemology

Considering knowledge gain as a socially situated activity (Vaditya, 2018) mental health carers knowledge should equally be viewed as socially situated - gained through personal reflection and co-learning with the care recipient that is influenced by external factors. Much like other critical theories which argue for the empowering of oppressed communities to generated knowledge about their experiences, a critical mental health carer knowledge as used to understand the social world, research, and policy making provides a framing for carers knowledge to be understood as distinct from those with lived experience; a knowledge basis that is unique and thus a valuable resource.

As the outcome of the constructivist grounded theory, a critical carer knowledge was illustrated through ‘involvement’ activities. Currently, mental health carers are not being uplifted and platformed to create their own knowledge and understanding of our social world, and this study illustrated how cares are being excluded from knowledge making via a lack of understanding and guidance on their inclusion. Somers and Gibson (1994) remind us, ‘every knowledge discipline needs an “epistemological other” to consolidate a cohesive self-identity and collective project’ (p. 38). Carer knowledge as understood through a critical lens one method of conceptualising and providing an epistemological framework for the categorising and legitimising caregiver knowledge within academic spaces through to social change spaces.

Understanding carer knowledge as a social epistemology, we are invited to focus on how mental health caregivers’ experiences, feelings, and practises intersect with and contrast with other kinds of knowledge within mental health and lived experience spaces. In social epistemology, the concern does not lie with whether things are true, but with the ways human processes enable certain things to be accepted as true (Latour and Woolgar, 1986) and how others are formulated as false or flawed (Gilbert and Mulkay, 1984) within particular social groups. Extending this to mental health carers knowledge, presence in social worlds, and subsequent role in social change and mental health research and policy making, therefore, critical care lens provided a framing for carers collective knowledges and understandings to be viewed as true, regardless of where they differ and contradict from classical knowledge bases like clinical knowledge or other critical lens like lived experience or survivor knowledge and research.

Hospitalisation #4

I tried to tell the truth thought I didn’t tell them why I was in A&E. Why at 13 I’d showed up alone. Off a bus that I’d left a blood stain on fading seatings. But they weren’t concerned with my truth. They had theirs and it didn’t matter I was weaving a story in contrast. I could have begged them that the violence they perceived had landed me there was not the case but the social workers decided that, that was the truth regardless.

Connecting social epistemology to social theory of knowing within health spaces, thus, enables us to consider the mental health carers experiences in healthcare settings as something distinct to their community. We can reflect on carers difficulties of gaining access to services, managing the challenges of being a carer, or working within the frameworks of assessment and service delivery as problems of *knowledge*. Not in the simple sense of carers and service users being-under-informed and in need of expert enlightenment, but as active sense-makers and knowledge makers whose involvement in their communities of knowing enables them to become social actors or agents in their own right. Critical theories understanding of knowledge generation further underpins the idea that carers are knowers with a unique understanding and connection to the social world shaped as much by their caring role as other facets in their life (Haraway, 1998).

In addition to recognising the significance of examining the individual and collective development of knowledge in relation to the act of caring, it is also valuable to explore the crucial role of socially embedded knowledge in shaping the practical aspects of care. For example, Mazanderani et al (2019) assert that informal carers play a vital role in managing health-related knowledge for the care recipient and Fuller (2016) suggests, knowledge in mental health encompasses much more than information about specific subjects such as risks, illnesses, or treatments. This work underscores that carers are not merely a group who need to be filled with expert-sanctioned knowledge, but rather are actively thinking about thinking and seeking to manage knowledge, both their own and that of practitioners with whom they come into contact.

8.1.2 The role of epistemological domination in carer knowledge

The complex reflexive work mental health carers undergo in making sense of their experiences as a foundation for knowledge led to the identification of a set experiences which were formative in knowledge gaining but they constructed them as hidden and/or occluded knowledge—things that no one tells you about or which cannot be disclosed to others. These occurrences were labelled as tensions and are understood through epistemic injustice (Fricker, 2007) and epistemic domination (Vaditya, 2018).

Epistemic domination (Harris, 2022) is a useful framing to understand both what constitutes mental health carer knowledge and the barriers facing it. A critical theory approach to carer knowledge pays particular attention to the kinds of knowledge experienced, assembled and curated by carers, with the primary tension laying in the ways in which a mental health carers knowing exists at odds with ‘official’ versions, or versions of truth that had significant amounts of academic backing, such as from mental health clinicians and psychiatry, mental health service users and service user/survivor research (Connor-Greene, 2006). To interrupt this epistemic domination, Vaditya (2018) argues for the value in examining the kinds of situated and socially construct knowledgeability of groups such as carers who classically have had fewer opportunities to contribute of official discourses in academia, policy making, and service design activities.

Foucault developed the view of knowledge and science, arguing that practices of so-called knowledge-seeking are driven by quests for power and social domination (1969, 1975), arguing that those in power will only novel ways of knowing when it directly compliments and benefits their position. The data in this study describes the way carers had been, in their view, excluded and marginalised as a result of other dominant parties such as clinicians placing constraints on their knowledge, via minimising information and resources they had access to and belittling their knowledge and experience.

The social construction of knowledgeability (Brown, 2021) further explains how those in power prevent other knowledge types from being valued. Traditional knowledges in mental health are socially situated with clinicians – or professional modes of knowing, whether psychiatry, or psychology, and mental health service users’ knowledges situated within clinical settings (Tuana, 2006; Vaditya, 2018) but mental health carers knowledge lacks a situatedness or setting, instead being based entirely within the knower.

Critical approaches make space for learning how to tell one’s story in a more nuanced way. The value of story within critical and justice driven approaches to mental health caring Adopting a critical approach to mental health carer knowledge offers news way for carers, service, users, clinicians, academics, and policy makers to work together, all as knowers, rather than carers being considered as almost experts whose knowledge needs ‘topping up’ (Brown, 2021).

A critical theory driven approach to mental health caring begins, therefore, to understand and investigate mental health carers as knowers and social actors in their own right. Offering a framing to understand how the explore, attempt to work around, subvert and challenge epistemic in justice. This parallels what Isham et al (2020) call epistemic injustice, where some of their carers' experiences where hard to represent in mainstream health discourse, lacked widely accepted terms or concepts or were unlikely to be taken seriously by the gatekeepers of knowledge (see section 8.2.5).

8.2 Critical carer knowledge and justice driven models of understanding mental health caring

The data from this work repeatedly presents rejections of the traditional language and ethos of care, preferring instead to consider a 'justice' model defined by self-determination, control/parity, and clearly defined knowledge. Interviewees drew directly and indirectly upon social justice lens, understanding mental health caring as an experience which with severe impacts on the self-sense of self and access to different social worlds but needs to be understood external to burden. To explore a justice driven model of care it is necessary, first, to theorise differing understandings of social justice in their relation to transforming inequalities.

8.2.1 Models of social justice and care ethics in mental health and care

While the paradigm shift from a predominantly biomedical understanding towards a broader social understanding of mental health and illness has been instrumental in establishing a growing interdisciplinarity between health sciences and social sciences, such critical interdisciplinary exchange has rarely been extended to questions of applied moral philosophy (Ruger, 2010). Meanwhile, theories of social justice within the literature on moral and political philosophy have historically been silent on the topic of health and care (Peter, 2001).

Historical and contemporary theories of social justice have often revolved around the (re)distributive justice paradigm (Beauchamp & Childress, 2001). At the core of this paradigm is concerned with the "morally proper distribution of social benefits and burdens among society's members" (Young, 2011, p. 16). What counts as fair distribution, however, varies between social justice theories and discourses including utilitarian, libertarian, and egalitarian theories (Beauchamp & Childress, 2001). Each propose differing criteria, applications, and justifications for conceiving social justice in mental health. I will be extending this to mental health caring, thus.

Utilitarian approaches to social justice focus on maximising the common good, placing premium on social utility to the exclusion of any concern about the distribution of benefits and burdens (Held, 2005). Utilitarian perspectives to justice and social order remain deeply engrained in public policy (Venkatapuram & Marmot, 2009) in particular mental health policy (Ibell, 2004) with Wodak (2007) illustrating how utilitarian arguments dominate current discussions about harm-reduction in substance mis-use and self-harm, showing little or no ethical concern for the injustices and structural inequities that make up the social context of substance-use and harm-reduction practices (Pauly, 2008).

Libertarian rights-based approaches "endorse[s] individual rights, individual freedom, and the liberal idea that people ought to be free to determine their conduct and lives as they see fit, so long as they do not violate others' rights," it is often referred to as a strand of liberalism (Palmer, 2009, p. 123). Similar to human rights–based approaches, which are increasingly evoked by health inequities scholars to portray inequities in health as human rights violations, a libertarian view focuses on rights as the relevant unit of social justice.

Egalitarian theories of social justice acknowledge that people's life opportunities are not utterly under their control and that it is therefore up to the state to equalise differences in advantage and disadvantage that lead to unfair distributions of opportunities and outcomes (Beauchamp & Childress, 2001). Within this conception, issues of inequalities in health are firmly placed within the category of natural goods – that is, outside the disposition of society and the realm of social responsibility. Within this, Rawls's theory of justice argues that social inequalities are inevitable in our society's current structures, arising from and determined by the random distribution of resource/goods both the social and natural worlds (1971).

This conceptualisation positions health in the category of natural goods; slightly awkward given, as Van Niekerk (2005) states, systems have authority to distribute health care equitably, particular as the majority of adults are healthy, able bodied, and autonomous, Rawls's (1971) development of social justice as fairness, centres on the individual rights and duties of independent or autonomous moral agents. As care ethicists have illustrated this morality is problematic because it implicitly construes dependency as a difference measured against a standard of normal, as in "normal mental health" or a "normal healthy body," and fails to take into account the realities of human interdependence and "the kinds of needs [and responsibilities] that arise from these experiences" (Hankivsky, 2004, p. 42; Sherwin, 2002, 2012).

In discussions of mental health caring through a critical lens, it is evident the action of caring and position of carer does not easily fit into any one model of social justice. Indeed, Brock (2000) points out that the lack of considerations around both health and care in equity/social justice literature has enabled the health sector to "focus on healthcare to the exclusion of other factors that have greater impact on health and health inequalities" (p. 286) – including the power providing care has over someone's health. Where providing care limits a person's ability to develop a foundational identity, have access to economic and educational opportunities', and subsequentially limits their ability to be seen as 'knowledgeable', as Fraser (2003) points to, unpaid caring becomes a significant factor in the redistribution of wealth.

8.2.2 Social justice as it pertains to mental health caring

A justice driven model of mental health caring is grounded in equality, equity and social justice through both parity of knowledge and parity of participation in different social worlds (Fraser, 2003). The key dimensions preventing justice driven understandings of mental health caregiving lies in the redistribution of wealth in terms of economic, political and cultural relations. In the creating of a normative framework for the three dimensions, Fraser (2003) argues for the notion of parity of participation as the central argument for her conception of social justice; stating "justice requires social arrangements that permit all (adult) members of society to interact with one another as peers" (p. 36). Two conditions are prerequisite for participatory parity: "First, the distribution of material resources must be such as to ensure participants' independence and 'voice.' Second, the institutionalized cultural patterns of interpretation and evaluation express equal respect for all participants and ensure equal opportunity for achieving social esteem" (p. 5). To ensure parity of knowledge and participation in social worlds, mental health carers need material resource to ensure both their independence and their voice is heard within our power structures (Lynch, 2013).

Firstly, given our current economic structures institutionalise deprivation, exploitation, and gross disparities in wealth, income, labour and leisure time, without distribution of resources to enable mental health carers independence to become knowers, exist within different social worlds and have parity of social interaction. Second, is the importance of parity in social status. A justice driven understanding of mental health caring insists on equal respect and equal opportunity in achieving social esteem. It would consider carer knowledge as something foundational, valuable, and held with parity to lived experience, clinical professional and academic ways of knowing (Kara, 2013; Beresford & Croft, 2001). To achieve this, the institutionalised patterns of cultural value that systematically belittle some categories of both people themselves and people's ways of knowing, thus denying them status and membership of social worlds. Finally, the political constitution of society must be structured in such a way to create equity of access to information that is traditionally held by those in power – whether electoral, media, or heads of systems. A justice driven understanding of mental health caring cannot be achieved until the systems which systematically deprive some people of their fair chance to influence decisions that affect them on all levels is dealt with (Fraser 2010: 365).

The caring relationship is a complex and often difficult relationship involving power and dependency. Although the provision of care is frequently portrayed and can be experienced as a process of control – where the caregiver is an 'agent' providing support to a passive recipient (Tronto, 1991, 1993). The data in this thesis however illustrates how mental health caregivers themselves are rejecting this as unrealistic. A justice driven understanding of mental health caring centres equality between caregiver and care receipt; positioning care is possible without becoming oppressive for both the care recipient and those 'doing' care (Kroger, 2009; see section 8.2.3). A justice driven model for unpaid care argues for fostering care-oriented environments led by those with explicit carer knowledge to challenge our traditional structures can thus alleviate the individual burden of care, while simultaneously propagating justice, wellbeing and a sustained sense of solidarity.

Acknowledging the connected experiences between mental health carers encourages a concern for the collective and caregiving action to address identified sources of inequity (Held, 2020). This study illustrated the first steps in this journey, demonstrating how mental health carers learn from and with each other. In many societies, caregiving is regularly conceptualised and experienced as a burden, in large part because the inequitable distribution and inadequate compensation of caregiving labour. However, through de-ideologizing and de-alienating practices, care is no longer relegated as a sole concern of families and intimate circles but has the capacity to become a concern for the community and broader society (Lynch, 2013). Mental health caring has the potential to become a collective activity.

The emotional relations where loving, caring and solidarity are internally placed and externally grounded constitute discrete fields of social action. Social justice issues are not just confined to questions of redistribution, recognition or representation, they also involve discrete sites of relational practice that impact on parity of participation, a principle which Fraser (2003) identifies as key to determining what is socially just. In other words, to understanding mental health caring and care as place for justice, we have to consider both the world of care and actioning of caring are not isolated from the rest of the social world. While care may take place within peoples own social worlds, they are not some semi-autonomous spheres where people dip in and out of at their leisure. Caring is a deeply personal process interconnected with economic, political, and cultural relations; where inequality is present in the latter it can undermine the capacities and resources to do love, care, and solidarity work (Baker et al, 2009).

Diary Extract #104

Let's reflect on if my life would be different if I hadn't ended up caring for someone with a severe mental illness? Yes… next question? In all seriousness I wonder if I would have had more choices? Intersectional theories when badly understood says no? I'm Black, I'm visibly *disabled, I'm not straight and then the social determinants side. But has caring been the thing that has had the most significant impact on 'all my lost potential' to quote my teachers? Is it none of those things or all of those things and caring? I feel like I'd have had a lot more authority over my life if she was well. Who knows.*

Building upon calls for a politicized ethics of care, a liberatory ethics of care encourages both integration of care values at the structural and policy level, and necessitates prioritisation of voices and perspectives that have been underacknowledged and underserved in the existing sociopolitical order. In this sense, a focus on care begets and maintains iterative movement towards collective liberation.

8.2.3 Giving and Receiving Care: Care as preforming oppression and caring as being oppressive

In response to the shortfalls in theorising social justice within the redistributive justice paradigm, a number of alternative ethical frameworks have been proposed. One such framework centres on an ethics of care, which emerged from a recognition of women's experiences of caring responsibilities, and of interdependent relationships as being significant spheres of moral practices in the reality of most women's lives (Hankivsky, 2004; Llewellyn & Downie, 2012; Sherwin, 2002, 2012). In this context some feminists and care ethicists have argued for the moral superiority of particular caring relationship such as the mother-child. However, more recent approaches argue for the focus being on meaningful relationships between two parties and two distinct ethics of care and justice (Hankivsky, 2004; Sherwin, 2002).

The intersectionality of inequalities in relation to caring are played out in justice domains. Unpaid care work has serious health implications for women who make up the majority carers (Cannuscio et al. 2004; Hirst 2003). Inequalities compounded by intersectionality are further deepened by caring responsibilities which, as evidenced in the data, limited people's ability to exist in a range of social worlds such including paid employment thereby impacting on their economic resources and indirectly generating are/distributive injustice in the economic sphere. Considering an equitable redistribution of power, Rummery (2009) draws attention to the way in which the commodification of care has led to the exacerbation of social divisions between both wealthy and poor carers *and* wealthy and poor recipients of care. More than economic resources, however, the data illustrated those with mental health caring responsibilities are limited in their abilities to learn, to earn a living, and thereby to exercise power and control over their lives, including through having sufficient economic resources (Feeley 2009; Lynch et al. 2009) with these disadvantages being all the more present with mental health carers that hold intersectional identities and experience multiple oppressions.

Adopting a critical perspective to mental health carer knowledge, challenges the perceptions of caring being an oppressive practice and carers being positioned as holding power. Feminist and disability rights scholars offer two perspectives on wider caring and its role as both oppressed and oppressive. With feminists' writers arguing for the recognition of the ethic of care and a valuation of its practice (Gilligan, 1982); writers from feminist social policy perspectives argue for care being conceptualised through labour theory – suggesting that care policies have become dependent women providing their labour either 'free' in the private sphere of the family, or in the 'public patriarchy' of the paid care sector (Daly, 2002; Daly and Lewis, 2000). By understanding care through a labour perspective, we are able to position it as an oppressive practice, as Lewis (2006) point out the feminisation and under-valuation of care work drives down wages and leaves carers open to exploitation and abuse.

On the other hand, disability rights authors such as Morris (2001, 2004) have argued that the arguments for increasing the valuation of care have predominantly focused on the theoretical and empirical viewpoints of caregivers, while often overlooking or minimising the perspectives of those who receive care. When we examine the role of caregivers, it becomes evident that care situations often involve a significant imbalance of power; for instance, parents typically hold more authority than their children, older siblings hold power over younger siblings, and aging parents tend to lose their power over their adult children. Disability rights perspectives point out the risk of violence, oppression, and coercive practice within these dynamics (Kittay, 2011).

Attempt #47

This one stays with me. It wasn't horrific or anything it was an overdose of the pets medication (imagine trying to answer those questions to the hospital nurses). No, it sticks with me because we fought. We argued a lot but this time she threw what I thought was me doing good back in her face. How I was complicit in all the violence she was experiencing, how I, for years, had been getting her locked up against her will cause I didn't want her. Now, parts of me dominated by psychiatry think about this in terms of psychosis. Intellectual parts of me admit quietly, maybe she had a point? I held authority over her I did not know what it meant or how to deal with. As a kid I thought I was acting in her best interested, and I was? But those best interests were learned from an oppressive system.

A justice-driven critical theory driven understanding of mental health caring, thus, needs to shed light on the ways in which multiple systems of oppression and domination are linked and operate within different contexts, including maintain the care recipient and carer in multiply oppressed positions. Particularly as the structural inequities of economic and social arrangements function to systematically deny people with mental illness, neurodivergence and intellectual impairments the means and resources they need to participate in public life as full citizens (Josewski, 2017).

8.3 Connecting carer knowledge with justice driven approaches for social change in mental health

Considering how a critical approach to carer knowledge can be adapted for work within mental health services is a necessary contradiction for this piece of work. Interviewees spoke at length about how their knowledge should be respected and taken for account in mental health services, research and policy making but account multiple occurrences where this had not happened (see chapter 7). I will be considering why the resistance to carer knowledge is so prevalent.

Fraser's three-dimensional theory of social justice derives from the subjective notion of "lived experience" as a legitimate form of knowing, at the same time as it acknowledges the validity of some realist epistemological positions. According to Thorne and Varcoe (1998), such an epistemological position "balances absolute claims in the postmodern context and a respect for individual subjective reality that balances ideological primacy within critical social theory" (p. 491). In other words, within the larger project of generating knowledge for promoting equity and social justice, we should both acknowledge the valuable insights gained from exploring the construction of subjective truths (intersubjective condition) and recognize the significance of quantitative or empirical science (objective condition). (Fraser & Honneth, 2003b).

Different interpretations of social justice highlight specific aspects of inequities and advocate for various, sometimes conflicting, solutions to address them. By clearly articulating the particular conception of social justice being utilized, one not only enhances the understanding of potential theoretical frameworks that can support actions aimed at addressing inequities (Sherwin, 1999, as cited in Pauly, 2008, p. 7), but also ensures ethical integrity across all levels of policy, practice, and research. In this instance if the objectives of social justice approaches to mental health caring are interpreted through the lens of parity of participation (Fraser 2003) the research and policy initiatives would have to address the multiple systems of oppressions that shape the lives and life opportunities of mental health carers (LeFrancois et al, 2013) – ranging from concerns for inclusion in decision and, importantly, knowledge making processes, to stigma reduction campaigns, to service design and improve work, through to considering social determinations on health and social determinants of needing care such as supportive housing, educational and mechanisms for meaningful occupation, and income security.

Thus, if a critical relational understanding of social justice were valued, then mental health service delivery and policy would be organised in a way reflective of a relational understanding of social inequities in mental health (Josewski, 2017). Situating people with lived experience, including mental health carers within the context of multiple intersecting systems of oppression. Policymakers and service providers would need to acknowledge: (1) the ways in which their actions and instructions are complicit in the reproduction of structural violence and; (2) being redistributing power and authority to other ways of knowing within mental health spaces.

8.3.1 Theoretical barriers to mental health carer knowledge for social change

As argued throughout this thesis, mental health carers experience their experiential knowledge being systematically denied by those in authority. Bourdieu et al (2013) describe “symbolic violence” a form of domination and oppression, symbolic violence refers to the ways in which realities are constructed that privilege the knowledge and culture of the dominant group through practices of social exclusion and inferiorisation. Symbolic violence operates through the internalisation of such constructions and practices by subordinate groups, as people may come to see their subordinate status as legitimate through “internalised oppression”, much like mental health service users and survivors have had to experience symbolic violence when their knowledge has been excluded and delegitimised from their care, as well as wider mental health spaces such as research and policy making.

The service user/survivor movement has resisted via symbolic struggle, challenging the ideological basis of social order in an attempt to recognise and expose the dominant forms of knowledge. Through the development of Mad Studies, service users and survivors are assigning alternative meanings and values to a new type of knowledge, one based in lived experience. A social justice driven knowledge of mental health carers has to draw upon the conceptual, activist principles of this work. Indeed, as the importance of mental health service user lived experience becomes habitus; a way of being, doing, and interacting with the mental health space that is now established to the point of not needing spoken/verbal social rules, instead being maintained via unspoken norms, values and principles understood by all those in the space. Research done by people with lived experience or survivor researchers, because of this habitus, is based on a set of taken for granted assumptions about who they are, how they arrived in research and social change position (Sweeney, 2013). For mental health carers, who are missing from the agreed habitus of lived experience knowledge, they are yet to be dubbed as knowers.

There are existing, ongoing conflicts within mental health social change spaces which see specific communities remaining reluctant to recognise lived experience-based work as a legitimate approach to knowing (Voronka, 2016). This is primarily fuelled by a lack of understanding of lived experience evidence in and of itself, as well as a rigidity around traditional knowledge hierarchies. Given that traditional knowledges are tied to academic successes, dependent on strong publication records in high-ranking academic journals and on the securing of large scientific grants (Schade et al, 2021; Freidson, 1972) or ways of knowing that have been legitimised by those in authority; a critical approach to carer knowledge positions mental health carers experiences as foundational for knowing without needing approval from those in authority.

There has been an overall trend in service users being regarded as credible producers of evidence and authority (Noorani, 2013) within traditional spaces such as academia and policy making, but within social change spaces too. Since change in the mental health field is multi-faceted drawing on a range of different knowledge types generated in different spaces – whether physiatry, academia, lived experience activism, or lived experience led policymaking, the value of knowledge that is situated in lived experience is becoming increasingly recognised. Frequently, arguments that aim to delegitimise lived experience knowledge claim that the robustness of experiential knowledge can be drawn into question (Baillergeau and Duyvendak, 2016).

Diary Extract #137

Being at Kings is weird. I struggled so much at the LSE in an environment where the type of knowledge I was arguing for felt like it was being systematically silenced. Now I'm surrounded by people who 'get it' and honestly its unnerving. That said, there is such a heavy swing toward service user knowledge here, I still feel alien (though I reckon that's more of a me issue).

For mental health carers to whom the current lived experience framework or theory does not effectively apply, the knowledge and expertise they bring to conversations is still open to debate, often still challenged by the assumed superiority of "professional" knowledge. What is more, while there are specific spaces for service user expertise to be shared, carer knowledge is still at the beginning of its journey to being viewed as valid. Thus, it is still positioned to be undermining propositional or declarative knowledge such as that coming from medical professionals such as psychiatrists or mental health nurses. Indeed, there are still claims that users and carers may be biased and may place too much emphasis on what is important from their perspective (Babu et al., 2008, p. 30).

Within involvement or knowledge-sharing activities specifically, the sociological notion of expertise is frequently employed according to which expertise is advisory by nature, and depends on the recognition of others (Eyal, 2019 p,24; Funtowicz and Ravetz, 1993 p. 748; Grundmann, 2017 p.26). This understanding is open to many types of knowledge that have uses for others and is clearly not limited to credentialed, scientific, or professional expertise.

8.3.2 Mental health carers and epistemic injustice

Historically carers have been written and spoken about, but rarely been given platform to speak for ourselves. Carers has continually existed as a homogenous academic and ministerial concept, rather than being granted humanity and agency over ourselves and sense of self. Carers have been portrayed as an unopinionated supportive agent in the wider system of supporting someone with mental illness (Porter, 1987). Carers have no voice of our own because it is has been assumed that any knowledge we create will be incoherent, lacking reason, detached from reality and severed from social significance by virtue of these attributes (Foucault, 2000; Porter, 1987).

Fricker's concept of 'epistemic injustice' is useful for the analysis (Fricker, 2007); Epistemic injustice is to define a person as not a credible source of knowledge. Fricker's original analysis was concerned with women and feminism. But Foucault made a similar point 50 years ago specifically about ‘mental illness’. He writes:

“The constitution of madness as a mental illness thrusts into oblivion all those stammered imperfect words without fixed syntax in which the exchange between madness and reason was made. The language of psychiatry, which is a monologue of reason about madness, has been established only on the basis of that silence” (Foucault, 1967).

The interviewees in this study illustrated multiple examples where they were not considered a credible knowledge source by those in power. I subsequentially am arguing that the secondary stigma occurred with being associated with someone with mental illness – the tacit assumptions about lack of capacity of those with mental health challenges and denial of structural inequalities- combined with the lack of theoretical foundations for carer knowledge to be respected are replicating epistemic injustices.

The above interwoven processes ensuring mental health carers remain position as non-credible, involves those holding power in the mental health system, denying an understanding that individual experience is shaped by socio-political structure, and that there is thus an inherent interconnectivity uniting lived realities. Acknowledging both the connected nature of carer experiences in the mental health system and the knowledge and authority carers would hold if they were considered a collective would put at risk the power being held by those in authority.

Diary Extract #103

What would they actually gain by acknowledging carers as knowers? In some ways maybe then services could force people they don’t want to treat on to them? But they already do that… case in point me. So, what would they gain from the perceive giving away of power by acknowledging other types of knowing?

8.4 The classificatory politics of lived experience

I mentioned at the start of this thesis that, at its most base level, it was about considering how mental health carer knowledge fits within our current lived experience paradigms. I have gone onto illustrate the role identity and caregiving tasks play within mental health carers knowledge, how, where, and what motivates carers learning, and shown carers current experiences as ‘knowers’ within research, system and social change within mental health. Having identified how critical theory and the need for epistemological foundations to carer knowledge will aid in parity the question we are left with is where does mental health carers experiential knowledge fit in with current lived experience epistemologies.

It is not that mental health carers inherently do not fit within any lived experience paradigm or way of knowing, but that, in their current form, the lived experience paradigms held in the mental health field do not go far enough to position other types of knowledge and knowing as of paramount importance in understanding how this thing called mental illness shapes individuals social worlds and access to others.

There is a hierarchy of evidence *within* the academy but also a hierarchy between academic knowledge and the rest. Diversifying the sites where knowledge was produced was central to the conduct of the project. It had always been agreed that we did not want to interview a random or even representative group of participants. The people we wished to engage in our work were people and organisations who were producing new knowledge. It did not need to be high theoretical knowledge, it could be and often was practical knowledge (Telford & Faulkner, 2004). Critical approaches to mental health carer knowledge allow for a wider understanding, interpretation, and utilisation of lived experience in mental health care. This has a number of benefits: most importantly, the fact that carers have their own rights and the right to a say in things which impact them (Kara, 2016). Carers have their own experiences and stories to tell regardless of the fact research is rarely primarily concerned with their experiences. As one of the interviewees in the study states:

> *"While [care recipient] deals with the decisions services made, we [mental health carers] also deal with the* ***consequences of decisions*** *made my mental health services, so shouldn't we have a say in them?'*

Diary Extract #104

So, how do we fit a social justice driven understanding of mental health giving within a lived experience paradigm – well it is already there right? Lived experience by nature is social justice work and vice versa?

Adopting a critical theory of mental health caring and mental health carer knowledge position mental health carers as a community of knowers in and of themselves, with unique experiences and interpretations of social worlds and subsequent social change. It provides direct challenge to approaches to involvement that have been criticised for using service users and carers to support and "flesh out" existing academic/professional knowledge and theories, rather than offering an opportunity for them to develop and articulate their own experientially based perspectives, which may challenge such knowledge or theories (Beresford and Croft, 2001). This practice of using lived experience to "flesh out" or support academic knowledge is one of the paramount reasons why involvement activities in mental health are accused of being tokenistic (Gatera & Singh, 2023; Smith & Dransfield 2019).

Our current understanding and interpretation of lived experience knowledge is limited by the tendency to force it to fit into readymade structures for knowledge acquisition and legitimisation, i.e., by making it so that those approaching mental health work from a perspective have to perform academia by submitting papers, getting peer review, and applying for funding and to ethics boards. By forcing lived experience knowers to submit to traditional methods and evidence hierarchies, we are reinforcing those traditional methods as the most valid forms of knowledge. This forces mental health carers to adhere to standards set and upheld by the cis, white, able-bodied, heterosexual, trauma-free man which Black and Indigenous feminists, intersectional scholars, and scholarship from critical perspectives has rallied against (Collins, 2004; hooks, 1989).

8.4.1 Critical theory to resist institutionalisation of carer knowledge

Institutionalisation of lived experience refers to the process by which lived experience has been commercialised, limiting the academic understanding and the subsequent impacts that could be ascribed to lived experience involvement. Institutionalisation of lived experience was identified through the grounded theory process as a significant barrier to the meaningful inclusion of mental health carers. Sometimes referred to as the professionalisation of lived experience, Roennfeldt and Byrne (2021) describe, in the context of peer work or lived experience workforce, it as a process of greater structure and formalization being put in place by systems to support the effective employment of lived experience workers. Further, Simpson et al (2018) detail an evolution of lived experience involvement in the mental health workforce in Australia, with formalised training opportunities and engagement.

In the UK mental health field, those with lived experience expertise have been forced into a role as described by Carr (2014) as pseudo-management consultants, where there is an expectation as to what lived experience involvement can look like and will achieve (Scourfield, 2007). For example, service users may be expected to act as "patient leaders" who collaborate in supposedly equal partnerships with professionals to improve patient experience, whereas their actual concerns relate to challenging the systemic and wider structural problems that impact them. The institutionalisation of lived experience, therefore, undermines the grassroots and critical nature of lived experience knowledge.

In 1985, Brudney predicted the commercialisation of lived experience involvement in service delivery, arguing that it is likely to lead to delivery arrangements in which citizens undertake activities that fit the administrators' preferences for citizen involvement and/or for the convenience of their present positions – rather than those that might augment service effectiveness or contribute to a restoration of communitarian values and citizenship (Brudney, 1985 p.252–253; Carr, in Beresford & Russo 2022). With current carer activism still deeply embedded in grassroots movements, there is concern that, should carer knowledge become more established, it will be forced into these already dominant hierarchies; "[the] current system configurations … and processes can actively prevent them from exercising their citizenship" (Carr, 2014 p.31).

8.5 Third spaces for knowledge generation and research

Reflecting the perspectives of people with lived experiences of mental health diagnoses, Mad and psychiatric survivor movements argue that psychiatrisation is a key axis for understanding the social justice. Drawing on Homi Bhabha's notion of the "Third Space," research done from within such a discursive space "opens up the possibility of articulating different, even incommensurable cultural practices and priorities" (Bhabha as cited in Rutherford, 1990, p. 211) by directing attention to the ways in which different epistemologies and ontologies can intersect productively when normative judgment or interpretation is guided by a critical, relational reading of social justice along the lines of redistribution, recognition, and parity of participation.

It is rare to find accounts or arguments that emphasise the importance of theory building as a necessary step in political and social action. One such example is the work of Naoyuki Kirihara (in Beresford & Russo, 2021), who outlines the history of Japanese mental health survivor movement. He describes action against an amendment of the Japanese Mental Health Act that intended to further restrict the human rights of people with psychosocial disabilities:

"We concentrated our biggest efforts on developing theories to oppose the Bill." (000)

The intellectual labour that sees collective ideas and concepts embedded in the everyday understanding of a phenomenon is not often associated with theoretical work. That said, taking a critical approach to understanding mental health caring is not likely to have immediate directive policy impacts. More, it is likely to over time shift how mental health carers and mental health caring is perceived by those in power.

The powerful mechanisms in place that actively exclude collective knowledge as something valid in social sciences, will remain the prime barrier to critical approaches to understanding mental health caring. In her essay "Theory as Liberatory Practice", bell hooks (1991: 4) describes the devaluation and marginalization of certain types of knowledge as a practice that serves to establish the academic notion of "theory". As discussed throughout this thesis, the lack of classical or traditional academic and tacit knowledge foundations to understanding mental health carer knowledge

One of the many uses of theory is in the production and enforcing of an intellectual class hierarchy, where the only work deemed truly theoretical is work that is highly abstract, jargonistic, difficult to read, and containing obscure references that may not be at all clear or explained (hooks, 1991). In this thesis and during my work with mental health caregivers, there has been a deliberate effort to move beyond the theoretical frameworks outlined by hooks (1991). This work suggests that the insights gained from the lived experiences of mental health caregivers are valuable and should not be overlooked by those making aiming to make social change within mental health fields.

Rather than theorising from “academic locations” (Russo, 2021), the action or activity of knowledge generation within political and activist movements are situated in the lived realities of their members. First-hand knowledge or experiential knowledge does not arise with the intention of replicating various realities or achieving a better understanding of social worlds (ibid). Rather, since it comes from within the reality that it is seeking to make sense of, first-person knowledge ends up with an alternative grounding. It is positioned as such to enable different epistemologies than the knowledge coming from any third-person, outside perspective (ibid).

Interlude 8

And when it came to organising your funeral every looked at me like,
‘Well, you’re a writer, why don’t you make a speech?’
But the truth is,
I knew my sister only as well as she knew me.
And when I saw her there,
Hanging,
Cat nestled in a perfect loaf under her feet.
I missed her.
I missed you instantly.

9 Conclusion or Whelp

Attempt #52

I was 21 when she died for the final time. It felt like she had always been sick but I guess as a kid through to young adult I thought loving her would be enough to make it go away. I wonder if I'll ever be able to tell this story in the detail I would like. In the detail I both want the world to hear for the injustice and I want to hold close to my heart where no one can touch or see. I was 21, it was November 17th when she finally did it. 52 attempts later I wasn't there to catch her when she fell.

9.1 What this research adds

The end of a work such as this should signal neither a conclusion nor a final word, but rather a punctuation in time that marks a stop merely to take a breath (Lincoln and Denzin 2005, p1115).

Where justice driven conversations around caregiving exist, they focus on the collective experience of care, tying it to love and community (The Care Collective, 2020). While this was present in this work, the focus of this thesis was on the individual knowledge validation toward liberation for unpaid carers of people with mental illness. To that end, this work is the first to take a critical and justice driven approach to a specific type of caregiving. The conversations about unpaid care and liberatory politics focus on community care, taking alternative approaches to working with and within distress and practicing mutual aid (ibid). Healing justice approaches to care centre how care is contextualised and how it can be sustainably developed (Wilkinson and Pickett, 2009; Dorling 2010). A limitation of this work is my lack of engagement with abolitionist approaches to care, particularly those engaging from a decolonising perspective.

Methodologically, it is the first piece of work to my knowledge to employ participant observation of involvement activities. Where research on involvement exists, it tends to be qualitative work about the experiences of doing involvement, or the creation of evaluation measures to assess the impacts of doing the involvement. This research is written from the perspective of a carer of someone with mental health problems – a viewpoint not commonly found in the literature (Kara, 2013). This research took what carers said, their words and stories at its face, discovering the discourses which make it possible – and in discovering those conditions for possibly, it aimed to learn how mental health carers can be actors for social change.

What does it even mean to have lived experience? In the end, all we, as academics, are doing is 'preforming the science' of operationalising peoples' lived experiences for the benefit of those already positioned to do something or nothing with that knowledge.

9.2 Meeting the criteria for a grounded theory

Whilst there are a number of standards and criteria for qualitative research, the criteria outlined by Charmaz (2006) for constructivist grounded theory research guided this research project to ensure the usefulness and quality of the final work. The four criteria used to evaluate this study are credibility, originality, resonance and usefulness (Charmaz 2006, p182). Ultimately however, it is the reader who judges the usefulness of the methods and the quality of the work (Charmaz 2006, p182).

9.2.1 Credibility

This research has explored mental health carers' identity, tasks and knowledge formation via interviews and a participant observation of an involvement activity. As is needed for a constructivist grounded theory approach, I acknowledge that the results of this piece of work cannot qualify as the ultimate truth per se, but represent a version of truth that is mediated, quantified, and qualified by my own interpretations and understandings (Kayrooz and Trevitt 2005). That is to say, the findings presented are not ‘facts’, but are instead ‘constructed truths’ with the extent to which the constructions vary and are defensible being dependent on my presentation of them to the audience in a way that is meaningful (Thorne et al. 2004).

A thread through this work is the constant usage of data being lifted verbatim in order to illustrate that the work as a solid data grounding. The types and range of data has provided a rich source from which the claims in this thesis have been made. Recordings of interviews, detailed transcripts, and the research diary of ongoing field notes maintained during the course of the study exist to facilitate dependability and reliability. The intention is that, as a result of these actions, an independent assessment of the clams made will draw similar conclusions due to the sufficient evidence available (Charmaz, 2006, p,182)

9.2.2 Originality

The study contributes to a readily existing body of work around lived experience involvement in mental health spaces and specifically focusing on the understanding of mental health carers. A number of qualitative works have explored lived experience from a service users’ perspective with unique conceptualising leading a range of disciplines and framings, most noteworthy being survivor research and PPI practices. By privileging mental health carers’ experiences, this work offers a fresh perspective on the scale and span of lived experiences which prove valuable to mental health service development. The analysis of the data, interviews and stories results in a new conceptual rendering that results in the theorising outlines in the research findings.

9.2.3 Resonance

The work conceptualises and conveys what is meaningful for mental health carers in considering their identity, role, and tasks and the ways this can lead to knowledge. The categories developed in the analysis portray the ways mental health carers conceptualise themselves and the ways they can be involved in policy making. They have revealed the taken-for-granted meanings that mental health carers assign to themselves and their importance in mental health care. What is more, this work begins to question what factors constitute as knowledge within lived experience.

9.2.4 Usefulness

The usefulness of a theory relates to the ability for the interpretations to be used in the everyday world. The theorising of this work is of particular interest to mental health researchers and policy makers. An increased understanding and an academic conceptualisation of caregiver knowledge allows for mental health carers a way of framing their experiences as something of use to policymakers and researchers, and positions policymakers and researchers in a way to share power through the processes.

9.3 Limitations

Is this piece of work ‘good’ social theory, then? This following section aiming to make transparent some of the limitations of this piece of work. The findings from this research drew on the experiences of 48 people who supported someone with mental ill health. This study lies firmly within the interpretive tradition as the analysis was contextually situated in time, place, culture, and situation (Charmaz 2006, p130-131). Therefore, the findings cannot and do not aim to be representative of the ways all mental health carers conceptualise their identity and how their caring role impacts their knowledge and access to social worlds. Generalisability as a concept in qualitative research is moot – as no research approach or singular method can grasp all the subtle nuance peoples experience. Qualitative approaches recognise there is no single interpretive truth (Denzin and Lincoln 2005, p8), and that qualitative research is the world of lived experience and so can provide important insights and knowledge (Denzin and Lincoln 2005, pp7-8).

9.3.1 Methodological Issues

Autoethnography, often criticised as a self-indulgent narcissism made public, is considered credible when a reader is convinced that the story is plausible (Ellis et al., 2010) and while I have done an informal autoethnography, this work could have flourish more intensely if I had truly committed to doing an autoethnography in its entirety.

Taking a narrative inquiry approach to this piece of work may have been a more suitable methodological foundation to build upon. I was drawn to constructivist grounded theory for its emphasis on co-creating between researcher and the community (Charmaz, 2000, 2002, 2005), but the importance of contextualised stories (historically and culturally) in critical inquiry would have positioned mental health carers stories as knowledge in a more ethical, libationary way. Indeed Creswell (2007) describes narrative is a medium in which intersectionality plays out in a complex manner without being watered down or only marginally taken up. Thus, narrative can be a forum in which to examine race, sex, class, national origin, and sexual orientation, and ways in which their combination play in a range of situations. A premium is placed on perspectivalism, the belief that a person's or group's position or standpoint influences how they see truth and reality (Delgado and Stefancic 2001). This work revealed how story-telling and co-learning from other mental health carers was a tool for nuance and complex communication, skill building, and community/culture building between mental health carers (see chapter 6). Thus, employing narrative research methods, would likely have acquired more useful data toward understanding this experience which my chosen methodology missed.

The method of cognitive interviewing is most commonly criticised for its lack of theoretical grounding and standardisation, with Conrad and Blair (1996) arguing that this variability needs to be considered when conducting, analysing, and assessing the validity of studies that adopt a cognitive interviewing method. Further, this technique is critiqued for being a “false environment” and for forcing “cognitive load” on respondents who, traditionally, would not think aloud or be probed whilst completing a questionnaire (Dillman, 2000).

9.3.2 Heterogeneity of the sample

This research project target at heterogenous population mental health carers primarily due to the limited evidence base which investigating the influences which make up carer knowledge. Where care ethics literature has written about critical approaches, it has tended to focus on equity for women and racialised people and not considered much wider than that. This piece of work does not question in more detail intersectional experiences of caregiving despite efforts being made to ensure a gender diverse sample, particularly was caring is so often conceptualised as ‘women’s’ work (Twigg,1989)

9.3.3 Analysis

The project could have been improved by considering the role of social organisation when it comes to mental health caring. he *social organisation of care* offers a detailed critique of the role of the state in shaping access to care. Irrespective of the different emphases of their disciplines, the two conceptual perspectives have contributed to the removal of *care* from the purely private realm. Instead, care has been reframed as a concept that is heavily intertwined with *the* ‘*economic*’ –the way that economies benefit from work that its neither recognised nor paid for; *the* ‘*social*’ –the class and gender relations that permeate social interaction; and *the* ‘*public*’ –the policies that directly or indirectly shape the provision of care (Esquivel, 2014).

Another limitation of this piece of work was in the analysis. Finding a way to combine together the empirical data with the influence of the critical friends and my own story. I struggle to effectively reconcile the different types of data being generated through the study. While the arts-based technique (Ellis, 2010) writing poetry to bring together themes was useful for my personal thinking, it was limited in its ability to put across the complexity of the findings.

9.4 Final personal reflection

I want to make clear doing this piece of work was not some sort of noble action. When we consider lived experience work in the academy it stems from someone's trauma, someone wanting to make a difference motivated by that trauma. But for me it was not motivated by a desire to help others or make sure no one experience the system the way I have. It was not noble. I wanted people to choke on my sisters name the way I choke on it when I wake up screaming.

How you enter the mental health system has more of a say than any of the treatment you get while in it. I entered the system as a problem. In my 99% white area my sister’s DID was a problem that had to be fixed by mental health services and when it couldn't be fixed it needed to be hidden. **She was a problem that needed to be hidden** and I was coerced, bullied, and lied too by professionals from every part of the mental health system - whether mental health social care or the police - into hiding her and when I couldn't they did it for me. As my sister’s carer, I was forced to give her as much care as I could pour out and be her custodian. A family care love shaped custodian who was backed by the system whose power is oppressive, unwieldly and unlimited.

Academia is not the setting for such statements of brutal honesty, but one of a measured minimisation of truths. Maybe I should be scrambling for objectivity to give my knowledge legitimacy but in doing so would I not be betraying myself, the memory of sister, and the foundational arguments I have been arguing throughout this thesis? So much can be gained from listening to people’s stories but we have built systems and policies to segment people’s lives into digestible sections. If we, the big we and the small, are truly invested in system change we must make room for nontraditional ways of knowing. It’s not going to be easy but when was learning and growing as a person ever comfortable.

During this thesis I received a Do Not Resuscitate order or DNR. It was three weeks into the Covid-19 pandemic and nearing the end of my first year when the government’s algorithms decided my life was not worth treating if I contracted Covid-19. The government decided it was the wisest decision to ferry limited resources toward those who have a better chance of survival, who contribute to our society. If we had even the smallest lived experience lens on healthcare maybe that wouldn’t have happened. Who was this faceless, nameless algorithm to decide my life was not worth living? On what metrics was my life deemed worthless?

This thesis is as much a lost child clambering for safety, security, and belonging as an academic scholar finding a theoretical research gap to insert alternative understandings and knowledge. To deny one is to deny both.

Can you hear me, Ciera? Are you proud?

10 Instantly

Taken for instance you,

Take for instance me,

Take for instance the trouble we use to get in immediately.

Like the night you shoved me to the bottom of a sleeping bag as we rode down the stairs,

Your cares evaporated until the crunch of my skull as it collided with the ground.

A sound that haunted you till your last day,

Every time you were in hospital you'd grasp my hand to say

Sorry

As if it had only just happened.

You were a good sister.

…

Take for instance your first hospitalisation when you asked if see you like this was breaking

And I felt myself faking a smile as I spluttered through tears,

No. No my hear is not breaking,

It’s only bending.

And I promised myself at that moment I would devote my energy to mending.

….

Take for instance you,

Take for instance me,

Take for instance the word instantly.

And how before you it was used to describe porridge, soups, and coffee.

How before you it was used to define love at first sight,

Now it is used to sum up your life.

They tell me you died, instantly.

…

As if there is some small quantity of comfort to be realised from the fact you are dead,

That this is what you wanted.

That you said no long goodbyes or last words?

Just gone.

The fact is, though you are a different kind of gone all together.

Gone like the promises we made for your wedding and getting those tattoos that would last forever.

Gone like the promises I muttered into my hands as I listened to you screaming.

Gone like my dreaming.

Gone as in never coming back.

Gone as in mum and dad sold our old house cause they couldn't bare to step into your old room.

Gone like that.

…

But they said you died, instantly?

They said it as if somewhere within you was the grace not to linger?

Like death pointed his finger at you and that was that?

Like there was no slow cause of death for us all to deal with?

They said is as if I should feel some sort of relief?

…

And I'm not saying I knew you better than most,

In fact, I am pretty sure I didn't,

But I'm also pretty sure you'd rather be alive.

Just not haunted by the things that haunted you.

…

My heart is bending

…

I keep re-reading the ending of your life expecting another chapter.

I keep expecting laughter.

I unexpected the success of this attempt so hard part of me still 8 years later believes I can make it not true.

You were the Gameboy advance, Pokemon training, anime protagonist of my youth

When I needed to organise your funeral, everyone turned to me as if to say

'You're the writer, make a speech'

But the true is, I knew my sister only as well as she knew me,

And when I saw here there swinging,

Cat in this perfect loaf under her feet,

I missed her,

I missed you instantly.

11 Appendix

11.1 Interviewee invite letter

INTERVIEW PARTICIPANT INVITATION LETTER

Title of the Study: Mental Health Carers Experiential Knowledge; Formation, Utilisation, and Application within the Formal Care Team and Beyond

You are receiving this as you have expressed interest in being invited to participate in a research study. Before you decide, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully. Feel free to ask questions you may have.

Who is carrying out the research?

My name is Cassandra Lovelock, I am a doctoral student at the Care Policy Evaluation Centre hosted at the London School of Economics and Political Science. Before that, I am a mental health carer supporting loved ones with severe mental illness. I am studying for a PhD in Health Policy and as part of my studies I am conducting the interviews detailed below.

What is the purpose of the research?

The purpose of the research is to explore what mental health carers do and – otherwise known as caregiving activities and if doing those activities has an impact on their identity. The activities could be, but not limited to, helping someone get dressed, helping them with finances, or wound care, for example.

I would like to understand

- What types of things you consider part of your caring relationship?
- How being a carer has influenced your identity?
- What ‘lessons’ being a carer taught you

My Research has been approved by my university ethics department at the London School of Economics and Political Science

I will be asking you a series of questions about these topics which have been developed in with the help of other mental health carers.

Who is invited to take part?

I would like to invite anyone who identifies as carer or a person who supports someone with any mental illness – this could be **but is not limited to** illnesses like depression and anxiety, or what is called severe mental illness such as psychosis or schizophrenia.
You are welcome to take part if you support someone without a diagnosis but is believed to be mental illness.
You must be over the age of 18 and able to consent fully to the project.

Do you have to take part?

No! It is up to you to decide whether you want to take part. Your participation in this research is completely voluntary.

What will your participation involve?

- You will be asked to read and sign a consent form before taking part.
- You will be asked questions around your experiences as a carer for someone with mental illness. You will **not** be asked to describe or talk about anything you are uncomfortable discussing.
- The interview will last for a maximum of 1 hour but if you prefer, we can split this across two sessions.
- The interview will be audio recorded so that I can transcribe it, however, I am the only person who will have a copy of the recording. You will also be given an opportunity to read your transcript.
- The interview will take place online using a platform called Microsoft Teams or Zoom. As this is an online interview, you will need to have access to a smartphone/laptop in order to take part.
- At the end of the interview, you receive a £30 voucher or £30 cash for your time and contribution to the study (or a charity donation). You will also receive a list of services to contact if you require further support.

Your taking part will be safe and confidential

Your interview will be audio recorded and only I will have access to the recording. The audio recordings will be typed into a transcript and you will be given the opportunity to read this. In order to ensure that neither you nor anyone else will be identified in the research, your name and any name that you mention will be changed in the transcript. The anonymised transcript will be reviewed by my supervisor, who will also be under agreement to keep the information confidential.

What will happen to the information that you provide?

- The information you provide will be securely stored on password protected computer or encrypted storage device.
- The audio recordings will only be accessed by me and will be deleted once the study is complete.
- Your name and any name that you mention will be changed in the transcript.
- The anonymised transcript will be reviewed by my research supervisor.
- You will be given a brief summary of findings at the end of the study if you would like.
- The final research will include a small number of quotes from the interviews. In addition to using the information to write up the thesis, information from the anonymised transcripts may be used to write up research in the future for publication in academic journals or for organisations that work with carers

What if you want to withdraw?

You are free to withdraw from the research study at any time without explanation, disadvantage, or consequence. Separately, you may also request to withdraw your transcript even after you have completed the interview, provided that this request is made

4 weeks after your interview (after which point the data analysis will begin, and withdrawal will not be possible).

Contact Details
If you would like further information about my research or have any questions or concerns, please do not hesitate to contact me:

Cassandra Lovelock., 07429428992, c.lovelock@lse.ac.uk

If you have any questions or concerns about how the research has been conducted, please contact the research supervisor:

Dr Sara Evans-Lacko., s.evans-lacko@lse.ac.uk
London School of Economics, Houghton Street, London WC2A 2AE

.................Column Break.................

11.2 Consent form

CONSENT TO PARTICIPATE IN A RESEARCH STUDY Date:

Title of the Study: Mental Health Carers Experiential Knowledge; Formation, Utilisation, and Application within the Formal Care Team and Beyond

Explanation	Initial
I have the read the information sheet relating to the above research study and have been given a copy to keep. The nature and purposes of the research have been explained to me, and I have had the opportunity to discuss the details and ask questions about this information. I understand what is being proposed and the procedures in which I will be involved have been explained to me.	
I understand that my involvement in this study, and particular data from this research, will remain strictly confidential. Only the researcher and her supervisory team involved in the study will have access to identifying data. It has been explained to me what will happen once the research study has been completed.	
I understand my interview or case study will be audio recorded for the purposes of transcription and that the recording be deleted once the study is complete. I also understand that anonymised quotes may be used in the thesis report and publications.	
For Case Studies Only I understand that my questionnaire data will be recorded and analysed with results deleted once the study is complete. I also understand that anonymised quotes may be used in the thesis report and publications.	
I hereby freely and fully consent to participate in the study which has been fully explained to me. Having given this consent I understand that I have the right to withdraw from the study at any time without disadvantage to myself and without being obliged to give any reason. I also understand that should I withdraw, the researcher reserves the right to use my anonymous data after the analysis has begun.	

Participant's Name (BLOCK CAPITALS)

………………………………………………………………………………….

Participant's Signature

…………………………………………………………………………………..

Researcher's Name (BLOCK CAPITALS)

…………………………………………………………………………………..

Researcher's Signature

………………………………………………………………………………….. ………………Column Break………………

11.3 Debrief letter

Interviewee DEBRIEF LETTER

Thank you for participating in my research study: **Mental Health Carers Experiential Knowledge; Formation, Utilisation, and Application within the Formal Care Team and Beyond**

This letter has some information that may be useful for you now that you have taken part.

What will happen to the information that you have provided?

The following steps will be taken to ensure the confidentiality and integrity of the data you have provided.

- The information you provide will be securely stored on password protected computer or encrypted storage device.
- The audio recordings will only be accessed by me and will be deleted once the study is complete.
- Your name and any name that you mention will be changed in the transcript.
- The anonymised transcript may be reviewed by my research supervisors.
- If you would like, you will be given a brief summary of findings at the end of the study.
- The final research will include a small number of quotes from the interviews.
- In addition to using the information to write up the thesis, information from the anonymised transcripts may be used to write up research in the future for publication in academic journals or for organisations that work with carers and hopefully mental health carer specifically.

What if you want to withdraw?

You are free to withdraw from the research study at any time without explanation, disadvantage or consequence. Separately, you may also request to withdraw your transcript even after you have completed the interview, provided that this request is made by August within 6 weeks of your interview taking place.

What if you have been adversely affected by taking part?

Talking about mental health caring, particularly the times when it is very difficult can be distressing and bring up difficult and unpleasant emotions. If you have been affected in any way distressing by taking part in the study, below are some resources you may find helpful.

- If you would like support from the research term in accessing help from your GP as a result of the study that can be provided.

- **Rethink Mental Illness** – advocacy, advice and peer support for carers for those with mental illness
  For Region Specific Help: https://www.rethink.org/
  Freephone: 08088010525
- **Carers UK –** Advice, support and advocacy for all types of carer
  Helpline: 0808 808 7777
  For Region Specific Advice: https://www.carersuk.org/help-and-advice/get-support/local-support

  For Online Support: https://www.carersuk.org/help-and-advice/get-support/carersuk-forum
  or email advice@carersuk.org
- **Mind –** National Mental health charity; there are also regional minds, whose details can be provided https://www.mind.org.uk/
  Email: info@mind.org.uk.
  Infoline Tel: 0300 123 3393

Text: 86463

- **Samaritans** – National listening service, available 24/7
  Tel: 116123
  Email: jo@samaritans.org
- **Carers Network –** A London based network set up to support and advocate for carers of all types
  Tel: 0208960 3033, Press 1 for Carers Helpline

Payment

As a big thank you for taking part I can give you £30 in whatever form is best for you; this can be by bank transfer, a charity donation, or in a voucher form of your choice! All you need to do is email me this sentence (please fill in the date of your interview) and let me know how you'd like your thank you reimbursement:

I can confirm that the claim for reimbursement of £30, for expenditure dated (XXX), is in respect of bona fide business expenses, incurred wholly, exclusively and necessarily on behalf of the SSCR.

(if you'd like a bank transfer I'll need your bank details or PayPal account, otherwise you'll get emailed over a voucher code or receipt)

Contact Details

If you would like further information about my research or have any questions or concerns, please do not hesitate to contact me:

Cassandra Lovelock., 07429428992, c.lovelock@lse.ac.uk

If you have any questions or concerns about how the research has been conducted, please contact the research supervisor:

Dr Sara Evans-Lacko., s.evans-lacko@lse.ac.uk
London School of Economics, Houghton Street, London WC2A 2AE

11.4 Constructivist interview guide

Research Team: Cassandra Lovelock, Sara Evans Lacko, Martin Knapp
Aims: The aim of these interviews is to gather information on how unpaid mental health caregivers perceive their role and who it feeds into their perception of self (identity). As well as what knowledge they have learn through being a carer.

Introduction	

• Introduce self and project
• Check full name of attendee and ask what they go by
• Key points:
  • Interview will take up to 1 hour
  • Participation is completely voluntary
  • Right to withdraw at any point
  • No pressure to answer any questions
  • As many breaks as you need
  • We would like to record interviews with your consent
• Explain confidentiality of interview data
  • We would like to use quotes in reporting, these will be anonymised
  • Data will be securely kept
  • We will have to break confidentiality if: (1)
• Participant information sheet
• Do you have any questions?
• Ask for consent to take part + audio record the interview
• Start audio recording (or start making notes if permission is declined)
• Read out consent form + ask for consent + hand over to sign
• Record name of participant, interviewers name, sign and date form	

Background Information	
Age, gender, ethnicity, Caring recipient illness Services received by Care recipient Duration of care provided Employment status	Fixed choice answers, recorded on template Receipt of benefits?
Identity Recognition	Prompts
When asked to describe (introduce?) yourself, what identities would you consider? Would you describe yourself as a Carer? Are there situations or people where you would be more likely to describe yourself as a carer?	Achieved or ascribed?

Are there times when you feel more like a carer?	More need from the service user?
ADLs/IADLs	
What kind of things does being XXX* involve on a daily basis or What does an average day looking like for you on a good versus a bad day? How would you conceptualise XXX? If you can remember, how did you life look before you started supporting someone? How have you learned to manage this with other aspects of life? How does your day to day differ depending on XXX wellbeing? What, if anything, could help you take care of yourself and the person you support better?	ADLS/IADLS – give examples from own experience if relevant If you took them out of context they would be normal activities. Consequences? Work, relations, socials, hobbies health, spirituality Tactics e.g. phone reminders More or less? Inpatient? This can be wellbeing, learning, professional development, income, mobility, friendships, changes to day-today
Optional Experiences with Services	
Have you interacted with statutory mental health services in relation to the person you support? **If yes, move on. If no then skip this section.** How do you think mental health services perceive unpaid carers/family members? Do you feel statutory mental health services have an awareness of your role in the care process? How could your relationship with statutory mental health services be improved?	Explain statutory if needed Institutional and Individual The ADLS/IADLs preformed
Life Lessons	
What are the most important things being a carer has taught you? If you were approached by someone who just started caring for a person with mental illness, what would you like them to know? How has you perception/knowledge/understanding of the mental health system changed due to your caring role?	In relation to services, society, stigma, balance, wellbeing etc Top 3 things?
Anything to Add	
Ending the Interview	

• Stop recording • Thank interviewee and ask for questions • Would they like a copy of the results? • Explain next steps: • (if recording has happened) inform it will be kept securely at LSE and transcribed • Transcriptions and notes will be kept securely • Circle contact information on info sheet • Give thank you sheet and helpline numbers • Ask what voucher they would like to receive and an email address to send it too	

11.5 Observation study information

CASE STUDY PARTICIPANT INVITATION LETTER

Title of the Study: Mental Health Carers Experiential Knowledge; Formation, Utilisation, and Application within the Formal Care Team and Beyond

You are being contacted as you have expressed interest in participating in a research study. Before you decide, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully. Feel free to ask any questions you may have.

Who is carrying out the research?

My name is Cassandra Lovelock, I am a doctoral student at the Care Policy Evaluation Centre hosted at the London School of Economics and Political Science. Before that, I am a mental health carer supporting loved ones with severe mental illness. I am studying for a PhD in Health Policy and as part of my studies I am conducting a set of case studies with people who support/provide care for someone with severe mental illness.

What is the purpose of the research?

The purpose of the research is to explore several different things but mainly I would like to learn what being a mental health carer entails for you on a day to day basis, what being a carer for someone with a mental illness has taught you, and how you share that knowledge.

This might sound confusing so I will explain in more detail below:

1. What does your day to day life look like; when the person you support is doing well versus when they are unwell, how does your daily life differ. What activities do you do to support them – this could be helping with finances, or wound care, or emotional support.
2. What has the experience taught you; in my thesis I refer to this as experiential knowledge which is a concept being adopted by statutory mental health services to refer to service user and carer experts. You may have seen adverts for ‘Experts by Experience’ in your local NHS mental health services.

- I would like to understand what the experience of being a carer has taught you, and if that experience means you consider yourself an expert

3. How you share your experiential knowledge; in policy making spaces do you find yourself sharing something from your experience caring to help the discussion? Do you sometimes feel unable to speak up? I would like to understand what motivates those feelings.
4. Statutory mental health services preform a self-audit every few years with the aim of investigating how well they are working with carers. To do this they use a questionnaire. The final part of the case studies involves us sitting down together to discuss this questionnaire and if it makes a space for you to be comfortable sharing your experiences and experiential knowledge with wider statutory mental health services.

My Research has been approved by the London School of Economics and Political Science Research Ethics Committee

Who is invited to take part?

I would like to invite any carer or person who supports someone with any severe mental illness(es) to take part. This could include **but is not limited to**, psychosis and related illnesses, schizophrenia and related illnesses, bipolar disorder, personality disorders, dissociative disorders, severe anxiety disorders such as PTSD or OCD, and major ongoing depressive disorder.

You must be over the age of 18 and able to consent fully to the project.

Do you have to take part?

No, it is up to you to decide whether you want to take part. Your participation in this research is completely voluntary.

What will your participation involve?

The case studies will be made up of four-five consultation periods occurring once a month for a maximum of three hours each time. You each consultation period is voluntary, and you can do as many or as few as you choose. You will be compensated for any time involved in the study.

Each consultation period will consist of a **semi-structured interview** which is a conversation with me about how the past month being a carer has gone. What your day to day life looked like each week, and what, if anything, you feel your caring experience has taught you. This is an open space for you to share anything about your caregiving experience, but will be guided by me.

Following this will be what is called a **cognitive interview**. This is a specific type of interview that involves the discussion of a questionnaire. In this case it is questionnaire currently being used by mental health services to assess how well they are working with carers. The cognitive interview will involve looking at this questionnaire and discussing it with me on topics such as the readability of the questions, or if they allow you to share your experiences in the style you would want.

Each consultation period this questionnaire will be adapted based off the feedback given in the last consultations.

At the beginning of each consultation period:

- You will be asked to read and sign a consent form before taking part.
- You will be asked questions around whether you told anyone about experiences as a carer for someone with mental illness. You will **not** be asked to describe or talk about anything you are uncomfortable discussing.
- The semi-structured interview will last for a maximum of 1.5 hours but if you prefer, we can split this across two sessions.
- The cognitive interview will last a maximum of 1 hour but is expected to last around 30 minutes.
- Both interviews will be video and/or audio recorded so that I can transcribe it however I am the only person who will have a copy of the recording. You will also be given an opportunity to read your transcript.

- The interview will take place online using a platform called Microsoft Teams or Zoom. As this is an online interview, you will need to have access to a smartphone/laptop in order to take part.
- If this is not accessible for you, we can examine looking into telephone interviews
- **At the end of each consultation period** you will receive £75 by bank transfer or in the form of a voucher.
- This will arrive in your bank account (or voucher code to your email address) within 3-5 working days of the interview.
- You will still be compensated even if you do not answer all the questions or end the interview early.
- You will receive a list of services to contact if you require further support.

Your taking part will be safe and confidential

Your interview will be audio recorded and only I will have access to the recording. The audio recordings will be typed into a transcript, and you will be given the opportunity to read this. In order to ensure that neither you nor anyone else will be identified in the research, your name and any name that you mention will be removed in the transcript.

What will happen to the information that you provide?

- The information you provide will be securely stored on password protected computer or encrypted storage device.
- The audio recordings will only be accessed by me and will be deleted once the study is complete.
- Your name and any name that you mention will be changed in the transcript.
- You will be given a brief summary of findings at the end of the study if you would like.
- The final research will include a small number of quotes from the interviews. In addition to using the information to write up the thesis, information from the anonymised transcripts may be used to write up research in the future for publication in academic journals or for organisations that work with mental health carers.

What if you want to withdraw?

You are free to withdraw from the research study at any time without explanation, disadvantage or consequence. Separately, you may also request to withdraw any of your transcripts even after you have completed the interview, provided that this request is made within to weeks of your consultation period (after which point the data analysis will begin, and withdrawal will not be possible).

Contact Details

If you would like further information about my research or have any questions or concerns, please do not hesitate to contact me:

Cassandra Lovelock., 07429428992, c.lovelock@lse.ac.uk

If you have any questions or concerns about how the research has been conducted, please contact the research supervisor:

Appendix

Dr Sara Evans-Lacko., s.evans-lacko@lse.ac.uk

London School of Economics, Houghton Street, London WC2A 2AE

11.6 Triangle of Care feedback questionnaire

The Triangle of Care Membership Scheme

Triangle of Care Carer Feedback Questionnaire

Guidance Notes for Organisations

The Triangle of Care membership scheme requires services to involve carers in their self-assessment process. Including large numbers of carers in the full self-assessment would be challenging, however it is important to ensure that carers are in receipt of a service and are therefore best placed to state whether or not that services is achieving the Triangle of Care standards.

The feedback from the questionnaires should be provided to carers who are involved in the self-assessment process as well as being included in your carer evidence.

We have developed a shorter feedback form for carers to complete that still maps to the standards of the Triangle of Care and will enable providers to ascertain if carers feel they are receiving the level of service that the provider thinks it is delivering.

This questionnaire is designed to be used by wards and teams not as an overarching questionnaire for an organisation.

The questionnaire should be used by teams and wards to improve the depth of their carer evidence, therefore it is important to identify which ward/team the carer is providing feedback on.

The questionnaire is a template and the organisation should add their own logo to the form.

It is important to use the opportunity to provide carers with information on support when asking them to complete the questionnaire. Please ensure carers are provided with details of local support services when asked to complete the questionnaire.

The Triangle of Care is a set of standards that ensure family, friends & carers are included and supported by Health & Social Care services.

(Insert Name of Organisation) has joined the Triangle of Care membership scheme, we are working to improve our commitment to carers and improve our services to carers. To do this we are trying to see how well we are doing at the moment; we will use all the feedback from carers to support our action plan which will work to improve how we include and support carers.

Standard 1 – Carers and their essential role are identified at first contact or as soon as possible afterwards.	
1. Were your views and knowledge sought throughout the assessment and treatment process?	
2. Were you regularly updated and involved re: care plans and treatment?	

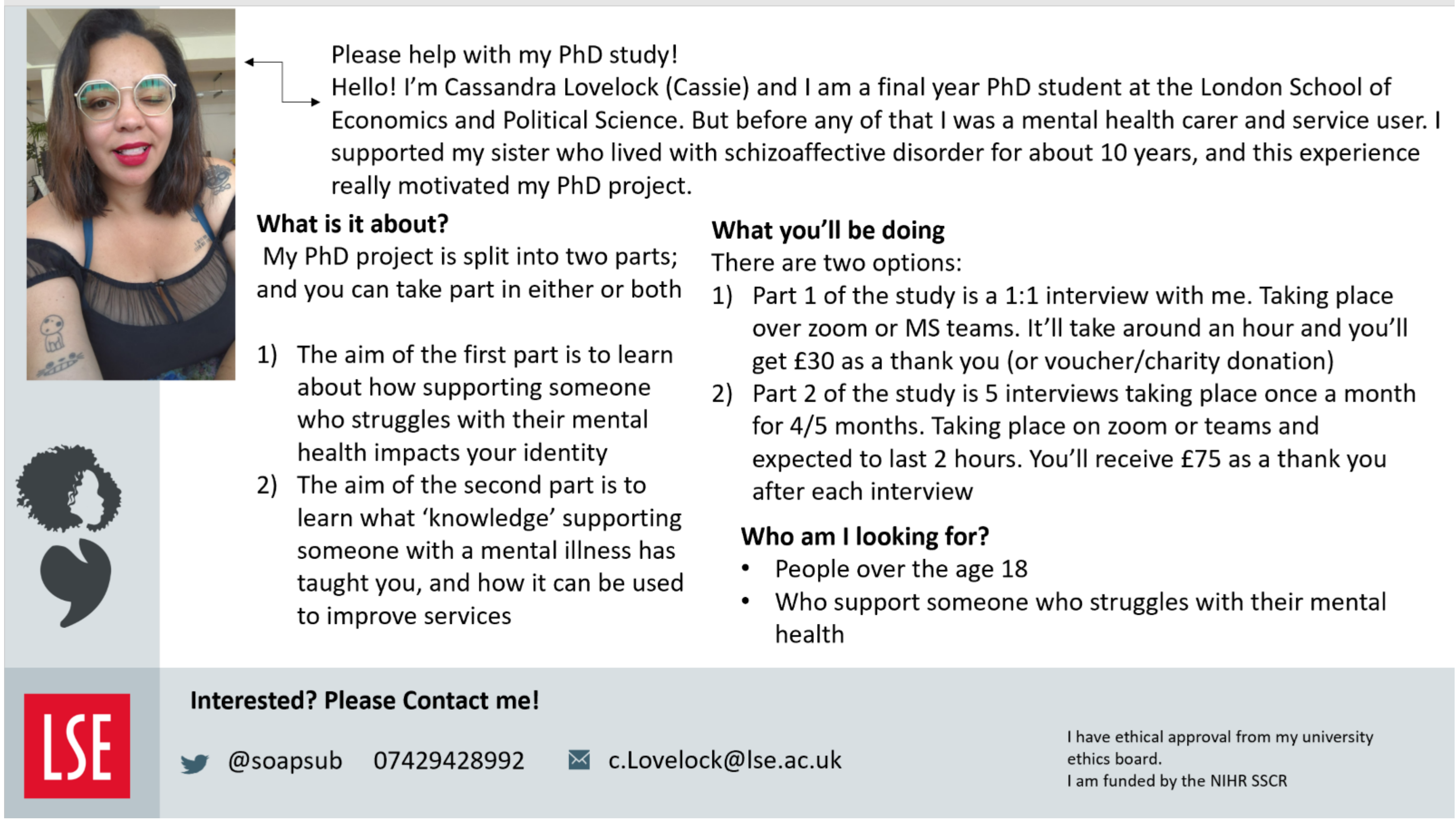
3. Were treatments and strategies for medication managements explained to you?	
Standard 2 – Staff are "carer aware" and trained in carer engagement strategies	
4. Did staff approach you in a respectful and kind way and show concerns for your needs?	
Standard 3 – Policy and practice protocols re confidentiality and sharing information are in place	
5. Did staff explain the confidentiality (what information could/couldn't be shared) to you?	
6. Were you offered support and general information when your relative (the service user) wished no disclosure?	
Standard 4 – Defined post(s) responsible for carers are in place	
7. Do you know who the carer lead/champion is on the ward/team?	
Standard 5 – A carer introduction to the service and staff is available, with a relevant range of information across the acute care pathway	
8. Were you offered an early formal appointment to hear your story, history and address your concerns?	
9. From the outset, were you given information about the service and key people providing care (i.e. psychiatrist, named nurse and care coordinator's name)?	
10. Did staff from the ward or team offer you the opportunity to have a conversation? Did you feel this was sufficient?	
11. Were you involved in the discharge planning (either from the ward or in the community from secondary services) process?	
Standard 6 – A range of carer support is available	
12. Have you been told about carers' service?	

13. Have you been offered a carer's needs assessment & have your needs as a carer been regularly re-assessed?	
14. Have you been told about other services available for families and carers including those for young people?	
Additional Comments:	

Thank you for taking the time to complete this questionnaire we value your feedback and will use it in the ongoing evaluation of our services.

i

11.7 Recruitment advert



Please help with my PhD study!

Hello! I'm Cassandra Lovelock (Cassie) and I am a final year PhD student at the London School of Economics and Political Science. But before any of that I was a mental health carer and service user. I supported my sister who lived with schizoaffective disorder for about 10 years, and this experience really motivated my PhD project.

What is it about?

My PhD project is split into two parts; and you can take part in either or both

1) The aim of the first part is to learn about how supporting someone who struggles with their mental health impacts your identity
2) The aim of the second part is to learn what 'knowledge' supporting someone with a mental illness has taught you, and how it can be used to improve services

What you'll be doing

There are two options:

1) Part 1 of the study is a 1:1 interview with me. Taking place over zoom or MS teams. It'll take around an hour and you'll get £30 as a thank you (or voucher/charity donation)
2) Part 2 of the study is 5 interviews taking place once a month for 4/5 months. Taking place on zoom or teams and expected to last 2 hours. You'll receive £75 as a thank you after each interview

Who am I looking for?

- People over the age 18
- Who support someone who struggles with their mental health

Interested? Please Contact me!

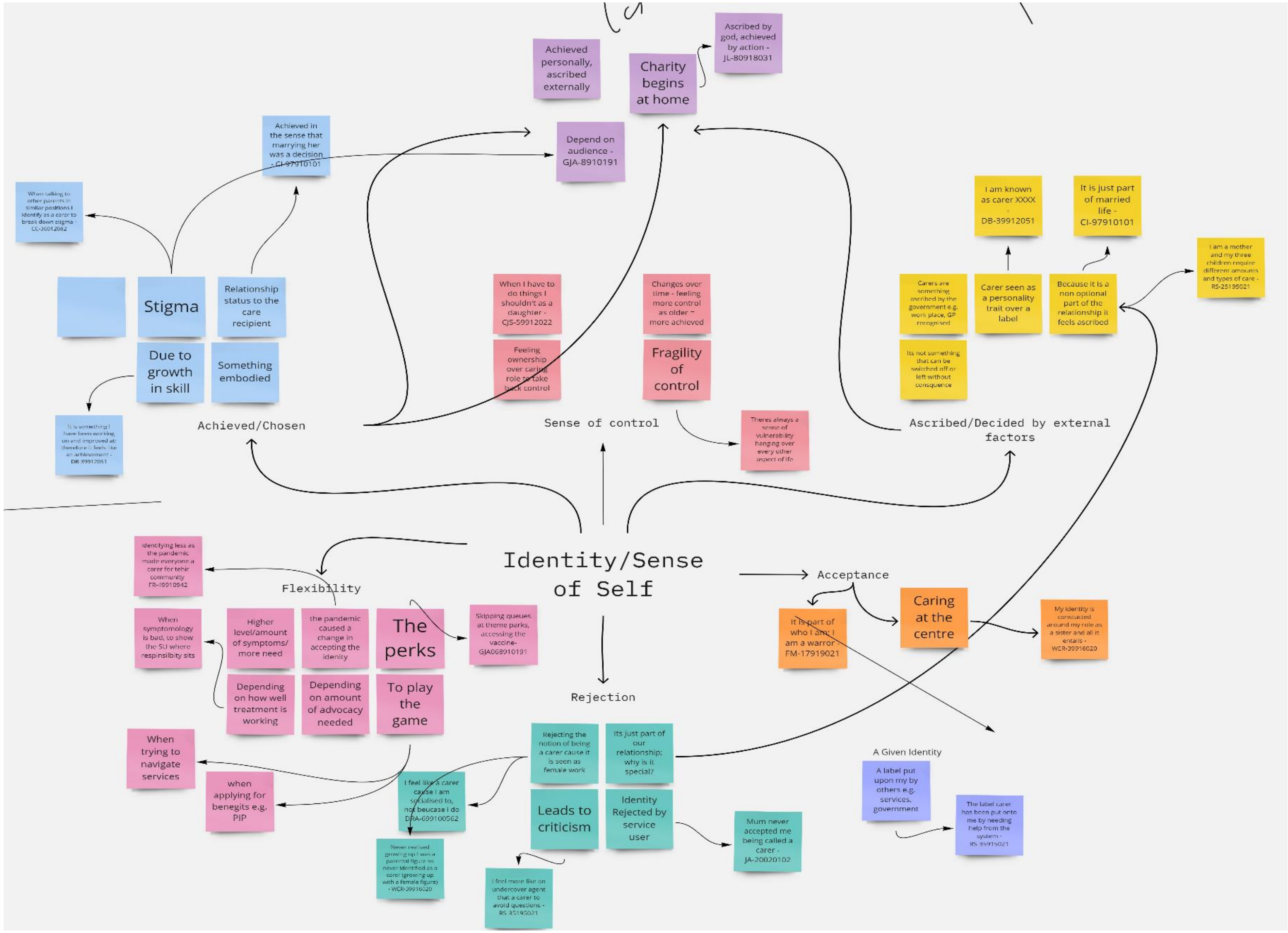
@soapsub 07429428992 ✉ c.Lovelock@lse.ac.uk

I have ethical approval from my university ethics board.
I am funded by the NIHR SSCR

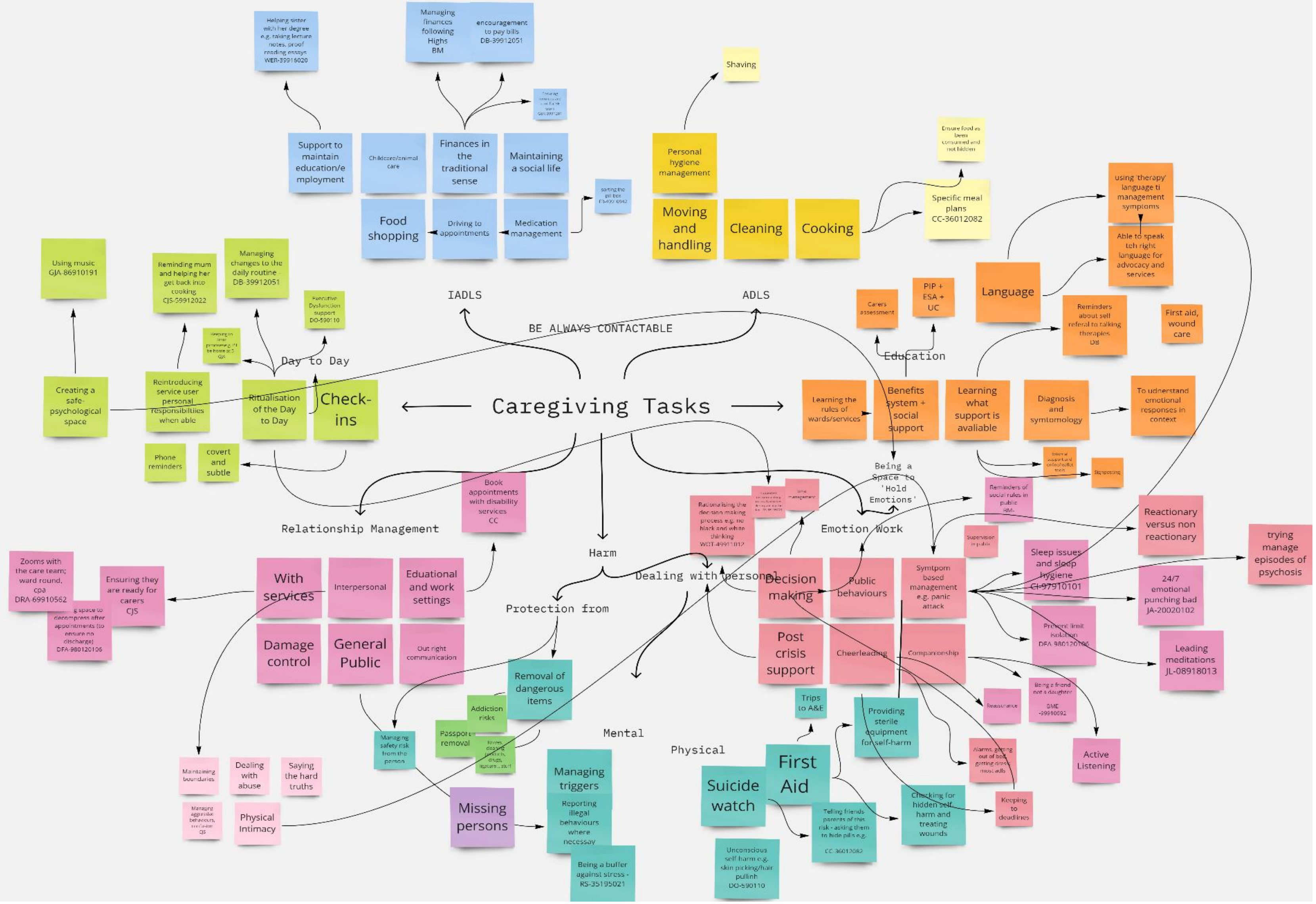
11.8 Recruitment strategy

Who was Contacted	Coms
Carers Centres Blackpool Carers Organisation Brent Carers Centre * Carers Support Southlakes Eden Carers Enfield Carers Fife Carers * Furness Carers Knowsley Carers Merton Carers * Swindon Carers Centre ** Wandsworth Carers Centre ** York Carers Centre **	Communication with all carers centres was done at first instance through their website; submitting an online form asking for they advert to be shown to people and/or the opportunity to give more information about the study. Carers centres with * next to them wrote back Carers centres with ** advertised the study
User Led Orgs Survivors Voices Matthew McKenzie carers newsletter Battlescars self-harm support Rollercoaster parents support	User Led organisations were communicated with through personal connections gained during the first year of the PhD process.
Newsletters McPin Foundation National Survivor User Network Centre for Society and Mental Health Newsletter	
Social Media Twitter Instagram Facebook	
Word of Mouth	

11.9 Themes around identity



11.10 Themes for caring tasks



11.11 Identity Paper Manuscrpit

Personal identity and the role of 'Carer' among relatives and friends of people with mental illness

Introduction

Informal caring continues to be an integral part of the mental health care process in the UK; as pressure has increased on treating people with mental illness in the 'community' rather than hospital settings, unpaid or informal carers, family, and friends are the ones supporting people with the day-to-day of living with mental ill health, thus it is assumed that informal carers will supplement formal care provision (Triantafillou et al, 2010). The assumption a carer will be available is foundational in how statutory services function in the UK (Carers UK, 2019). Despite the extensive literature on caregivers' identity, there is little research which examines mental health caring identity as something flexible, changeable and fluid.

A significant amount of attention has been paid to conceptualising identity over the past 20 years; with numerous disciplines adding to the literature on the definition and development of racial, religious, gender, disabled, and other identities. According to Thoits and Virshup (1997) people utilise socially meaningful categories to describe themselves, including sociodemographic characteristics (i.e., gender), social roles (i.e., husband, parent), social types (i.e., runner), or personality traits (i.e., funny, kind).

Among carers it is a common finding that carers rarely identify with the term 'carer' itself. Instead understanding themselves and their role through a range of personal, social and academic lens. The rejection of the notion of 'carer' is most frequently understood as by academics as unpaid carers perceptions of the support they provide as a regular part of their relationship (Molyneaux et al, 2011).

Caregiver identity theory suggests that caregiving is a fluid process of transformation (Montgomery et al., 2007). Evolving caregiving roles arise from an existing relationship, such as a child taking care of a parent or a spouse tending to a partner (Cox, 2007). Caregiving involves a progression from the initial role to a modified role (Montgomery & Kosloski, 2009; Friedemann & Buckwalter, 2014), often in conjunction with the evolving needs (e.g., amount or intensity) of the person receiving care over time. In other words, as caregivers offer more assistance, their sense of identity within the role undergoes change. O'Connor (2007) believes that initially caregiver identity is situated within the boundaries of the familial relationship, but the gradual deterioration of the person they support health often prompts carers to reconsider their identity. Given mental health caring tends to consist of fluctuating times of wellness, as opposed to a consistent steadily decline, it is possible that the boundaries of the family relationship also shift and change making that gradual deterioration O'Connor refers to as something more less smooth.

Another theory to explain identity is Hughes (1945) "master status." Master status refers to a role that has become more important than any other label or role at that time. This role often shapes a person's entire life, overshadowing all other roles. For example, racial and ethnic identity is one of the most common master statuses reported in the literature (Eifet et al, 2015). Master status has serious significance in identity renegotiation as a single role grows and becomes more dominant than any other role. Master status is referred to as master identity in contemporary research and has the same meaning.

The aim of this study, therefore, is to draw on qualitative data to examine the experiences of mental health carers and to explore how they interacted with and interpretated the label of carer. To learn how the label is bent to the needs and desires of the carers, and how symptomology plays into that narrative. This study was part of a wider grounded theory, with the analysis informed by identity theory, which aimed to illuminate how different mental health carers chose to conceptualise the term carer and its application to themselves, suggesting that the key component identifying as a carer is the sense of control over the given situation.

Defining Identity for Carers of Adults with Mental Illness

Defining identity is a complex task (Prato, Abley & Adamson, 2021). Stryker and Burke (2000) provide a definition of identity as the meanings that individuals assign to the various roles they typically have in today's societies. It should be noted that an individual's identity narratives tend to have contradicting and conflicting elements which Berger & Luckmann (1991) cite to being a product of human perception. Identity is also a complex play between different factors of external identities such as culture, social life, or marginalisation, and internal identities such as race or masculinity (Keating, 2021). However, scholars like Somers (1994) argue that individuals are able to create stable narratives of identity, referred to as "ontological narratives," which help them understand their steadfast individuality. What's more, Rodriquez (2013) has acknowledged the importance of language and communication in shaping one's self-narrative, highlighting that identity is only truly formed through social interaction (Goffman, 1963).

Common conceptualisations of carer identity are based in burden and identity disturbance, with Montgomery & Kosloski (2012) defining identity disturbance as when personal experiences fail to align with one’s sense of self, leading to distress. For carers this often takes the form of loss of self as the role of caring and the responsibilities that come with it superseded other social roles (Eifert et al, 2015). Further, this loss of self is linked to lower self-esteem and an increase in mental illness in particular depression among carers (Skaff & Pearlin, 1992). The capacity to address and resolve differences between the responsibilities of caregiving and one's own personal identity lessens the strain experienced by caregivers (Montgomery et al., 2011) and is likely to positively impact their overall state of well-being.

Resolving identity disruption can be achieved when family caregivers integrate their role as caregivers into their identities (Montgomery & Kosloski, 2012). This involves constructing a new aspect of their identity around the role of caregiver. The ability to establish a caregiver identity is especially crucial for the wellbeing of caregivers, as research has shown that experiencing role discrepancies can lead to increased burden and stress (Montgomery et al., 2011).

Study on mental health carer identity, similarly, tends to draw on identity disturbance and how the burden of mental health caregiving impacts people's sense of self. With a significant amount of evidence showing that mental health caring causes high levels of distress for carers (Smith et al., 2014; Stansfeld et al., 2014). With studies finding that caring for someone with mental ill health such as schizophrenia or psychosis as more demanding and stressful when compared to supporting someone with physical illness (The Schizophrenia Commission, 2012; NICE, 2014).

Methods

Forty constructivist semi-structured interviews with people who identified as ‘supporting a loved one with mental ill health’ were conducted between October 2021 and January 2022. The sample of interviewees was gathered predominantly through social media, charity newsletters, and adverts placed with local carers centres across England. It is acknowledged that these sample methods and the study overall were not accessible to carers experiencing the digital divide. In a few cases interviewees were found through snowball from existing contacts. Following initial contact with the research team to express interest in taking part in the study, potential interviewees were emailed over a Participant Information Sheet and offered a phone call to provide more details where need, or if it was the more accessible option for example interviewees with visual impairments. Following this, interviewees were then sent over a Consent Form by email and a time was sorted for the interview to take place. The study was approved by the London School of Economics Research Ethics Committee.

Data Generation and Analysis

The study was conducted using the constructivist grounded theory methodology, as proposed by Charmaz in 2014. This methodology is based in the belief that knowledge is co-created through interactions and influenced by historical and cultural norms, leading to a nuanced understanding of subjective meaning (Creswell, 2014). The use of this methodological approach is particularly appropriate for investigating complex social processes that have not received much attention previously, while also generating theoretical insights that can be practically applied (Charmaz, 2014)

Consenting interviewees completed a semi-structured constructivist interview lasting an average of 65 minutes. The interviews opened with the question “can you tell me a bit about your relationship with the person or people you support?” wth additional questions exploring details about their relationship, societal and cultural norms around mental health and caring, carers sense of self and identity, contextual changes (symptomology of the care recipient), changes to their behaviour (caregiving tasks, life style changes due to caring), and advice they would give other people in their position. In line with constructivist grounded theory principles, the interview questions evolved between interviews so as to build upon and generate theories through successive levels of data analysis and conceptual development.

Consistent with constructivist grounded theory (Charmaz, 2014), the interviewer and the interviewees mutually co-constructed meaning regarding their caregiver identity development during data collection and analysis; the resulting four themes are an interpretation of this phenomenon. A constant comparative approach was adopted to analyse the data through three stages: initial coding, focused coding, and theoretical coding (Charmaz, 2014).

Transcripts, memos, and field notes were read and a line-by-line “initial coding” of the transcripts was conducted with a focus on preliminary concepts. The codes were closely connected to the data, with a specific emphasis on the participants' utilization of language to generate codes whenever feasible. (e.g., “I am more of a teacher or a mum than a daughter,” or “caring is a lot of responsibility I had little choice over”). The evolving list of initial codes was discussed with the critical friends on the project - two mental health carers, two service users, and a fellow PhD student.

Results

In this section, I interpret the complexity and subtlety of what people said about caring identities, which included some apparent contradictions and some tensions. I describe four categories (which are not mutually exclusive); (1) The fluid mental health carer; (2) the labelled mental health carer; (3) embracing the mental health carer identity; (4) rejecting the mental health carer identity.

The Fluid Mental Health Carer

The most common construction of their identity came in the form of the fluid mental health carer. Carers described their identity, and its relation to caregiving, as something which fluctuates and changes depending on a range of external factors. Among fluid mental health carers, the experience of caregiving was not static or viewed as something inherently positive or negative, instead caregiving was interpreted as a standard part the relationship, which grew and changed as the relationship did.

'I am a mother and my three children require different amounts and types of care, it changes daily, weekly'

The fluid mental health carer tended to separate the person they support from the mental illness they are living with; describing their relationship with the person they support in terms of familial roles such as parent, or sibling.

The variation in caregiving tasks had an implication on the fluidity of identifying as a carer. Some interviewees fluctuated between accepting the identity and rejecting it depending on what support the care recipient required. Where the support was more 'traditional' for example Activities of Daily Living such as helping the person get dressed, feed themselves, or clean themselves, the interviewees were more likely to identify as a carer at those moments. Whereas in traditionally psycho-social support activities like providing emotional support the interviewees frequently rejected the identity.

*'Providing emotional stuff was always part of our relationship, but now she isn't working and I'm helping her do more and more stuff like … *pauses* sometimes helping her shower and I'm paying our bills. I'm not mad at her, she can't help being ill but… yeah, it's a lot sometimes'*

What's more, the severity of symptomology of the care recipient had an impact on the likelihood of personal identification as a carer. When the care recipients' symptoms were presenting as severe – particularly in relation to risk of harm – and the need for hospitalisation, interviewees were more likely to use the label of carer.

'Not necessarily when dad is having a dissociative episode, but definitely afterwards when I have to deal with the fallout of whatever happened/he has done do I feel most like a carer'

In contrast, external factors also played a significant role in the interviewees ability to related to the identity of carer. The Covid-19 pandemic being a prime example, as the lockdowns were announced in the UK some interviewees talked about feeling more like a carer, as they took on more caregiving and different care giving tasks. In contrast to this, other interviewees talked about how they withdrew, or their caring role shrunk.

*'The pandemic has definitely been interesting, like I identify less as a carer now [*December 2021] *than before. It made everyone care for their community more and vulnerable members of their community more, so being a carer is less of a thing'*

It was observed that those who had a fluid relationship with the identity of carer tended to 'try on' the label when it was beneficial. Examples given from interviewees revolved heavily around access services, statutory support, and advocacy. Interviewees described this as 'Playing the Game' or 'Gaming the system' where they would identify or label themselves as a carer in the hopes of giving themselves, and their experiences and knowledge credibility. Similarly, a few interviewees identified as a carer when it appeared beneficial to them. Described by two interviewees as 'The Perks' they gave examples such as earlier access to the Covid-19 vaccine, skipping queues at theme parks and on flights, and to get more flexibility in their work or education.

The Labelled Mental Health Carer

Some interviewees found themselves accepting the identity of carer once they perceived they were given permission or labelled by a statutory body but admitted to feeling tension in identifying before this occurrence as they did not consider their caregiving activities 'real caring.' Once given permission by being given a label, the labelled mental health carers tended to view their caring role in a predominantly negative light – being overwhelmed with exhaustion, often saying they felt 'spread thin' by their responsibilities.

'I didn't know I was a carer until I left home and realised other people's mums didn't steal all their money or threaten them. Obviously somewhere inside me I knew this but when I was told by a counsellor it all clicked together'

Interestingly, these conversations were marked with shame and guilt about finding their caregiving role a burden, until the interviewees were given permission to identify that way. One interviewee talked extensively about how they recognise the value that their caring role has and why it's important, but struggle to reconcile this with the fact they do not enjoy it. Further, even once they received recognition by receiving the label of carer – in this case by becoming recipient of carers benefit – this recognition did not make the role any less challenging.

The concept of the labelled carer also came into play where communication with statutory services was involved. Whether communication with benefits systems, with mental health services, or workplaces, being labelled as a carer by an external body was beneficial as it gave a level of legitimacy. Paradoxically, there were some carers who were labelled that way, not cause of the role but because of their personality. One interviewee spoke at the length about how, even though they care for a sibling living with SMI, they were labelled as a caring person, before a 'carer.' The use of person first language was significant to the interviewee, who expressed that being seen as a caring person ensured their presence in their identity, instead of being a carer which forces their entire identity to be relational to the person they support.

'…especially but at work, but honestly, I've always I've been known as like carer [name]. I've always been called a caring person, so like supporting my brother was just like part of that, until I went to a carers centre and he got respite'

Embracing the Mental Health Carer Identity

People can and do absorb and embody multiple identities simultaneously, including contradictory identities. For some people, sitting with the identity of a carer comes easily, regardless of caregiving activities or time spent caring. For those who embraced the identity, it is often because they viewed it as their master status (Hughes, 1945), with their further identity structured around their role as a carer.

Those most likely to embrace the identity of a carer were those where 'care giving' was not an establish part of the relationship as traditionally understood. Siblings, grandparents, and children in particularly were more likely to embrace the identity suggests that young people providing care for siblings may be overlooked as carers by social service professionals; previous research in England has also found that sibling carers are less likely to be engaged in formal support services compared to carers of other family members (Roth, Lindley, & Ashley, 2011).

Further Interviewees who built a narrative with a sense of pride in their role as a carer tend to be people who support someone with CMD with a milder symptomology; this links closely to second-hand stigma playing a role in identity formation (Spann et al 2020), where those whose care recipient was 'the least stigmatised' by societies wider understanding of mental illness seemed better position to feel a sense of pride in identifying as a carer.

*'When [care recipient] was diagnosed with depression, I came to terms with being her carer as well as her husband. But then the autism diagnosis came along I *pause* sort of stopped. I guess cause I didn't wanna out her as autistic? Probably cause of shame'*

Importantly, the term embracing sounds inherently positive, which in this case was not always true. Interviewees who embraced the identity of a carer understood their identity through both positive and negative lights. Some interviewees who embraced the identity found it had a positive impact on their wellbeing, their relationship with the person they support, and their relationship with caregiving tasks. In contrast, some interviewees spoke about embracing the identity of a carer to the point of losing their sense of self, feeling trapped or a like a prisoner in their relationship. When building this narrative these interviewees described getting engulfed in their caregiving role, losing sight of the things that bought them joy and defined them prior to supporting their loved one. This is a relatively common experience among caregivers with Skaff and Pearlin (1992) describing how loss of self is a result of limited contact and lack of social roles outside being a caregiver.

*'For a time, I had no idea who I was outside of mum then when she died I was *pause* lost. And I didn't know if it was ~just~ grief or like something more. I realised I had lost myself through mum's illness'*

'I am stuck… I do the same things every day, I cook, I clean, I call crisis… this is it. I'm trapped… this is all I am now'

Rejecting the Mental Health Carer Identity

Rejecting the mental health carer identity out right was quite rare within the data, but where it existed their were a wide range of motivations. There was no commonalities or consistencies among those who rejected the identity of a carer, despite the literature saying many people do not identify with the term 'carer' because they perceive their helping activities as a normal part of the relationship that they have with a person who is ill or disabled (Bowen et al., 2011; Henderson, 2001; Molyneaux et al, 2011; O'Connor, 2007).

'It is just part of married life; who decides my relationship is special'

One interviewee chose to reject the identity because in their experience it leads to unwanted questions and criticism from others. They stated:

I feel more like an undercover agent that a carer to avoid questions

Rejection of the carer identity in some cases was motivated by the care recipient themselves. Where the service user was unable to recognise their need for support, or unwilling to acknowledge the support they were being given by family members, this sentiment tended to be reflected by the interviewees. Particularly in relationships where the child was supporting the parent, the parents' rejection of the notion that their child was a carer led to the child rejecting the identity also.

'Mum never accepted me being called a carer'

Alternatively, rejection of the carer identity was in some cases motivated by external factors.

Two interviewees drew on feminist critiques of the term carer as justification for their rejecting the identity. Where caring is judged as female labour, these interviewees drew on the fact that if a male was preforming caregiving tasks they would be labelled as a carer, but because they were women these activities were seen as standard.

The Unknown Mental Health Carer Identity

For a few interviewees, the consideration that they may be a carer was an entirely new revelation. When seeking interviewees for the study the term carer was deliberately removed all recruitment instead seeking out people who 'identified as someone who supports a loved one with mental ill health.' This evidence speaks to, despite the efforts make by local councils, wider government, and the NHS (Jones et al, 2012), the identification of mental health carers is still behind when compared to the identification of carers for those with physical or sensory disabilities, as well as frailty and dementia.

For these interviewees, making sense of their identity with the label carer varied. Some of these conversations came close to coaching sessions with the interviewees talking at length about their experiences supporting someone, their interpretations of the identity of carer, and their capacity to relate the term to themselves. Of those who had never considered the label carer as something that applied to them, they were most commonly men supporting a partner.

'Never realised growing up I was a parental figure so never identified as a carer (growing up with a female figure)'

Themes	**Sub-themes**	**Codes**
THEME 1 Fluid Mental Health Carer	Symptomology based fluctuation	*‘Oh I definitely feel more like a carer when crisis is happening for sure or when theres a change in meds’*
		‘Maybe when she starts using again, I feel more like a carer. Specially cause I get more anxious’
		*‘Obviously when sh*t is really bad, like he can’t be alone’ – they feel more like a carer*
		‘When mum is in hospital or on her way to being in hospital I’m called a carer a lot more? Like the social workers and the doctors call me one, so then I feel like one’
	‘The Perks’	*‘I got earlier access to the [covid-19] vaccine cause I’m their ‘carer’, that was cool. Ohh and skipping queues at theme parks’*
		‘I guess a perk is getting extensions at uni. I can just tell me ac [academic coordinator] that something has happened and can’t meet a deadline without having to provide evidence’
		‘My line manager is really good, she lets me be flexible when things are bad’
	Wielding the identity as a weapon	*‘I probably identify most when playing the game’ – using the identity to give legitimacy to themselves while trying to gain specific things from statutory services*
		‘Oh we definitely include that I’m their carer on anything benefits/DWP related. Especially like when applying for PIP. it feels like it’s in every line cause we are that desperate for support’
		‘This’ll sound bad but like, I can hide behind being a carer sometimes. It gets me out of responsibilities at work. I know it’s bad.’

THEME 2 Labelled Mental Health Carer	Desire for permission	*‘well, do you think I’m allowed to call myself a carer’ – seeking validation from those perceived to have more power*
		‘I have definitely been labelled a carer by the system, I mean, they [they system] need by help to function’
		‘Don’t you need like, the government to say you’re a carer?’
	Imposter Syndrome/Shame	*‘Sometimes I think about going to carers groups, but I don’t think I belong there’*
		‘I’m not a carer because no one has told me so? I thought you were declared it by a GP or the DWP or something’
		‘It sort of depends on the audience, when I’m already labelled as a carer its cool. But I’d never introduce myself as one’
		‘Duty of care’ – feeling emotionally supported when discussing sensitive topics
THEME 3. Embracing the Mental Health Carer Identity	Sense of Pride	*‘Caring is part of who I am, I am a warrior’*
		‘My identity is structured around my role as a sister and everything that entails’
		‘Just being there for [care recipient] is what our relationship is based on, when they got worse it was natural to step up’
		‘It [caring] is something I have been working on and improved at. Therefore it feels like something I’ve achieved and am proud of’
	Losing sense of self	*‘Back before my revelation, being a carer was all I was. I lost everything about myself except caring for [care recipeint]’*
		‘The first time she started using severely and she was turned away from services, then I… [cries] … I was barely me anymore, she was barely herself’

		‘I moved across the country, rent this tiny studio all to be closer to her when she needs me, I left my friends, my job, my other kids’
THEME 4. Rejecting the Mental Health Carer Identity	Externally pressure	*‘When I floated the fact, I was a carer she just got super upset about it so I didn’t bring it up again or like, identified that way’*
		‘I bought it up at school one time, to like my form teacher and he was, well, not very good about it. He said I couldn’t be a carer cause I didn’t help [care recipeint] with like, intimate stuff. And I guess that really stuck with me, so I refused all help’
	Criticism	*‘I feel more like an undercover agent than a carer’ – to avoid questions and not risk outing the person they support as mentally ill*
		‘It’s [caring] is merely a facet of our relationship, who are you to decide if it is special’
		‘I don’t identify as a carer cause it just leads to criticism and unsolicited advice from my friends. I know they mean well but’
	Gendered work	*‘I feel like a carer because I am socialised to do so, not because I actually identify that way’*
		‘Obviously the gendered aspect is important. Am I carer or am I just female and take up this role cause I’m female?’

Discussion

Family members and friends adopted the identity of carer to different extents. Some acknowledge how the identity is flexible depending on different factors in their lives, while others have fully embraced or rejected the identity of carer. Through narrative sense making, insight was gained into how those who support people with mental illness make sense of that activity in relation to their personal identity. Analysis yielded four distinct caregiver identities: (1) Fluid mental health carer identity, (2) labelled mental health carer identity, (3) embraced mental health carer identity, (4) rejected mental health carer identity.

The caregiver identities found through this study represent four ways that mental health caregivers make sense of the experiences when providing care. The fluid mental health carer identity presents as something flexible with these carers construction of providing care as something primarily reactionary, dependant on the wellbeing of the person they support. It implies a degree of separation, with carers making sense of the identity as something to try on, when necessary, as opposed to something grounded within their sense of self. O'Connor (2007) similarly suggested that increasingly people are consciously adopting multiple, fluid identities to include the identity of carer if this identity helps them make better sense of their lives and gain or participate in networks of support.

The labelled mental health carer identity presents a person who makes sense of their identity as something that is given or requires permission. The labelled mental health carer makes sense of their caregiving identity through the concept of consent; whether they chose to be a carer or were forced into that role. They tolerate the bureaucratisation of their personal relationships in exchange for something which acknowledges and rewards the effort and costs of caregiving and thus make sense of their caring role through relating it to external factors such as statutory services who have 'labelled' them. Henderson (2001) suggested that care as an activity takes place within relationships, through negotiation and re-negotiation between the carer and the care recipient. They suggest that that the label of caregiver is negotiated between the couple and that the label is sometimes prematurely placed by professionals on the person without readiness or acceptance. For the labelled mental health carer, thus, its conceivable that sometimes they are labelled a carer before having that realisation themselves or within their relationship.

Carers who rejected the identity present a narrative around their relationship with the person they support. They prioritise other aspects, roles and identities within their relationship and themselves. They reject the notion of being a carer, viewing caregiving and caregiving tasks as something acceptable in some contexts, but not the contexts in which they are in. The data is parallel to Olsen (2000) who suggests that that the way we view the activities of caregiving are grounded in context, and that context implies the acceptability of the activity and thus the identity. The rejected mental health carer identity ties their caregiving activities to different contexts, thus removing the concept of caring from themselves.

Alternatively, Moore and Gillespie (2014) conceptualised the idea of "the caregiving bind," where caregivers often feel unable to share the demands and extent of their caring in order to protect the care recipient. They argue this ends up undermining the social processes that the caregiver needs to establish the caregiver identity. Their findings suggest that the caregiver bind delays the development of a caregiver identity due to a lack of acknowledgement from others that the person providing care is indeed a caregiver. For the rejected mental health carer identity, therefore, they may be experience caregiver bind, and rejecting the identity of a carer as no other person in their life as acknowledged their role in care.

The embraced caregiving identity present in two distinct ways. Firstly a more positive sense-making around the challenging in providing care, with those embracing the identity made sense of the challenges of mental health caring through self-growth, self-care, and skills development. The embraced mental health carer is someone who acknowledges their caring role and readily allows it to shape themselves and their decisions. Hayes et al (2015) suggest that carers who make sense of their role in the relational sense are often provided with a protective function which enables them to find satisfaction and relational closeness in providing care. For the embraced mental health carer, therefore, making sense of their caregiving role as an opportunity to strengthen relationships and inter-personal skills

The second type of the embraced mental health carer identity is made sense of through the the all-encompassing aspect of caregiving. These carers make sense of their identity as being, paramount, formative, and singular – having lost their identities outside of supporting the care recipient. The loss of identity and followed identity engulfment is common in the caregiver literature – with Skaff and Pearlin (1992) suggesting that caregiver identity develops as a result of the loss of self and role engulfment that often occurs through caring. They argue that carer can become a master identity when “ ... caregivers essentially expressed the sense that the only identity left to them is that of caregiver.”(p.658). Those who embraced the mental health carer identity as their main or only identity, therefore, a likely to have experience role engulfment.

Rooted in every narrative and interview conducted was the idea of consent during the caring role. Holding this in mind, examining the narratives through a lens of master status (Hughes, 1945) provides insight into the ways mental health carers construct, prioritise their identity, and have a sense of choice in their identity. Master identity theory or master status as defined by Hughes (1945) states that a person’s dominant identity is something either achieved or ascribe. Ascribe status refers to a the social status that is assigned from birth such as sexuality, ethnicity or disability. In contrast achieved status is a social position someone takes on voluntarily such as a job or parental status. For mental health carer’s identity, the discussion around consent – or seeing their caring role as something ascribed or achieved is key in learning how they make sense of their identities.

Achieved or Ascribed

The common thread which was drawn into every interviewees sense-making of their identity was the concept of consent; feeling like they had a choice or otherwise in the caregiving role. At its very essence, this did not differ depending on the four types of mental health giver this study has conceptualised, but we did fine that those who felt they had a choice in their caring role overall had a more positive narrative; tending to identify as fluid mental health carers or rejecting the identity entirely. Whereas those who felt the identity of the carer was something they had no choice in were more likely to embrace the carer identity within role engulfment or identify as a labelled mental health carer – having been given the identity by an external boy.

Mental health carers, particularly those who adopted the fluid mental health carer identity tended to make sense of their role through reciprocating behaviours with the person they support. This included behaviours around affection and meaning making in the relationship but extended to reciprocating or doing their part in household chores, eating together, or childcare. This links to the element of control and choice within caregiving, where when an increase in need from the carer, but decrease in acknowledgement, the interviewees often questioned their role.

For labelled mental health carers, conversely, they made sense of their caring role as something that was thrust upon by them by external forces, and that lack of decision-making leads the identity to be something ascribed. Labelled mental health carers often felt tied to their statutory obligations or felt like prisoners within their own role. Further, interviewees were likely to build a narrative where their consent in caregiving was flexible; explaining times where they consented, times where they were unable to, or felt that consent had been made for them by statutory services.

Statutory obligation is rooted in societal expectations of the role obligations and perceived moral expectations. Western culture has created a system of assumptions, beliefs, and values that situate the family, and particularly women family members as the caregivers. O'Connor (2007) found that the responsibility of providing care to a spouse or partner is assumed and related to being a 'good' partner. This assumption is carried forward in statutory mental health services with Warner and Wexler (1998) illustrating that statutory mental health services operate under the assumption that a carer will be available, planning care around that person being willing to take an active role in supporting the care recipient. This assumption often leads to people becoming carers by obligation; and only relating to the identity of carer when it appears thrust upon them by external powers.

Conclusion

The results of this study show that carers for people with mental illness conceptualise their identity in multiple ways depending on a range of factors. Many mental health carers chose to label themselves a carer as and when they choose and it has a purpose for them. Those supporting someone with SMI are most likely to identify as a carer. Some people are only willing to accept the identity once it has been 'given' to them by someone they perceive to be in a position of power. The findings have implications for understanding why people supporting someone with mental illness are less likely to be identified by statutory service

11.12 Carer Learning Types Manuscript

Understanding mental health carers learning processes toward identifying as experts by experience

Introduction

Service user participation in health and social care services design and policymaking has steadily gained importance (Gordon et al, 2020, Scanlan et al, 2020). This participatory approach aims to enhance the quality, relevance and usability of health and social care research and policy (Brett et al, 2014; Brett et al, 2021). There has been extensive research on patient and public involvement (PPI) focusing on issues such as the conceptualisations of involvement, benefits of doing involvement for health services, and issues related to implementation and attitudes of different stakeholder groups (e.g. Dent and Pahor 2015, Lehoux et al. 2012)

One of the ways that mental health carers participate in health and social care services is by sharing their personal stories about caring for or supporting a family member or friend with ill health. These stories can be used to inform practice, health policy, and research agendas (Nielsen et al, 2013) with those who utilise their stories being dubbed Experts By experience (Meriluoto, 2018; Noorani, 2016) or lived experience workers (Byrne et al, 2016). Traditionally, researchers and policy makers understand Experts by Experience as people with direct experience of living with an illness or social issue such as being unhoused. Experts by experience form the basis of their expertise off these life experiences and utilise them in different involvement activities (Fox, 2016; Fox 2020); often working as trainers, co-producers, or lived experience consultants, taking part in academic research, or being involved in policy and system change work at local and national levels.

The process of becoming an expert by experience is not well understood, especially for mental health carers who are missing from the majority of the literature on the subject (Kara, 2016). A principal aspect of identifying as an expert by experience is the construction of a personal narrative or story which is the primary resource for doing involvement activities (Jones, 2018). Whilst some studies have argued that becoming an expert by experience can be empowering, giving service users a different lens to interpret their experiences (Wilberforce et al, 2020) others have suggested becoming an expert by experience involves individual and collective processes that include sharing experiences and creating distance from them, combining experiences with existing competencies and developing an orientation towards the future (Toikko, 2016).

For this study a focus is placed on mental health carers, how and where they gain information to supplement their experimental knowledge, and the occurrences and motivations for that learning. This study aimed to examine mental health carers experiential learning through the lens of experiential learning theory (Kolb, 1984), examining both the types and learning processes mental health carers undergo to make sense of their experiences toward identifying as an Expert by Experience.

Experiential Learning Theory

Experiential learning, or active learning, interactive learning, or “learning by doing” has resulted in positive outcomes (Morris, 2020). It is commonly understood as a part of formal education process such as when students take an active role in the learning process the student’s learning is optimized (Smart & Csapo, 2007). However, experiential learning can also occur outside formal education settings, including in everyday life situations. Experiential learning theory defines the learning process as “the process whereby knowledge is created through the transformation of experience. Knowledge results from the combination of grasping and transforming experience” (Kolb, 1984, p.41). Kolb defines the experiential learning model as a cyclical process of learning experiences; where effective learning only occurs when the learner goes through the entire cycle. The four-stage learning model describes two differing dimensions of grasping experience: (1) concrete experience (CE) and (2) abstract conceptualization (AC). Followed by two opposite dimensions of transforming experience: (1) reflective observation (RO) and (2) active experimentation (AE).

Experiential Learning Theory has been further refined and elaborated by Kolb and colleagues with Kolb (2015) reiterating:

a four-stage cycle involving four adaptive learning modes (p. 66) … [where] Learning arises from the resolution of creative tension among these four learning modes. This process is portrayed as an idealized learning cycle or spiral where the learner “touches all the bases” – experiencing (CE), reflecting (RO), thinking (AC), and acting (AE) – in a recursive process that is sensitive to the learning situation and what is being learned. (p. 51)

Kolb (2015) asserts that knowledge results from a combination of acquiring experience (through concrete experience and/or abstract conceptualization) and transforming experience (through reflective observation and/or active experimentation). Experiential learning theory, therefore, views learning as “a cyclical process that involves the transformation of experience”, in which learners directly experience a phenomenon, reflect on that experience, develop a conceptual framework to integrate their experience with prior knowledge, and then engage in experimentation which begins the cycle again (Kolb et al., 2001).

Experiential learning refers to the learning that arises from life experiences as opposed to didactic forms of learning. It is a sense making process of active engagement between the inner world of the person and the external worlds and environments (Beard and Wilson, 2013 p.4). The success of experiential leaning in achieving various learning outcomes is frequently attributed to the fact that it supports a wide variety of learning styles and use skills/knowledge. Experiential learning theory has been applied across a range of fields including education, medicine, and psychology (Kolb et al., 224); it is intended to be a holistic learning process that merges experience, perception, cognition, and behaviour (McCarthy, 2010).

Experiential Knowledge in Mental Health

Experiential learning has several implications and applications for different fields and domains of knowledge, in mental health, it may be especially relevant for those who have personal caring experiences. Expertise and knowledge claims have historically been ascribed value and proper definition by professional agencies and institutions (Abbott 1988, Freidson 1972); with knowledge development being done through periods of study and learning hosted in professional environments (ibid). Within medicine, medical knowledge and particularly mental health, Foucault (1972) traced and labelled the modern organisation of medical knowledge to late 18th century medics using the 'medical gaze.' He argues that the study of patient's bodies, symptoms and behaviours – both live and dead – led to the partial separate of the patient's body and the patient as a person (Foucault 1973, Sullivan 1986). These developments led to an emphasis on objective forms of knowledge and expertise in professional healthcare teams (Gittell and Douglass 2012, Mol 2002) formalised as 'gold standards' which span contexts of care (Timmermans and Berg 2003) and national and international guidelines (e.g. National Institute for Health and Care Excellent in UK).

Experiential knowledge in mental health as dubbed mental health service users as experts by experience; starting thirty years ago with Beresford and Croft (1993) publishing their seminal book on citizen involvement in health and social care. Service user participation and involvement, with service users being labelled as experts by experience is implemented across different areas, such as the co-production of health and social services (Boyle & Harris, 2009; Needham & Carr,2009), research (Russo, 2012; Russo & Beresford, 2015) and social work education (Farrow & Fillingham, 2012; Robinson & Webber, 2013). In the field of mental health and social care, there is a a demand for experts who have particular knowledge that is based on personal experience with mental health problems (Tokiko, 2016) but scholars have not undertaken as intensive an examination of the emergence of expertise by experience.

Understanding the genealogy of the term lived experience and its origins in and how it is used in current mental health research and policy-making is vital to understanding the potential directions of the term and its academic theory. The aim of this paper, therefore, is to expand on the uses of experiential learning theory within UK mental health policy; using it as a framework to understand mental health carers knowledge generated through their experiences. Given the current understanding of expertise by experience in mental health speaks relatively exclusively to service user populations (Slay and Stephens, 2013; Bradley 2015), this study aimed to learn if mental health carers who had extensively experience of supporting someone with a mental illness identified in such a way and what learning they underwent to do so.

Methods

The objective of the study was to produce knowledge about how mental health carers undergo learning processes in their role toward understanding their identity as experts by experience; focusing on the following question: What processes do mental health carers undergo in identifying as an expert by experience? To explore this, a constructivist grounded theory was done with its origins based in symbolic interactionist approaches of Mead (Mead & Morris, 1934). The constructivist grounded theory methodology (Charmaz, 2006) focused on co-creating meanings between the interviewer and interviewees. The constructivist grounded theory approach was chosen as the research was already immersed in the interviewees contexts – being a passed mental health carer themselves (Charmaz, 2014).

The research undertaken adopted a multi-method approach using semi-structured interviews and cognitive interviews (Willis, 2013) The study received ethical approval from the London School of Economics and Political Science Research Ethics Committee *Ref: 25799*. 40 Semi-structured interviews took place online via Zoom or MS Teams with people who identified as 'supporting a loved one with mental ill health' were conducted between October 2021 and January 2022. The interviews took place at a time convenient to the interviewee. Interviewees recruited through a purposive sampling methods via social media, adverts placed in local carers centres and personal connections from the researcher. In a few cases there were snowball interviewees found via those who had already taken part in the study. Further description of the sample can be found in Table 1:

Semi-structured Interviews		
Demographic	Type	Number of participants
Gender	Woman (inc: trans)	19
	Man (inc: trans)	13
	Non-Binary	5
	Other	3
Age	18-24	6
	25-35	14
	36-46	11
	47-60	5
	60+	4
Care recipient identity	Parent	14
	Child	5
	Sibling	6
	Partner	11
	Grandparent	2
	Friend	1
	Neighbour	1
Cognitive Interviews		
Demographic	Type	Number of Participants
Gender	Woman (inc: trans)	5
	Man (inc: trans)	1
	Non-Binary	1
Age	18-24	1
	25-35	3
	36-46	0
	47-60	1
	60+	2
Care recipient identity	Parent	3
	Child	1
	Sibling	1
	Partner	1
	Friend	1

The cognitive interviews acted as a participant observation in which the researcher could witness and discern the ways mental health carers drew on their lived experience and what within the questions motivated that. The cognitive interviews involved the iterative assessment of the Triangle of Care Carers Feedback Questionnaire – conducted 5 times over a 5-month period. This questionnaire was selected as it had previously been co-created between mental health services staff, clinical academics, and mental health carers. The cognitive interviewing process was done online via zoom or MS Teams with mental health carers recruited from social media. 7 carers took part in the cognitive interviews all doing five interviews over the course of five months leading to 35 cognitive interviews in total.

Before any data gathering took place interviewees were given at least 24 hours to consider joining the study, they were emailed an information sheet detailing the purpose and aims of the research and the fact they could withdraw consent at any point. All interviewees had capacity to and gave consent to take part in the research and for their data to be drawn on in the write-up. The majority of interviews were audio recorded and interviewees were invited to review their transcripts once typed up and anonymized. In order to facilitate reflective practice and promote ongoing comparison, transcriptions, coding, and analysis of the interviews were promptly completed (Charmaz, 2006). They data was managed in MIRO software within initial coding focusing on exploring meanings and actions (Charmaz, 2006) before the subsequent analysis framed by Experiential Learning Theory.

Results

The mental health carers in the study outlined five types of learning they underwent and continue to undergo to supplement their lived experience of supporting someone with a mental illness. Drawing on their lived experience, the mental health carers in the study spoke at length about the different methods of learning, motivations for it, and key milestones where learning occurred. The five types of learning identified were:

(1) Pre-diagnosis Learning
(2) Collective Learning
(3) Action Learning
(4) Self-directive Learning
(5) Formal Learning

Pre-diagnosis or Pre-Statutory Involvement in Care

The majority of individuals started to learn about the condition the person they supported presented with prior diagnosis or statutory service involvement; becoming aware that the person was presenting with mental illness symptoms and seeking out knowledge in advance of statutory help. This learning tended to be done in online forums, social media, and through personal connections. A number of individuals in the study spoke about how they supported someone for a significant length of time while before they received a formal diagnosis. During this time, they focused their learning on the symptoms and condition being experienced, rather than wider support options. For mental health carers supporting someone who had a diagnosis but had not disclosed it yet, their pre-diagnosis learning was done more often with the care recipient – together learning how to manage the persons mental health without labelling it as such. This was particularly true for children supporting their parents and vice versa.

During this pre-diagnosis learning period mental health carers described primarily investigating the symptoms and condition but some also sought out where support from external agencies was needed or indeed possible. These agencies included schools, workplaces, statutory mental health services and the welfare support system. Often the context of the support seeking was not for their own personal support, but to see what was available for the person they are supporting.

‘I think I’d tried to get him to go to the GP about it long before he did. Before he even knew anything was really wrong’

Experiential learning theory views knowledge as something situated within context: emphasising the time, place, and motivations for learning (Morris, 2018). Experiential learning occurs at specified times or milestones (Smith and Segbers, 2018) and in interactions with specific people (Harper, 2018; Morris, 2018). For mental health carers engaging in pre-diagnosis learning, the surrounding context to motivate their learning is based off the interactions with the person they are supporting. Whether through a definite conversation, or through more abstract contact with them.

'Before [care recipient] told me about their diagnosis I'd already googled so much. I think my first stop was probably MIND [charity] or maybe Rethink [charity]. It was obvious something was going… she wasn't eating, she was barely sleeping'

'We didn't seek help from services until [care recipient] maybe third breakdown? Not really for any reason except we didn't think it applied to us? Mental illness is hearing voices not… this'

Experiential learning theory also states that the 'place' where learning occurs has significant sociocultural, historical, and personal meanings (Pipitone, 2018; Harper, 2018). For mental health carers engaging with the 'place' in pre-diagnosis learning is important as it allows them to mould their thinking to be more critical of basic societal norms, and the power structures (Deringer, 2017) which remain dominant in the mental health field. In pre-diagnosis learning mental health carers developed their own understanding of mental ill health, drawing on the experiences of the person they supported, their wide politics, and the context of the person they supported symptoms.

'Oh I wanted to learn everything. I think my ADHD hyper fixated on their symptoms and I trawled for any info of how I could support them. It took awhile to realise it was mental illness and not just being trans in a heteronormative society'

Interviewees also spoke about the unconscious learning and adaptions they had made to their behaviour, they only realised later into their caring relationship.

'I'm not really sure when I learned to do it, but like waking up with that cup of tea ready just made the day easier so I would do it'

'There's a lot of little things I picked up before they were diagnosed with PTSD. The usual stuff like not making loud noises but smaller things like when to squeeze their hand during a panic attack. Oh or on panic attacks recognising when they wanted to not be touched at all and just coached through breathing. I learn that long before [mental health nurse] told me about ground techniques'

Collective Learning

Community learning or collective learning, as named by the interviewees, was identified as a frequent way of learning. Taking place primarily in digital spaces, collective learning saw mental health carers learning from each other's experiences mostly on issues or challenges with statutory services. It was identified that collective learning occurred on social media, at carers support groups put on by charities or statutory services, and during research or policy involvement activities.

'Doing stuff like this [interviewer: like this interview?] yeah, it's a good way to learn from others. And being involved in studies is a way to meet others who also have rubbish experiences with the system'

Interviewees discussed how collective learning processes existed as a means of knowledge exchange – learning from each other's stories, errors, and successes. This is common within established communities of practice such as OT's who see story telling as a means of tacit knowledge exchange which ensures the justification of practice which sits outside of tradition or formal education (Moon, 2010). The majority of interviewees placed emphasis on the importance of finding community, meeting other carers or people with similar experiences as a place for learning.

'I'm at a point now where if some new goes wrong with [name] I can ask the twitterverse and someone while chat me through it'

'Yeah, yeah we met at a [charity name] event for young carers. Ages ago now. He has guided me through so much stuff.'

Within Experiential Learning Theory community learning or community engagement is a central process (Deringer, 2017); with Fifolt et al (2017) arguing that the role of experiential learning is to bring a community together. For mental health carers, this means that engaging in community learning as a collaborative process helps them establish their learning as knowledge. Isakk et al (2018) positions the educator and the learner as roles within community learning where the educator plays a role of facilitating the learning process, ensuring the learner stays open to novel solutions, encourages insistent attitudes/behaviours and promoting communication. Within collective learning among mental health carers, this presents itself as carers forming mentor/mentee relationships in virtual spaces. With a carer who has experienced a phenomenon taking the role of the educator to someone who is experiencing it for the first time – the leaner.

'Meeting [name] was the best. Yeah, yeah I realised, they gave me words to explain that I was carer, that this situation with mum was not normal. Yeah I learned a lot of them'

'We really need to platform more young voices in mental health caring. We can all learn from each other but god we need to hear some new people'

During discussions of the collective learning process interviewees identified common knowledge that mental health carers hold, establishing common realities to build their lived experience upon. Caron-Flinterman et al (2005) suggests that through the process of collective learning lived experiences often combine to become a collective pool of experiential knowledge.

Action, Doing, or Experimental Learning

For some interviewees, particularly those supporting their adult children with mental illness or those supporting their partners, learning occurred through 'trial and error.' When asked they constructed this learning process as 'Action Learning' or 'Doing Learning' where, when working with the person they support, the developed ways of supporting them via action and feedback. Action learning was the only learning method which was entirely dependent on interactions with the person being supported, being led by the needs, wants, and desires of the care recipient.

Experiential Learning Theory views learning and action learning by this definition as purposeful, with the learner taking responsibility for finding solutions through an inquiry process relating to specific real world problems (Morris, 2019). Action learning was most commonly present in for mental health carers in conversations about symptom management or caregiving tasks:

'When she was resistant to her meds [name] would start hiding them under her tongue so now I check out of habit even though she's been on these meds for god 8 years [laughs]'

'Ohh it was definitely a trial and error thing. Yeah like what her safe foods are in different moods. [name], husband, was rubbish at it. Never got the right brand of yoghurt for [Care recipient]'

What's more Kolb (1985) acknowledges that active experimentation, as part of experiential learning, utilises 'theories to make decisions and solve problems' (p.30). Across the data this presented as mental health carers trying to navigate learning habits and routines which function best for the person they support. In action learning, mental health carers assume collaborative responsibility for the learning process (Hou& Pereira, 2017) acknowledging that the care recipients needs are likely to fluctuate.

'Of its definitely with stuff like figuring out routines, what keeps them calm and like what works after an inpatient stay? Particularly within those first few days after. We've got a good thing going when they are discharged but it's taken until now'

Where the data illuminated the ways in which mental health carers underwent action learning with the wider mental health system as opposed to the care recipient it presented as the learner (carer) having a clear role, purpose and responsibilities in the done action and subsequent learning (Bialka & Havlik, 2016; Fifolt et al, 2018).

*'With services, god with services it was so much throwing sh*t around till it stuck. Endless phone calls, finding the person who would listen'*

'Oh in the end I just went to the ccg. Yeah? [laughs] just do it. Go straight to the top. It worked for me'

Self-Directive or Self-Motivated Learning

Every interviewee spoke at length about the individualised learning they have had to do to be able to perform their role as carer – if they identified it that way, or simply to support their loved one. They defined self-directive learning as filling in knowledge gaps or seeking out additional information to what was provided. Experiential learning theory encompasses the risk that is involved in learning; incorporating novel, challenging, and differing experiences (Davidson et al, 2017; Fuz, 2018). Mental health caring is often unpredictable (Dam & Hall 2016; Mackay & Pakenham, 2012) with carers constantly adapting, undergoing new experiences and subsequent learning.

'So, so, yeah much is just google. The constant acronyms? Initialism? Constantly googling looking at those cause they [clinical staff] chat like you're not there'

'Oh yeah I had to learn it all myself. Not even a leaflet on their diagnosis. All the new [experiences] yeah I have to do it [learning] all again'

Experiential learning is often an emotionally intense experience, particular with self-directive learning comes constant reflection and action on that reflection. Larsen (2017) finishes saying that experiential learning is a 'highly charged, emotional experience' (p.279). For mental health carers, self-directed learning seems to be their preferred type of learning, as they actively participate in it. However, they can find this activity challenging and draining. It is important to note that self-directed learning can be time-consuming and require substantial effort, particularly when there is a lack of support from others or knowledgeable leaders.

'I mean I had to learn the entire system, not just like when are visiting hours and what am I allowed to bring, but also what is a mental health OT what's a care co-ordinator, all the way to what on earth is an SSRI'

'Sometimes I wish it was all laid out for me, no winding down reddit threads from 3 years ago praying its not out of date'

Self-directed learning was the most expansive learning method identified, with every carer speaking at length about the topics, knowledge sources, and motivators that led them to doing it; with the motivators for self-directive learning dictated by the needs and desires of the care recipient.

Formal Learning Experiences

A few (n=8; 3.2%) interviewees spoke about formalised learning experiences; including attending courses at recovery colleges or local carer centres, in school, attending training at a local pharmacy, and various one off experiences with the person they support, their care coordinator or mental health staff member. Formal learning experiences were understood as traditional spaces for learning, often with a teacher, leader or facilitator.

'I was sent [by a social worker] on a course once about mental illness.'

'I went to a recovery college with [care recipient]. It was mostly for her but I found it helpful to see what she was learning and how I could fit in… it was like making a crisis plan'

There seemed to be no pattern in terms of who received a more formalised education about their caring role, however the formal learning experience that these interviewees identified tended to grant them an air of legitimacy in their role as a carer, given it had been acknowledged by a wider body and that their learning needs were attempting to have been met.

'I had like a 1:1 with his mental health nurse. I think cause I am a mental health nurse they saw me? But she gave me the full run down of the situation'

'My school did a PHSE session on young carers? If anything it made me feel even less like I counted as one'

Experiential learning theory discusses how learning experiences which have an instructor or are done with peers ensures deeper critical reflection (Asfeldt et al, 2018; Collins et al, 2016). Learning done in these spaces warrants the learner (carers) to critically reflect upon their assumed knowledge, allowing the carer a new level of self-awareness that comes with new or revised understandings (Hou & Pereira, 2017). For mental health carers, while they may not agree with the new knowledge they are equipped with in formal learning experiences, having the chance to reflect on their knowledge and it's beginnings in a space specifically designed for that purpose may have been beneficial.

'I went to one of the support groups things in [local mental health hospital]. What a waste of time, honestly I couldn't. The staff were so rude, I wanted to take over'

'I had support from a charity when I was in school… yeah I met other carers through that and it was nice. They, yeah, they weren't mental health but they gave me tips for managing school and stuff'

Milestones and Learning Points

The learning processes identified above can be understood as two distinct processes: personal learning and external learning. Within personal learning processes the mental health carer makes an observation, seeks out knowledge independently, and reflects on their experiences with the purpose of forming personalised or abstract concepts based on that individual learning – often combined with professional competencies. This reflects the experiences of any pre-diagnosis learning and any self-directed learning that takes place. On the other hand, the external learning processes – whilst having an impact on personal learning – sees mental health carers as groups or collectives who hold shared assumptions that create a new kind of knowledge. This type of knowledge is often co-created with another party whether other carers, clinical professionals, or the care recipient (Middleton, 2010). This can be seen in the collective learning processes and action learning processes described above.

Experiential learning and any subsequent experiential knowledge are inherently bound to the time and place it occurs (Blair, 2016). The mental health carers in the study took time to reflect on the key milestones and occurrences which motivated them to do active learning of any type. Time and timely experiential learning where key in establishing experimental knowledge for the mental health carers. For experiential knowledge to labelled as that expert by experience identity, it was common for the mental health carer to have been supporting someone who a substantial length of time.

There were common points or occurrences across the lived experience narrative that the carers explained where key places of their learning. In the interviews themselves this was often called 'life learnings' or 'life lessons.' For the vast majority of carers spoken to during the study, they described an experience of being left behind, forgotten or let down by statutory mental health services, as both a motivator and a place for learning. While the majority of interviewees understood that frontline staff are incredibly stretched and increasingly dependent on carers they explained that this dependence did not come with any training or consent and therefore they found themselves going at it alone.

*'There was a time when we had gone to St Thomas' A&E and just been sent home? Like fuck they just said if it was a real crisis you'd have called an ambulance [researcher: jesus I'm so sorry]. No no don't just yeah that was when I was like I've gotta get me sh*t together and figure this out'*

'I get that staff are stretched. I do. If anyone get that its me, I'm one of them. But it's the crushing sense of having to do it alone. It impacts us as the carers but the service users too. [care recipient] hates feeling like a burden'

Brown (2021) illustrated the perspectives of mental health carers in regards to the levels of awareness clinicians and wider statutory mental health services possess about the care process outside of hospital settings. The author observed that there seems to be limited comprehension among these professionals, with a few isolated pockets of embedded carer knowledge. For most interviewees, therefore, when questioned about when they first started identifying someone as an expert by experience their stories tended to begin with services not being able to provide what was needed whether this was drawn into crisis medication hospitals and beds or in a more intimate setting such as at home.

'I mean [care recipient] mentals fluctuates so much that its constantly learning?'

The mental health carers who participated in the study were more inclined to consider their knowledge as expertise if they had practiced the experiential learning cycle multiple times at various stages throughout their caregiving journey. This included undergoing experiential learning both individually and when co-learning with the care recipient. Those who identified as an expert by experience were those who labelled their experiences as a space for learning or growth, who often had a range of degrees of separation – personal and physical – from the person receiving support. This is similar to Toikko (2016) who found that service users who identified as experts by experience had created distance from their lived experiences.

Discussion

In this article I have explored data generated from a series of interviewees with mental health carers about their experiences learning and supplementing their experiential knowledge. Based on the findings, I argue that the process of coming to know through experiential learning is multi-facetted, with multiple different ways of learning employed at varying times and occasions during the caregiving process. It is the combination of these modes of learning which lead to mental health carers identifying as an expert by experience. These learning types provide the grounding of where mental health carers supplement their experiential knowledge with sought-out and learned expertise.

Exploring caregiver learning types through experiential learning theory allows for carers to be viewed as ‘learners’ who are actively involved and engaged in the learning process – learning how to support the care recipient with their needs. ‘Learning by doing’ is hardly a novel concept but is a foundational concept of experiential learning theory (Munge et al, 2018). Mental health carers have often experienced providing care before they identify as a ‘carer’ or as an expert by experience. This study makes evident the ways in which mental health carers learn from and with their experiences. While some had experienced learning in more formal settings most had not – feeding into experiential learning theories principles of learning being a ‘hands on’ task-orientated process (Blair, 2016; Dorfsman & Horenczyk, 2018).

Experiential learning posits that learning occurs in four stages: experiencing, reflecting, conceptualizing, and experimenting. For mental health carers the first stage involves concrete or a specific experience with a topic or activity, usually motivated by a change in the care recipients’ circumstances, where a direct exposure to the tangible experience or activity (Broussard & Teng, 2019) has occurred. The second stage is described as reflective observation of new information received during the activity (i.e., processing of experience into information), for mental health carers this often presents as knowledge seeking activities – whether self-directive or through collective learning methods and networks. In the third stage, the learner conceptualizes a model based on what they observed about the concrete experience. The learner’s new working model serves as a basis for testing new assumptions and ideas (Broussard & Teng, 2019). In mental health caring this can present as a change in routine with the care recipient, communication with statutory services, or a temporary measure to deal with a new time dependent symptom. In the fourth stage, the learner tests out their new working model and makes plans to approach new situations and engage in active experimentation (Broussard & Teng, 2019). After engaging in active experimentation (stage four), the experiential learning theory cycle begins again.

The learning types identified in this study can be understood through various perspectives; the collective learning type can be further understood through the idea that knowledge is co-constructed individually and within communities and wider society; in which we can view learning domains as a place where members interact to create collective, individual, and situational knowledge (Lave & Wenger,1991; Wenger,1998, 2000). Within this, communities of learning are expected to have, or create, cultures that support it (Brown and Lambert, 2013); ensuring expertise is acquired in particular situations. In mental health services work, this presents as mental health clinicians converting their experiences into tacit knowledge, which is the basis of situational expertise. For mental health carers, however, this presents as undergoing different types of experiential learning to created a set of common knowledge across carers.

External learning processes as branded above can be understood through Edward’s et al (2013) ‘distributed health literacy’ which occurs when individuals draw upon the health literacy skills of others in order to seek, understand and utilise health information. Specifically, in the current study, mental health carers shared their knowledge and understanding with each other across their social networks to access, evaluate, and expand their understanding of information. This included using their knowledge and skills of others to help them to work with the person they are supporting to help the manage their condition. Interviewees in the study primarily felt able to access information through a range of methods, but often turned to other mental health carers in order to evaluate it and compare other’s experiences. This was most evident around sectioning and inpatient treatment.

This evaluation and comparison of experiences allowed them to determine how useful and relevant the information is to their own circumstances.

The combination of different sources of learning appeared to generate more in depth knowledge and an increased likelihood of identifying as an expert by experience. For mental health carers this implies that once a certain amount of experience has been accumulated through different type of learning, there is more benefit to reflective observation, theorising, and conceptualising their knowledge (Kolb, 1984) than to gaining more experiences. Where some learning was granted through experience and repetition of tasks in some cases is automatic or unconscious; for example for mental health carers this can present in habits such as check-ins at specific times or ensuring they come home by a specific time in an effort to reduce anxiety. In contrast, self-directive learning or learning through deliberate articulation and codification sees specific knowledge sought out and the relationship to it consciously controlled.

Limitations

The chosen sampling method, purposive sampling, resulted in a sample that may not accurately represent the full diversity of the community (Etikan et al, 2016). In particular, mental health carers from UK minority ethnic populations may adapt and learn their mental health carer role differently to their white counterparts (Rabiee & Smith, 2014; Islam et al, 2015). Additionally, it is important to note that the semi-structured interview questions did not account for the potential evolution of various learning styles over time, which is a recognized limitation of the experiential learning theory.

A further limitation of the study is issues with participant bias. Particularly among the interviewees which took part in the cognitive interviewing process, it is likely social desirability bias and acquiescence bias. Given the process of cognitive interviewing is known to be fatiguing (Willis & Artino, 2013) it is likely towards the final interview mental health carers experience acquiescence bias merely agreeing with the research due to being fatigue of original input.

Experiential Learning Theory is specifically intended for application within education and management settings, and therefore may not be entirely transferable to the field of mental health care. What's more, as a framework for understanding learning it fails to take into account the significance of personal identity within learning. Nor does it account for individual values and notions of how mental health carers conceptualise their own learning. What experiential learning theory may label reflective observation, a mental health carer themselves may not consider themselves to have 'actively' engaged in any reflection at all. For this study, therefore, experiential learning theory is limited in its applications to mental health carers

Conclusion

While the position of mental health carers in the experts by experience narrative remains unclear, and the positions of experts by experience in health service design and policy making remains unclear (Jones and Pietila, 2018), it is vital we understand the ways in which mental health carers learn from and with their experience. As we become more dependent on unpaid care, with approximately 4.7 million carers in the UK (ONS, 2021) it is crucial to understand how carers come to know their role within the care team, how they gather information and from what sources, and how they learn from their lived experiences within systems. With the devolution of commissioning powers to local areas and the introduction of Integrated Commissioning Boards/Systems, community care for people living with mental illness is expected to expand further. However, this also implies that family, friends and carers will have to fill in the gaps in support that the formal system may not provide. Understanding mental health carers knowledge gained through experiential learning theory may not position caregiver knowledge as 'expert' in the traditional view;

given the objective knowledge that governs healthcare practice aims to remove the disorder or diagnosis from the context and lives of the people which it is situated within (Oborn et al, 2019; Quinlan, 2009), it is evident that mental health carers often fail to consider their knowledge as expert when it does not fit into this definition. However, it allows for understanding mental health carers learning and knowledge as situated within specific times and contexts and be utilised in care, research and policy making settings.

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