Caring for a friend or family member who has experienced psychosis and suicidal behaviour: A qualitative investigation

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Declaration by student

I declare that this is my own work and has not been submitted in substantially the same form for the award of a higher degree elsewhere. The following sections of this thesis have or will be submitted for publication:

Chapter: ‘Caring for a friend or family member who has experienced suicidal behaviour: A systematic review and qualitative synthesis’. This chapter has been submitted to (and at time of thesis submission is under peer-review by) *Psychology and Psychotherapy: Theory, Research and Practice*.

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Chapter: ‘The psychosocial impact of caring for someone with psychosis who has experienced suicidal behaviour. A qualitative interview study’. This chapter is formatted for and intended for submission to a relevant academic journal.

Chapter: ‘Carers’ understandings of the relationship between psychosis and suicidal behaviour. A qualitative interview study’. This chapter is formatted for and is intended for submission to a relevant academic journal.

The below statement of authorship outlines my contribution to the writing of the research in this thesis and confirms the contribution of other authors.

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Statement of authorship

A statement of authorship is provided for each multi-authored manuscript, with written certification by other authors of each chapter. The principal author of each chapter was the PhD candidate, Paul Marshall (PM). The project's primary supervisor was Professor Fiona Lobban (FL). The project was also supervised by Professor Steven Jones (SJ) and Professor Elena Semino (ES). Research in this thesis was supported by Dr Patricia Gooding (PG), Dr Heather Robinson (HR), Glorianna Jagfeld (GJ) and Keith Sansom (KS). Author contributions to each chapter are detailed below:

Chapter: Caring for a friend or family member who has experienced suicidal behaviour: A systematic review and qualitative synthesis

PM conducted database searches, article screening, data extraction, analysis, and writing of the manuscript. FL and SJ contributed to study conceptualisation, provided support with the analysis and feedback on each draft of the chapter. GJ supported article screening and provided feedback on each draft of the chapter. KS provided feedback on the analysis and each draft of the chapter.

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PM conducted data identification and extraction, analysis, and writing. FL, SJ, ES, and PG contributed to study conceptualisation, provided support with the analysis and feedback on each draft of the chapter. HR provided support with data extraction and feedback on the final draft chapter.

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Thesis abstract

*Background***:** Carers of people with psychosis often provide vital emotional and practical support to friends, family members and other social contacts. Yet while people with psychosis are at increased risk of experiencing suicidal behaviour, including thinking about, and attempting suicide, little is known of carers' perspectives of providing support when this happens. This thesis therefore aimed to address the question: 'What are carers' experiences of supporting friends or family members with psychosis and suicidal behaviour?'

*Methods***:** Three research methods were used to produce four articles. First, qualitative thematic synthesis was used to synthesise nineteen articles investigating carers' experiences of supporting a friend or family member with suicidal behaviour. Second, reflexive thematic analysis was used to analyse online peer-to-peer conversations related to caring for someone with psychosis or bipolar disorder and suicidal behaviour. Third, reflexive thematic analysis was used to analyse twenty in-depth semi-structured interviews with friends and family members of people with psychosis and suicidal behaviour. Two articles based on this interview data are reported, focusing on the personal psychosocial impact of caregiving in this context, and on carers' understandings of the relationship between psychotic experiences and suicidal behaviour, respectively.

*Results***:** Across studies, carers' experiences were characterised by profound and ongoing fear of suicide. This left many stuck in a vicious cycle of hypervigilance to suicide risk, exasperation, and fatigue. Feeling unable to understand why suicidal behaviour occurred left carers in a distressing state of uncertainty about how to respond, an experience that was particularly apparent in the early and more acute periods of psychosis. Developing an understanding of how psychotic experiences contributed to suicidal behaviour allowed some carers to identify strategies for mitigating or avoiding situations that could cause an escalation in distress, thus reducing the likelihood of their friend or family member experiencing further suicidal behaviour. Carers sought help with this task, and, where unable to keep their friend or family member safe at home, looked to health services for assistance with managing this responsibility. Effective health services were framed as responsive, safety-focused, and interpersonally sensitive. Yet negative experiences of inaccessible services, unwilling or unable to collaborate with carers, were widely evident and highly disempowering.

Conclusion: Necessary professional support for carers in this highly demanding circumstance is often limited and/or deprioritised within healthcare settings. To address this, policy, practice, and research priorities should emphasise: carer-inclusive, brief contact interventions to manage suicidal behaviour in crisis situations; strategies to communicate with and involve carers in transitions in and out of healthcare services following suicidal experiences; and ongoing carer-focused interventions, such as online support, to manage personal wellbeing and promote caregiving self-efficacy in this context.

List of figures and tables

List of abbreviations

A&E: Accident and emergency

CI: Confidence interval

CMCP: Cognitive model of caregiving in psychosis

EE: Expressed emotion

GRIPP: Guidance for Reporting Involvement of Patients and the Public

M: Mean

NHS: National Health Service

NICE: National Institute for Health and Care Excellence

NIHR: National Institute for Health and Care Research

OR: Odds ratio

PPI: Patient and Public Involvement

UK: United Kingdom

WHO: World Health Organisation

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Chapter 1. Introduction

1.1 Thesis introduction

A substantial body of research evidence emphasises how carers of people with psychosis face a range of challenges. These include problems with accessing appropriate mental health support, difficulties knowing how to provide care to someone with unusual experiences characteristic of psychosis, and increased risk of personal distress (Kuipers et al., 2010; Mui et al., 2019). However, little research attention has focused on the experience of supporting someone with both psychosis and suicidal behaviour. This oversight is significant in light of evidence that those with psychosis are significantly more likely than the wider population to experience suicidal behaviour (Yates et al., 2019).

Friends and family members are often those closest to people with psychosis and are therefore amongst those most likely to notice their emerging suicidal behaviour, seek help on their behalf, and, more generally, provide those in distress with close emotional and practical support. A more focused and nuanced understanding of the challenges carers face in carrying out these activities could inform changes to policy or practice that may improve support for carers and mental health service users. The aim of this thesis is therefore to address the question: ‘what are carers’ experiences of supporting friends and family members with psychosis and suicidal behaviour?’.

This introductory chapter will first review the key concepts under investigation in this thesis, namely, caring, psychosis, and suicidal behaviour. A review of background literature relevant to caring in the context of suicidal behaviour and psychosis will then be presented.

1.2 Terminology

Important debates regarding appropriate terminology in mental health are ongoing. Key issues include the validity of psychiatric terminology and its alternatives (Cooke & Kinderman, 2018), stigma linked to the use of specific terms related to psychosis, such as schizophrenia (Sideli et al., 2021), and mental health service users' (hereafter referred to as 'service users') preferences regarding self-identification with commonly used terminology, including terms such as 'client' and 'patient' (Costa et al., 2019). Terms used to refer to key concepts in this thesis, and opinions about those terms, therefore vary considerably in research, health services, and the general population. While it is important to acknowledge these debates, it is also necessary to select terms and apply them somewhat consistently to bring clarity to this thesis. Terms were selected based on existing conventions in (recent) mental health literature and within (predominantly British) organisations involved in mental health research. It should be noted that decisions were also guided by the author's educational background and research environment, both of which were influenced by psychological perspectives of mental health. The following section provides a brief glossary of key terms and their use in this thesis.

1.2.1 Carer

The UK National Health Service website states that:

"A carer is anyone, including children and adults who looks after a family member, partner or friend who needs help because of their illness, frailty, disability, a mental health problem or an addiction and cannot cope without their support. The care they give is unpaid." (National Health Service England, 2022)

This form of care is sometimes referred to as ‘informal support’ to distinguish this support from that provided by professionals in a formal healthcare context (Mind, 2017). The same website acknowledges that many people do not view themselves as carers and may see their caring role as indistinguishable from the relationship with those they support. Relationships are dynamic and at times they may be a carer, and at others, they may be cared for within the same relationship. Studies reported in this thesis focused on adult carers for primary data collection (18 years and above). For secondary data analyses, data from adolescent carers (16+) were also eligible for inclusion. Further detail and justification are provided in individual chapters.

1.2.2 Psychosis

This thesis will primarily draw on psychological perspectives of psychosis. Informed by the British Psychological Society (BPS) report ‘Understanding psychosis and schizophrenia’ (Cooke, 2017) the use of the term psychosis in this thesis refers, in a broad sense, to the following experiences:

- Hearing voices or experiencing other sensory phenomena which have no external cause. These experiences are sometimes referred to as hallucinations.
- Having strong, often distressing beliefs that other people do not hold and may find unusual, such as a belief in being under surveillance when there is no evidence to suggest that that is the case. These experiences are often referred to as delusions.

It is acknowledged that psychosis may also be characterised by difficulties with cognition, emotion and/or behaviour.

The term ‘psychosis’ will be used in this thesis as above, with the exception of references to studies that have used specific psychiatric categories, such as ‘schizophrenia’, in order to accurately convey cited research. A more detailed consideration of the nature and prevalence of psychosis is provided in section 1.4.

1.2.3 Suicidal behaviour

Suicidal behaviour is used here as a broad and inclusive term that refers to all thoughts and/or feelings related to ending one’s own life, and attempts to intentionally end one’s own life (O'Connor & Nock, 2014). Suicidal behaviour does not encompass non-suicidal self-injury, defined as self-injury without the intent to cause death (Grandclerc et al., 2016). Broad terms related to all suicidal experiences, including the commonly used phrase ‘suicidality’, have been criticised as lacking specificity and are applied inconsistently within the existing research literature (Silverman, 2016). It is also acknowledged that suicidal experiences are not categorical, but rather exist on a continuum from ideation, to intention and action (Tarrier et al., 2013) . However, it is likely that the distinctions between specific suicidal thoughts, urges, plans, and attempts (and indeed non-suicidal self-injury) are difficult to discern from the perspective of friends or family members of those experiencing them. It is also likely that, as in this thesis, research conducted exclusively with carers precludes assessment of the exact nature of service users’ suicidal experiences, necessitating the use of less specific terminology. For this reason, and in the interest of brevity, this thesis uses the term suicidal behaviour to reflect the state of thinking about and/or acting upon the desire to end one’s own life.

It should be noted that chapter 4 applies a broader definition of suicidal behaviour. Following a recent systematic review (Juel et al., 2021), this definition of suicidal behaviour includes suicidal ideation, attempts and self-injury regardless of intent. This is justified on the basis that chapter 4 reports an exploratory, secondary analysis of qualitative data from an online peer-support forum. This study design necessitated a broad approach to the identification of forum conversations related to suicidal behaviour and did not afford the opportunity for clarification with the carers involved whether their family member had experienced suicide attempt or non-suicidal self-injury. This inclusive approach to data identification is explained in depth in section 4.4.

1.3 Caregiving

This section provides background literature related to the provision of care by friends, family members, and other social contacts. As with following sections on suicide and psychosis, this section will attempt to provide a general overview of key literature on caregiving, with focus on studies conducted in the UK. This is intended to contextualise the research in this thesis, which was conducted in the UK and refers to national health and social care service contexts. This focus also helps to ensure specific policy and practice recommendations based on this research are relevant to the UK context in which this research is conducted. Explicitly extending the focus of this work to other countries with different conceptualisations of mental health and care is beyond the scope of this expertise and resources available for this thesis.

1.3.1 The prevalence of caregiving

The Global State of Care report highlights vast differences in the proportions of national populations engaged in caregiving (International Alliance of Carer Organizations, 2018). In Spain, for example, carers represent only 0.9% of the population (497,000), while that figure stands at 7% in Italy (4 million), 16.6% (43.5 million) in the United States, and

28% (8.1 million) in Canada. Variation in national definitions of care is likely to influence these estimates. For example, the Italian definition of carer is much narrower than the above cited NHS England description, including only those who support people who cannot complete daily living activities independently. Despite its title, the Global State of Care report largely relies on official statistics from western countries. Data from 67 countries representing a broader geographic range published by the International Labour Organization (2018) indicate that the average yearly hours dedicated to caregiving for someone in the same household does not follow clear regional trends. As a point of comparison, time spent caring by women in the UK (32 hours) is similar to women in Thailand (31), South Africa (29), and Tunisia (32), but notably lower than Ireland (94). However, globally, women consistently spend more time on care work (265 minutes per day) than men (83 minutes per day). While these data are limited in discerning the prevalence of care for specific health conditions, they do indicate that the experience of caregiving is ubiquitous and part of the lives of at least hundreds of millions of people worldwide.

The 2011 census in England and Wales included the question ‘Do you look after, or give any help or support to family members, friends, neighbours or others because of long-term physical or mental ill-health or disability, or problems related to old age?’ (Office for National statistics, 2011). Amongst 56.1 million respondents, 5.8 million answered ‘yes’, 2.1 million of whom reported providing over 20 hours of care per week. More recently, the 2018/19 Family Household Survey, completed by 19,000 families in the UK, reported 7% of respondents provided care at least once per week (Department for Work and Pensions, 2019). Up to the age of 75, women were more likely to provide this care than men. Of those caring for someone within their household, the recipient was most likely a spouse or child, whereas those caring for someone outside of their household most often supported a parent. Carer-related statistics for the 2021 England and Wales census are due to be published in 2023 (Office for National Statistics, 2022a).

A significant limitation of survey data related to the prevalence of caregiving is the propensity to group respondents into binary carer or non-carer categories, and UK government surveys do not systematically assess the health status of those receiving care. It is therefore difficult to precisely estimate the proportion of carers who provide support to someone with a specific mental health difficulty. One exception is the National Health Service (NHS) Survey of Carers in Households, which is now no longer regularly conducted. Its 2009/2010 publication collected data from a representative sample of 2401 carers, 13% of whom supported someone whose primary support need related to a mental health problem. This does not account for those carers supporting someone with a mental health problem not described as a primary support need and therefore likely underestimates the true figure. Furthermore, it has been suggested that household surveys underestimate the number of carers providing 'lower intensity' or irregular care (Pickard et al., 2016), as those in caring roles may primarily recognise themselves as friends or family members, rather than a member of a distinct 'carer' category. This presents a significant challenge to identifying and providing support to those in caring roles in the UK (NICE, 2020).

1.3.2 The health and social impact of caregiving

There is substantial evidence from peer reviewed and third sector research indicating that providing care to a friend or family member can have significant impacts on physical and psychological wellbeing. Carers UK's 2021 'State of Caring' report collected data from a representative sample of 8119 carers, 31% of whom reported their mental health to be ‘bad’ or ‘very bad’ (CarersUK, 2021). Indicating the scale of care undertaken by individual carers, almost half (48%) provided over 90 hours of care per week. This is with consistent research into the detrimental impact of caregiving on occupational outcomes, including financial loss linked to reduced likelihood of being in work (Bauer & Sousa-Poza, 2015). In the CarersUK sample, 28% stated that care and support services did not meet their needs, 66% highlighted a need for more support for their own wellbeing, and 52% wanted better recognition from the NHS. Seventy nine percent of respondents were women, which is significant in light of evidence that women are more likely than men to suffer negative mental and physical health outcomes as a result of caregiving (Pinquart & Sörensen, 2006). A meta-analysis of studies directly comparing the wellbeing of carers of elderly people with non-carers found that carers reported significantly higher stress, depression, poorer self-efficacy, and general health (Pinquart & Sörensen, 2003). Factors associated with poorer physical health in carers include older age, caring for someone with dementia, and lower socioeconomic status, with carer distress also associated with caregiving intensity and behavioural difficulties amongst those receiving care (Pinquart & Sörensen, 2007). Furthermore, differences in wellbeing amongst carers from different ethnic backgrounds have been observed after controlling for socioeconomic status, suggesting sociocultural influences explain some of the variability in caregiver health outcomes (Pinquart & Sörensen, 2005).

1.3.3 Caregivers in policy

The demand for informal care is expected to rise in Europe in the coming years as a higher proportion of national populations live into older age (Zigante, 2018). The European commission describe informal care as the ‘cornerstone’ of any national long-term healthcare strategy, allowing those receiving care to stay at home thereby relieving pressure on national health services (Zigante, 2018). Indeed, in the UK, the value of informal care to the economy was estimated at £132 billion in 2015, almost double the estimated £68 billion in 2001, and close to the total value of health spending of £134 billion in the same year (Buckner & Yeandle, 2015). The value of caregiving is reflected in recent developments in legal protections and welfare support for carers across several countries (International Alliance of Carer Organizations, 2018). However, many such changes fail to fully recognise this unpaid work as equivalent in value to other economic activities and caregiving responsibilities have been identified as a major factor in gender inequality worldwide, disproportionally affecting women's entry to the workforce (Lawson et al., 2020).

In the UK, carers are recognised by and given rights under specific legislation. The 2014 Care Act gives carers the right to assessments of the impact of caregiving on personal health and financial resources and dedicated support from local authorities (Carers Trust, 2016). However, a study conducted in the year following the introduction of the act found that many carers were still unaware of their rights and almost a third found the carer's assessment unhelpful (Carers Trust, 2016). The study suggested that local authorities should engage with strategies to raise awareness of carers' rights and improve their packages of support. The need to do more to support carers is also reflected in recent UK healthcare policy. The five year forward view for mental health (NHS England, 2016) mentions carers in several contexts, including the need for greater transparency in health information sharing, the value of carers' expertise by experience in developing services, and the need for clearer training for staff around working with carers. More recently, the NHS Long Term Plan (NHS, 2019a) commits to improving carer recognition and support, by, for example, extension of the recently trialled NHS Carer Passport scheme, designed to promote carer involvement in the professional healthcare received by those they support. Carer support remains a live issue for policy development. A recently completed public consultation on the promotion of wellbeing, published by the UK government in September 2022, identified carers as being at increased risk of personal distress relative to the wider population. It highlights demographic barriers to carer support, including being a young carer, on low-income, and from ethnic minority backgrounds (Department of Health and Social Care, 2022). Importantly, the report calls for an increase in research investigating carers' use of mental health services.

1.4 Psychosis

1.4.1 Defining psychosis

The term 'psychosis' defies simple definition. As the BPS note, the experiences commonly associated with psychosis are primarily those of hearing voices, sometimes described as auditory hallucinations, and/or holding strong, often distressing unusual beliefs not supported by evidence, also referred to as delusions (Cooke, 2017). Cooke emphasises that the experience of psychosis is highly idiosyncratic. In some circumstances, psychosis may include difficulties speaking or concentrating, described as thought disorder, and/or the appearance of listlessness, blunted affect or loss of motivation, described as negative symptoms. NICE group psychosis and schizophrenia together in their treatment guidelines, with the psychoses reflecting a specific cluster of psychiatric diagnoses (NICE, 2014b). Some diagnoses, such as schizoaffective disorder, depend on the extent to which experiences of psychosis occur alongside mood difficulties, while others, such as delusional disorder, require a more limited set of symptoms (World Health Organization, 1993).

A full review of the psychiatric classification of psychotic disorders is beyond the scope of this thesis as the research aim relates to carers' experiences. It is therefore instructive to consider the definitions of psychosis provided by public facing organisations likely to inform carers' understandings of the term. Websites for both the NHS and Rethink Mental Illness, a charity providing support to carers of people with psychosis, explain that psychosis is defined as a loss of contact with, or difficulty interpreting, what is real (NHS, 2019b; Rethink Mental Illness, 2019). The NHS state that "the combination of hallucinations and delusional thinking can cause severe distress and a change in behaviour. Experiencing the symptoms of psychosis is often referred to as having a psychotic episode." Rethink Mental Illness highlight the diversity of perspectives regarding how psychosis is conceptualised, noting that "you may not find it helpful to think of your experiences as symptoms of a mental illness. You may have a different reason as to why you experience psychosis. For example, due to traumatic experiences you may live with psychosis"(Rethink Mental Illness, 2019).

Its idiosyncratic nature and the fact that "psychosis is still defined by the clinical picture and not by laboratory, genetic, or neuroimaging investigations" (Gaebel & Zielasek, 2015, p.10) lends significance to accounts of the lived experience of psychosis in defining its character. A recent study describing the experience of psychosis, co-written by experts by experience and researchers, illuminated diverse phenomenological features across its typical stages (Fusar-Poli et al., 2022). In the premorbid stage, lived experiences are distinctly social, with descriptions of interpersonal sensitivity and anxiety, isolation, discrimination, and bullying. Prodromal experiences are imbued with a feeling of anticipation, a heightened sense of the meaning of personal experiences, and a perception of the self as being dissolved or perturbed. Loss of contact with reality, including with people, can contribute to withdrawal and attempts to hide these stigmatised experiences. During the first episode of psychosis unusual experiences, such as voices, may be intensified and particularly frightening, with a loss of boundaries surrounding the self and the wider world contributing to loss of agency and control. Periods of relapse bring grief of personal loss, depression, challenges with accepting a diagnosis, and reflections on a seemingly uncertain future. More chronic experiences involve adaptation to psychosis, with improved coping leading to gains in functioning and a sense that the worse may have passed.

A qualitative study of the medical notes of people experiencing first episode psychosis (n= 160) reported that common features of unusual beliefs included experiencing threats of harm, surveillance by others, involvement in a conspiracy, or the possession of extraordinary powers, while auditory hallucinations were often characterised by a critical or controlling voice (Jones et al., 2020). Of relevance to this thesis, 30% experienced a voice directing self-harm or suicide. A meta-synthesis of ninety-seven qualitative studies stressed that the experience of psychosis is not only characterised by loss of a sense of what is real, but a wider systemic loss across the lives of those affected. This included loss of: personal identity as a result of stigma; engagement with meaningful social roles; a sense of security of the physical self, perceived as being under attack from unusual experiences; hope for a better future; and of personal relationships (McCarthy-Jones et al., 2013). Indeed, social isolation following breakdowns in close relationships is a factor identified in qualitative research as contributing to suicidal ideation amongst people with psychosis (Skodlar et al., 2008). Recovery from psychosis may involve reversing these losses by re-establishing personal identity, a meaningful role in society, and key relationships with loved ones (McCarthy-Jones et al., 2013).

These definitions and lived experiences highlight how psychosis is understood in diverse ways, including as a feature of a medical diagnosis, but also as an aspect of personal experience that may take on a range of manifestations and meanings. The consistency with which nuanced accounts of social interaction feature in the experiences of people with psychosis demonstrates both the value of qualitative research in elucidating the layered challenges of living with psychosis and the importance of understanding the perspectives of carers likely to provide support during these experiences.

1.4.2 Prevalence

The Global Burden of Diseases, Injuries, and Risk Factors study estimated that there are approximately 20,000,000 people worldwide living with a diagnosis of schizophrenia (James et al., 2018). The study also indicated that age-adjusted rates of schizophrenia did not change significantly between 1990 and 2017. However, as Moreno-Küstner et al. (2018) highlight, studies of specific psychotic disorders underestimate the prevalence of psychosis within the general population. In their systematic review of international studies, Moreno-Küstner et al. (2018) reported a 12-month prevalence of 4.03 per 1000 (0.4%) and lifetime prevalence of 7.49 per 1000 (0.7%) for all psychotic disorders. This finding is comparable with the Adult Psychiatric Morbidity Survey conducted in England, which reported a similar prevalence of psychotic disorder in the preceding 12 months of 0.5% (95% confidence interval (CI) 0.4% - 0.9%) (McManus et al., 2016). The survey showed no difference in overall prevalence by sex, although rates of psychotic disorder were significantly higher in Black males (3.2%) than in white (0.3%) or Asian males (1.2%). Meta-analytic studies also indicate higher risk of psychosis in ethnic minority groups; in the UK, risk of psychotic disorder is elevated in Black African, Black Caribbean and south Asian groups (Kirkbride et al., 2012), while global estimates show increased risk in younger groups, men, and in migrants and their descendants (Jongsma et al., 2019). Jongsma et al. (2021) suggest that the consistently higher prevalence of psychosis amongst ethnic minority groups in western countries relates to structural economic inequalities and social exclusion, which act as barriers to the development of positive collective identities on which societal belonging and wellbeing are based.

Caution should be taken when interpreting population level estimates of the prevalence of psychosis. McManus et al. (2016) note that surveys that screen participants based on recent access to mental health services or current psychotic experiences are unlikely to account for those who are managing psychosis without active professional support and those yet to contact mental health services. Estimates based on studies that rely on data from specialised services may underestimate the prevalence of psychosis for other reasons, including suboptimal service coverage (Edwards et al., 2019). Consistent with this, a widely cited study conducted in Sweden that drew on multiple data sources (including self-report surveys, medical registers and clinical interviews) estimated the lifetime prevalence of psychotic disorder at 3.06% (Perälä et al., 2007). Furthermore, lifetime risk of psychotic experience in the World Mental Health Survey (McGrath et al., 2016) was estimated at 5.8%. This suggests that unusual sensory experiences and beliefs occur much more commonly than psychiatric disorder prevalence data suggest. Western and industrialised nations are typically overrepresented in relevant literature in this area and the extent to which cultural differences in the perception of psychosis influence prevalence estimates remains unclear.

1.4.3 Course and outcomes

The onset of psychosis typically occurs in adolescence or early adulthood. In the World Mental Health Survey, median age at onset of psychosis was 26, with no significant difference by gender (McGrath et al., 2016). This aligns with a recent large meta-analysis of the onset of mental disorders, which reported median age at onset of psychotic disorder of 25 (Solmi et al., 2022). Earlier onset of psychosis is associated with poorer psychosocial outcomes, including increased hospitalisation and relapse rates, and lower social and occupational functioning (Immonen et al., 2017). Meta-analytic studies have also reported small to moderate associations between the duration of untreated psychosis and a range of negative outcomes, including positive and negative symptoms, global functioning, and quality of life (Marshall et al., 2005; Penttilä et al., 2014). A recent systematic review of psychosis outcomes reported that 57.1% of those with first episode psychosis experience ‘complete’ recovery, defined as loss of psychiatric symptoms (Huxley et al., 2021). Amongst those with multiple episodes of psychosis, however, this figure is significantly lower at 37.75%. Using a definition of recovery that accounts for functional outcomes such as economic activity and personal independence, 47.5% of those with first episode psychosis and 43.5% of those with multiple episodes experience ‘social’ recovery.

A meta-analysis of studies investigating mortality in schizophrenia found reduced life expectancy of 15.9 years for men and 13.6 years for women, relative to the general population (Hjorthøj et al., 2017). This dramatic reduction in life years is likely related to vast health inequalities experienced by people with psychosis. A review of studies investigating the physical health of people with severe mental illness, including psychosis, reported increased frequency of health problems across a range of illness domains, including cardiovascular disease, metabolic disease, and sexual health (De Hert et al., 2011). Causal influences impacting on these outcomes are likely varied. However, key factors may include lifestyle behaviours, such as lower quality diet and an increased likelihood of smoking, and the detrimental impact of anti-psychotic medication on metabolic function and weight gain (De Hert et al., 2011). When causes of death are reviewed individually, specific-cause mortality relative to controls without psychosis is highest for ‘suicide or injury-poisoning or undetermined non-natural cause’ (Correll et al., 2022). Risk of suicide in people experiencing psychosis will be reviewed further in section 1.5.4.

1.4.4 Psychosocial factors and psychosis

Recent decades have seen significant advances in understanding the psychological mechanisms that contribute to the development and maintenance of psychosis. Full consideration of this extensive literature is beyond the scope of this thesis. However, influential models are referenced here to demonstrate the significance of close personal relationships and social factors in the experience of psychosis. In their model of persecutory delusions, Bentall et al. (2001) argue that early persecutory experiences may contribute to the development of predisposing psychological factors that increase the risk of psychosis, such as negative beliefs about the self or a tendency to attribute negative actions by others as having been caused by oneself. As Garety et al. (2001) explain in their cognitive model, negative beliefs about the self that maintain distressing hallucinations or delusions are likely influenced by adverse social environments, including social isolation and negative life events, and may interact with biases in reasoning such as ‘jumping to conclusions’ or cognitive inflexibility. Recent research has integrated conceptual perspectives of trauma (Hardy, 2017) and attachment (Berry & Bucci, 2016) to further the theoretical understanding of psychotic experiences. These important advances have significant clinical implications, with cognitive models in particular informing targets for modification through psychological interventions (Moritz et al., 2022).

1.4.5 Psychosocial intervention in psychosis

In their clinical guidelines, the International Early Psychosis Association Writing Group (2005) state that “psychosocial interventions have a fundamental place in early treatment, providing a humane basis for continuing care, preventing or resolving secondary consequences of the psychosis, and promoting recovery” (p. 121). Clinical guidance (NICE, 2014b) recommends that psychosocial support be routinely offered to those experiencing psychosis. In addition to cognitive behavioural therapy, NICE recommend that family intervention is offered to service users and those who care for them, which should focus on the relationship between the service user and their main carer and include a component on problem solving or crisis management. Evaluations of family interventions show that they can be effective in reducing relapse and hospitalizations in those with chronic forms of psychosis and improve functioning in those with early-onset psychosis (Ma et al., 2018; Pharoah et al., 2010; Rodolico et al., 2022). There is also some evidence that family interventions improve carer outcomes, including wellbeing, although not all studies have replicated this finding and the active components of such interventions is unclear (Claxton et al., 2017; Lobban et al., 2013). Qualitative data suggest family intervention may be particularly helpful for developing shared understanding of the experience of psychosis, recognising warning signs, and planning for the future collaboratively (Nilsen et al., 2016).

1.5 Suicidal behaviour

1.5.1 Prevalence

The WHO Mental Health Survey is a key source of cross-national data regarding the prevalence of suicidal behaviour. Using WHO data from 17 countries (n=108,705) Borges et al. (2010) reported 12-month prevalence estimates for suicidal ideation, specific suicide plans and suicide attempts in high income countries of 2.0%, 0.6 % and 0.3%, broadly similar to low income countries at 2.1 %, 0.7% and 0.4%, respectively. Consistent cross-national risk factors for suicidal behaviour include being a younger adult, female, unmarried, lower educational status, and having received a psychiatric diagnosis (Nock et al., 2008).

In the UK, suicidal behaviour is assessed as part of the Adult Psychiatric Morbidity Survey (McManus et al., 2016). Lifetime prevalence of suicidal ideation is marginally higher amongst women (22.4%) than men (18.7%). As in the above international study, women were more likely to report a previous suicide attempt (8.0%) than men (5.4%). Suicide attempts were highest for women between the ages of 16 and 24, and for men between 25 and 34. Rates of suicidal ideation and attempts did not differ significantly by ethnicity. Assessment of help-seeking behaviour following a suicide attempt showed 26.4% visited a GP, 25.5% attended hospital or other specialist mental health services, and notably, 21.7% sought help from family or friends. In England and Wales in 2021, 5583 people died by suicide, a rate of 10.7 per 100,000 (Office for National Statistics, 2022b). Seventy-four percent were men. This national estimate is similar to the global rate of 10.5 per 100,000, equivalent to 793,000 deaths by suicide in 2016 (WHO, 2019). WHO data show that males are almost twice as likely to die by suicide than women and that death by suicide is higher in Europe than any other continent for which data are available. It should be noted that limitations of the validity and reliability of suicide-related statistics have long been recognised. International variability in definitions and reporting of suicidal behaviour, potential legal repercussions of reporting suicide deaths, and widespread stigmatisation likely contribute to the underreporting of suicidal behaviour and deaths by suicide globally (Goldney, 2010).

1.5.2 Caring for someone who has experienced suicidal behaviour

The systematic review chapter of this thesis (chapter 3) synthesises qualitative studies that have investigated the experience of caring for someone with suicidal behaviour. More specifically, this systematic review includes qualitative data collected exclusively from those providing care to someone who has experienced suicidal behaviour and excludes data collected from other groups, such as service users or healthcare professionals. In the interest of brevity, this section will review research that falls outside of the scope of the systematic review chapter in this thesis but is relevant to understanding the experience of caring for someone with suicidal behaviour.

Existing research highlights carers' complex roles and interpersonal challenges in the context of suicidal behaviour. Carers take on extensive practical support responsibilities, including managing finances, organising healthcare appointments, and providing assistance with transport, in addition to continuously monitoring for signs of suicidal behaviour (Wayland et al., 2021). Mental health services have been described as difficult to navigate, with carers viewed as "a side-line act, but not a main event" (p. 668), leaving carers with an unmet need for individualised information and support. These findings corroborate earlier research with people who have attempted suicide and their carers (McGill et al., 2019) that emphasises carers' desires for practical advice with managing suicidal behaviour, signposting to relevant services, and peer support to challenge the stigma attached to suicidal behaviour. Carers state that this practical support should be delivered alongside emotional support, which should focus on strategies to manage reactions such as shame and helplessness (McLaughlin et al., 2014). Clinicians and carers of young people experiencing suicidal behaviour have emphasised the importance of tailoring information and support to carers' needs (Dempsey et al., 2019). At onset, carers report the need for information about the nature of suicidal behaviour and reassurance about the possibility of recovery; during crises they require more intensive psychosocial support; and at transition out of services carers require support with their own anxieties about safety in the community and strategies for managing risk at home.

The experience of caring for a suicidal friend or family member can also be characterised by interpersonal tension. Interviews conducted separately with suicide attempt survivors and their families revealed only half of dyads provided compatible explanations of the causes of suicide attempts, implying the existence of barriers to communicating associated difficulties within families prior to these suicide attempts (Asare-Doku et al., 2019). Indeed, in interviews with previously suicidal men and their family and friends, carers expressed how they had interpreted signs of sadness or stress as anger and aggression, contributing to a sense of disconnection with their loved ones which acted as barriers to carers offering help (Player et al., 2015). The same carers noted that their support strategies were based on a growing understanding of patters of moods and triggers, which, over time, helped them to identify opportunities to ‘interrupt’ the pathway towards suicidal behaviour. Differences in perspectives on suicidal behaviour and its management may also exacerbate interpersonal stresses. For example, men who had attempted suicide and their family members and friends identified a central tension between carers’ attempts to monitor and mitigate suicide risk, and the perceived intrusiveness and loss of autonomy this could cause amongst those experiencing suicidal behaviour (Fogarty et al., 2018). Participants noted that these tensions risked exacerbating relationship problems and triggering distress, and highlighted family-focused psychoeducation as a support need for overcoming these difficulties.

Perhaps the most widely cited research related to carers' experiences of recovery following a suicide attempt within the family is a series of grounded theory studies conducted in Taiwan by Sun and Long (2008). Their initial study drew on interviews with fifteen people recently discharged from hospital following a suicide attempt and fifteen of their family members. The resulting theory proposes that caregiving interactions, and the wider social context they occur within, influence the extent to which the family environment is conducive to recovery. As Sun et al. (2008) explain, a positive family environment following a suicide attempt can be exceedingly difficult to cultivate. While creating a physically safe home environment was somewhat straightforward, family members could not control these factors when they were away from home or manage risk when the person they cared for left the house, contributing to seemingly relentless fear and fatigue. The theory explains that these pressures occur within a specific cultural context, one which emphasises collective family stigma related to suicide. Many carers therefore felt isolated, unable to draw on external support systems, and thus relied on avoidant coping strategies. Both those who had experienced suicidal behaviour and family carers highlighted a mutual willingness to engage in open communication as a key factor underpinning progress during this challenging period of recovery.

Sun et al. (2009) expand on specific action strategies derived from their earlier grounded theory. Creating a nurturing environment to promote recovery included simply 'being there' for a family member following a suicide attempt. Carers also sought to avoid potential stressors to promote a sense of tranquillity within the home and gently encouraged hope by focusing on solving issues considered to be at the root of suicidal thoughts. However, providing round-the-clock care whilst experiencing an often-pervasive dread of further suicide attempts contributed to carers experiencing physical and emotional exhaustion. In light of these competing pressures, the grounded theory ‘core category’, to which all other carer experiences were related, was ‘impending burnout’. Sun et al. (2014) further developed their theory of healing following a suicide attempt in interviews with suicide attempt survivors and their families. Participants described how their home environment needed to feel sheltered and protected from pressures of the outside world. Being ‘at ease’ and accepted by others in their environment helped those recovering “feel secure inside and outside of self” (p.57). Factors that promoted the process of healing included feeling supported by close friends and family members, mental health professionals and other social contacts, such as colleagues or religious groups; having feelings validated by others’ lived experiences of distress; and resolving root causes of stress. Conversely, an exposure to stressful situations and family tension impeded the process of recovery.

1.5.3 Carer focused psychosocial intervention for suicidal behaviour

Carers are well positioned to provide support to people who are suicidal and many would benefit from support to promote caregiving self-efficacy in this context (Grant et al., 2015). A recent systematic review reported on 8 peer-reviewed articles based on 7 studies that had investigated interventions involving carers following the suicide attempt of a family member or friend (Krysinska et al., 2021). Four studies evaluated suicide prevention interventions for children or adolescents that included some carer involvement and reported carer outcomes. A CBT based program focused on social support for young people led to a reduction in parent depression and was rated highly on treatment satisfaction measures yet recruited only a small sample (n=35) and used a pre-post rather than trial design (Asarnow et al., 2015). Furthermore, a quasi-experimental study found larger positive effects on suicidal behaviour, and family functioning, following outpatient therapy for adolescents and their carers after contact with emergency department staff who had been trained to provide suicide-focused care (n=65), compared with those who received standard care (n=75) (Rotheram-Borus et al., 2000). However, the review also noted that neither a randomised controlled trial of systemic family therapy (n=832) nor a home-based intervention delivered by psychiatric social workers (n=162) led to overall improvements in family functioning (Cottrell et al., 2018; Harrington et al., 1998). Given the small number of relevant articles, limitations in designs existing study designs, and their tendency to focus on suicidal behaviour in young people, more evidence for the effectiveness of interventions that include carer involvement in post-suicide attempt is needed.

Of the 7 studies identified by Krysinska et al. (2021) just 3 described interventions primarily focused on supporting family carers following a suicide attempt. Sun et al. (2014) conducted a randomised controlled trial of a short (2 hour) psychoeducation programme for carers (n=74) which focused on understanding suicidal behaviour and caregiving skills. The intervention improved perceptions of caregiving and help-seeking ability, and attitudes towards family members, but did not impact caring stress and was only evaluated short term (3-month follow-up). A cross-sectional study of a crisis planning intervention (n=50) reported greater family awareness of preventative action before suicide attempts in the intervention group, but no difference with a control group on measures of family relationships or burden (Cho et al., 2015). A dialectical behaviour therapy-based group psychoeducation programme evaluated in a small study (n=13), using a pre-post design, saw reductions in carer distress and expressed emotion, but not depression or quality of life (Rajalin et al., 2009). As with suicide prevention interventions reporting carer outcomes, interventions designed specifically for carers are yet to show effectiveness in large scale, rigorous evaluations (Krysinska et al., 2021). However, this limited evidence base does demonstrate the feasibility of targeting psychosocial interventions at the level of the individual carer and at emergency department staff who are likely to interact with carers following suicidal crises.

1.5.4 Suicidal behaviour and psychosis

The experience of psychosis has been consistently linked with increased risks of suicidal ideation and behaviour. While estimates vary by research design, the robustness of these associations is supported by studies using clinical and non-clinical samples, cross-sectional and longitudinal studies, and international datasets (Hor & Taylor, 2010). A meta-analysis of population-based studies found that those who reported psychotic experiences were more likely than those who had not to experience suicidal thoughts (OR=2.47) and behaviours (OR=3.03) (Honings et al., 2016). The authors encourage caution in interpreting any effect of psychosis on suicidal behaviour due to the challenge of accounting for potentially confounding effects of other difficulties, such as co-occurring depression, and the prevalence of cross-sectional study designs. More recently, however, a meta-analysis of longitudinal population-based studies reported significant increases in the likelihood of suicidal ideation (OR = 1.59) and suicide attempt (OR = 2.68) subsequent to the experience of psychosis, after controlling for comorbid psychopathology (Yates et al., 2019). These findings suggest that psychotic experiences may represent important risk factors for future suicidal behaviour.

There is extensive evidence from clinical research demonstrating an increased risk of suicidal behaviour and death by suicide in those with psychotic disorders. Drawing on global estimates of suicidal behaviour amongst people with schizophrenia, Bai and colleagues (Bai et al., 2021) reported a lifetime prevalence of suicidal ideation and suicide plans as 34.5% and 44.3%, respectively. Lifetime prevalence of suicide attempts in schizophrenia is estimated at between 25% and 50% (Cassidy et al., 2018), yet just 2% in the general population (Nock et al., 2008). It has been suggested that suicidal thoughts and behaviours may cluster around the onset of psychosis (Cassidy et al., 2018). One possible explanation for this temporal elevation in risk is that depressed mood may develop in response to initial, highly distressing experiences of psychosis (Ayesa-Arriola et al., 2015). Indeed, those who experience psychosis in addition to major depression are at twice the risk of suicide attempt relative to those with non-psychotic major depression (OR=2.11), supporting the suggestion that psychotic experiences independently influence the likelihood of suicidal behaviour (Gournellis et al., 2018).

Causes underpinning the observed links between suicidal behaviour and psychosis are likely multidimensional. Suicide-related command hallucinations, such as voices that direct a person to carry out a specific life threatening behaviour, have been reported as a risk factor for suicidal behaviour in psychosis (Harkavy-Friedman et al., 2003; Wong et al., 2013). However, the same studies report that only a minority of those with psychotic disorders experience such hallucinations, suggesting that the contents of psychotic experiences alone are not sufficient to account for the observed relationship between psychosis and suicidal behaviour. Rather, existing research points to a range of often related risk factors. These include social and demographics factors, such as being young, male, experiencing substance abuse, and having poor access to social support, and psychological factors such as hopelessness and disordered thinking (Pompili et al., 2007). Theoretical accounts of suicide suggest that psychological factors that underpin suicidal thoughts and behaviours may be exacerbated by the experience of psychosis. For example, the schematic appraisals model of suicidal behaviour proposes that negative appraisals of past events, the self, and the future, informed by an established suicide schema, are central to the development of suicidal ideation (Johnson et al., 2008). It is possible that experiences common in psychosis, such as highly distressing voices and associated stigma or social isolation, could exacerbate such negative appraisals, thus contributing to cognitive mechanisms that exacerbate suicidal ideation and precipitate suicide attempts.

1.5.5 Suicidal behaviour in policy

Preventing suicide has long been the stated goal of governments worldwide (Taylor et al., 1997). According to a major report by the WHO, however, only 40 countries have implemented or are planning a national suicide prevention strategy (WHO, 2014) . The report noted that while significant policy advancements have been achieved since the United Nations (UN) published guidelines on suicide prevention in 1990, national prevention strategies remain rare. This has prompted organisations including the WHO, International Association for Suicide Prevention, and the UN, to develop and make available evidence-based strategies for suicide prevention and set new legal standards for suicide related behaviour, and mental health more broadly (WHO, 2018).

The UK government published its latest cross-government suicide prevention progress report in 2021 (Department of Health and Social Care, 2021). The document echoes the goal set out in the five-year forward view for mental health and NHS long term plan of prioritising a measurable reduction in rates of suicide in coming years. As part of this national strategy, suicide-prevention plans must be completed at a local level to improve the specificity of monitoring and related interventions. The strategy makes welcome reference to improving support for families bereaved by suicide, however, it does not substantially explore how carers could form part of a broader suicide prevention strategy. National clinical guidelines for suicide prevention, do, however, highlight the need for clinicians to engage with families and carers (NICE, 2019). This guidance recommends that clinicians should ask service users about their preference for family or friend involvement in their care. It also highlights the importance of clarity regarding the limits of confidentiality and procedures for sharing information with carers where people at risk of serious harm lack the capacity to make judgments about their care. This position was recently affirmed in a consensus statement on information sharing published by the National Suicide Prevention Alliance (2021) and endorsed by key organisations and government departments involved in mental health care.

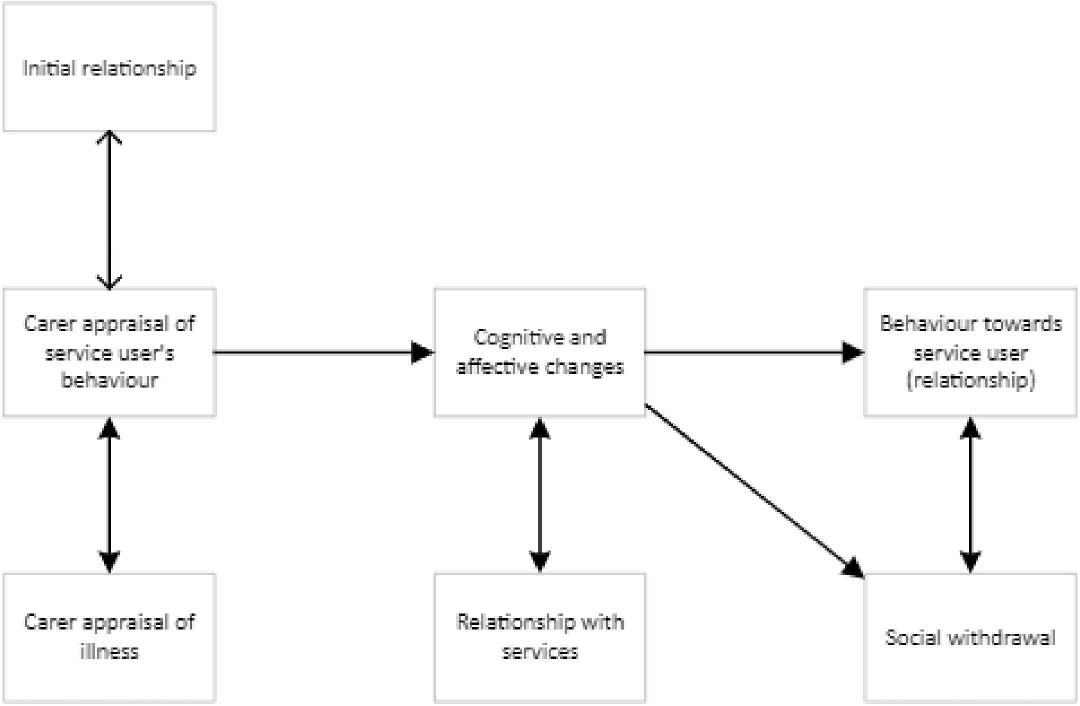
1.6 Caregiving in psychosis

Recent decades have seen significant advances in understanding the experience of caregiving in psychosis. This is evident in the publication of several relevant systematic reviews each with different conceptual and methodological emphases. These include qualitative studies of caregiving experiences (Mui et al., 2019; Shiraishi & Reilly, 2019); the concepts of burden and quality of life in carers of people with schizophrenia (Stanley et al., 2017); psychological factors involved in caregiving in early psychosis (Jansen et al., 2015a); and psychological interventions for people with psychosis and their families (Claxton et al., 2017). With a view to organising this broad literature, this section will present an understanding of caregiving experiences in psychosis with reference to key concepts identified by the cognitive model of caregiving in psychosis (CMCP) (Kuipers et al., 2010)

1.6.1 The cognitive model of caregiving in psychosis

The CMCP posits that carers’ appraisals of the behaviour of the service user (used to refer to the person experiencing psychosis) they support, and appraisals of psychosis, are important determinants of carers’ own psychosocial outcomes. Subsequent cognitive and affective changes impact the carer’s behaviour towards the service user and the carer’s propensity for social withdrawal. The CMCP proposes that carer appraisals of service user behaviour are likely to be influenced by the nature and quality of their relationship at the outset of psychosis. The connections between these constructs are demonstrated in figure 1.

Figure 1. The Cognitive Model of Caregiving in Psychosis (reproduced with consent from the publisher) (Kuipers et al., 2010).



The CMCP provides the above schematic as a framework for understanding the impact of caregiving in psychosis. Kuipers et al. (2010) highlight how each concept in this model is informed by domains of theoretical and empirical research, grouped here into the following categories: expressed emotion, attributions, illness perceptions, coping, social support, and positive experiences. The following sections first provide a brief overview of impacts of caring and psychosis, then review evidence for the significance of these areas of research.

1.6.2 Measuring the impact of caregiving in psychosis

The impact of caregiving in psychosis has been estimated across a range of physical, economic, and psychosocial domains. A recent survey study conducted in the UK revealed that relative to the general population, carers experience significantly lower psychological wellbeing (Sin et al., 2021). Risk factors for poorer wellbeing included supporting a partner, being a single carer, and providing more than 35 hours of care per week. Data from representative samples of 5 European countries show that carers of people with schizophrenia are more likely than carers of other conditions (including Alzheimer’s disease and cancer) to experience anxiety, physical pain and insomnia, and report lower quality of life than participants in non-carer control groups (Gupta et al., 2015). Carers of people with psychosis may also experience negative impacts on occupational functioning, with one UK study estimating that the proportion of carers giving up work entirely is 1.2% in early psychosis and 2.5% in carers of long-term service users (Guest & Cookson, 1999). Indeed, Gupta et al. (2015) report that just 31% of caregivers of people with schizophrenia have access to adequate financial resources to provide what they consider to be an adequate level of care. Qualitative research highlights how carers experience significant challenges in balancing work-related and personal commitments and, especially in the often-challenging early stages of psychosis, may defer help-seeking for fear of social stigma (Sadath et al., 2014). Psychosis-related factors associated with increased carer distress include more severe and longer term experiences of psychosis and greater functional impairment amongst those affected (Peng et al., 2022). The extent to which carer distress changes over time has also been demonstrated to depend on psychosocial factors, such as expressed emotion, carers’ coping styles and carers’ appraisals (Barrowclough et al., 2014; Roick et al., 2006). These factors will be reviewed in the following sections.

1.6.3 Expressed Emotion

A substantial body of research has accumulated around the concept of expressed emotion (EE) in caregivers of people with psychosis. EE is a characterisation of the relationship and emotional environment shared by carers and those they support. Carers are classified as showing ‘high’ EE if they meet threshold levels on any one of the dimensions of criticism, hostility, or emotional over-involvement (EOI), generally rated during an in-depth interview (the Camberwell Family Interview or a five minute speech sample in which they are invited to talk about the person they care for (Butler et al., 2019b)). Those who do not meet thresholds on any of these dimensions are characterised as low EE. Carers are also rated on the number of positive remarks they made, and level of warmth conveyed. However, these do not directly contribute to the EE classification, despite some evidence that they may be associated with outcomes in psychosis (Butler et al., 2019b).

Empirical evidence has shown that people with psychosis living in environments characterised by carers showing high EE are at increased risk of relapse (Butzlaff & Hooley, 1998; Lee et al., 2014). A review of 3 studies of EE suggests that critical comments, rather than EE more generally, may underpin these observations (Alvarez-Jimenez et al., 2012). Suggesting a possible mechanism, experimental evidence from a non-clinical sample indicated that personalised critical comments are associated with increased paranoia, whereas warm comments are associated with increased self-esteem, but not when participants are exposed to simulated social exclusion (Butler et al., 2019a; Ma et al., 2021). High EE is also associated with carer outcomes in psychosis, including distress and avoidant coping (Raune et al., 2004). Lobban and Barrowclough (2016) note, however, that a limitation of EE research lies in its focus on high EE. Less is known about the way in which low EE impacts outcomes. Some evidence suggests low EE carers may be more likely to develop acceptance of the experience of psychosis (Dorian et al., 2008). Indeed, a qualitative study conducted with low EE carers highlighted a tendency to develop understanding and acceptance of service users' experiences, with emphasis on responding with empathy and emotional insight (Treanor et al., 2013). However, it is also possible that low EE could indicate relational breakdown, where emotional investment in the relationship has been withdrawn.

1.6.4 Attributions and illness perceptions

Consistent with the claims of the CMCP, carers' appraisals of service user behaviour have been demonstrated to play key roles in carer outcomes in psychosis. Particular attention has focused on the role of attributional appraisals, or causal ascriptions (Weiner, 1985), and their relation to EE. Carers of people with psychosis who are high in critical or hostile dimensions of EE are more likely to make 'controllable' and 'personal' attributions. That is, they are more likely to view service users as having a greater degree of personal control over their experience of psychosis, thus making the service user more susceptible to blame for negative events (Barrowclough & Hooley, 2003). Carer attributions that ascribe self-blame for negative events in psychosis are associated with higher levels of distress (Barrowclough et al., 1996), a pattern which may be related to perceived failures to bring about positive mental health outcomes (Vasconcelos e Sa et al., 2017). Carer distress has also been demonstrated to be associated with appraisals of the severity and expected longer duration of psychosis, in carers of people experiencing both early onset and more chronic forms of psychosis (Addington et al., 2003; Fortune et al., 2005). Indeed, Barrowclough et al. (2014) reported that perceived negative consequences of early psychosis predicted carer distress at 6-month follow up assessments.

1.6.5 Coping

Carers of people with psychosis who adopt avoidant coping strategies, such as waiting for problems to self-resolve, have been shown to experience elevated levels of distress. This pattern has been observed in samples of carers of people with both long-term and recent onset psychosis (Onwumere et al., 2011). In an international sample of carers of people with schizophrenia, those who adopted more problem-based and less emotion-focused (including avoidant) coping strategies reported reductions in family burden at 1-year follow-up assessments (Magliano et al., 2000). As Jansen et al. (2015a) note, however, a relative lack of prospective studies in this area means the direction of effects between coping strategies and carer distress are unclear. Qualitative studies provide further context to the experiential component of coping during caregiving in psychosis. Huang et al. (2008) reported carers' use of numerous psychological (positive thinking, keeping oneself busy) and social (social support, accessing care) coping strategies, some of which were undermined by the stigma linked to psychosis. Coping with the challenges of supporting someone during early psychosis has been described as a learning process which can be facilitated through support from others with similar experiences (Wainwright et al., 2015). A key theme in interviews with low EE carers was the use of a range of adaptive coping strategies, which included gathering information about psychosis, using humour to cope with challenges, and developing realistic hopes for the future (Treanor et al., 2013).

1.6.6 Social and professional support

The presence of supportive friends, family members and peers can help with adapting to and managing the challenges of caregiving in psychosis (Wainwright et al., 2015). Consistent with this, Joyce et al. (2003) reported an association between baseline support from a confidant and effective coping at 9-month follow-up assessments, albeit in a relatively small cohort (n=39). In a much larger sample of 709 carers of people with schizophrenia, those with larger social networks experienced lower family burden (Magliano et al., 2003). Measures of practical support, psychological support, and assistance in emergencies were associated with lower psychological and practical burden, but only in female participants, which may reflect the widely reported tendency for women to be engaged in more extensive caregiving roles. A subsequent comparative study revealed smaller and less supportive social networks existed in carers of people with schizophrenia relative to carers of people with a physical health problem and a control sample (Magliano et al., 2005).

Both professional and informal assistance can represent positive experiences for carers of people with psychosis (Chen & Greenberg, 2004). However, several studies have reported challenges with access to appropriate support. Wainwright et al. (2015) describe attempts to access mental health services on behalf of relatives as a ‘fight’ with the system, with services’ strict adherence to service-user confidentiality procedures acting as source of frustration for carers. A meta-synthesis of qualitative studies of carers’ help-seeking experiences in early-psychosis (Cairns et al., 2015) suggests that carers contact services as a ‘cry for help’ after initially attempting to make sense of service users’ unusual behaviours. This period is characterised by complex and sometimes contradictory experiences; fear of the situation, yet relief regarding contact with a professional; desire for informal support that is accompanied in some circumstances by concern about social stigma; and feeling marginalised, but also assisted and unburdened, by mental health services.

1.6.7 Positive experiences

A meta-summary of the impact of caring for a family member with schizophrenia found that a minority of studies mentioned positive caregiving experiences including greater family solidarity, affection, and compassion (Shiraishi & Reilly, 2019). Indeed, a study of 560 family caregivers of people with schizophrenia found many had experienced 'caregiving gains', including greater sensitivity towards the person they supported (68.8%), awareness of inner strength (52.9%) and personal growth (48.9%) (Chen & Greenberg, 2004). These findings further emphasise the highly individual caregiving journeys experienced by those who have supported people with psychosis.

1.7 Carers' experiences of suicidal behaviour amongst people with psychosis: a systematic search for evidence

1.7.1 Rationale

The background literature presented in preceding sections of this thesis emphasises how suicidal behaviour represents a distressing and complex challenge for carers. Existing evidence also highlights significant personal and interpersonal challenges in the context of psychosis. Given the above identified evidence of a higher frequency of suicidal behaviour in people with psychosis than in the general population, the key role of carers and social support in recovery, and the significant personal impact of caregiving, it is important to understand the experiences of carers supporting someone with both psychosis and suicidal behaviour. Unsystematic literature searches conducted at the beginning of this thesis had failed to identify articles dedicated to investigating this specific experience using qualitative methods. It was decided that a systematic search for peer reviewed evidence was necessary to more thoroughly assess the state of existing literature and inform subsequent research design for this thesis. Initial scoping searches indicated that the volume of relevant search results would likely be insufficient to support the writing of a systematic review chapter dedicated to this topic. Therefore, a more comprehensive search for qualitative evidence of caregiving and suicidal behaviour forms the focus of the systematic review presented in chapter 3. To balance the demands of systematic searching and screening, a more focused search is reported here than is typically seen in more comprehensive systematic reviews, focusing only on peer-reviewed literature, and using a proximity search operator to improve search specificity.

The following section reports a systematic search for related peer reviewed literature, the results of which are reported narratively in the following section.

1.7.2 Search strategy

Search terms were developed in consultation with a specialist librarian at the Faculty of Health and Medicine, Lancaster University. As research into the experience of families of people with psychosis often refers to ‘carers’ and ‘support’ (Kuipers et al., 2010), these terms were combined with a proximity search operator (NEAR/5) to improve search precision (Sampson et al., 2009) and remove a large volume of irrelevant articles evident in test searches. To increase the likelihood that the search would identify relevant articles, database-specific subject terms were selected and applied to the search (appendix A) in all databases except Web of Science, which does not support this function. The concepts below were combined using the AND Boolean operator:

- famil* OR friend* OR parent* OR partner* OR relative* OR "significant other*" OR sibling* OR caregiver* OR carer* OR informal OR unpaid NEAR/5 (care* OR support*)

- psychosis OR schizophreni* OR schizoaffective OR psychotic OR “psychotic disorder” OR hallucination* OR delusion*
- suicid*

These terms were used to search the title and abstract fields of the following databases from inception to June 2021: Web of Science, PsychINFO, CINAHL, Medline, SocINDEX. Title and abstracts were screened independently by a primary reviewer (the thesis author) and secondary reviewer (a PhD student in health research) using the Rayyan systematic review platform (Ouzzani et al., 2016). Discrepancies were recorded and resolved in subsequent discussion. Eligible studies met the following criteria:

- Peer-reviewed articles available in English
- Data collected from carers of people with psychosis who had experienced suicidal behaviour, as per the definitions at the beginning of this chapter.
- For quantitative studies, the impact of suicidal behaviour amongst people with psychosis on carer outcomes was reported. Any measure of suicidal behaviour and psychosocial outcome was permissible. All study designs were included. Whilst financial burden is an important determinant of psychosocial wellbeing for carers (Caqueo-Urízar et al., 2009), financial impacts were excluded as this research sits beyond the methodological knowledge of the author.
- For qualitative studies, the analysis focused on carers’ experiences or views of suicidal behaviour amongst their family members or friends with psychosis.

Database searches were supplemented with hand searches of reference sections of eligible studies and with forward citation tracking, whereby the Google Scholar ‘cited by’ pages of eligible studies were reviewed for relevant studies missed by database searches (Bakkalbasi et al., 2006). An adapted version of the data extraction instrument in the JBI manual for evidence synthesis (Aromataris & Munn, 2020) was used to extract methodological details and relevant results from eligible studies. As shown in table 1, most articles did not have a specific focus on suicidal behaviour. In the interest of brevity, and to retain focus on the research aim of this thesis, only data directly relevant to carer experiences of suicidal behaviour in psychosis were extracted and are presented below.

Figure 2. Systematic search PRISMA diagram

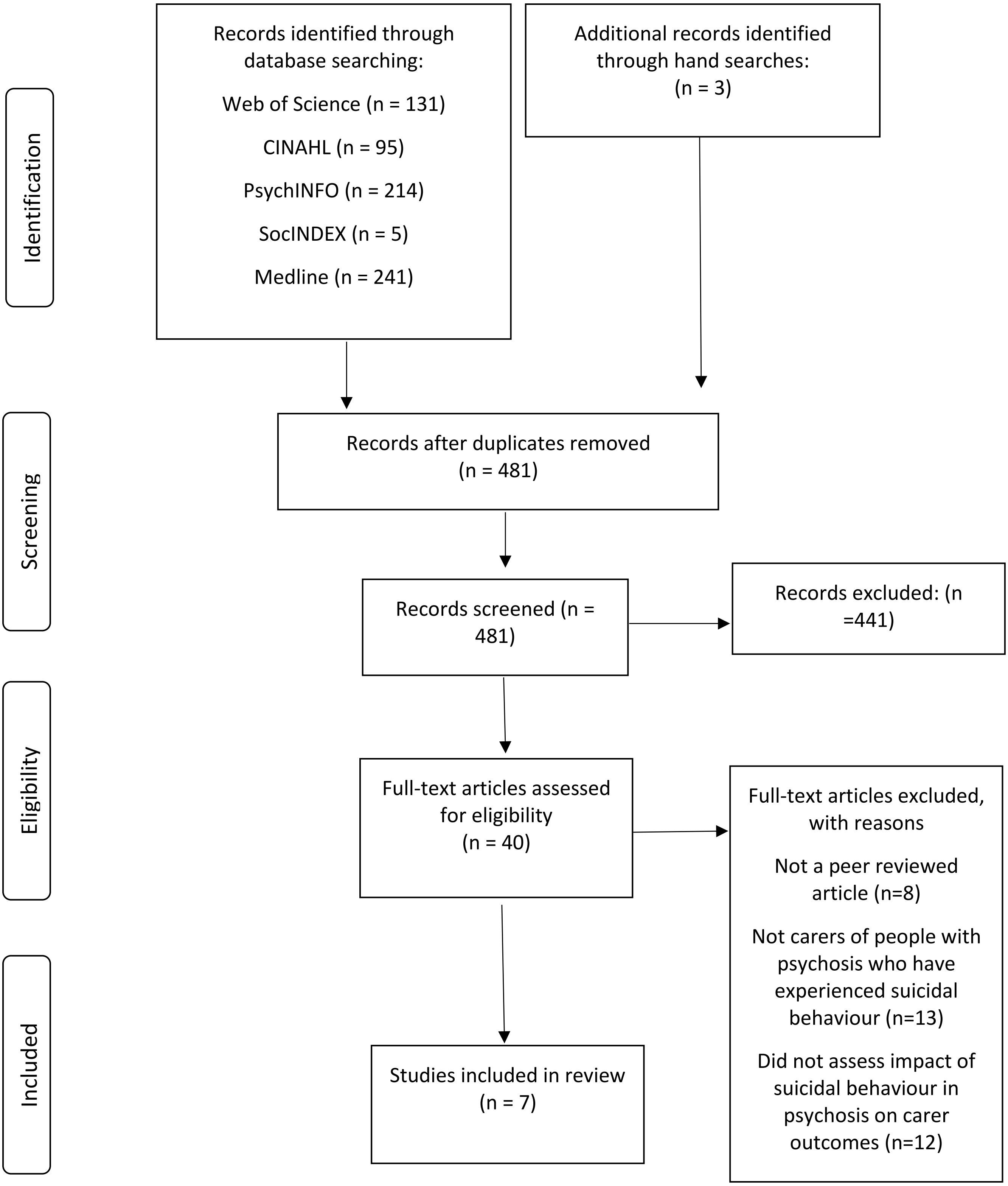


Table 1. Systematic search study characteristics

First author, year	Setting (country)	Study design	Sample (Service Users)	Sample (Carers)	Primary aim
Bowman et al., 2014	Early intervention service (Australia)	Cross-sectional survey	123 service users with first episode psychosis (FEP)	157 siblings	"characterise and establish the predictors of QoL [quality of life] for siblings of young people with FEP"
Bowman et al., 2015	Early intervention service (Australia)	Cross-sectional survey	123 service users with FEP	157 siblings	"characterize the sibling relationship in FEP and to examine the illness-related variables that influence this relationship"
Bowman et al., 2017	Early intervention Service (Australia)	Cross-sectional survey	123 service users with FEP	157 siblings	"characterize the experience of caregiving for siblings of young people with FEP"
Hsiao et al., 2015	Psychiatric outpatient clinic (China)	Cross-sectional survey	n/a	137 primary family caregivers	"assess the degree of caregiver burden and family functioning among Taiwanese primary family caregivers of people with schizophrenia …"
Hsiao et al., 2020	Psychiatric inpatient clinic (China)	Cross-sectional survey	133 service users with schizophrenia	133 primary family caregivers	"examine the degree of family functioning, particularly its concordance within patient–caregiver dyads…"
McDonell et al., 2003	Community mental health service (USA)	Randomised controlled trial	90 service users with psychotic disorders	84 family caregivers	"investigate the relationship between burden, its previously established patient and caregiver correlates, and other possible correlates such as substance abuse, depressive symptoms, and suicidality in outpatients with schizophrenia."
Yamaguchi et al. 2015	Emergency medical centre (Japan)	Qualitative interview study	7 service users with untreated schizophrenia	7 family caregivers	"investigate the discrepancies between the subjective experiences and observed behaviors in near-fatal suicide attempters with untreated schizophrenia"

1.7.3 Findings

Clinician-recorded suicide attempts predict poorer psychosocial outcomes amongst siblings

Across three articles reporting on research conducted in Australia (Bowman et al., 2014; 2015; 2017), 45 (36.5%) of the 157 young people with first episode psychosis (FEP) in their sample had attempted suicide, as per their medical records. It should be noted that while identical demographics are reported, these articles do not confirm that the same sample was used in each article, though this is being assumed. Bowman et al. (2014) reported significantly lower quality of life across all domains (psychological, social, physical, and environmental) amongst siblings of young people with FEP who had attempted suicide compared with siblings whose relatives had no history of suicide attempts. An exploratory analysis controlling for history of violence, age and gender showed that female siblings, but not males, experienced significant reductions in physical and environmental quality of life domains in the presence of suicide attempts. Bowman et al. (2015) investigated participants' perceptions of relationship quality using the Adult Sibling Relationships Questionnaire (Stocker et al., 1997). Siblings whose family members with FEP had attempted suicide reported higher conflict scores than those whose relatives had not attempted suicide, a result that remained significant in a multiple regression analysis controlling for history of violence and drug use. Most recently, Bowman et al. (2017) reported that siblings of young people with FEP who had attempted suicide scored significantly higher on the Negative Aspects of Caregiving subscale of the Experience of Caregiving Inventory (Szmukler et al., 1996) compared with siblings whose family members had not attempted suicide. Previous history of suicide attempt remained a significant predictor of negative caregiving experiences when controlling for history of violence, number of admissions, substance use, age, and gender.

Carer-reported suicidal behaviour predicts poorer family outcomes

Hsiao and Tsai (2015) reported that 16 of 137 (11.7%) family carers answered, 'yes' to the question "has your family member with schizophrenia ever thought about, threatened [sic], or attempted suicide?" (p. 1549). Carers aware of patient suicidal behaviour reported higher levels of caregiver burden, as measured by the Caregiver Burden Scale-Brief (Song, 2002), and those unaware of suicidal behaviour reported greater family functioning on the Family Adaptability, Partnership, Growth, Affection, and Resolve Index (Chen et al., 1980). Similarly, McDonell et al. (2003) reported that 15 of 85 (17.6%) family members were aware of service user suicidal behaviour, as per the Family Burden Interview Schedule (Tessler & Gamache, 1994). Awareness of suicidal behaviour was associated with greater carer burden and remained a predictor of burden when controlling for service user age and family resources. It should be noted that while this study used a randomised controlled trial design to assess an intervention for people with schizophrenia, the data relevant to this literature search were derived from cross-sectional surveys embedded within the study design.

Service user-reported suicidal behaviour predicts poorer family outcomes

In a dyadic study, Hsiao et al. (2020) reported that 35 (26.3%) of 133 people with schizophrenia in their sample had experienced suicidal behaviour, as per a yes/no item on a service user questionnaire. Family carers whose relatives had experienced suicidal behaviour reported lower family functioning, assessed using the Family Assessment Device (Chen et al., 2003). Suicidal behaviour remained a significant predictor of poorer family functioning when controlling for perceived quality of family centred care, service user education at high school level or below, and caregiver education at bachelor's degree or above.

Carers may not be fully aware of suicidal behaviour amongst their family members

In the only qualitative study identified by the literature search, Yamaguchi et al. (2015) interviewed carers following the 'near fatal' suicide attempt of a family member with schizophrenia. Interviews focused on carer's perceptions of their family member's mental health, their help-seeking behaviours, and their need for psychiatric care prior to the attempt. Only one carer out of a sample of seven recognised the possibility that their family member had psychosis and expected them to attempt suicide. Two carers stated that their family members did not seek help, and five reported 'low' help seeking by their family member prior to their suicide attempt (it should be noted that the perceived extent of help-seeking was not operationalized and as such it is unclear what a judgment of 'low' help-seeking represents). This suggests a discrepancy between actual suicidal behaviour and carer awareness of suicidal behaviour amongst family members. Indeed, McDonell et al. (2003) observed a discrepancy between service user (n = 90) and carer (n= 84) reports of suicidal behaviour. While twelve (13%) service users with schizophrenia reported suicide attempts and fifty-five (61%) reported suicidal ideation to a researcher or clinician, only 15 (17%) carers were aware of any service user suicidal behaviour.

1.7.4 Appraisal of identified research

Strengths of existing evidence

The above evidence is consistent in its conclusion that suicidal behaviour amongst people with psychosis is associated with poorer psychosocial outcomes for carers, compared with carers of people with psychosis who do not report suicidal behaviour. The primary use of regression analyses in these studies facilitated the identification of suicidal behaviour as a unique significant predictor of poorer psychosocial outcomes amongst carers. That these studies took place across three countries and in different health service environments with different service user groups further supports the transferability of this finding. Moreover, service user reports of suicidal behaviour, carer awareness of suicidal behaviour, and suicidal behaviour recorded in medical notes were all associated with poorer carer outcomes, providing converging evidence of the distressing nature of this experience for carers of people with psychosis.

Limitations of existing evidence

While the studies reported above did use validated psychosocial assessments to measure carer outcomes, several of the measures of suicidal behaviour reported here have notable limitations. First, suicidal behaviour recorded in medical notes captures only those for whom some clinical contact followed this suicidal behaviour. Notably, barriers to help-seeking such as mental health related stigma mean much suicidal behaviour goes unaddressed in clinical settings (Collin-Vézina et al., 2021), limiting the ability of this approach to identify suicidal behaviour in community settings. Moreover, the use of a binary assessment of suicidal behaviour, such as a question about whether carers are aware or not of any suicidal behaviour amongst those they support (Hsiao & Tsai 2015), provide only a limited indication of its impact on carer outcomes; using a validated continuous measure of suicidal behaviour would have allowed for the analysis of the magnitude of change in carer outcomes in relation to the severity of suicidal behaviour. Relatedly, as highlighted by McDonell et al. (2003) and Yamaguchi et al. (2015), accurately characterising suicidal behaviour is compounded by the fact that asking carers directly about their awareness of previous suicidal behaviour is unlikely to capture the full extent of such behaviour. Furthermore, as the quantitative studies reported here did not primarily aim to investigate suicidal behaviour (rather, suicidal behaviour was one amongst many predictors of carer outcomes) only a relatively small proportion of participants with psychosis had experienced suicidal behaviour in these samples, limiting the reliability of the above reported results. It is unclear whether the three articles by Bowman and colleagues used the same sample (Bowman et al., 2014; 2015; 2017). If this is the case, reliability would have been further compromised by the repeated analysis of data derived from the same participants. It is also notable that carer samples comprised only primary family caregivers or siblings and were recruited from clinical settings. This limits the transferability of these findings to other carers, such as friends and those providing support without assistance from services.

In-depth qualitative research is notably absent from studies identified by this literature search. Although Yamaguchi et al. (2015) bring attention to the potentially highly significant issue of carers being unaware of suicide risk amongst those they support, the absence of their awareness of psychosis and co-occurring suicidal behaviour precluded in-depth investigation of this experience in their interview study. Methodological limitations of this pilot grounded theory study are also evident, most notably the lack of transparency regarding methods of analysis. There is no evidence that the authors engaged with techniques key to grounded theory, such as theoretical sampling, comparative coding, or the generation of a central category, nor is the analysis supported by illustrative quotes. The findings do not therefore constitute a ‘middle-range theory’ (Charmaz, 2008), as they are neither rooted in data nor do they explain carers experiences at a more abstract theoretical level.

1.8 Thesis rationale and objectives

1.8.1 Thesis rationale

There is only limited evidence of carers' experiences of providing support to someone with psychosis who has also experienced suicidal behaviour. This is striking in light of the distressing nature of caring for someone experiencing either psychosis or suicidal behaviour, the importance of interpersonal factors in recovery from psychosis and suicidal behaviour and, as indicated by estimates of suicidal behaviour in psychosis, the likely many millions of people worldwide providing care in this context. The quantitative studies identified by the preceding systematic search provides evidence that carers of people with psychosis may experience poorer quality of life, family functioning, and caregiver burden where those they support also have experienced suicidal behaviour. However, the study designs adopted preclude firm conclusions regarding the mechanisms by which this may occur, and consequently are limited in their ability to inform the design or delivery of more specific support for service users and carers in this context. A qualitative study that explores carers' in-depth reflections about their experiences of supporting friends and family members alongside psychosis and suicidal behaviour will address this knowledge gap in existing literature and may inform future developments in research, policy, and practice related to this under-investigated aspect of carer experience.

1.8.2 Thesis aim and objectives

The overarching research aim of this thesis is to address the question 'What are carers' experiences of supporting friends or family members with psychosis and suicidal behaviour?'.

This will be achieved through the four following objectives:

1. A systematic review and qualitative thematic synthesis investigating carers' experiences of supporting friends or family members with suicidal behaviour. The introduction chapter of this thesis highlighted that there is insufficient qualitative research to support a systematic review of caring experiences of psychosis and suicidal behaviour, and a range of recent qualitative synthesis related to caregiving and psychosis have already been published (Boydell et al., 2010; Cleary et al., 2020; Mui et al., 2019; Oluwoye et al., 2020; Shiraishi & Reilly, 2019). Therefore, this qualitative review applied specific inclusion criteria related to caregiving and suicidal behaviour in order to develop an understanding of these experiences, with following studies investigating more specific aspects of caregiving and psychosis.

2. An exploratory qualitative study of online peer-support interactions related to carers' experiences of supporting family members with psychosis or bipolar disorder and suicidal behaviour. This study is a thematic analysis of data derived from a peer support forum delivered as part of a psychosocial intervention for carers. This unique data source is used to capture naturalistic interactions contemporaneous to carers' experiences of help-seeking, and supplements the in-depth semi-structured interviews presented in following chapters.

3. A semi-structured qualitative interview study of the psychosocial impacts of caring for friends or family members with psychosis and suicidal behaviour. This study is intended to fill the identified knowledge gap related to the impact of providing care in the specific context of psychosis and suicidal behaviour. In-depth interviews were conducted with twenty carers, whose data were analysed using thematic analysis.

4. A semi-structured qualitative interview study of carers' understandings of the relationship between psychosis and suicidal behaviour. This study draws on the same interview data with twenty carers and also applies thematic analysis. It is intended to provide a more focused exploration of the meaning carers attribute to psychotic experiences and suicidal behaviour when attempting to provide support for a friend or family member.

This thesis is presented in 'alternative format' following the Lancaster University (2022) manual of academic regulations and procedures. Correspondingly, chapters reporting original research are, though related, written as stand-alone research reports. While attempts have been made to limit repetition, some background literature and methodological detail is necessarily included across these chapters such that each is formatted as a coherent research article.

Chapter 2. Methodology

2.1 Chapter introduction

The aim of this chapter is to describe and justify the methodological decisions taken during the research conducted for this thesis. Critical realism, the meta-theoretical philosophy of science adopted in this thesis, will be positioned in relation to paradigms in the social sciences. How this approach informed the choice of methods of data collection and analysis used in this research will be outlined. This chapter will then examine the issues of reflexivity, quality in qualitative research, public and patient involvement, and ethical issues related to this research.

2.2 Philosophical position

A research paradigm is a foundational theoretical framework that provides a basis for decision making in scientific research (Guba, 1990). Guba states that a paradigm can be characterised by the way it informs four fundamental concerns, those of ontology – assumptions regarding the nature of reality; epistemology – assumptions regarding the nature of knowledge; axiology – values and ethical considerations; and methodology – a defined approach, or coherent system of research. This chapter will consider how these concepts relate to the research conducted in this thesis. It should be noted that descriptions of research paradigms in this chapter are necessarily brief and do not reflect the diversity of perspectives within philosophical and research traditions.

Selecting a research paradigm, theoretical perspective or research approach is a decision that is framed by the research aim (Willig, 2013). In this thesis, the overarching research aim of understanding carers’ experiences aligns in a general sense with a qualitative approach to psychological research (Braun & Clarke, 2013). Notwithstanding the many varied methodologies within the broad umbrella of qualitative research, qualitative approaches in psychological research typically seek to generate contextualised accounts of lived experiences, understanding of the meanings of such experiences, and/or the way in which participants construct their experiences, often through analysis of textual data. Qualitative methods as applied in mental health research are particularly valuable for "exploratory work and in generating understanding of phenomenon, stimulating new ideas or building new theory" (Peters, 2010, p. 36). Consistent with this, the research aim of this thesis was formulated with a view to addressing the absence of experiential research into caregiving in the context of psychosis and suicidal behaviour. Moreover, qualitative methods in mental health research provide a basis for ecologically valid investigations of complex psychosocial phenomena, which are often influenced by numerous interrelated contextual factors (Peters, 2010). Existing research with carers of people with psychosis points to a complex interaction of such factors, including social stigma, difficulties with access to appropriate healthcare services and a range of interpersonal challenges (Kuipers et al., 2010). Qualitative methods are therefore justified in this thesis on the basis of their ability to facilitate nuanced understandings of previously under-studied and likely multifaceted phenomena. Critical realism acts as the philosophical basis for qualitative studies described in this thesis.

Critical realism as a philosophy of the social sciences is associated with the work of Bhaskar (2013) and has been extended by other theorists and researchers in several domains of social science (Maxwell, 2012). The defining feature of critical realism is its combination of ontological realism with epistemological relativism. Critical realism has therefore been characterised as sitting 'in between' the influential paradigms of positivism and social constructionism on the continuum of social research philosophies (Willig, 2013). Positivism as a paradigm in the social sciences is closely associated with the ontological position of naive realism; the view that a comprehendible, measurable reality exists independent of those experiencing it (Cruickshank, 2012). Positivism also typically holds an epistemological commitment to empiricism, which emphasises the validity of sense-data acquired via perceptual input in arriving at scientific claims. In contrast, social constructionism as an ontological position views reality as socially constructed by individuals, primarily through social interaction, and thus typically places much greater emphasis on the role of language in social research. It therefore commits to an epistemological relativism in which knowledge of individuals' constructed realities are relative to the social structures and discourses they engage with (Cruickshank, 2012). Social constructionism has been and remains a widely adopted and influential stance in qualitative research and is seen in critical approaches that investigate how discourse is used to construct social categories (Alvesson & Skoldberg, 2009).

Critical realism combines the ontologically realist view of a mind-independent social reality with the relativist epistemological contention that "there can be no perception or understanding of reality that is not mediated by our conceptual 'lens'" (Maxwell, 2012, p. 20). Departing from naive realism, critical realism offers the view that information gathered through observation of social phenomena does not fully reflect reality, because reality itself is 'stratified' into three domains; the empirical, the actual, and the real (Zachariadis et al., 2010). The domain of the empirical represents the level at which events are experienced and observations are made. It is at this level that psychological and social science research is necessarily conducted. The level of the real refers to physical or social objects and their structures and causal powers. These objects exist at the level of the real regardless of our knowledge of them, or whether those causal powers are employed. The 'actual' domain refers to the level at which these powers are activated. Based on this ontological perspective, critical realism rejects Hume's view of causality as manifest in the law-like constant-conjunction of observable events, a principle embedded within study designs such as the randomised controlled trial (Wiltshire, 2018). Instead, critical realism represents the social world as a complex open system of interacting causal mechanisms that may not necessarily be reliably activated, owing to their context-dependency. Therefore, unlike the predicable law-bound function of causation in the natural world, causal influences in the social world are likely to vary across social and psychological contexts. Critical realism proposes that observable events at the level of the empirical can, however, provide tentative and partial evidence of the causal mechanisms at the level of the 'real' and 'actual'. This allows researchers to theorise causal mechanisms in the social world whilst recognising that they sit within specific social contexts and are mediated by the experiences and interpretive activities of both participants and researchers (Bryman, 2016; Maxwell, 2012).

Critical realism can provide a basis for qualitative research methods commonly used in health research, including the widely applied method for thematic analysis established in the field of qualitative psychological research (Braun & Clarke, 2014). As Braun and Clarke (2019) note, however, researchers should be clear about their philosophical approach and its implications when applying such methods. For example, a 'theme' generated from a purely social constructionist perspective is produced through interpretation of a locally situated, constructed reality, formed through discursive and interpretive practices, which does not reflect a mind-independent reality. From a critical realist perspective, however, a theme can be indicative of a pattern of context-dependent social reality, albeit mediated by participant and researcher interpretation. From a critical realist perspective, a theme is a 'transitive' object of human construction, yet the social reality researchers are trying to characterise is 'intransitive', that is, it exists beyond the research setting (Maxwell, 2012). From this perspective, while all individuals experience social phenomena in highly idiosyncratic ways, there may be some 'real' aspect of that phenomena, such as its latent causal power, which leads to identifiable patterns in the way people respond to it. The ability to develop explanatory accounts of psychosocial processes, and the implication that these are to some degree shared by participant groups with some common experience of the social world, provides critical realist researchers with a natural route to research impact, or real-world applicability of research findings. As Wiltshire (2018) notes, "since [research] impact is likely to rest on the notion that there are actual problems (to the best of our knowledge) to which we can find actual (evidence-based) solutions, one must at some point acknowledge the ontological status of phenomena (social and natural) at hand as real…in a way that the constructivist–interpretivist positions can preclude" (p. 532). A critical realist perspective is therefore particularly valuable in mental health research, which is typically conducted (either explicitly or implicitly) with a view to informing evidence-based practice or policy.

2.3 Use of psychological theory

In this thesis, the Cognitive Model of Caregiving in Psychosis (CMCP) (Kuipers et al., 2010) is used to frame existing literature and interpret the results of the studies presented in later chapters. This choice was guided by several considerations. First, the CMCP draws together a diverse literature by highlighting and providing conceptual links between prominent domains of research conducted in the decades prior to its publication. The model is more robustly supported by empirical research than others that could potentially be foregrounded in this thesis, such as the grounded theory of family caregiving following a suicide attempt reported by Sun et al. (2008). Indeed, a structural equation model conducted to test the CMCP found support for the hypothesised mediating role of carer appraisals, a concept central to the theory (Hesse & Klingberg, 2014). Second, cognitive perspectives are widely adopted in psychological approaches to intervention for psychosis. This is reflected in a higher prevalence of studies conducted to evaluate cognitively oriented interventions relative to other approaches (Turner et al., 2014). Indeed, cognitive behavioural intervention for psychosis with or without the involvement of service users are recommended in national clinical guidelines in the UK (NICE, 2014b). Contextualising the findings of the research presented in this thesis with reference to a cognitive model may therefore assist in identifying implications for psychosocial interventions that are more directly applicable to current practice. Finally, in addition to offering a means of navigating previous work, existing established theory acts as a 'blueprint' in dissertation research, highlighting gaps in knowledge and locating the outcomes of empirical projects (Osanloo & Grant, 2016). This is facilitated by the model's wide recognition in the field as indicated by its citations (264 as of December 2022). As such, the findings of the research presented here and implications for future research are interpreted with reference to the CMCP in the thesis discussion chapter (section 7.4.1).

2.4 Methods of data collection and sampling

2.4.1 Systematic review databases

The systematic review chapter reports systematic searches using five databases. Database choice and search strategy formulation were supported by a specialist librarian at the Faculty of Health and Medicine, Lancaster University. Databases were selected based on the disciplines covered by the journals they index, and their relevance to the research aim: PsychINFO indexes psychological science journals; CINAHL focuses primarily on healthcare research; SocINDEX includes journals in social science; MEDLINE indexes biomedical science journals; and Web of Science is a large, multi-disciplinary database. This combination of databases, supplemented by forward and backwards citation chaining to retrieve papers missed by database searches, was expected to provide widespread coverage of relevant literature.

It is noted that other potential databases could have been included, such as EMBASE (biomedical literature) or SCOPUS (life, social, and health sciences). However, it was decided that broadening the search to additional databases would be impractical given resources available for the review, especially given the decision to apply double-checking to all title and abstracts returned by database searches. The decision to not search for and include unpublished or ‘grey’ literature was also borne out of concern for the practical challenges involved in this form of search. Excluding grey literature ensures that included studies meet minimum quality standards of peer review and avoids inclusion of potentially highly heterogenous and large documents, such as thesis and third sector reports. This may, however, have led to the exclusion of highly insightful documents related to the research question, a noted limitation of this approach.

2.4.2 Online forums

Data from the Relatives Education and Coping Toolkit (REACT) online peer support forum (Lobban et al., 2020) were used as the basis for secondary qualitative analysis in this thesis REACT is an online intervention designed to support friends and family members of people with psychosis or bipolar disorder which included an online peer-support forum. As part of a randomised controlled trial to evaluate REACT, participants in the intervention arm could use the online forum to discuss their experiences and seek support from other participants. The forum was moderated by REACT Supporters, who were people with lived experience of caregiving trained to offer emotional support and signposting to forum users. Participants had the option of contributing to ongoing discussion or starting their own titled discussion thread, which were viewable by all forum users. The forum also included a direct messaging function where forum users could communicate with REACT Supporters, one-to-one, in private conversation. Participants provided consent for this dataset to be used for additional research.

Where more traditional qualitative data collection methods, such as focus groups and interviews, facilitate in-depth narrative exploration of personal experiences within what could be described as a somewhat artificially constructed social interaction between participant and researcher, online forums encourage naturalistic interactions, often amongst participants with some shared experience brought together within an online community (Im & Chee, 2006). In this way, online forums can mimic the dynamic co-creation of knowledge evident in group interactions, albeit in an asynchronous fashion. Anonymity on online forums may be of particular value in the context of sensitive health research where discussions depend on disclosure of often highly personal information (Seale et al., 2010). Indeed, on the REACT forum participants used pseudonyms to protect their anonymity. Moreover, qualitative research methods such as interviews and focus groups often require participants to recall their prior experiences. On the REACT forum, however, participants accessed the forum because they were distressed and help-seeking, as per inclusion criteria for the trial (Lobban et al., 2020). This unique context therefore provides contemporaneous and spontaneous accounts of peer support in the context of caregiving.

Using the REACT forum offered further distinct advantages related to its status as an intervention designed as part of a research study. First, the forum was closed to the public and full consent to use the online data for research purposes was established before the trial. This avoided a number of ethical issues related to seeking consent to use publicly available data and the issue of 'ownership' of online spaces (Roberts, 2015). Second, the forum was actively moderated by REACT supporters who were trained to provide non-advisory support and were supervised by clinical psychologists to minimise potential distress. REACT supporters also had lived experience of supporting someone with psychosis or bipolar disorder and could therefore be considered part of the peer community. It is notable that REACT supporters were proactive in providing peer support, often referencing their own experience in doing so. Self-disclosure in qualitative research can help develop rapport and encourage participants to feel comfortable sharing their experiences (Dickson-Swift et al., 2007). REACT supporters' interactions may therefore have assisted in developing the richness of the final dataset, which was ultimately co-produced by moderators and forum users, rather than researchers.

Disadvantages of using online forums in qualitative research should be noted, and include the inability of the researcher to develop rapport, recognise and respond to social cues, and probe phenomenon of interest in real time (Smedley & Coulson, 2021). Because the dataset was fixed prior to analysis, it was by its nature limited in the extent to which it allows specific research questions to be interrogated. Furthermore, the forum was not set up to elicit conversations related to suicidal behaviour and so a strategy for the extraction of relevant data was necessarily applied before analysis. As is further explained in chapter 5, this involved manually identifying forum posts in which suicidal behaviour was discussed, which itself represented a time-consuming process requiring additional checking by a second researcher for consistency and reliability.

2.4.3 Semi-structured interviews

Semi-structured interviews were selected for the primary research in this thesis on the basis of their ability to facilitate in-depth exploration of lived experiences consistent with both a critical realist account of the complexity of social reality (Brinkmann & Kvale, 2018) and the overarching research aim of this thesis. This complements the more static, limited, and pre-determined nature of online forum data. As data collection took place in 2020 and 2021, participants were offered the option of completing their interviews by phone or on Microsoft Teams (video call) rather than in person, due to the COVID-19 pandemic. Although it has been suggested that telephone and video interviews risk limiting the opportunity for rapport building and, potentially, may lose some of the nuance captured within the context of in-person interaction, they do allow for more convenient recruitment from a broader geographic range and facilitate the involvement of participants for whom face-to-face interaction may be particularly challenging, (Sturges & Hanrahan, 2004) or as was the case at time of recruitment, legally restricted

Sampling was purposive and directed at research networks within the UK likely to be accessed by carers with experience of supporting friends or family members with psychosis. This included: the research opportunities mailing list at the Spectrum Centre for Mental Health Research, Lancaster University; the NIHR People in Research website; and the charities Rethink Mental Illness and the McPin Foundation which focus their services on support and information for mental health difficulties including psychosis. Notably, permission to recruit from NHS services was not sought, and so participants were not identified through mental health services. This was done to ensure that the pool of potential participants was broadened to facilitate participation amongst those who may not have been accessing services in the capacity of a carer, had not done so for some time, or who were supporting someone with psychosis and suicidal behaviour who was not in contact with the services. Inclusion criteria were intentionally broad to maximise participation; eligible participants were aged 18 or over, based in the UK, and self-identified as having supported a friend or family member with experience of psychosis and suicidal behaviour (as per the previously noted definitions). While carers in the UK can be legally entitled to dedicated governmental support from the age of 16 (National Health Service, 2021), it was decided that the additional potential ethical challenge of conducting highly sensitive research with young people under 18, likely focused on the mental health of their immediate family members, would require significant adaptations to the methods used for data collection, and training and supervision for the author. These factors which were deemed to represent significant barriers to the ethical conduct of the research.

Development of an initial draft interview topic guide was informed by familiarisation with important topics of existing research (Kuipers et al., 2010) and aspects of carers' lived experiences highlighted by the REACT forum analysis. A draft topic guide and research protocol were then presented to the Spectrum Advisory Panel, a patient and public involvement (PPI) group at Lancaster University. Two key issues arose from discussions of the interview study in this thesis. First, participants approved of the inclusion of both friends and family members in the study population but noted how the term 'caregiver' or 'carer' may not resonate with some potential participants, who may view the word as indicative of a paid role or indeed may view the support they have provided to someone with psychosis not as ‘caregiving’, but a natural feature of their relationship. The term ‘care’ was therefore substituted for ‘support’ in study materials (appendix B). Second, the PPI group emphasised the significant impact providing support had on their other personal relationships, both through the positive impact of social support and the potentially detrimental breakdown of their social networks. Leading from this, an additional topic and prompt related to ‘personal impact’ was added to the topic guide to allow for a more focused consideration of these aspect of participant experiences. This resulted in six final topics (see appendix B for the full interview topic guide):

- ***The supportive relationship*** – an introductory topic exploring the relationship between the person the carer supported, and that person’s experience of psychosis
- ***Suicidal experiences*** – a topic to investigate suicidal experiences of those receiving support, from the carers’ perspective
- ***Health service interactions*** – questions to explore carers’ experiences of health services, with specific focus on psychosis and suicidal behaviour
- ***Personal impact*** – the personal impact of caregiving on participants
- ***Coping and self-care*** – questions investigating the ways in which carers managed their wellbeing during their caregiving experiences
- ***Improving support*** – a final topic reflecting on support for carers and directions for further service development

These wide-ranging domains of experience were appropriate given the overarching thesis objective of understanding carers’ experiences of supporting people with psychosis and suicidal behaviour. Following initial interviews using this topic guide, reflection on this data, and discussion within the supervisory team, it was decided that this initial broad research question could be meaningfully refined into two more specific research questions. This is methodologically consistent with the above-described research design, given, as Braun and Clarke (2022, p. 26) note, that “for reflexive TA [thematic analysis] research questions can evolve, narrow, expand, or sharpen as your analysis takes form – as long as your final questions are part of a conceptually coherent design”. The first relates to the personal psychosocial impact of caregiving on carers (chapter 5) and a second relates to carers’ understandings of the relationship between psychosis and suicidal behaviour (chapter 6). Given the breadth and therefore the flexibility offered by this initial topic guide, and the richness of data elicited in initial interviews, it was decided that no substantive change to the guide was required to answer these revised research questions.

2.4.4 Information sufficiency

In qualitative research, decisions regarding the point at which sufficient data have been collected and consequently when it is permissible to cease data collection and analysis are often made with reference to the concept of saturation. One widely applied definition of saturation relates to the point at which no new information or analytic outputs emerge from the ongoing process of data collection and analysis (Guest et al., 2006). However, this principle has been critiqued as inconsistent with qualitative research that takes a relativist epistemological position (Braun & Clarke, 2021d) due to the implication that concepts derived from qualitative analysis are discovered rather than developed, and therefore can be reliably observed with sufficient time and resource. This is to view the meaning of individuals' experiences as fixed, rather than the product of a researcher's unique interpretive efforts.

Saturation as conceptualised above is inconsistent with the relativist epistemology and reflexive methods applied in this thesis. Instead, information sufficiency in the interview research described in this thesis was approached with reference to the model of information power proposed by Malterud et al. (2016). This approach provides guidance in the form of key questions researchers may ask of their data to inform sample sizes in qualitative research. Specific considerations include the specificity of the research question under investigation; the researcher's ability to generate in depth data and the richness of the data itself; and the aim of the analytic method used. Generally, research questions investigating narrow experiential perspectives taking an ideographic approach to analysis will require fewer interviews to generate rich and informative outputs than those investigating broader questions using analyses seeking to generate patterns of understanding across participants. In the interview studies in this thesis, the decision to cease data collection was informed by a reflection on the quality and depth of conversation in interviews, which were perceived by the lead author, in discussion with the supervisory team, to be sufficiently rich to support the identification of nuanced patterns of meaning in relation to the research questions. While these are essentially subjective judgements, they do provide researchers with methodologically coherent principles by which to consider information sufficiency when conducting research from a relative epistemological position.

A related challenge is how to approach information sufficiency in qualitative evidence synthesis and secondary data analysis. As in the systematic review and online forum analysis in this thesis, data in these types of research are necessarily limited. To the author's knowledge, guidance regarding information sufficiency in secondary qualitative analysis informed by a critical realist perspective has yet to emerge from the literature. However, based on the principles outlined above, an assessment was made regarding the breadth, richness of the data available, and the research question and analytic methods were adapted accordingly, with limitations of underlying data acknowledged. In both the systematic review and the analysis of online forum data the datasets were limited and as such, no modification to the original broad research questions were made during each study.

2.5 Methods of data analysis

2.5.1 Relevant analytic approaches

The qualitative research methods used in this thesis were selected with reference to two primary concerns. First, the methods were required to be consistent with the research aim of developing in-depth understanding of participants' lived experiences. Second, the methods were required to be consistent with critical realist ontology and epistemology. Based on these considerations, and through increasing acquaintance with the research literature in this area, three primary methods of analysis were considered: interpretive phenomenological analysis (IPA), grounded theory, and thematic analysis. IPA is phenomenological in its attempt to elucidate the nature and meaning of participants' conscious experiences, and interpretive through an acknowledgement that such knowledge necessarily involves the 'double hermeneutic' practice of interpreting participants' own interpretations of the meaning of their experiences (Eatough & Smith, 2008). The reliance in IPA on data collection methods that facilitate in depth exploration of personal experience (primarily interviews) made IPA inappropriate for the study of data derived from a user-guided peer-support forum where conversations were asynchronous and varied in depth.

Grounded theory is an inductive approach to developing theoretical concepts from qualitative data (Strauss & Corbin, 1997). While grounded theory takes the view that 'all is data', its application of theoretical sampling – the targeted recruitment of participants based upon concepts that develop from the ongoing analysis of data – may have presented logistical challenges if applied in this thesis. If it was the case that an emerging analysis pointed to, for example, the significance of suicidal crises in carer's experiences, it may be impractical to apply theoretical sampling with a view to recruiting participants with recent or current experience of such crisis situations. Due to the context of data collection at the height of the Covid19 pandemic, there were already extensive restrictions to data collection, so this iterative and targeted approach to data collection was considered unfeasible. Moreover, significant methodological heterogeneity exists in grounded theory research. Debates exist regarding the underlying philosophical assumptions of different grounded theory procedures, such as the extent to which literature reviews, common in PhD research, are permissible before conducting a grounded theory study, and the epistemological status of theoretical saturation, which defines when theoretical sampling ceases (Braun & Clarke, 2021d; El Hussein et al., 2014)

2.5.2 Thematic analysis

Thematic analysis is a research method used to identify patterns across qualitative datasets. The six-step approach codified by Braun and Clarke (2006) does not require a commitment to any one philosophical perspective, yet since its publication, broad 'schools' of thematic analysis have developed with distinct underlying assumptions (Braun & Clarke, 2019). The approach identified by Braun and Clarke as ‘reflexive’ thematic analysis is consistent with the research aims of the studies in this thesis and with a critical realist approach to qualitative research. Reflexive thematic analysis conceptualises themes as capturing rich patterns of shared meaning across a qualitative dataset, which are typically organised around a central concept, and are the product of researcher interpretation (Liamputtong, 2019). Less ideographic than IPA, this method permits the analysis of data collected from a range of sources, including semi-structured interviews and data derived from online sources. Thematic analysis is also not tied specifically to any one research paradigm. This facilitated the combination of thematic analysis with thematic synthesis within this thesis, both of which can be approached from a critical realist perspective. On this basis, it was determined that reflective thematic analysis would be an appropriate choice for the analysis of data collected from the REACT forum and semi-structured interviews.

2.5.3 Thematic synthesis

While it would have been possible to apply several different analytic methods to the primary research in this thesis, using reflexive thematic analysis to analyse forum and interview data served to maintain methodological consistency across these studies. The desire to maintain this consistency throughout this thesis also informed the selection of thematic synthesis (Thomas & Harden, 2008) as a method for qualitative evidence synthesis. Thematic synthesis as a method of secondary data analysis developed through adaptation of the procedure outlined by Braun and Clarke (2006) for the purpose of synthesising qualitative evidence in the field of health research. Furthermore, thematic synthesis is underpinned by a realist epistemology (Booth et al., 2016) and the method allows for the development of analytic themes that “go beyond the primary studies and generate new interpretive constructs, explanations and hypothesis” (Thomas & Harden, 2008, p. 1) . As with thematic analysis, thematic synthesis is therefore consistent with the overarching research aim of this thesis and the critical realist conception of knowledge generation as interpretive, yet also involving theorising of ‘real’ phenomena.

2.6 Quality in qualitative research

Conceptualisations of good practice in qualitative research vary across research paradigms, making definitive statements regarding quality challenging (Majid & Vanstone, 2018). One strategy for assessing quality is through the use of appraisal tools such as the Critical Appraisal Skills Programme (CASP) checklist (CASP, 2018). Such checklists are intended to aid researchers in considering the presence of key features deemed to characterise transparent and rigorous qualitative research. For example, checklist items may prompt researchers to consider the clarity with which authors describe their analytic procedure or the appropriateness of the methods used in light of their research aims (CASP, 2018). However, confounding factors in the development and application of such checklists include significant heterogeneity in theoretical assumptions across qualitative research methodologies and highly variable applications of the same method, as indicated by a wide variety of published articles using ostensibly similar methods. One example relates to the divergence of thematic analysis methodology into multiple somewhat distinct approaches, some aligned to more positivist assumptions regarding, for example, the importance of reliable analytic claims, with other, more constructivist forms committed to the value of reflexive, interpretive practice (Braun & Clarke, 2021a). As Braun and Clarke (2021c) note, universal criteria against for judging research quality should be applied with acknowledgement of the underpinning theoretical implications of this approach.

The use of quality appraisal checklist is most often addressed in the domain of evidence synthesis. In thematic synthesis of the sort applied in this thesis, it is permissible to use quality appraisal tools as a form of ‘sensitivity analysis’ (Thomas & Harden, 2008). Here, the contribution of primary studies to synthesised results is evaluated in order to inform discussions of whether lower quality articles contributed disproportionately to the final analysis. Reviewers may exclude low-scoring primary research articles to avoid this issue a-priori. In contrast, the thematic synthesis conducted in this thesis took a middle-ground approach to the use of quality appraisal tools. The CASP (2018) qualitative checklist was applied and reported, but not used to inform exclusion criteria or a sensitivity analysis. This is in recognition that thorough reporting of research practices is likely to promote transparency across methodologies, yet transparent reporting alone may not reveal the extent to which primary articles provide valuable insight into the issue under investigation. As noted by Majid and Vanstone (2018), excluding articles judged as lower quality also risks de-prioritising articles that fail to communicate awareness of theoretical and methodological issues in qualitative research, but may nonetheless include valuable results regarding the phenomena under investigation. The CASP (2018) tool was therefore used in this thesis to chart the methodological transparency and rigor of articles within the systematic review chapter, by assessing the degree to which authors of primary studies reported their research practices, and the appropriateness of their methodologies. In addition to highlighting potential methodological issues in a given area of research, this allows readers of the subsequent thematic synthesis to make their own judgements about the quality of data underlying the analysis.

Qualitative analyses in this thesis were guided by principles of methodological transparency and rigour, consistent with the underpinning critical realist philosophical position. Transparency refers to the extent to which readers can identify the methodological procedures applied within a given piece of research (Tuval-Mashiach, 2017). Transparency was promoted in several ways throughout the thesis. For the systematic review, a protocol was published online (Marshall et al., 2020) prior to searches being conducted and the chapter is presented with reference to PRISMA (Page et al., 2021) reporting guidelines. Moreover, chapters detailing primary research were guided by items from the CASP (2018) checklist. As such, for the analysis of the REACT forum, a thorough description of the data-extraction and analytic procedure is given, and each interview study provides a thorough account of data collection and analysis. For all studies, the rationale for qualitative methods is clearly stated, the relationship between researcher and data considered, and limitations of the approach recognised. The author's methodological reflections are presented at the end of each chapter, highlighting issues with data collection and analysis. These reflections serve to illuminate challenges with the applications of specific methods, further promoting transparency.

Transparency is related to the concept of transferability, considered a marker of good practice in qualitative research (Tuval-Mashiach, 2017). Transferability refers to the ability of a reader to make judgements about the extent to which insights from a piece of qualitative research can be transferred to other situations and contexts, therefore, the more transparent qualitative research is regarding the context under which data were collected and analysed, the better able a reader is to understand the contextual congruence between the research setting and other circumstances (Braun & Clarke, 2021c). This places the burden for judging transferability with the reader, yet authors can facilitate these judgments by providing thorough contextual description. In this thesis, this was facilitated by inclusion of the demographic and caregiving-related details of participants in the REACT trial and interview study, characteristics of the research team (including professional backgrounds and experiences), and detailed descriptions of the analytic process for each chapter, including where participants were recruited from and how they were interviewed.

The principle of methodological rigour was guided by aspects of research quality and good practice aligned to what Braun and Clarke described as ‘Big Q’ qualitative research (Braun & Clarke, 2021b, 2021c). This term refers to research methodologies that apply a ‘fully qualitative’ approach. This can be contrasted against (small q) qualitative research that is based on underlying ontological/epistemological assumptions typically aligned with quantitative research, such as the necessity of minimising research bias. An important challenge for authors therefore lies in developing ‘theoretical knowingness’ (Braun & Clarke, 2019) characterised by the application of research practices that are consistent with the theoretical underpinnings of their stated approach. Values of Big Q qualitative analysis that the author attempted to adopt here include the recognition of meaning as a key target of analysis, the acceptance that knowledge is necessarily partial and generated by analysts rather than straightforwardly discovered, and the importance of critical reflection on assumptions embedded within a given analytic context (Braun & Clarke, 2021c). Specific strategies to facilitate rigour included immersion within the data, facilitated by multiple readings of the REACT forum prior to data extraction, and author transcription of interview recordings. Critical awareness of positionality was maintained with the support of colleagues with diverse professional experience and lived experience experts. This broad range of experience facilitated refinement of the analysis through multi-perspective reflection on the developing analytic process. This served to enhance the credibility of reported analyses, where credibility refers to the extent to which readers are convinced that research truthfully captures the experiences under investigation (Levitt et al., 2017) .

In Big Q qualitative research, the role of the researcher involves active interpretation. Here, subjectivity and creativity are central to the research process, thus, good practice emphasises engagement with the act of reflexivity, through which researchers develop critical awareness of their own role in knowledge generation (Braun & Clarke, 2021b). As such, methodological reflections demonstrating transparency and reflexive practice are included throughout this thesis. More positivist conceptualisations of rigorous research, characterised by minimisation of bias and an emphasis on the reliability of analytic claims are therefore misaligned with the assumptions of Big Q qualitative research (Braun & Clarke, 2021c). Consequently, research practices such as the generation of statistics demonstrating inter-rater coding reliability or attempts to recruit a fully representative sample reflecting the wider population, were not conducted.

2.7 Patient and public involvement

The involvement of people with relevant lived experiences at each stage of the research process can serve to make research more reflective of service users' experiences and priorities, and enhance the appropriateness of research conducted with a given sample (Townend & Braithwaite, 2002). PPI in the research reported in this thesis included:

- As above, the interview topic guide was reviewed and refined through consultation with a PPI group at Lancaster University, which included carers with experience of supporting people with psychosis.
- Prior to beginning recruitment for the qualitative interview study, an advisor with experience of supporting someone with psychosis and suicidal behaviour

recommended recruitment strategies and provided links with charity representatives who then hosted the study on their websites (Rethink Mental Illness and McPin Foundation).

- A REACT supporter with experience of supporting a family member with mental health difficulties and who provided extensive support to users on the REACT forum reviewed and provided feedback on initial and final drafts of the thematic analysis of the REACT forum dataset.
- An advisor with experience of delivering mental health support through local recovery colleges and who has experienced supporting a family member with mental health difficulties reviewed and provided feedback on an initial and final draft of the qualitative synthesis reported in this thesis.
- A service user researcher at the Spectrum Centre for Mental Health research facilitated the PPI group referred to above and completed a practice interview with the author to help refine interview technique.
- The three previously mentioned individuals reviewed the thematic framework produced as part of the interview studies in this thesis and engaged with the author in discussion of the meaning and implications of this research for carers' services.

PPI activities were funded using the author's PhD funding consistent with INVOLVE guidelines (NIHR, 2016). This included payments of £25 for briefly reviewing documents or short meetings without preparation, £50 for more extensive reviewing of documents or meetings requiring preparation, and £100 for extensive reviewing of documents equivalent to a day's activity.

A reflection on the impact of these PPI activities on this thesis is provided in the strength and limitations section the thesis discussion chapter (section 7.5.5).

2.8 Reflexivity

2.8.1 Reflexivity and qualitative research

Qualitative research conducted from an epistemologically relativist perspective typically conceptualises subjectivity not only as an inevitable consequence of researchers' personal experiences and identities, which cannot feasibly be separated from the human act of social scientific inquiry, but as a resource drawn upon in the process of interpretation of qualitative data (Braun & Clarke, 2013). How subjectivity informs qualitative research is considered in the practice of reflexivity. Reflexivity can be defined as "the process of continually reflecting upon our interpretations of both our experience and the phenomena being studied so as to move beyond the partiality of our previous understandings and our investment in particular research outcomes" (Finlay & Gough, 2008, p. 108). This reflexive practice may involve critical self-awareness achieved through questions such as "what is my relationship to the phenomena I study? Why is that so? What drives this interest? With whom do I forge research relationships? Where are my beliefs, biases, and values present? Am I transparent about these facets?" (Meixner & Hathcoat, 2019, p. 55).

The answers to such questions will invariably be influenced by personal experience of the phenomena under investigation, but also to some extent by the researcher's identity, including their class, gender, and ethnic background (Willig, 2013). These social categories are made relevant by the critical realist conception of social categories as 'real' in the sense that they may impart causal influence on the research process (Roberts, 2014). Moreover, the 'reflexive' title of reflexive thematic analysis is intended to emphasise the way in which the researcher applies their own interpretive perspective to the active process of knowledge generation (Braun & Clarke, 2019). Given the centrality of reflexivity to the epistemological position and to the rigorous application of methods applied in this thesis, the author began engaging with reflexivity by producing a reflexivity statement before beginning any analytic work. Indeed, as Shaw (2010, p. 235) notes, by “proactively exploring our self at the start of our research inquiry, we can enter into a dialogue with participants and use each participant’s presentation of self to help revise our fore-understanding and come to make sense of phenomenon anew”. Analytic notes were used on an ongoing basis to facilitate reflexive thinking. These were used to track reflections on interview technique, points of interest during familiarisation with the literature and collected data, and emergent analytic ideas throughout the process thematic analysis and synthesis. The following section, written in the first person to communicate the introspective nature of reflexive thinking, is presented here as a way to demonstrate the methodological transparency referred to by Meixner and Hathcoat (2019). This focuses initially on the motivation and beliefs carried by the author into the research process. A reflection on the changing nature of the author’s relationship with the research process is also considered with reference to the insider-outsider heuristic proposed by Hellawell (2006) to assist researchers with reflexive thinking.

2.8.2 Reflexive commentary

Coming to my qualitative PhD research from a quantitative master’s project, firmly rooted in (largely implicitly held) positivist assumptions regarding the role of the researcher in the generation of knowledge, I found it difficult to transition into viewing my subjectivity and involvement in the research process as things to explore and ultimately embrace rather than quash in pursuit of scientific objectivity. During my initial attempts to engage with reflexive thinking, I tried to make my unarticulated assumptions about my role in this project clearer to myself through extensive note taking. This often resulted in personal reflections that were in no way pertinent to the research process. Although it took some time to grasp, conceptually, the purpose of engaging with reflexivity as part of my research, I did realise that my experiences and perspective inevitably influenced my approach to this work. For example, I had personal relationships with people who fall within the 'carer' definition used in this thesis and whose experiences I had absorbed into my own expectations concerning the kinds of issues I would likely come across through this research. Namely, that caring for someone with psychosis would be highly distressing and that mental health services were difficult to access and engage with. That knowledge likely implicitly influenced the way I engaged with the topic and reveals that I was and am not a value-neutral, detached observer, but someone seeking to engage with research with a view to ultimately have some positive impact on those these issues affect.

As a non-member of the participant group, at the start of the project I perceived myself as holding an 'outsider' rather than 'insider' perspective on the phenomena under investigation. I now realise that this was an oversimplification. As Hellawell (2006) states, one definition of an 'outsider' is someone with no a priori familiarity with the setting and people who are participants in research. Yet, as Hellawell goes on to note, the extent to which someone is familiar with others' experiences is more of a continuum than a dichotomy, and the potential dimensions of such experiential understanding are multiple and shifting. They are also potentially relevant to the way my role as a researcher influences the data I collect, analyse, and report. For example, my interviewing of a participant of the same age, class, and cultural background as myself may make relevant points of familiarity that could afford me certain interpersonal resources, such as common points of reference or vocabulary, which may influence the way I build rapport or probe personal experiences. I can only speculate how such points of perceived familiarity may have influenced the research process, but it is reasonable to suggest that a researcher with different personal characteristics and motivations would have engaged with the process of data collection and analysis in ways subtly different to myself.

One concrete example of this relates to my perspective of suicidal behaviour, an issue central to this thesis. Caring for someone experiencing suicidal behaviour is something that I did not personally have significant acquaintance with prior to this project. This was made evident in a practice interview, where it was noted that I looked hesitant and notably nervous raising and exploring the issue. This may well have been a manifestation of my latent discomfort with discussing what remains a highly stigmatised and emotive topic in my own and many other societies. Speculating on how this could have influenced my early interviews with research participants, it may have been that I was more reticent than I perhaps should have been in probing participants' experiences of suicidal behaviour. Quite possibly, those for whom discussing suicidal behaviour is more familiar may have found it easier than I did to engage with the topic in an inquisitive manner conducive to the collection of 'rich' qualitative data.

Borrowing the idea of 'research distances' (Hellawell, 2006), this issue relates to the emotional distance between myself, as someone with little experience of the emotions attached to personally being impacted by caring and suicidal behaviour, and the participants in my study who evidently did. That I had not experienced these emotions may have impacted my confidence in raising and exploring the topic. Fortunately, parallel to my research training, I trained as a listening volunteer for an emotional support phone line focused on suicide prevention. Through this, I became acquainted with and ultimately more confident in asking others about their experience of suicidal behaviour. I remained an outsider to the research participants to the extent that I was not supporting friends or family members, but I did develop a greater insight into, and empathy regarding, the kinds of thoughts and emotions that can emerge when doing so. I thus felt better equipped as a researcher to approach the issue of suicidal behaviour with the kind of enquiring sensitivity I struggled with initially, which helped me feel more self-assured in the interpersonal context of the research interview. This experience also prepared me well for telephone interviews and perhaps contributed to my feeling that interviewing participants in this way did not hinder rapport building or the emotional depth of discussions, at least from my perspective. Rather, in the absence of having to consider factors relevant to in-person interviewing, such as body language, eye-contact, or the background noise of a busy university, I felt better able to concentrate on listening and formulating responses in the moment.

This commentary highlights some of the issues related to reflexivity relevant to this project. In order to evidence my ongoing engagement with reflexive practice, I have added a short methodological reflection, written in the first person, to the end of each individual study and thesis discussion chapter. My aim is to highlight and explore methodologically oriented reflections pertinent to this thesis and, by extension, my own learning experience.

2.9 Ethical considerations

All of the studies conducted as part of this thesis received appropriate ethical approval prior to commencement. This includes the REACT trial (Lobban et al., 2020) which received ethical approval from the Health Research Authority. As part of this procedure, all participants consented for their REACT forum posts to be analysed. Lancaster University's

Faculty of Health and Medicine approved the request to conduct secondary analysis of the REACT forum data and the qualitative interview study (see appendices C and D for ethical approval letter0073). In both qualitative studies, a key ethical consideration related to the protection of participant confidentiality. As such, raw data used in these were stored in Lancaster University's OneDrive, consistent with data protection requirements in the UK. During analysis, participant names were replaced with ID numbers as a means of pseudonymisation, and care was taken not to include any personally identifying information when reporting direct quotes. In the interview study, participants recognised and confirmed during the consent procedure that the conversations would remain confidential to the research team, but that the interviewer would break this confidentiality agreement in the event that they were made aware of imminent risk of harm to the participant or another person.

When planning the interview study, it was important to consider the potential for emotional harm to participants when discussing potentially highly distressing personal experiences. Several steps were taken to mitigate this. Three practice interviews were conducted prior to recruitment, two with experienced interviewers/clinicians and one with a service user researcher. These interviews helped to refine the author's interview technique, with a focus on achieving a balance between probing emotionally challenging topics and avoiding participant distress. At the beginning of each research interview, participants were reminded of their right to refuse to answer questions, take breaks, reschedule, or withdraw from the study without providing a reason. At the outset, the interviewer used an intentionally broad open question (e.g., 'can you tell me about your relationship with the person you supported?') in order to build rapport and sense the nature of participants' comfort with disclosing their experiences before attempting to probe potentially more distressing issues related to suicidal behaviour. At debrief, participants were asked how they found the interview, were offered a 24-hour wellbeing check by phone, and were engaged in everyday conversation prior to ending the call to help return a sense of normality after discussing highly emotive topics. All participants were provided with a resource attached to the participant information sheet detailing relevant carer support services, including a link to the REACT toolkit.

Interview participants were provided with a £10 voucher as a thank you for participation in the research. It is recognised that this is a potentially contentious ethical issue, with ongoing concerns around issues such the extent to which participant payment in health research represents a coercive practise (Groth, 2010). Payments here were informed by convention within the department, conversations with the supervisory team about the appropriateness of the payment procedure, and practical concerns around the availability of PhD research funding.

Chapter 3. Caring for a friend or family member who has experienced suicidal behaviour: A systematic review and qualitative synthesis

3.1 Chapter introduction

The systematic search for evidence presented in chapter 1 highlighted an absence of qualitative evidence regarding carers' experience of suicidal behaviour in psychosis. At the research planning stage of this thesis, recent systematic reviews had captured qualitative research into caregiving and psychosis (Mui et al., 2019; Shiraishi & Reilly, 2019). As the below chapter identifies, less research attention has focused on the experience of caregiving and suicidal behaviour, consistent with the definitions of these concepts applied in this thesis. Therefore, this systematic review synthesises qualitative evidence of caregiving and suicidal behaviour, where those being supported do not also experience psychosis. In combination with later chapters focused on caregiving in psychosis, this is intended to highlight experiences that are pertinent across mental health difficulties and those that are specific to the additional context of psychosis.

3.2 Abstract

Purpose

Friends and family members can be important sources of support for people who are or have been suicidal. This review aimed to synthesise qualitative evidence regarding informal carers' perspectives of supporting someone who has experienced suicidal behaviour.

Methods

Five electronic databases (Web of Science, CINAHL, PsychINFO, MEDLINE, and SocINDEX) were searched from inception to May 2022. Eligible qualitative studies were published in English and investigated the caring experiences of friends or family members of people who had experienced suicidal behaviour, defined as any form of suicidal ideation and/or attempts. Studies focused on non-suicidal self-injury or suicide bereavement were excluded. Data from nineteen eligible studies were analysed using thematic synthesis.

Results

Initial carer reactions to suicidal behaviour included profound anxiety and intensive monitoring for signs of increased suicide risk amongst those they supported. Carers reported significant challenges with understanding how to provide effective interpersonal support following suicidal crises. Professional support was perceived to be most effective when provided in a timely, interpersonally sensitive, and safety-focused manner. However, several studies detailed carers’ difficulties with accessing appropriate support and challenges with managing their own distress.

C*onclusions*

Carers face significant challenges with knowing how to respond to suicidal behaviour, where to find appropriate help, and how to manage their own distress. Future research may seek to investigate the effectiveness of easily accessible methods of information provision and support tailored for carers of people at risk of suicide.

3.3 Introduction

It is estimated that approximately 800,000 people die by suicide worldwide each year (WHO, 2019). Suicidal behaviour, defined as suicidal ideation or suicide attempt (O'Connor & Nock, 2014), is many times more common, with cross-national lifetime estimates of 9.2% and 2.7%, respectively (Nock et al., 2008). It has been well established that the social environments of people who experience suicidal behaviour play important roles in suicide-related outcomes. For example, the Integrated Volitional-Motivational Model of Suicidal Behaviour identifies perceived burdensomeness, thwarted belongingness, and absence of social support as motivational moderators that strengthen links between feelings of entrapment and suicidal ideation (O'Connor & Kirtley, 2018). Conversely, perceiving oneself to be socially supported is associated with lower risk of suicidal ideation and lifetime suicide attempt (Kleiman & Liu, 2013).

Provision of support to someone with a healthcare need in the community is an issue of increasing international significance, with between 10% and 30% of adult populations in European countries self-reporting participation in this form of care (Zigante, 2018). Challenges with identifying carers, including some people not recognising that their supporting roles fall within this definition (NICE, 2020), likely underestimate the true scale of this form of caregiving. Research into caregiving in the context of suicidal behaviour emphasises the complex and demanding nature of this role. At onset, carers experience difficulties with interpreting suicidal intent and with knowing when to communicate concerns about suicide risk to others (Owen et al., 2012; Owens et al., 2011). Carers report balancing the impulse to guard their loved one to prevent suicidal behaviour against the desire to create an autonomy-supporting environment to promote recovery (Sun et al., 2009), and the significance of contextual factors in recovery following suicidal behaviour, such as cultural beliefs about the meaning of suicide (Sun et al., 2008). Supporting someone who has experienced suicidal behaviour can be highly distressing and lead to poorer psychological wellbeing and general health (Morgan et al., 2013), and increased caregiver burden (McDonell et al., 2003). Yet there are unresolved needs to understand how carers can be supported with effective psychosocial interventions (Krysinska et al., 2021) and how healthcare professionals supporting people who are suicidal can build collaborative links with carers (Littlewood et al., 2019).

A significant body of qualitative evidence has accumulated regarding caring in the context of suicidal behaviour. A review of 35 qualitative studies with parent caregivers highlighted how breakdown in parent-child communication impedes caregiving and exacerbates feelings of hopelessness and shame within families (Simes et al., 2021). This is consistent with an earlier review of 44 qualitative studies, also with parents of children who had experienced suicidal behaviour, which highlighted carers' experiences of low mood and disempowerment, a sense of relational distancing between parents and their children, and parental difficulties implementing effective support strategies (Lachal et al., 2015). Juel and colleagues' (Juel et al., 2021) meta-ethnographic analysis of 12 studies on the experience of caring for a suicidal relative elucidated the process by which families sought to regain normality following experiences such as guilt, shame, powerlessness, and anger in response to suicidal behaviour. Some carers experienced a sense of feeling helpful in the recovery of their family member, yet many described the powerlessness of being unable to effectively provide support and consequently being stuck with feelings of grief and loss. Taken together, this literature emphasises the importance of equipping relatives with tools to mitigate suicide risk and manage their own distress, as recommended by UK national (NICE, 2019) and international healthcare guidelines for suicide prevention (WHO, 2019).

Previous qualitative reviews in this area are limited in the extent to which they elucidate the specific experience of caring for a friend or family with suicidal behaviour. Some have applied study selection criteria inclusive of studies related to caring and self-injury, where suicidal intent may or may not be present (Juel et al., 2021; Simes et al., 2021). However, suicidal and non-suicidal self-injury can be distinct experiences with different triggers, functions, and relational implications (Cipriano et al., 2017). As per psychological and sociological theories of suicide, absence of social integration, the undermining of feelings of belonging, and negative perceptions of the availability of interpersonal support may contribute to the desire to escape psychological pain through suicidal behaviour (Mueller et al., 2021) . However, non-suicidal self-injury is postulated to emerge as a means of emotional regulation, which while potentially triggered by interpersonal challenges (Edmondson et al., 2016), is to a greater degree related to dampening or enhancing intensity of affect (Horne & Csipke, 2009). Focusing specifically on studies of caregiving experiences related to suicidal ideation and attempts may therefore help to identify unique and/or clinically significant aspects of this lived experience. Moreover, many studies in this literature have focused on family carers, particularly parents, yet there is evidence that other social contacts, such as friends, provide important sources of support to people who are suicidal (Czyz et al., 2012; Giletta et al., 2017; Massing-Schaffer et al., 2020). Indeed, UK clinical guidelines define a carer as someone who provides unpaid support to a family member, partner or friend with a health or social care need (NICE, 2020). It is therefore important to broaden the scope of research in this area to include the experiences of those who fall under this wider carer definition.

To date, qualitative systematic reviews have typically not sought to synthesize carers' lived experiences of supporting friends or family members with suicidal behaviour, where suicidal intent is present. The current study addresses this gap in evidence by applying thematic synthesis to qualitative data collected exclusively from studies in which suicidal ideation or attempt is established. The aim of this review is to address the research question: 'What are carers' experiences of supporting friends or family members with suicidal behaviour?'

3.4 Methods

Design

This review applied thematic synthesis as described by Thomas and Harden (2008). Informed by guidance on selecting qualitative evidence synthesis methods (Booth et al., 2016), this approach was selected as its realist epistemological basis can aid in identifying meaningful recommendations for health research and practice. This review is reported with reference to PRISMA guidelines (Page et al., 2021).

Search strategy

The search strategy was developed through an iterative process of test searching with assistance from a specialist librarian. Database-specific subject terms were used to improve search comprehensiveness and are available at the PROSPRO record registered for this review (Marshall et al., 2020)

The following concepts were combined using the 'AND' Boolean operator:

Concept 1: suicid* OR self-harm* OR self-injur*

Concept 2: carer* OR caregiv* OR famil* OR friend*

Concept 3: qualitative OR mixed-method* OR interview* OR focus-group*

Searches were applied to title, abstract, and keyword fields of PsycINFO, MEDLINE, CINAHL & SocINDEX databases via EBSCO, and the Web of Science, from database inception to May 25, 2022. Citation tracking was completed by hand-searching reference sections and ‘citied by’ Google Scholar pages of all eligible studies (Bakkalbasi et al., 2006).

Study eligibility

Eligible studies met the following criteria:

- reported the experiences of carers, defined as those who have provided unpaid support to a friend or family member (including partners) (Roth et al., 2015), separately from other stakeholders.
- investigated carers’ experiences of supporting a friend or family member who had experienced suicidal behaviour, defined as any form of suicidal ideation and/or suicide attempts (O'Connor & Nock, 2014).
- used qualitative or mixed methods. Only the qualitative components of mixed-methods studies were extracted for this review.
- were primary research articles published in English-language peer-reviewed journals.
- included carers aged 16 or over, reflecting the age at which carers are entitled to needs assessments and governmental assistance in the UK (National Health Service, 2021).

Studies were ineligible if they met any of the following criteria:

- carers were bereaved by suicide, as the experience of bereavement is sufficiently different from the focus of the research question.

- involved fewer than three participants to avoid reports based on a small number of participants disproportionately impacting the final analysis.

Study selection

Titles and abstracts of studies identified through database searches were deduplicated via Endnote (Bramer et al., 2016) and screened against eligibility criteria using the online systematic review platform Rayyan (Ouzzani et al., 2016). All titles and abstracts were screened independently by a primary and secondary reviewer. The full texts of remaining studies were reviewed against eligibility criteria by the primary reviewer. A random selection of 20% of full texts were reviewed by the secondary reviewer to check for consistency in application of the screening procedure. Differences were resolved in open discussion between reviewers.

Quality appraisal

Each study was assessed by the first author using the 10-item Critical Appraisal Skills Programme (CASP) qualitative tool by the primary reviewer (CASP, 2018). Given the broad range of qualitative methodological approaches with varying definitions of research quality, this quality assessment was not used to determine a standard for inclusion or sensitivity analysis (Thomas & Harden, 2008), but rather to record the methodological transparency and rigour of relevant literature.

Data extraction

Study details (including carer demographic characteristics, country, and methods of data collection and analysis) were extracted using a standardised data extraction form (Harris, 2011). Full results sections (including author interpretation, participant quotes, tables, and figures) of eligible studies were copied verbatim into NVivo version 12 (QSR, 2020) for qualitative synthesis. Only results detailing carers' experiences, and not those of other stakeholder such as health professionals, were extracted for analysis.

Data synthesis

Data synthesis followed the procedure outlined by Thomas and Harden (2008). Initial line-by-line coding of the results sections was conducted by attaching labels to each section of text, briefly summarising its meaning. These initial codes were then grouped by patterns of meaning into descriptive themes, which remained relatively close to the surface level meaning of the primary data. Through an iterative process of reviewing descriptive themes and their underlying data, these themes were grouped again by shared meaning and developed into analytic themes at a higher level of abstraction. Line-by-line coding and the generation of initial candidate themes was completed by the first author. These candidate themes were reviewed, refined, and finalised in discussion with the wider research team.

Reflexivity

This thematic synthesis was informed by a critical realist perspective. This philosophy of science emphasises that researchers' interpretations of social reality are inevitably influenced by their particular interpretive perspectives, including personal characteristics, experiences, and beliefs (Maxwell, 2012). We therefore sought to embed reflexivity, the practice of maintaining a critical awareness of the influence of these perspectives on the research process, throughout the analysis (Finlay & Gough, 2008). To facilitate this, the first author drew on the insider-outsider heuristic (Hellawell, 2006). This concept was initially used to write a reflexive statement, highlighting beliefs and expectations about the research topic. Ongoing reflexive writing throughout the review was used to remain cognizant of the shifting perspectives brought to the analysis and the lead author's relationship with the research topic. The study team included researchers with broad academic, clinical, and lived experience of investigating and managing mental health difficulties in the context of caregiving and suicidal behaviour. Our aim was to draw on this experience to develop a nuanced analysis of carers' lived experiences through discussions and iterative written feedback.

3.5 Results

Figure 3 presents the process of study identification. Database searches returned 4121 unique articles. Of these, 145 were read in full and checked against eligibility criteria. Nineteen studies published between 1987 and 2022 met eligibility for inclusion. Citation tracking returned no additional relevant articles. Characteristics of included articles are presented in Table 2. Results of study appraisal using the CASP (2018) checklist are presented in table 3. Application of the CASP checklist revealed that across all included studies, qualitative methods were appropriate in light of their stated research aims (CASP items 1 and 2). However, twelve failed to provide sufficient detail to support judgements regarding whether the relationship between the authors and participants had been considered (CASP item 6), thus reducing confidence that these articles had critically considered the authors' roles in the research process. Moreover, six studies provided only limited detail regarding their analytic procedure (CASP item 6), limiting their methodological transparency. Notwithstanding these limitations, all studies provided convincing justification of the scientific and/or practice-based value of their research findings (CASP item 10). Table 4 presents the thematic framework alongside supporting illustrative quotes. Three interrelated analytic themes were developed (figure 4) each with supporting descriptive themes.

Figure 3. Systematic review PRISMA diagram

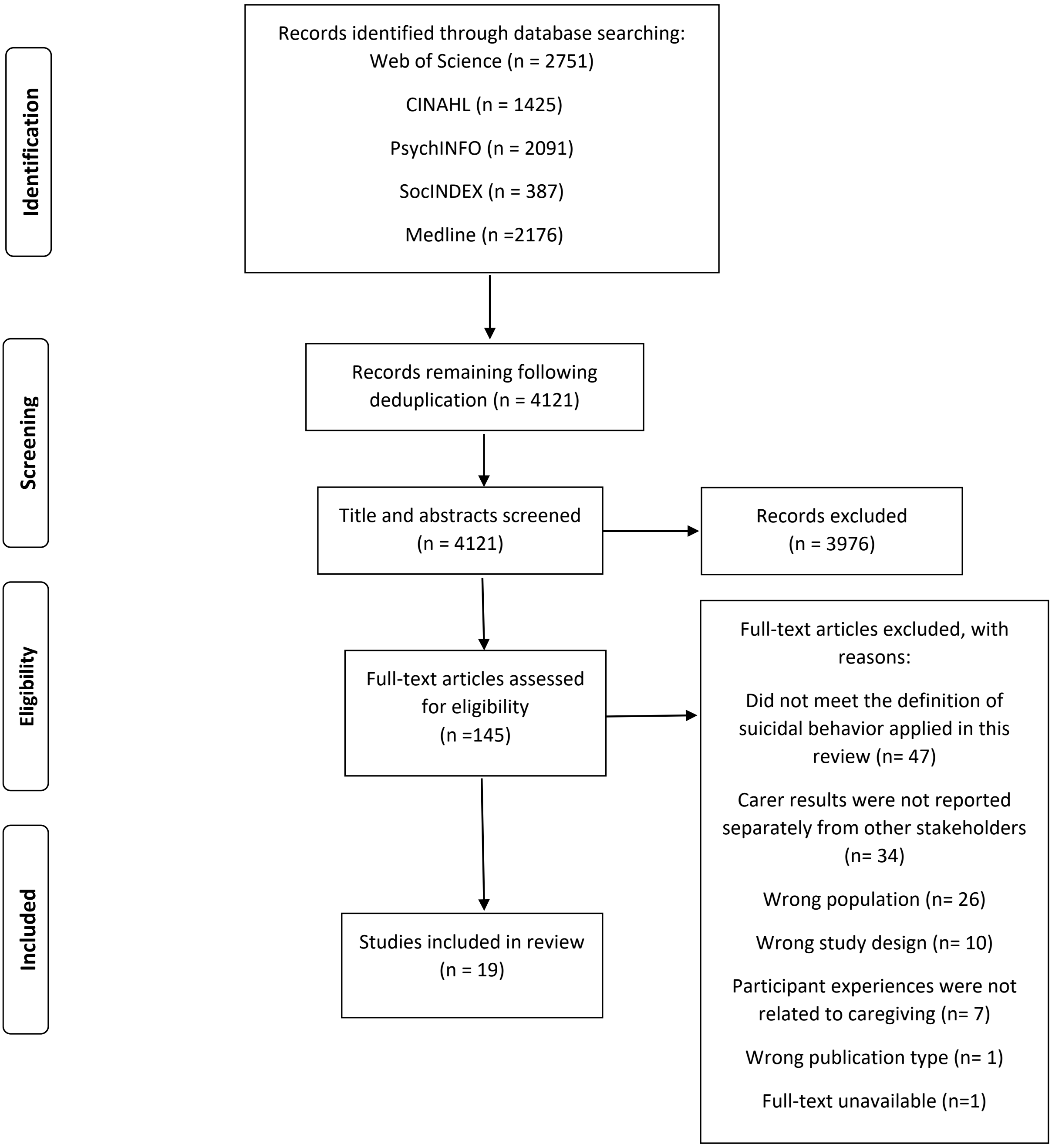


Table 2. Characteristics of included studies

Authors (s) (year)	Aim/objective	Country	Description of carers	Description of persons receiving care	Data collection	Analytic approach
Asare-Doku et al. (2017)	"to understand the experiences of the families of [suicide] attempt survivors and how they cope with the aftermath of the attempt"	Ghana	10 family members (4 fathers, 2 mothers, 1 brother, 1 husband, 1 aunt and 1 sister)	10 suicide attempt survivors who had received care at an emergency unit	Semi-structured interviews	Interpretive Phenomenological Analysis
(Buus et al., 2014)	"to gain further insights into the experiences of parents of sons or daughters who have attempted suicide and how these parents respond to the increased psychosocial burden following the attempt(s)"	Denmark	14 parents (9 mothers, 6 fathers) attending a support programme for relatives of people who had attempted suicide	Suicide attempt survivors (15-35 years)	Focus groups	Thematic analysis
Daly (2005)	"describes and enhances the understanding of what life is like for 6 mothers living with suicidal adolescents"	Canada	6 mothers participating in outpatient family therapy	Adolescents (12-16 years) "diagnosed with mental illness…and had exhibited suicidal behaviours"	Unstructured interviews	Phenomenological approach
Doyle et al. (2021)	"to better understand Black mothers' and White mothers' qualitative reactions to their adolescents' hospitalizations due to suicide attempts"	United States	40 mothers (20 Black mothers and 20 White mothers) recruited approximately 1 month following a child's suicide attempt)	Adolescents (mean age 15 years) hospitalised due to suicide attempts	Semi-structured interviews	Grounded theory
Dransart and Guerry (2017)	"the study aimed at grasping how significant others perceived, were involved in, and dealt with suicidality…of loved ones, and what they did (or not) to seek help for their loved one or for themselves"	Switzerland	18 significant others (5 partners, 3 children, 3 mothers, 3 sisters, 2 ex-partners and 2 friends	19 people (19-77 years) assessed by their significant other to be suicidal or have attempted suicide	Semi-structured interviews	Qualitative content analysis
Fu et al. (2021)	"to explore parents' and the front-line medical staff's experience of an adolescent with suicide-related behaviours admitted to the psychiatry department of a general hospital in China"	China	15 parents (11 mothers, 4 fathers)	Adolescents (12-18 years) with suicide-related behaviours (suicidal ideation, planning or attempts) receiving care at a psychiatric ward	Semi-structured interviews	Thematic analysis
Garcia-Williams and McGee (2016)	"qualitatively describing the self-reported responses college students have engaged in, at any point in their lifetime, when a friend or family member disclosed being suicidal"	United States	126 undergraduate students	Student-identified family member or friend who had experienced suicidal thoughts	Open-ended online survey	Thematic analysis
Hellerova et al. (2022)	"to determine caregivers' perceptions about mental illness in their children, specifically regarding suicidality and depression, the impact of the children's mental health on the caregiver, and barriers to and facilitators of treatment"	United States	20 mothers (primary caregivers)	Children (6-17 years) presenting with suicidal behaviour to a paediatric emergency department	Semi-structured interviews	Qualitative descriptive methodology
Inscoe et al. (2021)	"The purpose of this study was to identify, from the perspective of caregivers, clinical practices that are sensitive to the needs of youth with co-occurring traumatic stress and suicidal thoughts and behaviors, as well as common barriers to receiving care."	United States	13 caregivers (12 female, 1 male)	Youth with caregiver-identified histories of trauma and co-morbid suicidal behaviour who had accessed community mental health services	Semi-structured interviews	Grounded theory
de Lange et al. (2021)	"to explore experiences and needs related to formal and informal mental healthcare for SGM [sexual and gender minority] youth who experience suicidal ideation"	Netherlands	16 parents (11 mothers, 5 fathers)	Sexual and gender minority youth (11-22 years) with parent-identified histories of suicidal ideation	Semi-structured interviews	Reflexive thematic analysis

Ngwane and van Der Wath (2019)	"to understand the psychosocial support required by parents through exploring their lived experiences of how they made sense of their adolescents' attempted suicide"	South Africa	10 mothers	Children receiving inpatient psychiatric care following a suicide attempt	Semi-structured interviews	Thematic analysis
Nosek (2008)	"examined the process families use to care for a depressed and suicidal family member at home."	United States	17 family members (7 partners, 1 sibling, 1 daughter, and 8 parents)	People with a recent episode of depression (within 6 months) who had been hospitalised due to suicide risk	Semi-structured interviews	Grounded theory
Nygaard et al. (2019)	"to gain insight into how a parent's relationship with a partner was affected after their son or daughter's suicide attempt or serious suicide threats"	Denmark	19 parents (7 fathers, 12 mothers) in contact with a counselling and support organisation for families affected by suicidal behaviour	People (14-54 years) who had either made suicide threats or attempted suicide	Semi-structured interviews	Thematic analysis
Sellin et al. (2017)	"to describe the phenomenon of participation, as experienced by relatives of persons who are subject to inpatient psychiatric care due to a risk of suicide"	Sweden	8 (5 women, 3 men) "close relatives"	People who had received inpatient psychiatric care related to suicide risk	"phenomenon-oriented interviews"	Phenomenological approach
Thapa et al. (2021)	"This study aims to find out the level of stress among caregivers of suicidal patients and various factors associated with it."	Nepal	5 primary caregivers (provided care for at least 6 months)	People who had attempted suicide and were receiving inpatient care	Semi-structured interviews	Thematic analysis
Talseth et al. (2001)	"to illuminate the meaning of relatives' lived experiences of being met by mental health care personnel during the care of their family member at risk of committing suicide"	Norway	15 "adult relatives" (8 female, 7 male)	15 people receiving inpatient psychiatric care at risk of suicide	Narrative interviews	Phenomenological hermeneutic method
Vandewalle et al. (2021)	"to develop an understanding of family members' expectations of care and treatment for their [suicidal] relative"	Belgium	14 family members (5 partners, 3 parents, 3 adult children, 3 siblings)	People receiving inpatient care who had experienced suicidal ideation in the previous year	Semi-structured interviews	Grounded theory
Wolk-Wasserman (1987a)	"describe and analyze the abuse patients' and their significant others' efforts to obtain help from public care institutions in the presuicidal situation"	Sweden	33 significant others (13 partners, 10 parents, 10 other relatives or friends)	People admitted to an intensive care united because of intoxication with the purpose of attempting suicide	Semi-structured interviews	Type of analysis not given
Wolk-Wasserman (1987b)	"to describe and analyse attempts by neurotic and prepsychotic/psychotic patients and their significant others to seek help from psychiatric, somatic and social care institutions in the presuicidal situation, and to analyse the reasons why the contacts with care institutions failed to have a preventative effect"	Sweden	37 significant others (11 partners, 13 parents, 13 other relatives or friends)	People "classified as neurotic or prepsychotic/psychotic" admitted to an intensive care unit after attempting suicide by overdose and/or consumption of alcohol	Semi-structured interviews	Type of analysis not given

Table 3. CASP Qualitative checklist results

CASP question number †

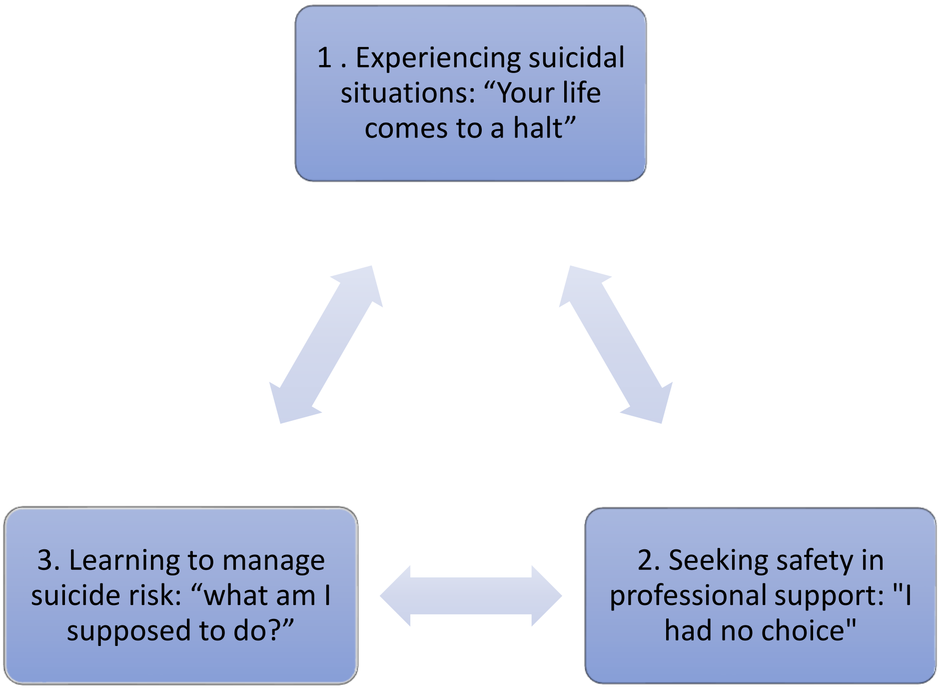
First author (year)	1	2	3	4	5	6	7	8	9	10
Asare-Doku et al. (2017)	✓	✓	✓	✓	✓	—	✓	✓	✓	✓
Buus et al. (2014)	✓	✓	✓	✓	✓	✓	✓	—	✓	✓
Daly (2005)	✓	✓	✓	✓	✓	—	✓	✓	✓	✓
Doyle et al. (2021)	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
Dransart and Guerry (2017)	✓	✓	✓	✓	✓	—	✓	✓	✓	✓
Fu et al. (2021)	✓	✓	✓	✓	✓	—	✓	—	✓	✓
Garcia-Williams and McGee (2016)	✓	✓	✓	✓	✓	—	✓	—	✓	✓
Hellerova et al. (2022)	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
Inscoe et al. (2021)	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
de Lange et al. (2021)	✓	✓	✓	✓	✓	—	✓	✓	✓	✓
Ngwane and van Der Wath (2019)	✓	✓	✓	✓	✓	—	✓	✓	✓	✓
Nosek (2008)	✓	✓	✓	✓	✓	—	✓	✓	✓	✓
Nygaard et al. (2019)	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
Sellin et al. (2017)	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
Thapa et al. (2021)	✓	✓	✓	✓	✓	—	✓	✓	✓	✓
Talseth et al. (2001)	✓	✓	✓	✓	✓	—	✓	—	X	✓
Vandewalle et al. (2021)	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
Wolk-Wasserman (1987a)	✓	✓	—	✓	✓	—	✓	—	✓	✓
Wolk-Wasserman (1987b)	✓	✓	—	✓	✓	—	✓	—	✓	✓

† Yes (✓) No (X) Can't tell (—). CASP questions: 1) Was there a clear statement of the aims of the research? 2) Is a qualitative methodology appropriate? 3) Was the research design appropriate to address the aims of the research? 4) Was the recruitment strategy appropriate to the aims of the research? 5) Was the data collected in a way that addressed the research issue? 6) Has the relationship between researcher and participants been adequately considered? 7) Have ethical issues been taken into consideration? 8) Was the data analysis sufficiently rigorous? 9) Is there a clear statement of findings? 10) How valuable is the research? (this final question has been adapted to 'is there a clear statement of the value of the research?' in the above table)

Table 4. Analytic themes (bolded) and descriptive themes (italicised) with illustrative quotes

Thematic framework	Illustrative quote
1. Experiencing suicidal situations: "Your whole life comes to a halt"	"If he would have been admitted to the right ward straightaway, he would never have never been so deeply affected… The 3-week waiting period at home was a nightmare… it is like your life comes to a halt.… It is very serious for those with suicidal thoughts, but I dare to say that it is just as hard for the whole family to live in such a situation" (Vandewalle et al., 2021, p. 7)
1.1 Emotional responses to suicidal behaviour: "I was completely floored"	"…it was very painful to me and I was thinking something that is not possible: reversing it and not seeing what has happened now."(Ngwane & van Der Wath, 2019, p. 377)
1.2 Coping alongside suicide risk	"I try not to let the fear overwhelm me … take it one day at a time."(Doyle et al., 2021, p.82)
2. Seeking safety in professional support: "I had no choice"	"My only responsibility was to keep him alive. I strived to help him by going for walks, chatting… but that was not helping any longer. He was no longer safe with those suicidal thoughts. I had no choice other than hospitalisation" (Vandewalle et al., 2021, p. 5)
2.1 Sharing the responsibility of care	"I contacted their family members and described the severity of the situation so that [the suicidal peer] could get help in a hospital setting. They were very angry and felt I betrayed their trust, but I did it anyway because it was what they needed to prevent harm." (Garcia-Williams & McGee, 2016, p. 83)
2.2 Being informed: "I feel safer at once"	"We were called to several meetings. We were told how things were and they informed us about the patient. They told us how they worked with (the patient) and that it would take time. We were informed about what has been happening the whole time. Now I understand my son's condition better." (Talseth et al., 2001, p. 251)
2.3 Being overlooked: "I never felt truly heard"	"I hope they understand that her situation is very critical. I expect that they keep her safe and have a treatment plan, which I can follow. But I am actually very uncertain about all that. They do not involve me, and I do not know what is happening." (Vandewalle et al., 2021, p. 4)
2.4 Barriers to accessing professional support	"On the day following his suicide attempt, I told myself 'I really have to find a psychologist or someone', well, I tried calling some and I was told everywhere 'there is a 6-month waiting list'." (Dransart & Guerry, 2017, p. 5)
3. Learning to manage risk: "what am I supposed to do?"	"I think it is my responsibility to show her the correct way, but if she does this [attempt suicide], what am I supposed to do?" (Ngwane & van Der Wath, 2019, p. 379)
3.1 Seeking understanding of suicidal behaviour	"I asked myself that maybe she had long standing problems and not knowing with whom to share with. I keep asking myself who made her sad, is it me or what, l kept asking myself questions. Initially if I failed somewhere, she could tell me that I have disappointed her or send me an SMS" (Ngwane & van Der Wath, 2019, p. 377)
3.2 Monitoring for risk: "It was red alert 24 hours a day"	"We'd go on this watch of when's it gonna happen?...we started to know him like the back of our hands. We knew exactly what he was doing…So you knew what the pattern was…but you didn't know exactly when it was going to happen" (Nosek, 2008, p. 40)
3.3 The value of companionship	"…let [them] talk to me about what [they were] feeling and going through because [they] felt like [they] had no one to go to and I reassured [them] that [they] could always come to me" (Garcia-Williams & McGee, 2016, p. 82)

Figure 4. Analytic themes



Analytic theme 1: Experiencing suicidal situations: "your whole life comes to a halt"

This analytic theme highlights carers' often-profound distress emerging from a foundational shift in their lives, characterised by ongoing and pervasive fear of further suicidal behaviour. Owing to the severity of this seemingly unrelenting anxiety, many carers experienced challenges with coping and/or sought individual professional support to manage their distress.

Descriptive theme 1.1: Emotional responses to suicidal behaviour: "I was completely floored"

Fourteen studies described participants' emotional reactions (Asare-Doku et al., 2017; Buus et al., 2014; Daly, 2005; Doyle et al., 2021; Dransart & Guerry, 2017; Garcia-Williams & McGee, 2016; Hellerova et al., 2022; Ngwane & van Der Wath, 2019; Nosek, 2008; Nygaard et al., 2019; Talseth et al., 2001; Thapa et al., 2021; Vandewalle et al., 2021; Wolk-Wasserman, 1987b). The period following suicidal crises was described as "emotional turmoil" (Daly, 2005, p. 27) that left some in states of shock and anger at the apparent desire of their friend or family member to end their lives (Asare-Doku et al., 2017; Buus et al., 2014; Daly, 2005; Doyle et al., 2021). Emphasising the magnitude of this emotional impact, one study identified post-traumatic reactions to the disturbing nature of witnessing a suicide attempt, including experiences such as re-living the incident and emotional numbing (Ngwane & van Der Wath, 2019). Initial reactions gave way to ongoing stress as carers attempted to adapt to living alongside suicide risk (Buus et al., 2014; Daly, 2005; Doyle et al., 2021; Dransart & Guerry, 2017; Ngwane & van Der Wath, 2019; Nosek, 2008; Nygaard et al., 2019; Sellin et al., 2017; Talseth et al., 2001; Thapa et al., 2021; Vandewalle et al., 2021). This persistent apprehension was described as "a constant concern. A constant worry…it's horrible" (Nosek, 2008, p. 39), with one participant recalling "you can't sleep properly at night and you sit around feeling anxious all day. It's a dreadful situation to be in" (Talseth et al., 2001, p. 254).

Context-specific factors influenced carers' emotional reactions. Some carers faced suicide-related social stigma which included being marginalised by other family and community members (Asare-Doku et al., 2017; Daly, 2005; Ngwane & van Der Wath, 2019; Wolk-Wasserman, 1987b) and guilt focused on failures to prevent suicidal behaviour (Buus et al., 2014; Daly, 2005; Doyle et al., 2021; Ngwane & van Der Wath, 2019; Vandewalle et al., 2021; Wolk-Wasserman, 1987b). Guilt was particularly prominent amongst parents, whose responsibility to protect their child was perceived as having been undermined by their suicidal behaviour and thus evidence of carers' own personal failings (Buus et al., 2014; Daly, 2005; Doyle et al., 2021; Ngwane & van Der Wath, 2019).

Descriptive theme 1.2: Coping alongside suicide risk

Fourteen studies communicated carers' coping needs and experiences. Coping strategies included attempting to accept what had happened (Doyle et al., 2021; Ngwane & van Der Wath, 2019; Sellin et al., 2017; Talseth et al., 2001), drawing on social support (Asare-Doku et al., 2017; Doyle et al., 2021; Hellerova et al., 2022; Ngwane & van Der Wath, 2019) and seeking spiritual guidance (Asare-Doku et al., 2017; Doyle et al., 2021; Ngwane & van Der Wath, 2019). For some, respite from their caregiving responsibilities was identified as necessary for self-care, owing to the highly demanding interpersonal context of caring for someone at risk of suicide (Doyle et al., 2021; Dransart & Guerry, 2017; Nosek, 2008). Indeed, thinking about and addressing a family member's experience of suicidal behaviour was highly distressing (Asare-Doku et al., 2017; Doyle et al., 2021; Ngwane & van Der Wath, 2019; Nosek, 2008), such that avoidance and distraction became key coping strategies for some carers: ""I keep myself busy… because I don't want to think … I could have been burying my child." (Doyle et al., 2021, p. 83). Two studies framed coping with respect to sociocultural factors. A US study reported that both black and white mothers drew on prayer and social support as means of coping, yet white women focused more specifically on their experiences of distress and the need for dedicated professional support (Doyle et al., 2021). A study conducted in Ghana (Asare-Doku et al., 2017) identified social support as a coping resource for mothers, but not fathers, interpreted by the author as evidence of gendered responses to the experience of suicidal behaviour within the family.

Some carers had sought professional emotional support, primarily in the form of individual counselling (Garcia-Williams & McGee, 2016; Nosek, 2008; Nygaard et al., 2019; Vandewalle et al., 2021; Wolk-Wasserman, 1987a) while others identified personal professional emotional support as an unresolved support need (Dransart & Guerry, 2017; Inscoe et al., 2021; Ngwane & van Der Wath, 2019; Wolk-Wasserman, 1987b).

Analytic theme 2: Seeking safety in professional support: "I had no choice"

Analytic theme 2 reflects carers' attempts to engage with professional support as a necessary strategy for reducing suicide risk. Healthcare services that instilled a sense of competence and interpersonal openness were highly valued. Conversely, services that were hard to access, difficult to understand, and did not seek to include carers' own expertise in managing suicide risk further exacerbated carers' feelings of frustration and anxiety.

Descriptive theme 2.1: Sharing the responsibility of care

Thirteen studies described the experience of contacting professionals to help manage suicidal behaviour (Buus et al., 2014; de Lange et al., 2021; Dransart & Guerry, 2017; Garcia-Williams & McGee, 2016; Hellerova et al., 2022; Inscoe et al., 2021; Ngwane & van Der Wath, 2019; Nosek, 2008; Sellin et al., 2017; Talseth et al., 2001; Vandewalle et al., 2021; Wolk-Wasserman, 1987a, 1987b). Several carers described their help-seeking motivations rooted in a desire to establish their friend or family member's physical safety when their situation became so severe that they felt unprepared to manage suicide risk and thus sought to share this responsibility with those appropriately trained to do so (Dransart & Guerry, 2017; Garcia-Williams & McGee, 2016; Sellin et al., 2017; Vandewalle et al., 2021; Wolk-Wasserman, 1987a). Sharing the heavy responsibility of managing suicidal behaviour with professionals was a source of profound relief for some carers (Garcia-Williams &

McGee, 2016; Sellin et al., 2017; Talseth et al., 2001; Wolk-Wasserman, 1987b). Indeed, a carer's experience with inpatient services prompted the reflection that "I am always restless and anxious, at home, at work… and then his admission created a moment of rest, to take some time off for myself. Because I knew: they will take care of him" (Vandewalle et al., 2021, p. 1142).

Descriptive theme 2.2: Being informed: "I feel calmer at once"

Eight studies described the importance of effective communication with healthcare staff providing care for a suicidal friend or family member (de Lange et al., 2021; Dransart & Guerry, 2017; Garcia-Williams & McGee, 2016; Inscoe et al., 2021; Sellin et al., 2017; Talseth et al., 2001; Thapa et al., 2021; Vandewalle et al., 2021). Carers appreciated being kept informed by healthcare professionals and were relieved when staff were proactive in information sharing: "And in the evening, at 19h, the psychiatrist calls me and then she tells me 'you know, I have contacted your husband's GP...'. I found this fantastic!" (Dransart & Guerry, 2017, p. 7)

A collaborative interpersonal approach was recognised as important in four studies (Inscoe et al., 2021; Sellin et al., 2017; Vandewalle et al., 2021; Wolk-Wasserman, 1987b). Carers described how a welcoming attitude and reassurance contributed to positive interactions with healthcare staff, for example: "It felt good for somebody to look at me as a mother and say, 'Hey mom, you're hurting too. And that's okay" (Inscoe et al., 2021, p. 656). Exemplifying the significance of professionals' interpersonal style, one participant identified that:

> *That therapist says the same things as others, but in a way that makes me feel, "Okay I know I am falling short on this, but I can improve." I like that style. When I speak to*

this other [Mental Health Professionals] it is like "You are falling short", which makes me feel guilty. (Vandewalle et al., 2021, p. 1144).

Descriptive theme 2.3: Being overlooked: "I never felt truly heard"

Ten studies highlighted the difficulties carers experienced when attempting to communicate with healthcare professionals (Dransart & Guerry, 2017; Fu et al., 2021; Inscoe et al., 2021; Ngwane & van Der Wath, 2019; Nosek, 2008; Sellin et al., 2017; Talseth et al., 2001; Vandewalle et al., 2021; Wolk-Wasserman, 1987a, 1987b). Lack of appropriate information provision by healthcare professionals left carers feeling disempowered (Dransart & Guerry, 2017; Talseth et al., 2001; Vandewalle et al., 2021), underinformed about their friend or family member's care (Dransart & Guerry, 2017; Talseth et al., 2001), and unsure whether professionals had a thorough understanding of the severity of the situation (Dransart & Guerry, 2017; Fu et al., 2021; Talseth et al., 2001). Reflecting on their experience of attending hospital, one carer recalled "a person is sitting there who you know you cannot leave for half an hour because she will try to take her own life, and no one listens to you…" (Talseth et al., 2001, p. 253). Other consequences of poor communication with healthcare professionals included feelings of guilt surrounding the inadequacy of family members' own actions (Ngwane & van Der Wath, 2019; Vandewalle et al., 2021) and a sense of being an informant rather than partner in the support offered to a service user (Dransart & Guerry, 2017; Vandewalle et al., 2021; Wolk-Wasserman, 1987b). One carer described this experience as "a *feeling of not being listened to, of not knowing where to go, whom to reach out to, how to find help...we are alone, powerless, we don't know what to do."* (Dransart & Guerry, 2017, p. 6)

Carers experienced significant distress when their insight into the situation, specifically about ongoing risk of suicide, was not listened to and factored into the care offered by health professionals (Dransart & Guerry, 2017; Fu et al., 2021; Sellin et al., 2017; Talseth et al., 2001; Vandewalle et al., 2021; Wolk-Wasserman, 1987a):

"The real disappointment for me was when her suicide attempt led her to the hospital, but after three days, they just released her and that was it. Yet I told them 'but listen, she is not ready to get out, we've been dealing with this for ten years, you can be sure that she will try again'." (Dransart & Guerry, 2017, p. 6)

Descriptive theme 2.4: Barriers to accessing professional support

Ten studies highlighted additional barriers experienced by carers when seeking mental health support (Buus et al., 2014; Daly, 2005; Dransart & Guerry, 2017; Fu et al., 2021; Hellerova et al., 2022; Inscoe et al., 2021; Talseth et al., 2001; Thapa et al., 2021; Vandewalle et al., 2021; Wolk-Wasserman, 1987a). This included long waiting times and a lack of hospital bed availability (Dransart & Guerry, 2017; Fu et al., 2021; Hellerova et al., 2022; Talseth et al., 2001; Vandewalle et al., 2021). Others described how available treatment options were insufficient to meet the needs of a family affected by suicidal behaviour, due to staff misunderstanding the nature of the situation (de Lange et al., 2021; Wolk-Wasserman, 1987a) or because services were focused to a greater degree on physical health problems (Fu et al., 2021). Other barriers to professional support included a lack of continuity in care which caused carers to repeat details of distressing circumstances to multiple staff members (Dransart & Guerry, 2017), an absence of effective follow-up post discharge (Vandewalle et al., 2021) and the prohibitively expensive cost of private healthcare (Garcia-Williams & McGee, 2016; Hellerova et al., 2022; Thapa et al., 2021).

Analytic theme 3: Learning to manage risk: "what am I supposed to do?"

This final analytic theme highlights carers' efforts to understand and mitigate suicide risk. Carers struggled with making sense of friends' and family members' motivations for suicidal behaviour, which confounded attempts to conceptualise how they could effectively provide support to reduce this risk. A reflexive and emotionally exhausting monitoring of friends' and family members' emotional and physical states was a common response to this situation, especially in carers' early experiences.

Descriptive theme 3.1: Seeking to understand suicidal behaviour

Participants in 14 studies reflected on the process of developing a deeper understanding of suicidal behaviour and their role in its management (Critchfield et al.; Daly, 2005; de Lange et al., 2021; Doyle et al., 2021; Dransart & Guerry, 2017; Fu et al., 2021; Garcia-Williams & McGee, 2016; Ngwane & van Der Wath, 2019; Nosek, 2008; Nygaard et al., 2019; Sellin et al., 2017; Talseth et al., 2001; Thapa et al., 2021; Vandewalle et al., 2021; Wolk-Wasserman, 1987a). Initially, some carers experienced a state of being "thrown into it" (Vandewalle et al., 2021, p. 1143) , with a disorientating lack of understanding of what to do leading to a sense of "having blindfolds on" or "being in the dark" (Nosek, 2008, p. 39). This reflected a wider perception of uncertainty, characterised by the feeling of being ill-equipped to effectively support a friend or family member (Dransart & Guerry, 2017; Nygaard et al., 2019; Vandewalle et al., 2021), powerless regarding how to help (Ngwane & van Der Wath, 2019; Talseth et al., 2001), or unsure how to behave around someone at risk of suicide (Daly, 2005; Ngwane & van Der Wath, 2019). One study described understanding suicidal behaviour as involving a cyclical process of observing a family member, intervening to help, then revising this approach based on the perceived outcome: "OK, let's not try that again, let’s try this approach…and a lot of it was hit and miss” (Nosek, 2008, p. 40). Over time, this iterative process of experiential learning helped carers to move from a position of being aware of suicide risk, “to take the second step…being able to cope with the behaviour” (Nosek, 2008, p. 40). Relatedly, participants in nine studies highlighted that professional help with knowing how to care for a suicidal family member was a key support need (de Lange et al., 2021; Doyle et al., 2021; Dransart & Guerry, 2017; Fu et al., 2021; Garcia-Williams & McGee, 2016; Nosek, 2008; Vandewalle et al., 2021; Wolk-Wasserman, 1987a):

> *Educating all parties on what to look for, what’s happening, you know that was helpful with us just really trying to know the signs because a lot of people just don’t know what suicidal thoughts look like or what does this shift in behavior mean and the little nuances that a kid might go through that is having those thoughts. (Inscoe et al., 2021, p. 656)*

Descriptive theme 3.2: Monitoring risk: “It was red alert 24 hours a day”

Carers in 13 studies reflected on their heightened degree of vigilance to and monitoring of suicidal behaviour (Buus et al., 2014; Daly, 2005; Doyle et al., 2021; Dransart & Guerry, 2017; Garcia-Williams & McGee, 2016; Hellerova et al., 2022; Ngwane & van Der Wath, 2019; Nosek, 2008; Nygaard et al., 2019; Sellin et al., 2017; Talseth et al., 2001; Thapa et al., 2021; Vandewalle et al., 2021). For many, this heightened state of awareness was a response to ongoing anxieties about the possibility of suicide which were mitigated by increasing the frequency of contact with a friend or family member (Doyle et al., 2021; Ngwane & van Der Wath, 2019; Nosek, 2008; Sellin et al., 2017; Vandewalle et al., 2021). This resulted in carers feeling “’’sleep deprived’, ‘exhausted’, ‘very tired all of the time’, or that they ‘can’t have one peaceful night [sleep]’” (Doyle et al., 2021, p. 81). Carers also reported monitoring physical risk factors to reduce access to means of self-injury:

> *Let me describe a typical day. I tiptoe in her room and watch the clothes, looking at the blankets to see if they are moving up and down. Then I check the pill bottles. I give her the ones she needs, and then I count what is left. Depending on what kind of workday I’m having, I’ll probably go home at lunch to check on her. Sometimes I take all the pills with me to work in my purse.* (Daly, 2005)

Descriptive theme 3.3: The value of companionship

Nine studies described the therapeutic value of offering companionship to a friend or family member in the period following suicidal behaviour (Buus et al., 2014; de Lange et al., 2021; Doyle et al., 2021; Dransart & Guerry, 2017; Garcia-Williams & McGee, 2016; Ngwane & van Der Wath, 2019; Nosek, 2008; Nygaard et al., 2019; Vandewalle et al., 2021). Participants described the importance of making themselves available for their loved one in any way they found useful (Sellin et al., 2017), providing moral support (Dransart & Guerry, 2017), and convincing their suicidal friend of their value to others (Garcia-Williams & McGee, 2016). As one participant stated, simply being with their family member was perceived to be beneficial:

> *“it gives a lot when the family manages it and when you bear to be close, and you bear to be there. Thus, it is enough just to sit and watch TV together, just such a thing. Just that you are demonstrating that I am here. So that means probably a lot I believe”* (Sellin et al., 2017)

For others, companionship involved engaging family members or friends in everyday activities to “keep their mind off the [depression]” (Nosek, 2008, p. 39); supporting them in deciding to access services (Garcia-Williams & McGee, 2016; Nosek, 2008); or offering opportunities to discuss their mental health experiences (de Lange et al., 2021; Ngwane & van Der Wath, 2019; Nygaard et al., 2019; Sellin et al., 2017; Vandewalle et al., 2021), often in a compassionate and supportive manner: “I sat down and talked them through it. I told them how much I cared” (Garcia-Williams & McGee, 2016, p. 82).

3.6 Discussion

The purpose of this review was to synthesise qualitative evidence regarding carers’ experiences of supporting friends or family members with suicidal behaviour. A review of 19 eligible studies highlighted how carers’ emotional reactions to suicidal behaviour are characterised by profound anxiety emerging from the possibility of suicide. Carers frequently sought support from health services, with positive experiences characterised by collaborative interactions with professionals. Carers’ attempted to understand and manage the ongoing uncertainty of living alongside suicide risk by adopting strategies including monitoring for signs of suicidal behaviour and offering emotional support. However, personal challenges with coping often confound adjusting to the ongoing stress of caregiving in this context. This literature evidences carers’ deeply distressing experiences of supporting suicidal family members and friends, with interacting psychosocial challenges manifesting at the intrapersonal, relational, and wider systemic levels.

This qualitative review contextualises quantitative evidence of increased caregiving burden (McDonell et al., 2003) and poorer wellbeing (Morgan et al., 2013) amongst carers of people who have experienced suicidal behaviour. Results indicate that carer recovery is likely to be highly idiosyncratic and influenced by factors such as availability of professional support and sociocultural perceptions of suicidal behaviour and caregiving. However, an important implication of this review is that across contexts, carer recovery is likely to involve improving carer self-efficacy in reducing suicide risk. Indeed, as shown by previous research, positive change for carers involves developing strategies to manage ongoing suicide risk whilst re-establishing positive interpersonal relationships (Sun & Long, 2013; Sun et al., 2009). This review suggests that meeting carers' needs for assistance with how to support a friend or family member at risk of suicide may help to mitigate the disempowering and anxiety-inducing response to the possibility of future suicidal behaviour, exacerbated by difficulties with recognising and managing suicide risk, which lead some carers to an emotionally fatiguing reliance on hypervigilance to and monitoring for signs of suicidal behaviour.

Previous qualitative reviews have characteristically included carers of people experiencing self-injury regardless of intent, and/or recruited family carers, with focus on parental experiences (Juel et al., 2021; Lachal et al., 2015; Simes et al., 2021). Results reported here suggest that feeling disempowered, an ongoing sense of fear, and a pressing need to keep a loved one safe, are relatively consistent carer experiences across this literature. In the presence of suicidal behaviour, carers report the need for greater access to convenient and non-judgemental healthcare support (Simes et al., 2021), with results here strengthening the transferability of this important finding. Building on this prior evidence, this review suggest that these challenges are likely to be influenced by the extent to which carers feel able to meet their personal responsibilities for protecting those they support from suicide. Carer, distress, particularly the guilt, shame, and trauma of parents, was most prominent where the ability to meet this responsibility was undermined. Health services' attentive focus on safety and transparent communication helped carers to manage this responsibility. How this experience varies by relationship type remains unclear. The broad carer-related inclusion criterion used in this review revealed that a majority of research in this area relates to family experiences. This limitation of existing literature is significant given that friends are a key source of support for people experiencing suicidal behaviour (Czyz et al., 2012; Massing-Schaffer et al., 2020). Further research investigating the influence of relationship type and caregiving in this context is necessary to further elucidate the support needs of people in this important but under-investigated caregiving role.

The desire for greater professional support with managing suicide risk was evident in carer accounts of the period immediately following suicidal behaviour and on a more ongoing basis. This aligns with what Buus and colleagues (Buus et al., 2014) describe as carers' experience of a 'double-crisis', one experienced at the point of suicidal behaviour and the other reflecting the ongoing impact of trauma and stress on families. Several potential models of intervention involving carers have demonstrated efficacy in these contexts. Family Intervention for Suicide Prevention is a cognitive behavioural approach that includes resources to improve initial emergency care for suicidal service users in addition to ongoing family support, which is effective in increasing follow-up care utilization (Hughes & Asarnow, 2013). Longer term psychotherapeutic approaches that target self-injurious behaviour and include family members also show efficacy, with the strongest evidence for dialectical behaviour therapy for young people and their families (Glenn et al., 2019). However, this review suggests that carers face difficulties accessing such support and the extent to which similar resources have been successfully upscaled into clinical practice is unclear.

Carer support needs highlighted by this review, such as timely access to information about how to support someone at risk of suicide, make relevant methods of support that are accessible and scalable. One potential strategy for meeting the above-described needs lies in signposting to evidence based online resources tailored for this context, the development of which has been spearheaded by charitable organisations. One example is the 'You Are Not Alone' online resource hosted by SANE Australia, developed on the basis of qualitative research with carers (Coker et al., 2019). The resource provides carer-directed information regarding what to do in crises, ongoing support for people who are suicidal, and emotional support for carers, issues that relate directly to those expressed in this review. Other similar resources, such as the online toolkit for people impacted by suicide attempts (Mental Health Commission of Canada, 2018) and guidance for parents of young people who self-harm hosted by the UK platform HealthTallk (Ferrey et al., 2016), represent sources of rigorously developed psychoeducation for carers directly relevant to this context. Further research investigating the cross-cultural applicability, effectiveness, and implementation of such resources is warranted.

Carers face significant challenges when seeking professional support for friends or family members experiencing suicidal behaviour. As positive carer experiences have been characterised by collaborative, safety-focused relationships with professionals, and, conversely, negative ones by poor communication, efforts should be made to improve training and support for healthcare professionals likely to interact with carers of people at experiencing suicidal behaviour. Indeed, general practitioners have reported the desire for professional education in suicide prevention (Michail & Tait, 2016) and psychiatric inpatient staff have identified training needs related to developing therapeutic relationships with suicidal service users (Awenat et al., 2017). Relevant models of intervention delivered by or to healthcare professionals have been evaluated that may address these needs. For example, specialized emergency room care combining staff training and family therapy has been demonstrated to reduce suicidal behaviour (Rotheram-Borus et al., 2000) and nurse-delivered family psychoeducation focused on suicide prevention improves perceived caring ability amongst family carers (Sun et al., 2014). Involving professionals in suicide prevention training with a focus on the role of carers is therefore feasible and, as per the results of this review, should be an important consideration in the design of health services.

Implications for practice and research

Carers require tailored support with how to care for a friend or family member at experiencing suicidal behaviour. As carer distress is often rooted in anxiety regarding further suicidal behaviour, it is important to help carers to achieve a greater degree of understanding and control over their often-disempowering circumstances. Practitioners may seek to draw on evidence-based strategies in pursuit of this goal, for example by involving carers in crisis or safety planning (Stanley & Brown, 2012), but also by building collaborative interpersonal relationships with carers. Research with carers who are in contact with mental health services following suicidal situations has highlighted how professional-patient confidentiality can confound the development of such relationships (Dransart & Guerry, 2017; Nosek, 2008). In order to balance carer involvement, patient safety, and the obligation to maintain patient confidentiality, practitioners could consult dedicated, evidence-informed guidelines for determining how and when to disclose risk-related information with carers (National Suicide Prevention Alliance, 2021).

Carers require support with the often-profound distress they experience in the context of suicidal behaviour. To date, some psychosocial interventions have demonstrated positive impacts on carer outcomes including reduced caregiver burden and improved caregiving self-efficacy (Krysinska et al., 2021). However, the findings of this review reinforce the recommendations made by Krysinska and colleagues (Krysinska et al., 2021) for the need to upscale and evaluate interventions for carers in order to provide practitioners with evidence-based models of support. Furthermore, evidence presented here detailing the culturally contingent nature of carer distress suggests that such interventions should be tailored to the social context and local healthcare infrastructure in which suicidal behaviour occurs. Empirical and theoretical research supporting the significance of social factors in suicidal behaviour could also inform further intervention development (Mueller et al., 2021). Targeting specific mechanisms implicated in suicidal behaviour, such as thwarted belongingness or perceived burdensomeness (O'Connor & Kirtley, 2018), has been shown to be feasible as part of clinician-delivered interventions (Allan et al., 2018; Short et al., 2019). Further research may seek to build on evidence in other areas of health research, such as communication training for people with physical and mental health difficulties (Morris et al., 2018; Treasure & Todd, 2016) which could potentially serve dual functions in suicide-prevention and carer support. This necessary intervention development research could also capitalise on extensive and growing literature regarding the use of digital health platforms to deliver carer-directed psychoeducation and peer support (Lobban et al., 2017; Sin et al., 2022).

Strengths and limitations

This qualitative synthesis represents a novel contribution to the literature by applying qualitative synthesis to primary data derived from studies of caring experiences related to suicidal behaviour where suicidal intent is present and by extending the definition of carer to include friends. However, the scope of this review was limited to English language studies, owing to limitations in access to translation services. The transferability of these findings to other contexts captured by non-English literature is limited. Including only published studies ensured that they had met the standard for publication but may have excluded relevant qualitative data within grey literature.

Conclusion

There is a pressing need to understand the social context of suicidal behaviour to inform suicide prevention strategies worldwide. Yet, as the results of this review demonstrate, the lived experiences of caring for a friend or family member who is or has been suicidal are characterised by significant emotional and interpersonal challenges, in addition to difficulties accessing appropriate professional support. Without supporting those who provide care for suicidal friend and family members in the community, the potential leveraging of social support in the pursuit of suicide prevention strategies is likely to be undermined. The available evidence justifies a renewed research focus on psychosocial support for carers.

3.7 Methodological reflection

Articulating the nuance of lived experience

One of the challenges I experienced when analysing published research data was how to reconcile the aim of producing a qualitative synthesis that communicated nuanced accounts of carers' lived experiences, with the fact that many studies provided, by necessity, relatively limited volumes of supporting data in the form of illustrative quotes. I found that this made the process of familiarisation with the topic and immersion within the data notably more difficult than when working with large volumes of textual data during studies reported in chapters 4, 5, and 6. Moreover, while the stated goal of thematic synthesis is to synthesise concepts from primary studies, many of these studies reported relatively descriptive themes that appeared close to the surface meaning expressed in participant quotes. It may be that these two issues contributed to my own analytic output focusing on three quite practical experiential issues (emotional reactions, caregiving strategies, and professional interactions) at a level of abstraction that to me appears as conceptually grounded – or close to the text – rather than extending to a higher level of abstraction. Notwithstanding, the issue of meeting and managing personal responsibility in the context of suicidal appeared to underpin many of the lived experiences within the literature. This was a key insight that shaped my conceptual thinking when moving forward with subsequent research.

Chapter 4. Caring for a family member with psychosis or bipolar disorder who has experienced suicidal behaviour: An exploratory qualitative study of an online peer support forum

4.1 Chapter introduction

The following chapter presents a qualitative analysis of carer perspectives of supporting people with psychosis or bipolar disorder who have also experienced suicidal behaviour, as expressed through comments posted to a peer support forum. This chapter builds on insights from the preceding chapter by narrowing the experiential context under investigation to psychosis or bipolar disorder. Psychosis and bipolar disorder represent often highly distressing and enduring mental health problems, grouped by some into the category ‘severe mental illness’ (Public Health England, 2018) . There is some overlap in these groups as some people experiencing with bipolar disorder will also report unusual experiences characteristic of psychosis. Indeed, a recent systematic review of the prevalence of psychotic experiences in bipolar disorder estimated a prevalence of 57% during manic episodes and 13% in depressive episodes (Aminoff et al., 2022). While individuals’ and families’ experiences of psychosis or bipolar can vary widely, the following chapter argues that carers in both context experience significant and under-investigated challenges with understanding how best to support their friend or family member in the context of suicidal behaviour. It was therefore decided that this exploratory study would include carers’ views regardless of whether the person they supported had a primary diagnosis of psychotic disorder or bipolar disorder. The more focused context of psychosis is considered in depth in chapters 5 and 6.

4.2 Abstract

Background. The likelihood of experiencing suicidal behaviour is elevated amongst people with psychosis or bipolar disorder. This study aimed to understand how carers experience supporting family members with psychosis or bipolar disorder and suicidal behaviour.

Methods. Qualitative thematic analysis of online peer forum posts on the Relatives Education and Coping Toolkit (REACT) website, an online intervention for carers of people with psychosis and bipolar disorder. Analysis was based on 178 posts by twenty-nine forum users. Posts were selected based on their relevance to suicidal behaviour.

Results. Three themes were generated. 'Suicide as the ultimate threat' highlights fears emerging from carers' difficulties with understanding and managing suicidal behaviour. 'Bouncing from one crisis to another' reflects carers' experiences of recurring crises and the challenges of relying on emergency healthcare support. 'It definitely needs to be easier to get help' emphasises carers' desires to be acknowledged by healthcare professionals and included in support offered to service users.

Conclusions. Health services may benefit from greater carer involvement when working with service users who experience suicidal behaviour. Further research is needed to explore and test inclusive crisis care approaches that work with informal support systems of people with psychosis and bipolar disorder.

4.3 Introduction

Approximately 8.8 million people in the UK are involved in the provision of care for friends, family members, and other social contacts (CarersUK, 2021). In the UK, healthcare policy explicitly recognises the value of this support by committing to develop best practices for carer recognition and assistance as part of the National Health Service Long Term Plan (NHS, 2019a). Yet while community support for people experiencing mental health problems relieves considerable strain on national financial resources, it is often provided at significant personal cost to the carer (Andrew et al., 2012; Simon et al., 2021). Carers of people with psychosis and bipolar disorder consistently report high levels of distress, negative financial impacts, and limited access to social resources (Beentjes et al., 2012; Caqueo-Urízar et al., 2009). Qualitative studies with families of people with psychosis and bipolar disorder also highlight difficulties accessing appropriate mental health services to support family members, especially during periods of crisis (Baruch et al., 2018; Wainwright et al., 2015), and only 22% of those experiencing first episode psychosis in England receive family-based psychological intervention recommended by UK clinical guidance (Royal College of Psychiatrists, 2021).

People with psychosis or bipolar disorder are significantly more likely than the general population to experience suicidal behaviour, including making attempts on their own life (Nordentoft et al., 2013). This is likely to be particularly challenging for carers. Suicidal behaviour is associated with increased caregiver distress amongst people with schizophrenia (McDonell et al., 2003), first episode psychosis (Bowman et al., 2017), and bipolar disorder (Chessick et al., 2007). However, to date, mechanisms underpinning these associations remain unclear. In an interview study following suicide attempts by people experiencing psychosis, family members were largely unaware of any increased likelihood of suicidal behaviour prior to these suicide attempts, nor the need for additional mental health support (Yamaguchi et al., 2015). This suggests that psychosis may present carers with additional barriers to recognising and responding to suicidal behaviour. Furthermore, interviews with service users and family members of people experiencing bipolar disorder investigating perceptions of healthcare support highlight how carers' desires to be actively involved in care offered to service users are not always met (Clements et al., 2019). Challenges included difficulties accessing professional healthcare support in suicidal crises, conflict with staff, and confidentiality, which restricted carer access to information that may have assisted with understanding suicidal behaviour. This emerging evidence base provides some indication of the challenges faced by carers when supporting someone with psychosis or bipolar disorder and co-occurring suicidal behaviour. However, explanations for why carers are more likely to experience distress in the presence of suicidal behaviour amongst those they support, compared with carers of people with psychosis or bipolar disorder who do not experience suicidal behaviour, are limited (Bowman et al., 2017; Chessick et al., 2007; McDonell et al., 2003). Further qualitative research focused on developing in-depth accounts of carers' lived experiences in this context may assist with generating insights absent in existing literature.

The aim of the current study was to understand the experience of caring for a family member with psychosis or bipolar disorder who has also experienced suicidal behaviour. This aim was addressed through an exploratory qualitative investigation of data from the Relatives Education and Coping Toolkit (REACT) online forum (Lobban et al., 2020). REACT is an online, peer-supported self-management intervention which aims to offer NICE recommended education (NICE, 2014a; 2014b) and emotional support to carers supporting people with psychosis or bipolar disorder. It was developed with extensive involvement from carers, evaluated in a large randomised controlled trial, and was used to identify critical factors impacting on the implementation of digital health intervention into UK mental health services (Lobban et al., 2020). REACT included a moderated online forum designed to facilitate peer support.

Online support forums are increasingly used by researchers to access naturalistic interactions focused on specific healthcare topics (Smedley & Coulson, 2021). Factors such as the ability to post anonymously and the tendency for comments to be guided by forum users' own priorities facilitate forms of personal disclosure less likely to occur in other contexts, such as research interviews (Seale et al., 2010). Research with online mental health forums has highlighted how a forum's culture and modes of interaction generate both peer support and interpersonal challenges (Smith-Merry et al., 2019; Tucker & Goodings, 2017) including for those experiencing suicidal behaviour (Mokkenstorm et al., 2020; Scherr & Reinemann, 2016), psychosis (Gleeson et al., 2012), and bipolar disorder (Latalova et al., 2014). Online forums for carers of people with mental health problems including psychosis have been developed and evaluated (Sin et al., 2022). However, to date, they have not been used to inform qualitative research into suicidal behaviour and bipolar disorder or psychosis from carers' perspectives. A recent quantitative, computational linguistic analysis of the entire REACT forum revealed 'death and suicide' as one of 5 prominent thematic domains (Jones et al., 2022). Other domains of discussion included negative emotions, conflict and abuse, illness and hospitalisation, and time. As such, this dataset represents a valuable information source for investigating carers' experiences of supporting a family member with psychosis or bipolar disorder and suicidal behaviour.

4.4 Methods

Design

This qualitative study is a secondary analysis of forum posts collected as part of a randomised controlled trial to evaluate the REACT intervention (Lobban et al., 2020). Data were generated by forum users between April 2016 and June 2018.

Participants

To be eligible for the REACT trial, participants were required to be aged 16 or over and live in the UK (Lobban et al., 2020). All participants self-identified as having a close friend or family member with psychosis or bipolar disorder. This broad inclusion criteria is justified on the basis that UK clinical guidance recommends dedicated psychoeducation and support for carers of people with any form of psychosis (including schizophrenia and related disorders) or bipolar disorder (NICE, 2014a, 2014b). The research team recognize that these mental health experiences are not mutually exclusive, however, only the primary diagnoses of those being cared for were collected from participants in the REACT trial. All participants self-identified as help seeking and experienced high levels of distress associated with their friend or family member's mental health, as indicated by a score of ≥ 3 on the General Health Questionnaire item 'have you recently been feeling nervous and strung up all the time?' (Goldberg & Hillier, 1979). Access to the forum was restricted to participants in the intervention arm of the REACT trial (n=399). All forum users were identified by a self-selected username that did not contain any personally identifiable information. Participants could contribute to the forum by writing messages, or 'posts,' within forum 'threads', which were conversations visible to all forum users. The forum was moderated during working hours by REACT Supporters, who were family members or friends of people who had experienced psychosis or bipolar disorder. REACT Supporters were trained to provide emotional support and were supervised by a clinical supervisor (SJ) and the trial chief investigator (FL), both of whom are clinical psychologists. Participants also had access to a direct messaging function through which they could communicate with REACT Supporters. Direct messages were not visible to other forum users. Forum posts and direct messages were text-only and unrestricted in length.

Data extraction

As the forum did not specifically direct participants to discuss suicidal behaviour, the following data extraction process was applied to identify conversations relevant to the research aim. As per a recent systematic review of caregiving experiences and suicidal behaviour, we applied a definition of suicidal behaviour that included any reference to suicidal thoughts, feelings/urges, plans, and/or attempts, in addition to self-injurious behaviour regardless of intent (Juel et al., 2021). While it is acknowledged that approaches to the definition of suicidal behaviour and self-injury vary, the exploratory nature of this qualitative study justified a broad approach to data inclusion. To be eligible for inclusion in the analysis, forum posts related to suicidal behaviour were required to also refer to the experience of caregiving. Eligible posts could refer to present or past experience of suicidal behaviour. Abstract references to suicidal behaviour, or posts that only referred to carers' own suicidal behaviour and not those of the person they supported, were excluded. To identify relevant data, the full REACT forum including all threads and direct message conversations was downloaded in Microsoft Word format. Each forum user was allocated a random participant (P) ID number. Multiple readings of the dataset were conducted by the first author (PM) to identify eligible forum posts. A second researcher (HR) then independently reviewed these candidate forum threads/direct message conversations to check their relevance to caregiving and suicidal behaviour. Differences were reviewed and resolved in subsequent conversation between researchers. Within each individual conversation, only forum posts written by participants who had referred to suicidal behaviour were coded as part of the analysis. Comments made by REACT Supporters were excluded.

Analysis

Data were analysed using thematic analysis (Braun et al., 2019) from a critical realist perspective. Critical realism combines ontological realism with epistemological relativism and takes the view that while a mind-independent social reality exists, analysis of this reality is necessarily mediated by researchers' individual interpretive perspectives (Maxwell, 2009). We therefore chose to apply the form of thematic analysis described by Braun and Clarke(2019) as 'reflexive' thematic analysis, as part of which researcher interpretation is framed as an analytic resource rather than a source of undesirable bias. The first author is a PhD candidate in health research (PM), supported by an expert in the psychological science of suicide who is also an expert by experience (TG), academics with extensive research experience related to psychosis and bipolar disorder (FL, SJ, and HR), and clinical experience working professionally with service users with psychosis, bipolar disorder, and their family members (FL and SJ). Our aim was to use this diversity of experience and perspective to generate a nuanced account of participants' experiences through iterative feedback on the developing analysis.

The analytic procedure followed guidance for reflexive thematic analysis (Braun & Clarke, 2021c). First, PM conducted data familiarisation through multiple readings of extracted forum conversations, during which initial impressions and features of the data were noted. PM conducted initial coding by attaching brief labels capturing expressions of meaning to sections of forum text. Codes were generated inductively, that is, without reference to a pre-existing framework or theoretical constructs. PM generated initial sub-themes by identifying salient patterns of meaning across the dataset through an iterative process of reviewing underlying data, initial codes, and groups of codes that could be encompassed by overarching candidate themes. These candidate themes were refined based on feedback from the wider research team. A revised thematic structure was 'sense-checked' via written feedback by a REACT Supporter who was active on the forum throughout the delivery of the intervention (Byrne, 2021). Analysis was conducted on NVivo 12 (QSR International Ltd, 2018).

4.5 Results

The final dataset comprised 178 posts written by twenty-nine forum users. Posts appeared within twenty-eight open forum threads and eight direct message conversations. A majority of forum users in this sample were female (n=26) and from a white British background (n=25). The mean age of the sample was 49 years (range: 23-68 years). As indicated by table 5, most (n=24) forum users in the sample posted fewer than 10 times in reference to suicidal behaviour.

Table 5. Forum study participant demographics

ID	Age	Gender	Ethnicity	Relationship	Primary diagnosis of person being cared for	Time caring (years, months)	Forum posts analysed
P1	54	Female	White British	Not given	Not given	24, 7	1
P2	50	Male	White British	Partner	Bipolar disorder	4, 0	10
P3	65	Female	White British	Mother	Bipolar disorder	20, 0	21
P4	25	Female	White British	Daughter	Bipolar disorder	18, 7	2
P5	45	Female	White British	Mother	Bipolar disorder	14, 0	1
P6	23	Female	Mixed	Daughter	Bipolar disorder	7, 0	1
P7	44	Female	White British	Partner	Bipolar disorder	3, 0	1
P8	47	Female	White British	Mother	Psychosis	3, 11	1
P9	65	Female	Irish	Mother	Schizophrenia	15, 6	1
P10	63	Female	White British	Mother	Bipolar disorder	24, 11	4
P11	57	Female	White British	Sibling	Psychosis	0, 4	4
P12	50	Female	White British	Sibling	Schizoaffective disorder	20, 0	2
P13	60	Female	White British	Mother	Bipolar disorder	12, 0	7
P14	58	Male	White British	Partner	Bipolar disorder	15, 0	2
P15	68	Female	White: Other	Not given	Not given	19, 0	1
P16	45	Female	White British	Partner	Bipolar disorder	17, 10	19
P17	60	Female	White British	Mother	Bipolar disorder	11, 9	1
P18	63	Male	White British	Partner	Psychosis	3, 0	1
P19	52	Female	White British	Mother	Bipolar disorder	3, 0	5
P20	51	Female	White British	Not given	Not given	11, 0	1
P21	30	Female	White British	Daughter	Bipolar disorder	9, 3	1
P22	45	Female	White British	Partner	Bipolar disorder	1, 6	5
P23	51	Female	White British	Partner	Psychosis	3, 0	5
P24	37	Female	White British	Partner	Schizoaffective disorder	16, 0	13
P25	60	Female	White: Other	Mother	Schizophrenia	6, 9	1
P26	42	Female	White British	Partner	Bipolar disorder	5, 8	2
P27	34	Female	White British	Not given	Not given	9, 4	58
P28	33	Female	White British	Partner	Schizoaffective disorder	7, 6	6
P29	50	Female	White British	Partner	Psychosis	0, 6	1

The analysis generated three themes, each with two sub-themes (table 6).

Table 6. Table of themes and sub-themes

Themes	Sub-themes	Illustrative quote
1. Suicide as the 'ultimate threat'	1.1 Living in fear of suicide	*“I worry constantly about his mental well-being and safety as he has talked about suicide on several occasions in the past. I feel like I'm always waiting for 'that phone call'” (P20)*
	1.2 Negotiating responsibility for living	*“Things cannot get much worse and maybe the kinder option would have been to not interrupt his plan to die, at least he would be at peace but then I doubt I could live with th*at” (P10).
2. 'Bouncing from one crisis to another’	2.1 Responding to crises	*“I have spent several nights sitting in A&E [accident and emergency] with my daughter in an agitated/manic state…I feel the environment only contributed to her state and the wait and the busy environment only increased my own state of anxiety which was high already. I have to comment that we have experienced several different hospitals and the situation is similar in all” (P19).*
	2.2 Being left 'at a loss' about what to do next	*"…he walked out [of hospital] yesterday with no care plan and no idea of support” (P13)*
3. 'It definitely needs to be easier to get help'	3.1 Being (un)involved in professional care	“*I really feel like no one wants to speak to me about my husband and it makes me feel very guilty as if I’m making it up*” (P22).
	3.2 Peers address unmet support needs	“*I have literally just joined and already feel such relief that I have somewhere to ask these questions and find information*” (P8).

Theme 1: Suicide as the ‘ultimate threat’

Carers’ forum posts highlighted their profound anxiety regarding the possibility that their family members may experience mental health crises involving suicidal behaviour. For one carer, this ongoing ‘threat’ was informed by prior experience of suicidal crises: *“his [sic] a history of attempting suicide and we are so scared that we will lose him and that is his ultimate threat*” (P17).

Sub-theme 1.1: Living in fear of suicide

Carers’ fears about suicide were persistent and difficult to control. Distress appeared most prominent where carers felt that they were hopeless in the face of their family member’s deteriorating mental health: “*She won’t speak to anyone else except me…everything I do/say is wrong. She is again now telling me she wants to kill herself. I am so emotionally exhausted I don’t know what to do*” (P23). Such comments reflect a sense of desperation and fatigue which was particularly evident in carers who were providing support to a family member in crisis at the time of their posting to the forum.

A key factor that appeared to exacerbate this fear was carers’ difficulties with understanding what had caused the apparent escalation in the severity of their family member’s mental health difficulties. For example, one carer recalled that the difficulty of identifying a reason for their family member’s suicide attempt *“in a way scares me, as I think what was it all about?*” (P11). In the absence of an explanation for these experiences, carers expressed limitations in their perceived ability to manage suicidal behaviour in the community: *“When he was released from hospital, we were given no help or support from* *anybody, we were left living in terror, not knowing why this had occurred"* (P12). This immediate, terrified response to hospital discharge highlights how supporting a family member following the transition out of health services represents a potentially highly stressful period of uncertainty.

Sub-theme 1.2: Negotiating responsibility for living

The issue of responsibility for the welfare and safety of a family member was reflected in posts by forum users who struggled to establish a balance between their own wellbeing and provision of care. The emotional impact of feeling responsible for the life of a family member may be intensified in the context of parenthood. The socially salient expectation that parents should seek to provide life-maintaining support in-formed a uniquely isolating experience that detached one carer from their broader social network:

"*I know that there aren't really many things other people can do to help with the pain and anguish, the worry of losing your children through suicide and the alienation you feel from your friends whose children are doing as you expected yours would do*" (P13).

In a similar vein, prioritising self-care may at times be necessary, but particularly difficult for parents where a 'threat' of suicide exists. Negotiating a balance between these competing priorities was particularly difficult for one carer:

"*With the threat of self-harm or suicide as an action from them it's always so hard to protect ourselves but also support and fight for them. What I am learning is we do have to be kind to ourselves and at times step back as a parent that is so hard to do!"* (P19)

The type of relationship shared by carers and service users may frame the negotiation of caregiving responsibilities in the presence of suicidal behaviour. As one carer recalled regarding their partner: "*He was verbally abusive to me and I left. Not the first time this has happened. I came back because I was worried about his safety - he has attempted suicide twice in the past year*" (P28). In response, a carer offered support by drawing from their own lived experience:

> *"My husband and I separated for a time when he was at his most ill, he made several suicide attempts during this time and I realised that this was not my fault, it was his illness. One of my conditions for getting back together was that he engaged with mental health services and another was that he took responsibility for his own mental health"* (P27)

This comment illustrates how recognising that the carer was not to blame for the situation, and that the service user had to some extent take responsibility for their own mental health, allowed this carer to re-negotiate the parameters of their personal relationship to protect their own wellbeing.

Theme 2: 'Bouncing from one crisis to another'

Many carers had experienced multiple periods of intense distress. Participants' average time spent providing care was over 9 years, during which many had lived through recurrent mental health crises within the family. Health services were largely viewed as insufficiently considerate of the role of the carer, both at the point of first contact during an emergency, and later, following transition to community care.

Sub theme 2.1: Responding to crises

Carers recounted multiple experiences of supporting their family members through mental health crises: "*I've lost count of the number of suicide attempts and contacts with crisis team*" (P27). Rather than discrete events, crises were viewed as cyclical disruptions to normality and family functioning: *“I really know that feeling of ‘as soon as I start to relax something kicks off again’ as we lived with that for so long*” (P27). Suicidal crises were characterised by a heightened sense of urgency, where immediate risk of harm demanded carers act to ensure their family member’s safety. One carer recalled directly intervening to prevent their sibling from engaging in self-injury, which left a lasting impact on the family: “*I was hanging on to him to try and prevent him harming himself. It was a terrifying experience from which we have never recovered*” (P12). Carers’ initial actions during crises often included contacting emergency services, primarily the police. Some appreciated that the police were reliable sources of support in dangerous situations and could facilitate access to medical treatment:

> *“Another avenue I have found helpful is 111 [non-emergency telephone health service] to get and [sic] out of hours GP to come and assess my husband at home when things were really bad one evening...It was the police that suggested that. To be honest most of what I have learned about negotiating mental health crisis services has been from the police”* (P27)

Carers’ own primary motivations overlapped with those of the police, namely, establishing the immediate physical safety of those involved. However, seeking help in this way created additional challenges that could contribute to distressing encounters:

> *“It was extremely traumatic as they [police] came 'mob handed' expecting a fight but were eventually persuaded to let me take her to the hospital in my car, which was probably good for her but didn't do a lot for my feelings of guilt*” (P18)

Carers expressed mixed views on support offered by crisis and emergency health services. One forum user saw clear value in seeking admission and anti-psychotic medication in crisis situations, "*He went into hospital because voices were telling him to kill himself which he tried to do, and these have been stopped with meds*" (P22). However, this could be followed by challenges with medication adherence post-discharge:

> *"He was completely psychotic, with no insight and had just been discharged from hospital following a suicide attempt, yet there seemed to be no concern that he hadn't been to collect his meds or had any contact with crisis team*" (P27)

Sub-theme: 2.2 Being left 'at a loss' about what to do next

Carers expressed how post-crisis transitions to community-based support had been rushed or unsupported, an experience which "*leaves families, who are often terrified and at a loss themselves, clueless how to help"* (P12). Transition points in and out of services were particularly problematic. Carers were concerned that those who were voluntarily admitted to hospital could leave of their own volition:

> *"by the time [A&E staff] they actually see him he will generally say 'No I don't want to kill myself I was just being stupid' (even when it's been the second time that day) and has just been referred back to his GP with probable depression*" (P27).

Community based support was valued where available but seen by some as limited in scope due to the challenge of maintaining contact with health services over time, "*He had about four meet ups with his care worker but no care plan that I was aware of nor any constructive support*" (P13). This absence of ongoing health service contact served to reset the cyclical recurrence of escalating mental health difficulties, in which carers are left without support:

"The crisis team and local crisis centre have been good when he's come under their wing a few times, but he has been very quickly discharged from their care once the crisis is over and that's where we lose contact" (P20)

Theme 3 'It definitely needs to be easier to get help'

This final theme highlights the ways in which forum users struggled to access mental health support, underpinned by factors such as health service emphasis on confidentiality at the expense of carer involvement, and the suggestion that a mental health crisis is necessary to initiate healthcare support: "*the thing that makes me most angry is that my husband had to reach crisis point before getting any help"* (P27). Participants appeared to use the peer-support forum to fill gaps in their own self-care and help-seeking strategies.

Sub-theme 3.1: Being (un)involved in professional care

Whilst seeking help, carers acted as mediators positioned between professionals and their family members, aiming to promote interactions and engagement between the two. Yet where contact with health services had been made, some found healthcare professionals distant and their decision-making processes unclear. Carers had intimate knowledge of their family members' personal histories and, often, years of experience supporting them. This expertise was not always acknowledged and used by professionals, resulting in some carers feeling that their potential contribution to their family member's care had been overlooked. Discord between professional and carer perspectives was pronounced where carers' concerns about suicidal behaviour were not reflected in professionals' decisions:

“She tried to take an overdose 4 weeks ago. They are now saying that she can leave tomorrow. Her husband is very concerned, as to how he treats the situation. Does he just let her get on with her 'life' or has he always got to be there watching what she is doing?” (P11)

In contrast, being actively involved in the care process is highly valued by carers: *“I'm so lucky with my husband's CPN [Community Psychiatric Nurse] as he says that keeping communication open with me is in my husband's best interest and that as he has stated when he is well that he wants me involved, he is following his wishes when he lacks capacity to make the decision.”* (P27)

This involvement was particularly appreciated by the same carer who explained how psychotic experiences can interact with suicidal behaviour to produce additional challenges with professional help-seeking:

“*he thought…that I was an undercover police officer monitoring him, that I was trying to poison him… on one occasion that week things were getting really bad [sic] get him in to A&E to speak to crisis team but he would only tell them about feeling suicidal and sent me out when I tried to explain what was really happening*.” (P27)

Health service confidentiality and the requirement for service users to pro-actively engage with health services represented barriers for carers seeking support. Strict adherence to these principles was perceived by two carers as incongruent with the severity of the situation: “*he has recently felt suicidal. When I called the hospital for help they told me that he would have to ring himself and they couldn’t help*” (P26) and “*…had a bad weekend. Daughter would not consent to crisis team on Saturday. She had distressing voices telling her to kill herself. On and On. I was very anxious after she told me this*.” (P3).

This placed some carers in a paradoxical situation, where a lack of motivation to engage with services seemed to be attributable to the very mental health difficulties carers sought help for:

"They said 'yes he sounds very poorly to us but unless he wants us involved, we can't do anything'. OK so he was completely delusional and had no insight into the fact he was ill, at what point were they expecting him to say: 'oh yes please I'd like some help with my mental health'?" (P27).

Sub-theme 3.2: Peers address unmet support needs

Carers' reflected on the importance of having a space to share their experiences and access validating accounts of others' similar experiences, opportunities that were evidently not often present within some carers' wider lives: "*I tend to write about all the bad bits here because it's the only place I can*" (P27). For one forum user, the presence of peers whose life experiences resonated with their own provided "*relief that I am no longer feeling so alone and isolated dealing with my son*" (P20). Particularly welcome was the use of personal experience to inform advice, in comments such as "*my advice to anyone supporting another person is to put your own mental and physical health first. I have learnt this the hard way*" (P27). Indeed, those who had been through similar difficult situations readily offered valued insight beyond what appeared to be available outside of the forum.

4.6 Discussion

The aim of this study was to understand carers' experiences of supporting people with psychosis or bipolar disorder who have also experienced suicidal behaviour. This is the first use of comments made on an online peer-support forum to investigate these specific caregiving experiences. There were several important findings across three overarching themes. First, forum posts revealed how carers experienced a sense of personal responsibility for the lives of those receiving support, along-side a difficulty with understanding and managing suicidal behaviour. This engendered significant stress and ongoing fear across carers' lives. A second theme high-lighted how many had supported their family members through multiple crises and had largely found professional support for carers to be unsatisfactory, especially at points of transition between health services and the community. Some carers saw their attempts to seek help rebuffed by health professionals due to their inflexible application of confidentiality procedures or lack of consent and engagement amongst their family members. A third theme highlighted how carers' often unmet desires for ready access to collaborative health services in suicidal situations. Within this context, carers found relief and comfort in an online community of peers, which represented a safe place for sharing and accessing lived experiences that resonated with their own.

Previous quantitative analysis of the REACT forum highlighted how carers used the service to connect with peers over challenging aspects of their lives, including ongoing stressful events, conflict, and suicidal behaviour (Jones et al., 2022). Our focused analysis of posts related to suicidal behaviour of those receiving support highlighted how, consistent with previous research, carers live with intense fear regarding the possibility that their family members may experience further suicidal behaviour (Buus et al., 2014; McLaughlin et al., 2014; Spillane et al., 2019). Distress was particularly prominent during situations in which carers found it difficult to understand the reason for, and how to reduce, the likelihood of suicidal behaviour. Findings from this study add context to quantitative evidence showing elevated carer distress amongst families of people with psychosis who have also experienced suicidal behaviour, relative to those without prior experience of suicidal behaviour (Bowman et al., 2014; McDonell et al., 2003). This literature suggests that suicidal behaviour in psychosis is associated with poorer quality of life across all life domains, lower family functioning, and more negative appraisals of caregiving (Bowman et al., 2014, 2017; Hsiao et al., 2020). Evidence presented here suggests that this broad psychosocial impact may be related to the uniquely pervasive anxiety apparent in the lives of carers of people experiencing suicidal behaviour (theme 1), repeated suicidal crises and limited support between them (theme 2), and lack of access to carer-inclusive professional support (theme 3). Prior research also indicates that beliefs in greater future severity and lower controllability of psychosis are linked to greater carer distress (Kuipers et al., 2010). One interpretation of carers' lived experiences described here is that ongoing fear of further suicidal behaviour and challenges with understanding how to mitigate its reoccurrence exacerbate these appraisals and thus contribute to more severe impacts on carer wellbeing. These psychological processes represent potential but as yet under-investigated mechanisms by which carers may experience poorer psychosocial outcomes in the presence of suicidal behaviour.

As in a prior study with families of people with bipolar disorder receiving healthcare support following suicidal behaviour (Clements et al., 2019), health services were described as unable or unwilling to include carers in key decisions regarding their family member's care or provide information regarding how carers could effectively support their family members. Findings of the current study also indicate that feeling unsupported by health services when caring for someone experiencing suicidal behaviour exacerbates carer distress, especially in circumstances where carers feel that their potential involvement in care is overlooked. Individualised care plans that are developed collaboratively alongside carers and draw on their knowledge of their family member’s circumstances represent one strategy for addressing carers’ desires for greater involvement in healthcare delivery (Edwards et al., 2021). However, a systematic review of families’ experiences of involvement in mental health care planning highlighted a number of barriers consistent with carers experiences in the current study (Doody et al., 2017). This included underappreciation of families’ lived experiences and inflexible adherence to principles of service user confidentiality that limit valid and mutually beneficial interactions between carers and healthcare staff. Contemporary policies (in the UK) do, however, allow for constructive information sharing between professionals and carers that highlight carers’ needs within the boundaries of service users’ rights (Zero Suicide Alliance, 2021). Best practices for suicide prevention recommend establishing information sharing principles with families, including the limits of confidentiality and circumstances under which information would be provided to families if service users lose capacity to consent to information being shared (NICE, 2019). Future research may seek to evaluate barriers to the implementation of initiatives that address these challenges.

The absence of service user consent to engage voluntarily with healthcare support can present carers of people experiencing suicidal behaviour with a significant obstacle to help-seeking (Castelli Dransart & Guerry, 2017). In this study, one participant noted how their family member’s experience of psychosis exacerbated this challenge. Attempting to understand delusional beliefs, especially those focused on carers, can be a particularly difficult and distressing task that involves attempts to piece together a coherent understanding of others’ mental states (Onwumere et al., 2016). Carers are likely to have extensive experience of, and insight into, the nature of their family member’s mental health experiences which may be invaluable to the provision of appropriate mental health care.

Including carers in professional support would likely rely on open communication with mental health professionals, yet as has been reported in previous research (Rowe, 2012; Wainwright et al., 2015), some carers in the current study noted that service user confidentiality acted as a barrier to accessing information about their care. Guidance related to this issue suggests that clinical judgements about information sharing should prioritise harm-reduction, and where information sharing is not appropriate, clinicians should engage with carers regarding their own support needs (Slade et al., 2007). This could involve referral for a dedicated carer's assessment (Rapaport et al., 2006). Additional qualitative work drawing on multi-stakeholder perspectives may be of value in identifying how these best practices can be effectively applied in suicidal crises, in a way that accounts for the views of service users, the needs of carers, and the professional obligations of healthcare staff.

Carers' reflections on the cyclical and demanding nature of crisis situations align with previous research indicating that these periods are especially challenging for families (Lavoie, 2018). Mental health crises, and particularly those in which there is concern about suicide, are characterised by conflicting emotions in carers regarding how to respond, apprehension concerning police intervention, and the experience of being 'invisible experts' regarding their family member's mental health (Lavoie, 2018). Indeed, in the present study, forum users noted a tension between the need to engage with emergency services and the potential for distress during a family member's involuntary admission to health services. Efforts have been made to embed mental health expertise within police response to mental health crises, including as part of 'co-response' teams comprising mental health professionals and law enforcement personnel. However, a recent systematic review (Marcus & Stergiopoulos, 2022) of related literature reported that while co-responder models show improvement in some crisis outcomes relative to police only models, such as arrest rate, the existing evidence base provides mixed support for their overall effectiveness and is limited to largely low-quality studies. The extent to which these models contribute to improved outcomes for families of people experiencing crisis is currently unclear. This is significant given evidence of service users' preferences for the involvement of family members rather than police personnel in crisis situations (Boscarato et al., 2014) and carers' reflections on the frightening and sometimes traumatising nature of mental health crises involving police intervention (Brennan et al., 2016; Riley et al., 2011). Evidence presented here supports the recommendation (Marcus & Stergiopoulos, 2022) for research into co-designed crisis models and subsequent large-scale evaluation to address this highly significant point in the care pathway for people experiencing mental health crises and their families.

As described here, many carers supporting people with mental health difficulties experience challenges accessing carer-focused information and support. A scoping review by Landeweer and colleagues (Landeweer et al., 2017) revealed barriers at the level of the individual carer (low expectations regarding involvement in care, unequal power relationships with health professionals) and healthcare organisation (lack of carer-focused service provision, concern over the impact of family involvement). The WHO comprehensive mental health action plan (2013-2030) calls for the strengthening of carer involvement in the design and delivery of integrated healthcare systems (WHO, 2021). The results of this study highlight implications for service development at multiple levels of provision. Digital interventions are feasible and hold potential for the efficient delivery of rigorously developed psychoeducation and peer support (Migliorini et al., 2021). Yet as was highlighted by a multiple case study of REACT implementation (Lobban et al., 2017), such services require extensive and iterative support to promote their integration within and uptake by health services. Carer-inclusive information sharing and support is also desirable at the point of contact with health services. Indeed, health professionals working in suicide prevention have identified that developing stronger links with families would enhance their ability to deliver safe care for those experiencing suicidal behaviour (Appleby et al., 2019). Brief evidence-based strategies for carer involvement in this context include safety planning, which could be used to highlight the role of carers in suicide prevention and important factors such as managing lethal means of self-injury at home (Ferguson et al., 2021; Stanley & Brown, 2012). At a systemic level, alternative models of mental health care that foreground social relationships are likely to promote carer engagement. One example is Open Dialogue, which frames the service user and their social network as the focus of intervention (Lakeman, 2014). Crisis care therefore involves extensive carer involvement, inclusive information sharing, and collaborative decision making. Increased implementation of these principles is likely to address carers' feelings of exclusion from the care process and reported difficulties with accessing information about the care their family members receive.

Strengths and limitations

A moderated online forum designed to elicit peer support amongst carers of people with psychosis and bipolar disorder represents a novel source of data for understanding carers experiences and support needs, independent from the somewhat artificially constructed context of other research settings. Posts focussing on suicide related content were extracted, offering an opportunity to explore an important and under-researched issue. Analysis was informed by a range of professional and lived expertise. However, there were some limitations. While an inclusive approach to the identification of relevant forum conversations was applied, including terms such as ‘self-harm’, it is appropriate to acknowledge that not all self-injury is motivated by an intent to cause death. The sample in this study was UK based, predominantly female, White British, and IT literate. As such, carers’ experiences may not align with those of other groups, such as ethnic minorities or those without access to online resources. A further limitation is that a large number of forum posts were written by a minority of users. This reflects the tendency in online forums, including those designed for mental health support, for a small number of ‘superusers’ to generate the vast majority of forum posts (Carron-Arthur et al., 2016). Indeed, on the REACT forum as a whole, 93% of forum users posted 5 times or fewer (Jones et al., 2022).

Conclusions

This study is the first to draw on online forum data to investigate carers’ perspectives of supporting people with psychosis and bipolar disorder who have also experienced suicidal behaviour. Findings indicate that greater attention should be paid to understanding how carers can be assisted at each point in the care pathway, from initial emergence of suicidal behaviour through to post-crisis care. A key challenge for both researchers and practitioners lies in designing strategies that can meet these goals and which account for the needs and expertise of carers, whilst also respecting the rights and wishes of service users within healthcare settings.

4.7 Methodological reflection

Generating conceptual links between themes

In the results section for this chapter, I did not present a thematic map demonstrating conceptual links between themes (as are included in chapters 3, 5 and 6). The decision to omit such a figure was based on my impression of the nature of the data underlying these themes. Forum data, as with the REACT dataset, are typically organised into relatively brief comments, in threads that vary in length and may follow a clear exchange of ideas, or switch focus abruptly. This can be contrasted with interview data which by its nature facilitates targeted, in-depth, narrative discussion of related experiences. Because the REACT forum data focused on specific comments within threads, somewhat disjointed from the wider narrative of the participant’s experience, I found it difficult to articulate a coherent or compelling narrative across the analysis. Where interviews may facilitate the generation of data that naturally links experiences, either conceptually or temporally, forum data here represented short but often quite grave and support-focused insights into carers’ lives. Reflecting on this learning, I decided not to attempt to link concepts in the final thematic map so as not to give the impression that themes and sub-themes were linked to a greater extent than the analysis might suggest. I felt that the level of interpretation of the data required to do so would be moving beyond what was supported by the underlying text.

Chapter 5. The psychosocial impacts of caring for someone with psychosis who has experienced suicidal behaviour. A qualitative interview study.

5.1 Chapter introduction

While chapters 3 and 4 highlight general impacts of caring for someone who has experienced suicidal behaviour, and some of the challenges faced by carers who also support people with psychosis, respectively, they do not present in-depth explorations of how these issues interact to impact carer experiences. Moreover, the systematic search for evidence presented in chapter 1 highlighted how suicidal behaviour amongst people with psychosis is associated with poorer psychosocial functioning amongst their carers but failed to identify in-depth qualitative research to explain these associations. In-depth semi-structured interviews and thematic analysis was applied to fill this gap in existing knowledge.

Chapters 5 and 6 are based on data derived from the same interviews. The decision to analyse these data using two separate research questions was based on an interim analysis of the first seven interviews, reflection on the potential contribution of the data to existing literature, and discussion within the supervisory team. This process highlighted how a single broad research question related to carers' experiences in general would likely not do justice to participants' nuanced conceptualisations of their roles as carers and the personal meanings their experiences held for them. Data were analysed with respect to these two research questions such that individual codes and underlying data do not overlap across the following two chapters, with each paper reporting analyses of unique interview data:

- To develop insight into the apparent link between suicidal behaviour in psychosis and poorer psychosocial outcomes and build on the non-psychosis specific insights from chapters 3 and 4, chapter 5 reports a thematic analysis of the psychosocial impact of caring for someone who has experienced psychosis and suicidal behaviour.
- In order to facilitate in-depth understanding of carers' perspectives of this situation, chapter 6 reports a thematic analysis of carers' understandings of the relationship between psychosis and suicidal behaviour amongst those they support.

5.2 Abstract

Background

Psychosis is associated with intense, prolonged, and frequent suicidal experiences, including thoughts, attempts and deaths. While friends and family members often provide vital support to people with psychosis, little is known of their perspectives of providing this care at a time of co-occurring suicidal experience. This study sought to investigate the personal psychosocial impacts of caring for a friend or family member with psychosis and suicidal behaviour.

Methods

Twenty semi-structured, individual interviews were conducted with UK-based adult carers who had supported someone with psychosis and experiences of suicidal behaviour, including any form of suicidal thinking and/or suicide attempts. Data were analysed using reflexive thematic analysis.

Results

Two overarching themes were developed. *Meeting the responsibilities of care: 'it's like juggling knives',* articulates a central tension between the necessity of providing vital interpersonal support in often highly stressful, time-sensitive suicidal crises, and ongoing attempts to maintain carers' own wellbeing. This tension was exacerbated by difficulties interpreting unusual behaviour attributed to psychosis. *Working with (or against) others to manage safety* highlights difficulties accessing health services able to collaborate with carers in promoting the safety of those experiencing psychosis and suicidal behaviour. Caregiving was invariably embedded within wider social networks that manifested additional context-specific interpersonal challenges, including the limiting effect of mental health stigma on support seeking and giving.

Conclusion

Accessible, empathic, and carer-inclusive healthcare services, designed to support carers in negotiating the challenges of keeping their friend or family member safe, especially during crises, are essential for relieving the immense pressures associated with caring for someone experiencing psychosis and suicidal behaviour.

5.3 Introduction

Reducing death by suicide is a policy aim of increasing international significance (Platt et al., 2019). Prior suicidal behaviours, including suicidal ideation and suicide attempts, are significant predictors of subsequent suicide deaths (Bostwick et al., 2016) . Understanding the ways in which people experiencing suicidal behaviour can be supported to manage their distress is therefore an important scientific, clinical, and societal goal. As identified by the interpersonal model of suicidal behaviour, thwarted belongingness and perceived burdensomeness are risk factors for suicidal behaviour (Christensen et al., 2014).

Indeed, amongst people experiencing psychosis, social isolation increases risk of positive symptoms, depression, and suicidal ideation (Bornheimer, Li, Im, Taylor, & Himle, 2020). Conversely, positive perceptions of social support represent a protective factor for suicide (Kleiman & Liu, 2013). Friends, family members, and partners of people who are suicidal, likely to provide such support, therefore occupy highly significant roles in the support networks of people with psychosis at risk of suicide.

Recent research has advanced the understanding of caregiving in the context of suicidal behaviour. A systematic review of qualitative studies highlighted that a central aspect of the carer experience involves a shift to a fundamentally disrupted state of family living, characterised by immediate feelings of shame, guilt, and personal blame (Juel et al., 2021). Fear of further suicidal behaviour, unproductive relationships with health professionals, and grief regarding loss of prior family relationships represent significant personal challenges to participating in and contributing to the recovery of a previously suicidal family member (Juel et al., 2021). At the point of suicidal crisis, carers may face the trauma of witnessing suicidal behaviour and difficulties accessing specialist support (Ngwane & van Der Wath, 2019; Hellerova et al., 2022). This is followed by a period in which carers attempt to formulate effective interpersonal support strategies, a task often accompanied by pervasive anxiety about further suicidal behaviour (Nosek, 2008; Talseth et al., 2001). Carers consequently report the need for dedicated professional support, including psychoeducation, to understand how to provide effective care to a suicidal family member alongside managing their own distress (Inscoe et al., 2021; Vandewalle et al., 2021).

Internationally, a majority of people who die by suicide experience mental health difficulties (Cho et al., 2016). People with a diagnosis of 'serious mental illness', including schizophrenia and bipolar disorder, are overrepresented within this group (Schmutte, Costa, Hammer, & Davidson, 2021). However, it is currently unclear how specific mental health experiences, including psychosis, interact with suicidal behaviour to influence carers' experiences. A relatively small body of evidence indicates increased psychosocial distress in carers of people with psychosis in the presence of suicidal behaviour amongst those they support. Suicidal behaviour, as assessed by carers and service users, is associated with greater caregiver burden and poorer family functioning (Hsiao et al., 2020; Hsiao & Tsai, 2015). Sibling carers of people experiencing early psychosis report lower quality of life, poorer relationship quality and more negative caregiving experiences in the presence of suicide attempts, relative to carers whose siblings have no history of suicide attempt (Bowman et al., 2014, 2015, 2017). This literature presents a consistent picture of higher levels of distress amongst carers in the presence of suicidal behaviour in psychosis. Yet to date, explanations for these associations are yet to emerge from the literature. Absence of dedicated in-depth research in this context is significant given that people with psychosis are at increased risk of suicidal ideation, suicide attempts, and death by suicide (Yates et al., 2019).

One possible interpretation of this evidence is that the presence of suicidal behaviour exacerbates patterns of distress known to contribute to caregiver outcomes in psychosis. Beliefs in greater perceived severity and chronicity of psychosis, and attributions of self-blame for not providing adequate care, are associated with increased caregiver distress, including burnout (Fortune et al., 2005; Onwumere et al., 2008; Onwumere et al., 2017; Vasconcelos et al., 2017). These responses show similarity to carers' descriptions of ongoing distress in the context of suicidal behaviour, often focused on anxieties around the possibility of suicide (Buus et al., 2014) and an undermined sense of being able to control and reduce suicide risk (Simes et al., 2021). It is also currently unclear whether suicidal behaviour exacerbates specific difficulties highlighted by research with carers of people with psychosis. This includes loss of personal and social resources, highly distressing and recurrent crises, and ongoing uncertainty regarding the trajectories of families' futures (Cairns et al., 2015; Shiraishi & Reilly, 2019). Carers consistently report the need for increased psychosocial support, including access to psychosis-specific information to support caregiving and improved access to health care services that take an inclusive approach to working with carers (Oluwoye et al., 2020; Stuart et al., 2020).

To date, in-depth analyses of carers' experiences of psychosis and suicidal behaviour have not been conducted. Little is therefore known of how the interaction of these experiences may manifest in carers' lives. This gap in evidence is significant in light of recommendations in clinical guidelines for the management of both psychosis and suicidal behaviour for the provision of carer-focused support (NICE, 2014b, 2019). While calls have been made for clinicians to proactively build collaborative relationships with carers and place families at the centre of suicide prevention strategies (Edwards et al., 2021) an absence of tailored healthcare support remains a central feature of carers' experiences in suicidal crises (Dransart & Guerry, 2017; Vandewalle et al., 2021). Advancing the understanding of carers' lived experiences in this specific context may assist with identifying changes to policy or practice that could help to better meet these needs. The current study therefore aimed to understand the personal psychosocial impacts of caring for someone with psychosis who has experienced suicidal behaviour.

5.4 Methods

Participants

Participants were recruited through advertisements posted to UK-based health research websites including the NIHR People in Research website and Lancaster University's Spectrum Centre for Mental Health mailing list, and on relevant mental health charity websites for Rethink Mental Illness and the McPin Foundation, respectively. Eligible participants self-identified as having provided care to a friend or family member who had at any time experienced psychosis and suicidal behaviour, defined broadly as any form of suicidal experience, including suicidal thoughts and/or attempts (O'Connor & Nock, 2014). All participants were aged 18 or over, lived in the UK and had sufficient English language proficiency to provide written informed consent and participate in a one-to-one qualitative interview.

Data collection

Semi-structured, one-to-one interviews were conducted by the first author (PM) between July 2020 and July 2021. For most of this time, the UK was under national lockdown as a result of the Covid 19 pandemic. Therefore, all recruitment and data collection was conducted remotely. Participants were offered the option to take part through online video call or by telephone. A topic guide (appendix D) was used flexibly to facilitate in-depth exploration of participants' experiences, consistent with semi-structured interview technique (Low, 2013). To promote acceptability of the study procedure, the study protocol and topic guide was reviewed in discussion with a patient and public involvement group at Lancaster University which included mental health service users and carers. The topic guide was then piloted in practice interviews with a service user researcher and two clinical psychologists experienced in qualitative methods.

Interview procedure

At the beginning of each interview, the researcher reiterated that the purpose of the interview was to understand participants' experiences of supporting a friend or family member with psychosis who had experienced suicidal behaviour. Participants were given the opportunity to ask questions about the study before their interviews, were encouraged to take breaks as needed, and were reminded that they could withdraw from the study at any time without giving a reason. At debrief, participants were engaged in casual conversation to mitigate distress that may have arisen during the interview. All participants were offered a resource list of national support services for carers and a wellbeing check by phone 24 hours after the interview if necessary.

Analysis

Interviews were audio-recorded, transcribed verbatim by the author, and analysed on NVivo 12 (QSR International Ltd, 2018). The research team approached the analysis from a critical realist perspective. This philosophy of science accepts the existence of a social reality independent of the researcher, but acknowledges that any knowledge produced through the research process is mediated by the human act of interpretation, which is necessarily influenced by their background and beliefs (Maxwell, 2012). As such, reflexive thematic analysis (Braun et al., 2021c; Terry et al., 2017) was chosen as an appropriate analytic strategy, as this approach recognises the active role of the researcher in the production of necessarily partial and socially situated knowledge, and encourages explicit reflection on this role throughout the process. Consistent with the procedure of reflexive thematic analysis (Braun et al., 2021c; Terry et al., 2017), the first author conducted data familiarisation during transcription of interview recordings and re-readings of each interview transcript. An inductive analysis was deemed appropriate given the absence of existing research related to the research topic. Coding was therefore not completed with reference to a pre-existing conceptual framework. Initial line-by-line coding was completed by attaching short labels to sections of text with a focus on identifying the personal meaning of participants' experiences related to the research question. Initial codes were grouped by shared meaning into more substantive candidate themes at a higher level of abstraction to capture patterns of personal meaning across interviews. Groups of codes were labelled to create candidate themes. A candidate thematic structure was shared by the first author with the wider research team for iterative refinement based on written feedback. Data sufficiency was considered with reference to the concept of information power, which identifies factors impacting on the utility of qualitative data (Malterud et al., 2016). As such, the decision to cease data collection and the parallel process of data analysis was informed by the research team's judgement of data quality based on the richness of interview transcripts, the sufficiency of the data in addressing the research question, and the resources, timescales and practicalities associated with the research project.

Rigour and reflexivity

Quality standards for reflexive thematic analysis emphasize the importance of research practices consistent with the theoretical assumptions of reflexive qualitative research (Braun & Clarke, 2019). In adopting a critical realist approach, the research team acknowledges that personal perspectives inevitably influence each stage of the research process (Maxwell, 2009). Several steps were therefore taken to embed reflexivity throughout the research process and thus improve rigour. First, the first author wrote a reflexive statement prior to beginning the study and discussed this with team members experienced in qualitative methods, thus acknowledging the pre-conceived perspectives and motivations carried into the study. Reflexive notes were taken throughout the study to maintain awareness of researcher positionality. This was aided by the insider-outsider heuristic proposed by Hellawell (2006), used by the first author to frame reflexive thinking and writing across the study. In recognition of the partiality of the first author's interpretive perspective, the developing analytic framework was reviewed by members of the research team with diverse academic and clinical experience related to psychosis and suicidal behaviour, and discussed in consultation with three mental health service user researchers to 'sense-check' the meaning articulated by each theme (Byrne, 2021).

Ethical considerations

This study received ethical approval from the Faculty of Health and Medicine Research Ethics Committee at Lancaster University. Prior to interview, all participants provided informed consent via the online platform Qualtrics, at least 24 hours after receiving the participant information sheet to allow full consideration of potential participation. All data was de-identified and stored on a secure server at Lancaster University. All names presented in this paper have been changed to conceal participants' identities. Participants were offered £10 in cash or online vouchers in recognition of their contribution to the study.

5.5 Results

Twenty participants were recruited for interview. Eighteen interviews took place by telephone and two by online video call. Interviews lasted an average of 63 minutes (range: 32 - 138 minutes). A majority of participants (n=17) had supported their friend or family member for at least 1 year (range: 8 months – 30 years). Relationship types represented in the sample included friends (n=11), mothers (n=4), cousins (n=2), a sibling (n=1) and a daughter (n=1). One participant preferred not to report their relationship status, living status or time spent caring. Full demographic details are presented in table 7.

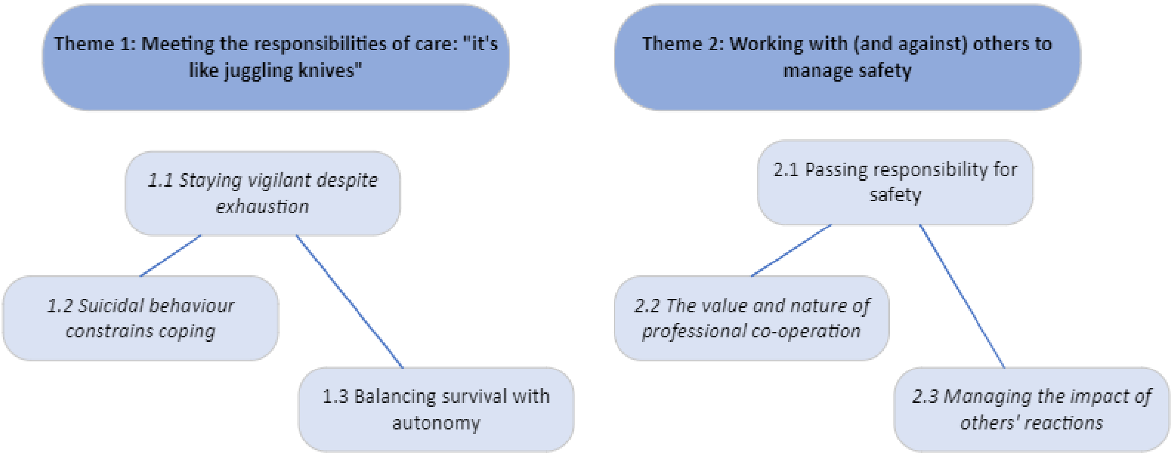
Table 7. Participant demographic details

Participant number	Age group	Gender	Ethnic group	Relationship	Time spent caring	Living together	Average time caring per week
P1	46-50	Female	British Asian	Friend	4 Years	No	10-20 hours
P2	51-55	Female	White British	Friend	15 years	No	10-20 hours
P3	46-50	Female	White British	Mother	6 Years 7 Months	Yes	>20 hours
P4	51-55	Female	White	Friend	1 Year 6 months	No	>20 hours
P5	66-70	Female	White British	Mother	2 Years	No	Varies
P6	46-50	Female	White British	Friend	2 Years 3 months	No	<10 hours
P7	56-60	Female	Other White Background	Friend	Varies	No	Varies
P8	36-40	Male	Other Mixed Background	Sibling	11 Years	Yes	>20 hours
P9	31-35	Male	Other ethnic group	Friend	1 Year	No	<10 hours
P10	41-50	Male	Pakistani	Cousin	2 Years	No	<10 hours
P11	71-75	Female	White British	Mother	30 years	No	>20 hours
P12	51-55	Male	White British	Friend	3 years	No	<20 hours
P13	41-45	Female	Other white background	Daughter	20 Years	No	Varies
P14	56-60	Female	White British	Mother	5 Years	Yes	>20 hours
P15	46-50	Female	White British	Friend	8 months	Yes	>20 hours
P16	21-25	Male	Asian/Asian British: Bangladeshi	Friend	1 Year	No	<10 hours
P17	46-50	Female	White British	Friend	4 years	No	<10 hours
P18	36-40	Male	Asian/Asian British: Pakistani	Cousin	2 years	No	<20 hours
P19	46-50	Male	White British	Friend	7 Years 3 months	No	10-20 hours
P20	26-30	Female	Asian/Asian British: Bangladeshi	Preferred not to say	Preferred not to say	Preferred not to say	Preferred not to say

Thematic overview

The analysis produced two overarching themes, each with three sub themes (figure 5). *Meeting the responsibilities of care: 'it's like juggling knives'* details how reducing risk of suicide represented a goal of primary importance for carers across contexts. However, difficulties understanding psychotic experiences, and emotional fatigue emerging from supporting someone experiencing suicidal behaviour, acted as barriers to carers' abilities to meet their perceived caregiving responsibilities. *Working with (or against) others to manage safety* reflects how a common response to this situation involved seeking the support of health professionals, with whom carers desired, but were often prevented from developing, a collaborative working relationship (theme 2).

Figure 5. Interview study 1 themes (bolded) and sub-themes (italicised)



Theme 1: Meeting the responsibilities of care: "it's like juggling knives"

Participants experienced a central tension between the provision of vitally important instrumental and emotional care, and the need to buffer the ongoing stresses of their circumstances to continue caregiving. For many, their own wellbeing was deprioritised in pursuit of service users' physical safety when the severity of psychotic experiences triggered suicidal behaviour.

Sub theme 1.1: Staying vigilant despite exhaustion

A central thread running throughout many carers' experiences was the necessity of remaining vigilant to the emergence of suicidal behaviour. Constant vigilance combined with participants' competing life pressures manifested in feelings of chronic stress, described by one participant as "*almost like being on the edge of a precipice all the time*" (P3, mother). As one carer noted, the unpredictable nature of their family member's behaviour during periods of psychosis acted as a trigger for their own mental health difficulties:

"I'm always being on the toes, like, are they gonna do, are they gonna harm themselves? You can't do this every day because it's like being in an army, you never know what's gonna happen you know, like being in a warzone, you never know what's gonna happen, and it will kill you. We'd develop trauma and anxiety" (P13, daughter)

Carers experienced a heavy sense of responsibility for supporting someone at risk of suicide, yet also faced a painful sense of uncertainty surrounding how to respond appropriately. During psychotic crises, converging caregiving responsibilities combined to create highly stressful situations, with carers' concerns about safety necessitating hypervigilance to signs that things could go wrong. Reflecting on the period following a psychotic episode, one participant recalled:

"it's exhausting, it's stressful, it's, it's like juggling knives, you know, you're trying to do the best for the person but you're also slightly terrified, you're also dealing with the family, girlfriend, you know, if he's in trouble you're dealing with other people that you don't know, trying to explain what's going on, erm, you know, it's constant attention, at those times, you've got to be sort of, hypervigilant, and, yeah, it's, when he struggles, it's a full-time job" (P19, friend)

In these circumstances, judgements regarding the extent to which suicidal behaviour was imminent were made more challenging by the presence of psychotic experiences, perceived as confusing and exhausting to try to comprehend:

"somebody's after him, he owes somebody money, somebody's gonna kill him, erm, you're never quite sure in the end whether they are, or he made it up, or he thinks it's true. You just can't, you haven't got the energy to follow it through…it is quite exhausting" (P2, friend)

This evidently impacted some carers' views of their ability to maintain vigilance to ongoing suicide risk and provide interpersonal support during psychotic episodes. For example, one participant described how distressing exposure to psychotic experiences caused them to question their own perception of reality, necessitating a step back from the interpersonal context of caregiving to maintain their own wellbeing:

"I have good days where I'm, you know, mentally able to give her support, show love, show encouragement, I try and distract her, and get her to think more realistic…I must say

there are days when, I, oh my god, I can't cope with this…I started being a little bit paranoid about people and the way I, so, it just, it's hard to describe but it just felt like I was picking up on some of her traits and behaviours…I had to then make a decision to keep a bigger distance" (P10, cousin)

Sub theme 1.2: Suicidal behaviour constrains coping

Carers emphasised both the importance, yet also the difficulty, of developing self-care strategies in the context of ongoing concern about suicidal behaviour. Making time for activities such as exercise or reading was important for providing, "*pure escapism…it just gets you out of the situation really*" (P3, mother). Others attempted to define a more boundaried approach to caregiving to allow them to remain supportive:

"If I had to spend with her more than a couple of hours, I would lose my boundaries, and I would just think, either I would end up saying things which are not appropriate, or I would completely disengage with her and not ever make contact" (P10, cousin)

However, setting boundaries was not always possible, particularly amongst those who perceived their support as essential to service users' feelings of safety. For example, one carer was reticent to pursue respite out of concern than doing so would risk a deterioration in their family member's mental health: "*he said he used to just panic at the thought of knowing that I wasn't around…there would be some catastrophic event that happened every time that I tried to go away"* (P11, mother). Although this seemed a particular issue for very close family members and those in traditionally the most intense caring roles, such as mothers, the sense of being trapped and unable to set boundaries was also experienced by friends. One participant felt trapped by the perceived necessity of providing support during crises:

“If they ring you in an emergency you don’t want to just put the phone down….sometimes you feel like doing that. But it’s just very difficult. Cos it’s, cos it’s, at that time, it’s like, as I say, it’s having a huge effect on me… I feel…claustrophobic” (P1, friend)

Professional coping support primarily focused around managing the ongoing emotional impact of the situation and on learning how to more effectively cope with psychotic experiences. The former included a desire to step away from the pressurised interpersonal context of caregiving, for example, by talking to: “*somebody completely outside of the situation just to be able to offload onto*” (P11, mother); while the latter represents a more direct need for psychoeducation: “*I knew that he was, you know, psychotic, but I didn’t know exactly what he was going through, if I had more information I could have reacted better*” (P9, friend).

Sub theme 1.3: Balancing survival with autonomy

Tensions emerged within caregiving relationships where carers’ sense of their own supportive responsibilities were in conflict with service users’ willingness to accept their help. One carer described how her family member did not recognise their own experience of psychosis and was therefore reluctant to engage with health professionals, even at times of increased suicide risk: “*I can see that they feel offended when they’re offered the medication, or we talk about the illness, but we still have to do something, safety comes first*” (P13, daughter). This tension was particularly heightened for another participant, whose family member had been expressing suicidal thoughts and behaviours over an extended period of time:

“he spent so long not wanting to be on this earth, erm, that it’s a horrible position to be put in as a parent, erm, do you, you know, do you carry on battling to make sure that they

are still on this earth or do you let them do what they want, what they so patently want to do? (P11, mother)

This reflection on the difficulty of navigating the appropriate balance between one's own desire to manage suicidal behaviour and the recognition of service users' autonomy pervaded one participant's experience of recovery following a psychotic episode, described as:

"*a balancing act all the time between how much leeway do you give the young person, so they can be independent, so they can make all the choices that the health professionals tell us they should be able to, and, how much do you protect them from themselves?"* (P14, mother)

While participants reflected on the difficulty of identifying personal boundaries, especially as they related to responsibility for living, a notable exception included a carer whose recognition of the limit of their ability to entirely eliminate suicide risk informed a protective attitude of acceptance. Reflecting on the possibility of their friend's death by suicide, this carer noted:

"I'm an optimistic realist, really, I hate it when people, you know when people say, don't worry, it'll all work out in the end and people have all these clichés…rather than burying my head under the sand, and then if she was to kill herself be totally hysterical, because if she did kill herself, I wouldn't be totally hysterical because I'm kind of expecting it" (P4, Friend).

Theme 2: Working with (and against) others to manage safety

Carers described the vital importance of help from others during periods of psychosis involving suicidal behaviour and how they tried to cultivate and manage these supportive relationships, particularly with health professionals. When participants were able to access health services, they valued welcoming and validating interactions, yet many encountered little acknowledgement of the importance of their role as close caregivers. Caregiving often took place within complex social networks that presented additional interpersonal challenges for some carers.

Sub theme 2.1: Passing responsibility for safety

Suicidal situations in which carers sought professional healthcare support often developed rapidly, were chaotic and distressing, and involved contacting emergency or crisis services. Input of mental health services was perceived as helpful for de-escalating suicidal crises and managing ongoing suicidal behaviour safely, thus relieving carers of their sense of uncertainty and anxiety: *"when she was in hospital that first time, while it was horrific when she was taken in, over 5 weeks it was like a real rest…because we knew she was safe, and it was a secure environment"* (P14, mother). However, sometimes this support ended abruptly, with a jarring shift of responsibility for the safety of a loved one passed back to carers to manage on their own. Reflecting on interactions with medical staff following a suicidal crisis, one carer noted, "*I was absolutely flabbergasted when they walked off, and then the doctor came along and said right, you can go home with her, you know, in the next 20 minutes*" (P17, friend), and, similarly, another encountered the attitude: "'*you've been medically discharged, you're not our problem', erm, and it happened over and over and over again"* (P11, mother)

Beyond the context of hospital settings, challenges with understanding the often-opaque health and social care system and difficulties with continuity of care contributed to carers' feelings of frustration and disempowerment. Seeking access to professional support was described by one participant as leading to:

"the feeling of you are bashing your head against the brick wall of the system…just being that person continually ringing people going, ok right so what's happened about this and have you done that, and was, is the bit that's really frustrating" (P2, friend)

As such, carers noted how services specifically designed to reduce help-seeking demands through timely advice, especially regarding how to navigate the mental health system and who to speak to in crisis situations, could have had a significant positive impact if it had been offered in that manner:

"someone who's absolutely panicking as they're watching their loved one, you know, fall apart in their eyes, and just, someone saying 'ok, this is what you need to do now', and that would, oh god, the difference that would make" (P19, friend)

Sub theme 2.2: The nature and value of professional collaboration

Participants who were in contact with mental healthcare teams sought collaborative relationships with staff, focused around delivering optimal support for their loved ones. Carers were comforted in situations where healthcare support was readily accessible and transparent: "*his treatment was fantastic, and there was always someone there to discuss things with and to talk about plans"* (P19, friend). A central aspect of positive relationships with services was the carer being an active and respected member of that team, who contributed to the dynamics of understanding what was happening in the interplay between psychosis and suicidal behaviour. Reflecting on their extensive experience of interactions with health services following psychotic crises, one carer noted:

“the most important support would be to be treated as a member, a valid member of the team...and actually listened to, rather than just being seen as ‘oh, that’s Mark’s mum, she’s just a mum’, you know, she wasn’t just a mum” (P11, mother)

Collaborative relationships with professionals were made possible by sensitive and engaging interpersonal interactions, characterised by “*empathy, I suppose, and understanding*” (P20), with one carer stating that in crisis situations involving professionals “*the tone of voice matters the most*” (P1, friend). Indeed, professionals’ interpersonal communicative styles could have significant impacts on carers’ experiences of suicidal crises. One participant highlighted how personal disclosure of a staff members’ own lived experience was particularly validating:

“one of the crisis team actually had been through something similar with her own daughter and she recognised what we were going through and stopped and said, look it’s ok…please don’t worry, we’re going to take him somewhere safe, we’re gonna talk to him, we’re gonna do this, that” (P3, mother)

However, several participants had experienced dismissive and oppositional attitudes, exacerbating their distress. This was described by one participant as: “*a huge lack of empathy or understanding or…reassurance or any of those things that you may naively expect*” (P2, friend). Some saw this problem as rooted in the view that carers are seen as adjacent yet redundant to the relationship between healthcare professionals and service users. Reflecting on their caregiving experiences, participants recalled, “*the theme that runs through all of it is me not being listened to*” (P11, mother), and:

"not all professionals, it's not all, but some, unfortunately my experience, and that of lots of people I know, is the majority is they tend to disregard what patients and family, friends, carers say, it's, they seem to confuse, erm, authority, which they have, with superiority, especially epistemic superiority" (P15, friend)

This comment locates the essential barrier to collaborative relationships with the reluctance by (some) professionals to recognize carers as credible sources of valuable, clinically relevant information.

Sub theme 3.3: Managing the impact of others' reactions

Caregiving experiences were embedded within wider relational contexts that had significant impacts on both the lives of carers and those they cared for. For some, this made it necessary to mediate between service users and other social contacts in order to buffer the distress caused by mental health crises. One carer recalled that, during a psychotic episode, they "*had to hide it completely from my dad, because he'd lost my mum, and he was not coping at all*" (P3, mother). This additional responsibility was considered by another carer, also a mother, as an important yet overlooked aspect of the family response to the disruptive experience of repeated psychotic crises:

"*the effect on the rest of the family, I mean I said before, I have a daughter who is 3 years older than David was, erm, and it blighted her life…that's not explored at all, the effect it has on the family*" (P11, mother)

Conversely, other carers attempted to protect those they supported from the potentially triggering impacts of other family members' views of their mental health:

"she's got severe psychosis, very very, suicidal ideations…but my cousin's sister gets very misunderstood, because sometimes there are a lot of nasty, harsh words said, 'she just wants attention, she's never gonna commit suicide, it's just her way of getting, you know, attention… it worries me because I'm thinking, if she feels alone, in the wrong hands, they might actually tip her over the fence, where she does actually, act it out" (P10, cousin).

In this quote, suicidal behaviour is seen as attention seeking, which not only reduces the support from the wider family for the individual with psychosis, but also minimises the distress and challenges that the carer is facing in trying to manage this risk.

Socio-cultural factors such as the perception of mental health, represented additional considerations for carers to manage in interactions with wider social contacts. Referring to cultural influences on help seeking, two carers noted specific influences of community background on engagement with mental health support: *"…the background, there's a lot of stigma around mental health…it's not even on the obvious level of being embarrassed or shy about the whole thing, it's just that they don't have that idea of 'yeah, I've got to get help" (*P4, Friend), and similarly:

"*because of the community and the background, we come from, it being such a difficult topic to broach, how, where do you go? And of course if you do go somewhere somebody could see you, or somebody that you know could be there….one person becoming unwell, especially with mental health problems, then can affect the rest of us"* (P8, sibling)

One carer located issues of stigma as being rooted in societal failures to open conversations about psychosis or suicidal behaviour: *"they keep saying mental health is more out in the open now… it's not the kind of mental health problems that we're talking about, which are hidden, still hidden"* (P11, Mother).

5.6 Discussion

This is the first qualitative interview study to examine the psychosocial impact of caring for someone with psychosis who has experienced suicidal behaviour. A state of uncertainty contributed to significant personal distress for carers who, even in the absence of a clear sense of how to provide support to a friend or family member in this situation, shouldered immense responsibilities for ensuring their safety. Carers also expressed a tension between holding responsibility for life maintaining support and knowing when and how to pass this responsibility both to health services and a person experiencing a motivation to end their life. Health professionals able to identify with and validate role of carers in this context, and who were able to hold some of the responsibility of care for those in distress were highly valued, though not consistently available.

Previous research has indicated that the presence of suicidal behaviour in psychosis is associated with a range of detrimental psychosocial outcomes for carers, including poorer quality of life, family functioning and family burden, relative to families that do not report suicidal behaviour (Bowman et al., 2014; Hsiao et al., 2020; McDonell et al., 2003), yet potential explanations have remained limited. The present study highlights potential mechanisms by which this may occur. The first relates to the specific unique difficulties presented by the interaction of psychotic experiences and suicidal behaviour. Psychotic experiences, including unusual beliefs and the unpredictable nature of behaviour that can occur during periods of psychosis, can be barriers to carers' making sense of what their friend or family member is going through, the degree of suicide risk, and therefore what might help make the situation safe. This context renders attempts to provide support at this time highly distressing, leading to emotional. Secondly, the experience of psychosis and suicidal behaviour appeared to exacerbate and intensify the impact of known issues faced by carers of people with psychosis. This includes difficulties with balancing caregiving against carers' own emotional wellbeing (Oluwoye et al., 2020), accessing and collaborating with professional support services (Wainwright et al., 2015), and managing caregiving responsibilities in the wider context of stigma and family disruption (Shiraishi & Reilly, 2019).

Findings here highlight how a key concern for carers in this context involves balancing their caregiving responsibilities with their ongoing distress, in order to remain vigilant to signs of suicidal behaviour. Interviewees' thoughts and emotions, including anxiety focused on suicidal behaviour and a perceived inability to manage their loved one's mental health, overlap with psychological factors identified in previous research as important determinants of negative caregiving experiences in psychosis (Jansen et al., 2015a; Kuipers et al., 2010), such as low perceived controllability and high severity of psychosis. Furthermore, experiences expressed in the current study including pervasive worry, the need to moderate involvement in caregiving due to the immense pressures of providing support in this context, and watchful attentiveness to the possibility of an outcome as grave and consequential as the suicidal behaviour of a loved one, may naturally limit opportunities to employ adaptive coping strategies, such as problem-focused approaches and acceptance, which are associated with improved caregiver wellbeing (Fortune et al., 2005; Onwumere et al., 2011). Notably, one carer's acceptance of the possibility of suicidal behaviour appeared to confer some protection from anticipatory distress linked to the possibility of their friend's suicide.

Implications for service provision

This study raises important implications for health service provision for both service users and carers. Carers play vitally important roles in mediating between service users and healthcare professionals at transitions into and out of health service settings. Interviewees noted how feeling acknowledged and listened to during interactions with health professionals represented a key support need. Health professionals may therefore wish to draw on strategies for improving meaningful engagement with carers that are both interpersonally sensitive and account for carers' unique and potentially highly valuable contributions to understanding service users' circumstances. The UK-based Zero Suicide Alliance describes best practices for engaging with families and carers of people experiencing suicidal behaviour, which directly relate to the issue raised by participants in this study (Zero Suicide Alliance, 2021). They suggest that interactions should, where appropriate, involve the seeking of information from social networks that may contribute to improved service user outcomes; signposting to carer-relevant services offering support and information tailored for helping people understand and manage suicidal behaviour; and an approach to information sharing that accounts for service user consent yet prioritises safety.

The transition from health services to community care (and vice versa), represents a shift of responsibility for maintaining the safety of a service user from health professionals to carers. This study highlights how unsupported transitions out of the what carers perceive as the relative safety of healthcare settings can be highly distressing for carers, particularly where risk of suicide remains. Services may wish to consider how best to prepare carers for this transitionary period by identifying context-specific actions to promote carer self-efficacy and service user safety. A range of strategies may meet this need. For example, Edwards et al. (2021) suggest that services could be proactive in discussing with carers plans for how to create a physically safe environment post-discharge; how ongoing risk will be monitored;

likely triggers or risk factors to be avoided or mitigated; and easily accessible referral options to support continuity of care. This could build a sense of shared responsibility, rather than a feeling that responsibility for a service user's safety is being passed back onto carers.

It should be noted that the wider context of service provision is likely to influence carers' perceptions of health services. Importantly, healthcare staff likely to come into contact with carers of people with psychosis who are experiencing suicidal behaviour need to be adequately trained and supported to provide person-centred care to both service users and carers. This could include ensuring staff are confident in applying best practices for information sharing with carers when supporting people who are suicidal (Zero Suicide Alliance, 2021). Survey data from a large sample (n=2331) of clinicians working in mental health services identified that developing strong relationships with service users and staff is a hallmark of good practice in the context of suicide prevention (Littlewood et al., 2019). However, health services require time, resources, and capacity to implement optimal care into routine practice. In the UK, there is growing demand for mental health support which is occurring against a worrying background of health service recruitment challenges and poor staff retention that requires long-term strategic planning to resolve (Anderson et al., 2021). While not determined by a single factor, success in meeting the goal of improving term carer support and preventing suicide will be bolstered by addressing these wider systemic challenges.

Implications for further research

This study represents an initial exploration of caregiving in the context of psychosis and suicidal behaviour. Further research dedicated to understanding key contextual factors, such as carers' socio-cultural backgrounds, type of relationship, and length of time caring, is vital to developing this evidence base and informing the design of effective, context-specific support for carers. Dedicated investigation of the roles and personal impacts for different carer groups, including under-researched groups such as ethnic minorities and siblings, therefore represents an important avenue for further research. As highlighted by one participant here, families' critical attitudes about psychosis can trigger distress and increase anxieties around suicidal behaviour. This is significant in light of evidence that family critical comments are associated with increased risk of suicidal ideation in schizophrenia (Lopez & Weisman de Mamani, 2020) and somewhat consistent evidence that high-expressed emotion is associated with poorer outcomes for people with psychosis (O'Driscoll et al., 2019). Further understanding these interpersonal dynamics, particularly the reciprocal and longitudinal relationships between carer and service user behaviour in the context of suicidal behaviour in psychosis, is important for understanding these interpersonal influences and may direct attention to potential avenues of intervention development for carers.

Strengths and limitations

This study contextualises the limited yet consistent body of quantitative evidence showing increased risks of carer distress in the context of suicidal behaviour and psychosis Bowman et al., 2014; Hsiao et al., 2020; McDonell et al., 2003). Individual interviews allowed carers to talk about their personal and often highly distressing experiences in-depth, exploring what was important to them, and an inductive thematic analysis ensured that the findings reflected the key issues they raised. Broadening inclusion criteria to reflect a legal definition of 'carer' contributed to a sample comprising a high proportion of participants who were friends of those they supported, thus capturing the perspective of a broad range of social contacts. These findings represent a perspective not typically described in research with carers, which characteristically draws on samples of family members (Oluwoye et al., 2020; Shiraishi & Reilly, 2019). However, the study also had some limitations. This is a UK-based convenience sample recruited during the Covid 19 lockdown. This is a unique social climate, limiting transferability and possibly influencing participants recollection of the support they have received from services which were often highly restricted at the time of interview. The sample consists of participants volunteering to be interviewed and so is likely to include those with a strong desire to share their story, possibly because it was particularly negative. The sample is heterogenous in terms of age, gender, ethnicity, and carer relationships, making it difficult to draw firm conclusions about how these variables may influence carers experiences. It is probable that the psychosocial impact of caregiving and carers' support needs vary across the illness trajectories of those receiving care (Peng et al., 2022). Understanding carer experiences in more specific related contexts, such as early psychosis or when in contact with emergency services, is likely to further advance this literature and generate context-specific recommendations for service delivery.

Conclusion

Carers supporting people with psychosis and suicidal behaviour seek to offer safety-focused interpersonal support, whilst also managing significant personal emotional impacts, and challenges with finding appropriate professional care. Carers require more empathic and inclusive support that is readily accessible at times of suicidal crisis and continued support during transition back into the community. Support with understanding the specific links between the experience of psychosis and the likelihood of suicidal behaviour, is also likely to benefit carers attempting to understand how to respond to a friend or family member in distress.

5.7 Methodological reflection

Interviewing at a distance

The interviews conducted as part of this thesis took place primarily over the phone with some by video call. It is impossible to verify, but interesting to consider, whether the absence of visual cues to aspects of my identity (e.g., my age, ethnicity, and professional affiliation) influenced participant engagement with their interviews. I certainly found it easier to focus on verbal interaction without having to think about how I was being perceived based on how I looked, and I hope that from participants' perspectives, being able to take control over aspects of the remote interview (including where they were and how they looked) facilitated disclosure and engagement. Relatedly, as this study was not framed as sitting within a health service context, it could be that participants were disinhibited from sharing challenges they have had with health professionals as they were not interacting with a health professional and the interview did not occur within a clinical space.

From my perspective, I found it difficult to gauge participants reactions, especially to potentially emotionally distressing aspects of their interviews. For example, silence could represent participants becoming emotional, but equally it could just be that they were taking a second to think. It was difficult to sense participants' emotional reactions through their voice alone, and therefore quite challenging to know exactly where to guide the conversations. For this reason, I tried to be mindful of allowing participants to feel that they were in control and consciously used pauses, and pre-warnings around sensitive topics (‘do you mind if I switch topic and ask you about x…’) to try to give the interviews a gentle and inquisitive, rather than interrogative tone. However, I did often feel some anxiety around probing particularly distressing aspects of participants experiences, given the limited tools I had in the moment to make sense of what was happening and therefore how to respond appropriately. On reflection, I think I should have more proactively and confidently explored these aspects of participant experiences.

Chapter 6. Carers' understandings of the relationship between psychosis and suicidal behaviour. A qualitative interview study.

6.1 Chapter introduction

This chapter presents a qualitative analysis examining the question "What are carers' understandings of the relationship between psychosis and suicidal behaviour amongst those they support?". This question was formulated in response to research presented in earlier chapters of this thesis which emphasises how carers are often challenged by understanding the nature of the mental health difficulties of those they support, including their reasons for suicidal behaviour, and how to respond effectively to mitigate risk of suicide. As such, understanding how carers conceptualise suicidal behaviour and its relation to psychosis may help to elucidate how exactly this challenge is negotiated in the specific context of psychosis.

6.2 Abstract

Background

While carers play important roles in supporting people with psychosis, little is known of how carers conceptualise the interaction between psychotic experiences and suicidal behaviour. This study therefore investigated carers' understandings of the relationship between psychosis and suicidal behaviour amongst those they support.

Methods

Twenty semi-structured individual interviews were conducted with adult carers who had supported someone with psychosis and suicidal behaviour, defined as any form of suicidal ideation or attempt. Data were analysed using reflexive thematic analysis.

Results

The hidden and often confusing character of psychotic experiences, and the highly distressing and chaotic nature of suicidal crises, presented carers with significant barriers to understanding the mental states of those they supported. Carers drew direct links between suicidal behaviour and the content of psychotic experiences, such as voices, and also described how psychosis leads to suicidal behaviour through its profoundly destabilising impact on the wider life circumstances of those they support. Carers sought to personalise their support strategies in light of their growing understandings of the way in which psychosis exerted influence on suicide risk yet remained sensitive to the need to draw on support from health services to prevent suicide in particularly high-risk situations.

Conclusion

Carers perceive psychosis as exerting highly idiosyncratic and escalatory influences on the likelihood of their friend or family member experiencing suicidal behaviour. Helping carers to develop contextualised understandings of suicidal behaviour in psychosis, to identify specific strategies for identifying signs of developing risk, ways of mitigating escalation of associated distress, and what to do in crises, should be important goals for health services in contact with carers.

6.3 Introduction

Care provided by family, friends, and other social contacts is described by the European Commission as a cornerstone of healthcare provision (Zigante, 2018). Carers often represent vital sources of instrumental and emotional support for people with mental health challenges, including psychosis (Fleury et al., 2008; McCann et al., 2015). Psychotic experiences include hallucinations, which often take the form of voice hearing; delusions, which are typically strongly held, distressing beliefs others may find unusual or lacking evidence; and challenges with mood and cognition (Cooke, 2017). Care provided by social contacts for people experiencing psychosis has an estimated value to public finance of over £1 billion in the United Kingdom alone (Schizophrenia Commission, 2012) and longitudinal research suggests that people with psychosis who report feeling socially supported experience improved clinical outcomes, including more time in remission and fewer hospitalizations (Norman et al., 2005; Tempier et al., 2013). The vital importance of carer support in psychosis has been recognised by NICE (2014b), whose guidelines state that healthcare services should support carers with understanding psychosis and managing their own wellbeing.

Previous research has emphasised that the experience of supporting someone with psychosis can be highly demanding. As explained by the CMCP (Kuipers et al., 2010) carers' perceptions of the nature of psychosis are key determinants of their emotional and behavioural responses. For example, negative subjective appraisals of the impact of psychosis, including expectations of detrimental future outcomes resulting from psychosis and an inability to cope with its impacts, are associated with long-term carer distress (Barrowclough et al 2014; Kuipers et al., 2010). Conversely, carers who appraise their caregiving as including more positive experiences, for example, those characterised by impressions of positive impacts on the relationship with the person they support, are less likely to experience distress linked to their caregiving responsibilities (Jansen et al., 2015b). Carers’ interpersonal responses informing the emotional environment, as described by the concept of expressed emotion (EE), also make important contributions to carer and service user experiences. High EE, defined by highly critical or emotionally overinvolved relationships, is associated with poorer carer wellbeing and increased risk of relapse in psychosis (O'Driscoll et al., 2019). In contrast, families’ expressions of emotional warmth may reduce the likelihood of relapse amongst people with psychosis (Ma et al., 2021). As noted in a literature review by Jansen et al. (2015a), existing evidence supports the suggestion that carers’ perceptions and resulting emotions and behaviours represent understandable, yet sometimes unhelpful reactions, often based in fear or misunderstanding of psychosis. These theoretical insights have informed models of intervention intended to modify such beliefs with a view to reducing carer and service user distress (Lobban & Barrowclough, 2016; Onwumere et al., 2018).

Despite these advances in theory, research and evidence-based support, to date, there has been no in-depth investigation of carers’ perspectives of psychosis and its relationship with co-occurring suicidal behaviour, defined here as any form of suicidal ideation (including motivations, compulsions and/or plans) and attempts (O'Connor & Nock, 2014). This gap in existing literature is significant for three primary reasons. First, the experience of psychosis has been consistently linked to increased likelihood and severity of suicidal behaviour. Clinical samples of people experiencing psychotic disorders show elevated risk of suicide attempts and death by suicide (Barbeito et al., 2021; Nordentoft et al., 2015) and in large population surveys, psychotic experiences are associated with increased likelihood of subsequent suicidal ideation and attempts (Bromet et al., 2017; DeVylder et al., 2015). This implies that supporting a friend or family member who is experiencing psychosis and suicidal behaviour is a relatively common but as yet under investigated phenomenon.

Second, psychological pathways to suicidal behaviour in psychosis are influenced by social support likely to involve close friends and family members. As per the Schematic Appraisals Model of Suicidal Behaviour, amongst people with psychosis, lack of available social resources are an important aspect of negative self-appraisals that can contribute to the formulation of suicidal ideation (Johnson et al., 2008). This is consistent with qualitative research highlighting how psychosis can lead to breakdowns in social networks, with the resulting loss of social connection, isolation, and alienation exacerbating suicidal thinking (Skodlar et al., 2008; Xanthopoulou et al., 2022). However, perceived social support is associated with reduce risk of subsequent psychotic experiences (Crush et al., 2018) and suicidal behaviour (Christensen et al., 2014). Indeed, resilience to suicidal experiences in psychosis is bolstered by social support from significant others (Harris et al., 2019). In-depth exploration of carers' perspectives of providing this interpersonal support is, however, absent in existing research.

Third, there is a limited yet consistent body of evidence indicating that carers experience poorer psychosocial outcomes when their family members with psychosis also experience suicidal behaviour, relative to carers whose family members do not. A series of studies conducted in Australia show that amongst young people, those with siblings whose medical records reported psychosis and a previous suicide attempt experienced lower quality of life, relationship quality, and appraised their caregiving experience as more negative compared with siblings whose brother or sister with psychosis had not attempted suicide (Bowman et al., 2014, 2015, 2017). Similarly, in dyadic research, both carer and service user-assessed suicidal behaviour is associated with poorer caregiver outcomes, including impaired family functioning and greater caregiver burden (Hsiao et al., 2020; McDonell et al., 2003). Mechanisms by which this increased psychosocial impact may occur are as yet unarticulated and may be elucidated by targeted in-depth qualitative research.

Research conducted with carers of people who have experienced suicidal behaviour, but who have not experienced psychosis, provides some insight into the way in which carers make sense of the experience of those they support. Initially, carers report shock, disbelief, and a disempowering sense of uncertainty (Asare-Doku et al., 2017; Daly, 2005). Nosek (2008) describes how carers of people at risk of suicide embark on a process of experiential learning, described as moving along the 'not-knowing – knowing continuum'. Here, by seeking information about the causes for and severity of ongoing suicidal behaviour, carers develop an understanding of their situation sufficient to inform a trial-and-error process of intervening to manage suicidal behaviour. This could include attempting to distract their loved one during periods of low mood and contacting appropriate health services during periods of particularly high risk (Nosek, 2008). Indeed, a central support task for carers during this time relates to the identification of appropriate strategies to mitigate the likelihood of suicide and promote recovery. Following suicide attempts, carers report attempts to foster a tranquil home environment, prompting engagement with treatment and remedial activities, and aim to promote a positive sense of self amongst those they support (Sun & Long, 2008). The way in which these challenges are influenced by the additional context of supporting someone experiencing psychosis, such as attempting to understand the content and impact of delusional beliefs (Onwumere et al., 2016), remains unclear.

In summary, carers' perspectives of psychosis and suicidal behaviour are important determinants of caregiving behaviours and carers' emotional responses (Dransart & Guerry, 2017; Kuipers et al., 2010). However, it is uncertain how carers perceive the interaction of psychotic experience with suicidal behaviour and how this knowledge informs their impressions of their caregiving relationships. The purpose of the present study was therefore to investigate carers' understandings of the relationship between psychotic experiences and suicidal behaviour and explore how these understandings inform the support offered to friends and family members at a time of co-occurring psychosis and suicidal experience.

6.4 Methods

Participants

This study used an opportunity sampling strategy. Study advertisements were posted to online health research networks and mental health charities in the UK. Eligible participants were:

- Carers, including family members, friends, or partners
- Self-identified as having supported someone with any form of psychosis and suicidal behaviour
- Aged 18 or over
- Lived in the UK
- Had sufficient English language ability to provide informed consent and participate in individual interviews

Data collection

Individual semi-structured interviews were conducted by the first author by telephone or online video call. Interviews followed a semi-structured interview guide (appendix B) which was developed in consultation with a PPI group and piloted with a service user researcher prior to interview.

Analysis

Verbatim interview transcripts were uploaded to NVivo 12 (QSR International Ltd, 2018) for manual analysis. Analysis progressed through the following stages and was informed by guidance for reflexive thematic analysis (Braun & Clarke, 2021c; Terry et al., 2017):

- The first author took extensive field notes and transcribed the recorded interviews. This facilitated the process of data familiarisation.
- The first author conducted initial coding and theme generation. Coding involved attaching short labels to sections of text. These labels were intended to articulate the personal meaning of participants' experiences in relation to the research aim.
- Codes were grouped into initial candidate themes by bringing together those that highlighted a prominent aspect of shared meaning.
- Initial themes were organised with reference to each other to produce a candidate thematic framework, named, and reported with supporting illustrative quotes. The first author used reflexive writing to maintain critical awareness of positionality throughout this process.
- This framework was shared repeatedly with the wider research team for iterative feedback, during which themes were reviewed, refined, and re-named, where necessary. The research team included academics and clinicians with varied backgrounds related to psychosis, suicidal behaviour, and caregiving.

- This thematic framework was shared and discussed with three service user researchers with diverse expertise by experience in caregiving and psychosis. This sense checking exercise involved reviewing the credibility of the results and their wider meaning in relation to implications for services.

Ethical considerations

This study received ethical approval from Lancaster University Faculty of Health and Medicine Research Ethics Committee. All participants provided written consent prior to interview. Participants received £10 in recognition of their contribution to the study.

6.5 Results

Twenty semi-structured interviews were conducted. Two were by Microsoft Teams and 18 by phone (mean duration = 63 minutes). Notably, majorities were aged 41 or older (n=15) female (n=13), friends of those they supported (n=11) and did not live with the person receiving care at time of interview (n=17). Full demographic details are presented in table 7.

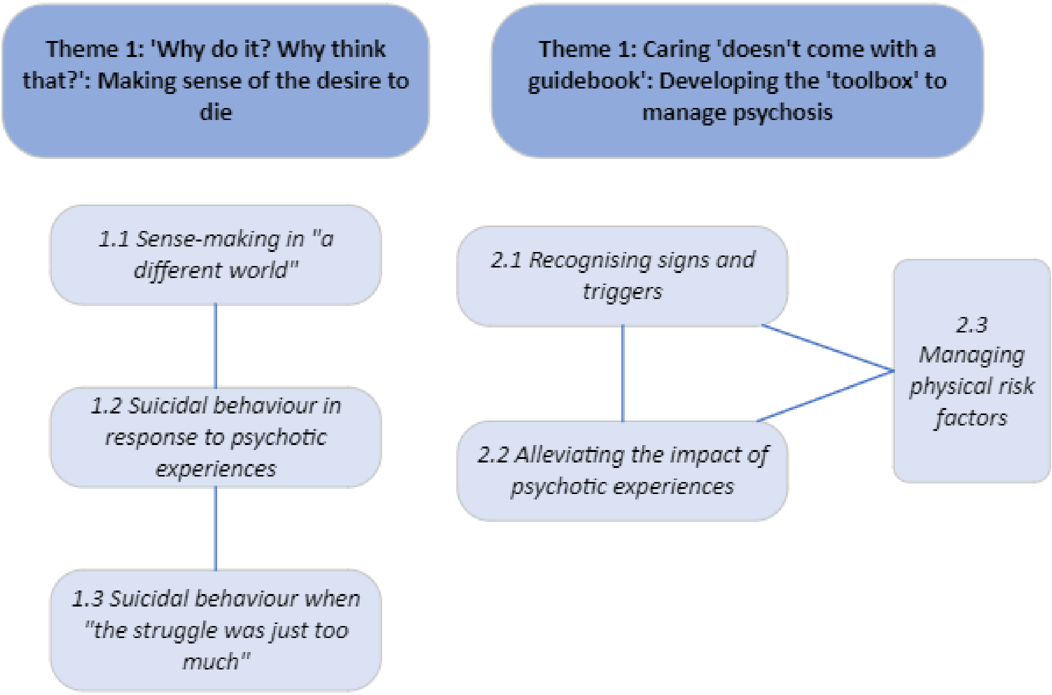
Table 7. Participant demographic details

Participant number	Age group	Gender	Ethnic group	Relationship	Time spent caring	Living together	Average time caring per week
P1	46-50	Female	British Asian	Friend	4 Years	No	10-20 hours
P2	51-55	Female	White British	Friend	15 years	No	10-20 hours
P3	46-50	Female	White British	Mother	6 Years 7 Months	Yes	>20 hours
P4	51-55	Female	White	Friend	1 Year 6 months	No	>20 hours
P5	66-70	Female	White British	Mother	2 Years	No	Varies
P6	46-50	Female	White British	Friend	2 Years 3 months	No	<10 hours
P7	56-60	Female	Other White Background	Friend	Varies	No	Varies
P8	36-40	Male	Other Mixed Background	Sibling	11 Years	Yes	>20 hours
P9	31-35	Male	Other ethnic group	Friend	1 Year	No	<10 hours
P10	41-50	Male	Pakistani	Cousin	2 Years	No	<10 hours
P11	71-75	Female	White British	Mother	30 years	No	>20 hours
P12	51-55	Male	White British	Friend	3 years	No	<20 hours
P13	41-45	Female	Other white background	Daughter	20 Years	No	Varies
P14	56-60	Female	White British	Mother	5 Years	Yes	>20 hours
P15	46-50	Female	White British	Friend	8 months	Yes	>20 hours
P16	21-25	Male	Asian/Asian British: Bangladeshi	Friend	1 Year	No	<10 hours
P17	46-50	Female	White British	Friend	4 years	No	<10 hours
P18	36-40	Male	Asian/Asian British: Pakistani	Cousin	2 years	No	<20 hours
P19	46-50	Male	White British	Friend	7 Years 3 months	No	10-20 hours
P20	26-30	Female	Asian/Asian British: Bangladeshi	Preferred not to say	Preferred not to say	Preferred not to say	Preferred not to say

Thematic overview

Figure 6 provides an overview of the thematic framework resulting from the analytic process. This includes two over-arching themes, each with three sub-themes. Carers tried to understand the causes of suicidal behaviour emerging from the experience of psychosis (theme 1) to inform appropriate action to mitigate suicidal behaviour (theme 2). This was described as a process of learning by experience, through which some participants transitioned from a disorienting state of disempowerment (theme 1.1) to a period of relative stability in which nuanced understandings of psychotic experiences allowed them to actively moderate the impact of psychosis on suicidal behaviour (theme 2.2).

Figure 6. Interview study 2 themes (bolded) and sub-themes (italicised)



Theme 1 – "Why do it? Why think that?": Making sense of the desire to die

Unusual behaviour attributed to psychosis represented a significant barrier to making sense of service users' mental states, particularly in participants' early caregiving experiences. Growing recognition of risk factors and triggers to worsening distress appeared to confer confidence in proactively responding to signs of psychosis. While some carers conceptualised psychotic experiences as directly leading to suicidal behaviour, for example via commanding voices, psychosis was also understood to cause a devastating impact on quality of life, contributing to a desire to escape emotional pain through suicide.

Sub theme 1.1 – Sense-making in "a different world"

At the onset of psychotic episodes, carers found the unusual experiences of their friends or family members highly distressing and difficult to interpret. During this disorienting time, often characterised by immensely stressful crises, understandings of the specific link between psychotic experiences and suicidal behaviours were typically limited. Carers therefore had little choice but to be reactive and rely on instinct in responding to suicidal behaviour during psychotic episodes: *"I didn't know anybody who'd been through this...you're trying to keep your young, your child alive, and you feel that you're in a different country in a different world, with no experience, it's crazy really"* (P3, mother)".

Carers highlighted specific challenges with conceptualising the mental states of those they supported and therefore how to respond effectively. A particular challenge related to how the content and causes of psychotic experiences are typically hidden, especially during acute periods of distress: "*...for people all around to try to understand what's going on underneath all of that, make sense of it and do something that will work, you know, erm, it is difficult*" (P7, friend). Fear and powerlessness were common consequences of carers' difficulties with sense-making, with one participant reflecting on how this uncertainty prompted thoughts such as: "*How else can I help? I have self-doubts. It keeps people in the family in emotional limbo, you know?"* (P13, daughter*)* and, similarly:

"Their family, people closest to them, are absolutely terrified…what do we do? How do we do this? Where do we go? Who do we turn to? All of those things are crashing around them at the time while they're also trying to help the person, you know, and it's a hugely, hugely frustrating, confusing, and scary time" (P19, friend)

For many participants in the early stage of their caregiving journeys, lack of a clear way to mitigate the distress associated with psychotic experiences led them to draw on emergency or crisis care in response to suicidal behaviour, the only support options that appeared appropriate for the severity of the situation:

"I just kept saying, 'it's all right, it's all right, it's all right. That's the only thing I could think of just to calm her down but that didn't work. It didn't work because she was seeing, you know [hallucinations]…she's been in A&E many times and I've took her to A&E many times" (P1, Friend)

In the absence of an understanding of psychosis that could inform ways of offering emotional support to reduce suicidal behaviour, managing the physical safety of a friend or family member was a primary and reflexive strategy for carers at this confusing and frightening time.

Sub theme 1.2: Suicidal behaviour in response to psychotic experiences

Exposure to suicidal crises and the personal experience gained through providing care during these situations helped some carers to identify causal connections between the content of psychotic experiences and suicidal behaviour. This included a voice that directed suicidal behaviour: "*I don't think that she tells herself to kill herself, I think sometimes the voices…I think it's her voices that take over*" (P10, friend), and, "*9 times out of 10, the hallucinations, the delusions, 'they told me, they told me to open the window and jump out, they told me to take the knife and start cutting'*" (P12, friend).

Situations characterised by anxiety or low mood were frequently identified as triggers to a pathway of distress that could exacerbate the severity of psychotic experiences and lead to suicidal behaviour. Regarding their friend's voice hearing, one participant noted that:

> *"it would occur at periods of time, usually in the wake of a period of sustained stress, and erm, and then she would experience, erm, a certain voice, Alex, and Alex was the suicidal voice*…*when the voice is so bad Sam can't resist it, and her voice is telling Sam to hurt herself and she's hitting herself and you know, I can't do anything to intervene, and you know, that's really, it's really painful to see Sam in that kind of state of mind" (*P15, friend)

Another carer described how this pathway towards suicidal behaviour related to the directive content of a controlling voice, which prompted the service user to hide their distress. This limited help-seeking and increased risk of self-injury: "*He bottled everything up because if he spoke out about any of his unusual thoughts or his paranoia…his voices would go mad at him. And that's when he'd self-harm*" (P3, mother).

These comments illustrate how carers framed psychotic experiences as exerting an escalatory influence on the distress of those they supported. This exacerbated suicidal ideation and culminated for some in self-injury.

Sub theme 1.3: Suicidal behaviour when "the whole struggle was just too much"

Carers also perceived the wider psychosocial impact of psychosis as a key factor contributing to service users' motivations to end their lives. This typically occurred in the wake of more acute periods of psychotic experience and related to their profoundly destabilising impact on service users' life circumstances. As one carer recalled: "*I got a phone call from him…he just said, 'I can't do it anymore'…he'd tried to take his own life*" (P3, mother).

Suicidal behaviour was, in these situations, characterised as a way to escape the pain caused by psychosis, rather than as a response to the content of specific psychotic experiences. "*I understand that they're trying to kill themselves 'cos they are in pain as well, you know, all this pressure, muscle pain and everything comes with psychosis and being unwell*" (P13, daughter). Another carer identified a similar pathway from the impact of psychosis to suicidal thinking:

> *"It gets unbearable for her, I think she gets very agitated, very frustrated, gets really unbearable for her, she loses it, she can't sleep at night, she's pacing up and down, and you know, she's probably got, her kids make fun of her at times, she's probably got her husband, shouts at her at times, there's probably times when he has enough and can't cope and then I think it gets too much for her, and just thinks 'I'm better off dead'"* (P10, cousin)

These situations, especially when sustained for extended periods of time, were described as particularly high risk for suicide: "*it was just too much for him, he was just tired…the whole struggle was just too much*" (P11, mother). Factors underlying this suicidal behaviour included emotional exhaustion, loss of previously valued relationships and social roles, and the desire to escape from a life marked by intense distress:

"her whole, you know, identity, and obviously she's a mum and stuff, so she's lost that, she's lost her mum and her dad and her brother…she wants to commit suicide because she doesn't think that she will ever recover from the psychotic episode" (P4, friend)

Theme 2 – Caring 'doesn't come with a guidebook'. Developing the 'toolbox' to manage psychosis

As carers developed deeper understandings of the idiosyncratic relationships between psychosis and suicidal behaviour, some were able to implement sophisticated support strategies based on this knowledge. Typically, carers aimed to prevent the above-described escalation in distress by avoiding or attenuating psychotic experiences, thus moderating the likelihood of further suicidal behaviour. This represents a transition in the caregiving relationship, from an early point at which *"you're watching someone you love deteriorate, and there's not much of an answer…it doesn't come with a guidebook*" (P8, sibling) to a stage at which *"he has a toolbox of things to call on, so the [psychosis], it hasn't gone away, but he's now got a toolbox to call on when he's struggling"* (P3, mother). However, managing physical risk factors for suicidal behaviour, such as means of self-injury, and being able to escalate severe suicide risk to appropriate services, were described as essential to maintaining service user safety across contexts.

Sub theme 2.1: Responding to signs and triggers

As carers identified psychosis as a trigger to subsequent suicidal behaviour, learning to manage suicidal behaviour involved recognising, avoiding, and mitigating the impact of specific psychotic experiences. This required carers to develop an acute sensitivity to shifts in service user thinking and behaviour that could indicate the onset of unusual distressing experiences, a process which was facilitated by carers' intimate understandings of those they supported: *"as a parent, as a carer, you know those signs, cos you're there all the day, you know, all the time….you pick up when things are slightly changing*" (P14, mother), and, "*some of it is really subtle and I don't know whether you would pick it up but, you know, he used to bite his nails… for other people, a lot of those things probably wouldn't be picked up*" (P2, friend).

Avoiding triggers to psychotic experiences, or factors that could exacerbate their severity, represented an important strategy for limiting worsening distress. One such strategy involved distracting family members and friends from their emerging unusual experiences. Recreational activities, eating, exercise and encouraging self-management strategies represented ways to "*sort of calm things down with a normal activity*" (P2, friend), however, such approaches became more challenging in periods of acute psychotic experience:

*"her voices are completely negative…just basically says it's not worth you living, you'll be better off gone, and often she can, she has strategies to try, you know, control them, she'll listen to audio books cos it's loud and she's got something else in her ears, erm, that type of thing, but the more low she gets, and the more she starts to hallucinate, and things like that, the worse they get, and that's obviously what triggers her to then try and self-harm" (*P14, mother).

Sub theme 2.2: Alleviating the impact of psychotic experiences

Over time, some carers built in-depth understandings of how specific psychotic experiences were related to suicidal thoughts and behaviours. Some used this knowledge to alleviate associated distress by directly challenging unusual beliefs by, for example, "*trying to make him, well, try and make him understand that actually at home he was safe, and that there wasn't anybody in the back garden looking in*" (P8, sibling). One carer highlighted how, using gentle questioning, they could highlight inconsistencies or anomalies in her son's logic, which was sufficient to loosen his firm belief in distressing unusual thoughts:

> *"…he was thinking somebody was following him, you know, you'd say, ok, erm, so why is he following you? Why are you important? And his answer would be 'because I know about the network and they're going to kill me'. Why have they not killed you already? And that would then make him think, he'd be like, 'oh? Yeah, that's a point', so you'd sort of challenge all those unusual thoughts, and just get that tiny glimmer, of, 'yeah, that is a bit strange', and once you had him with that tiny glimmer of, 'oh, maybe it's not right'…that was a massive step" (P3, mother)*

Others saw value in providing patient empathetic listening during escalating periods of suicide risk linked to psychosis. For one carer, active listening could provide an outlet for their friend, with the explicit aim of keeping them engaged in conversation to outlast the psychotic experience. Reflecting on a period of increased suicide risk, this carer recalled:

> *"maybe, as I say, we're on the phone for 3 hours and on the third hour…he'll say to me, 'well actually, Tim, I think I'm tired now, it's better I go to bed, isn't it now? Or I'll go and lay down, they're not gonna come back tonight, are they, the voices?', …. 'no, they're not, and you're gonna have a good sleep, and tomorrow is another day'"* (P12, friend)

Taking a similar approach, another carer noted that compassionate listening was the most appropriate strategy for supporting someone experiencing unusual thoughts that may be resistant to logical refutation: *"…listening and validating what he's saying, you know,* *because unfortunately that's his reality. Like, you know, I'm not gonna see the patterns in things that he does, and he's not seeing the kinds of solutions I see*" (P8, sibling). Although listening to experiences of psychosis could be disturbing, tiring, and frightening, the opportunity to manage distress through cathartic discussion these experiences was seen by one participant as essential to reducing suicide risk:

"when she talks about the suicidal impulse, you know, you know, I know it's not then to say don't, don't, don't. What helps is for me to listen, to hear her saying why she's feeling this way, and to understand, and giving her the kind of space to express herself, and that validation, because I can understand why she feels that way. Helping her feel heard, validated, that makes her feel calmer, that makes her feel more centred and reassured, and that pulls her back from the edge" (P15, friend)

Sub theme 2.3: Managing physical risk

The above-described process of learning by experience, where exposure to suicidal situations helped carers to develop ways to manage psychotic experiences, was not a universal and linear process. Where understandings of the relationships between psychotic experiences and suicidal behaviour were limited, or in particularly severe periods of psychotic experience where interpersonal support was perceived to be inappropriate, carers instead sought to manage the physical environment to reduce risk of suicide. This included increasing the frequency of contact with a service user in order to monitor their behaviour:

"When they're having this psychosis, you can't really talk to them, you know? Their thoughts are racing, they can't really focus on what I'm saying, so just to be there and keep them safe because they kept telling me they're gonna end their life that day" (P13, daughter)

Carers also described maintaining keen awareness of potential means of self-injury, for example: "*I'm sleeping on the floor next to her…we keep drugs locked up, when she's on acute stage we keep bleach locked up, we have 1 knife out, you know*" (P14, mother), and, *"sometimes we had to physically keep her in the house, cos she was harming herself, you know, she tried to hang herself, or breaking things in the house, so sometimes we had to physically interfere"* (P13, daughter). Indeed, many carers recognised the limits of their ability to manage suicidal behaviour in psychosis in the community and thus sought emergency or mental health services to help establish safety: *"you don't really manage it…you have to call the ambulance, you have to get somebody to give her something, inject her, I don't know" (*P20), and, similarly: "*he was suicidal, he would wake up in the night as well, roam around, roam around, it came to an extent home treatment had to be called immediately…we can't manage it*" (P18, cousin).

6.6 Discussion

This study aimed to investigate carers' perspectives of the relationship between psychosis and suicidal behaviour. Suicidal behaviour was considered to be both directly related to the content of psychotic experiences and more indirectly related to highly detrimental systemic consequences of psychosis. Carers who developed contextualised understandings of the nature psychotic experiences used this to identify corresponding strategies for managing suicidal behaviour, including avoiding triggers to psychotic experiences to limit worsening mood, challenging unusual beliefs, and active listening and validation of distress. However, carers also reported managing the physical environment to reduce means of self-injury and seeking professional intervention, essential to keeping those they supported safe.

Carers’ reflections on attempts to mitigate suicide risk by engaging in compassionate and attentive emotional support are consistent with prior qualitative research with carers of people with suicidal behaviour (Garcia-Williams & McGee, 2016; Ngwane & van Der Wath, 2019; Sellin et al., 2017). As identified by Player et al. (2015), identifying ways to ‘interrupt’ the pathway to suicide attempts is of vital importance to friends and family members, and can include distraction, practical activities, and emotion-focused support. This study presents two important findings in the specific context of psychosis. First, participants recalled a highly disorientating initial experience characterised by difficulties making sense of the confusing and hidden nature of psychosis amongst those receiving support. As has been highlighted in previous qualitative research (Cairns et al., 2015) carers, especially in early psychosis, may have relatively little opportunity to formulate a detailed understanding of psychotic experiences and therefore what may help reduce their severity. This is particularly significant where such an understanding is necessary for determining how to manage suicidal behaviour. Second, while carers sought to offer emotional support and foster physically safe environments to moderate suicide risk, as in research with non-psychosis samples (Sun et al., 2009), these strategies were contextualised with reference to the specific content of psychotic experiences. Indeed, carers used their intimate understanding of their friend or family member, and their growing knowledge of psychosis, to refine and personalise their emotional and practical support.

Carers’ focus on developing strategies for managing suicidal behaviour highlights the vital importance of empowering carers to identify solutions and experience a sense of control over their circumstances. As per the CMCP, in the absence of such strategies, carers and their families may become ‘stuck’, inspiring feelings of defeat, exhaustion, and fatigue (Kuipers et al., 2010). Consistent with this, there is evidence to suggest that greater caregiving self-efficacy amongst carers of people with psychosis is associated with reduced burden of care (Durmaz & Okanli, 2014; Ramzani et al., 2019). In the present study, carers described the development of context-specific support strategies primarily via personal experience, through which they identified caregiving behaviours that appeared to moderate the distress associated with psychosis and thus suicide risk. This suggests that accelerating the development of caregiving self-efficacy in the context of suicidal behaviour in psychosis could represent an important strategy for reversing the distressing sense of uncertainty highlighted here in participants’ early caregiving experiences. In addition to specific support strategies for psychosis and suicidal behaviour, providing carers with knowledge of how to access health services when managing suicidal behaviour in the community becomes impracticable, will also likely promote carers’ abilities to manage particularly severe psychotic crises.

Clinical implications

Practical resources that are adaptable to carers’ individual circumstances, such as guidance for how to speak with a friend or family member who is experiencing suicidal thoughts, or local mental health crisis resources including immediately accessible telephone support services, may help carers address needs for actionable advice in this context. Moreover, widening the availability of family interventions for psychosis, which include information about psychosis, crisis planning, communication skills, and structured problem solving (McFarlane, 2016), is likely to address carers’ desires for understanding how to provide appropriate care for suicidal friends and family members. Less resource intensive interventions may also promote caregiving self-efficacy during crises, such as advanced directives that can inform clinician-carer interactions during acute periods of distress (Maître et al., 2013) or care support plans that prepare families for how to respond in situations of increased suicide risk (Stanley & Brown, 2012). Support planning alongside carers may benefit clinicians by capitalising on carers' often intimate understandings of the patterns of thinking and behaviour experienced by those they support, such as triggers to psychotic experiences.

Implications for further research

Qualitative research conducted with carers, in addition to service users and clinicians, has helped to advance this literature by highlighting how interactions between these key groups contribute to outcomes for people experiencing psychosis and suicidal behaviour (Asare-Doku et al., 2019; Askey et al., 2009; Lachal et al., 2015). Further multi-stakeholder research may help to identify implications for service delivery not elucidated in interviews with carers alone, such as the support preferences of those who experience suicidal behaviour and psychosis, the influence of EE on carer and service user outcomes in the context of suicidal behaviour, and clinicians' perspectives on their own training needs in support carers and service users. Furthermore, while systematic reviews demonstrate that carer-directed interventions for psychosis have undergone extensive development and show efficacy in intervention studies (Lobban et al., 2013; Sin et al., 2017), a recent review of interventions to support carers of people who have attempted suicide highlighted that the evidence base is characterised by relatively few high quality, large-scale evaluations (Krysinska et al., 2021), none of which were developed specifically for psychosis and therefore were not adapted to help carers and service users to manage the challenges highlighted by this study. When taken with carers' desires for assistance with developing caring self-efficacy in this context, there is a clear need for further research to develop and evaluate interventions to support carers of people with psychosis who have experienced suicidal behaviour.

Strengths and limitations

Strengths of this study include the recruitment of a sample with diverse relationship types; the depth of the data exploring such a complex issue; and the involvement of experts by experience in the design and piloting of the research procedure. The latter was particularly important given the potentially distressing nature of the research topic. Limitations include the recruitment of a convenience sample which limits transferability to more specific caregiving contexts, such as those supporting people in early psychosis; the lack of underrepresented groups, such as fathers, which would require more purposive sampling to address; and absence of clinical service user information that may have proved valuable in contextualising carers' experiences.

Conclusion

Social support is an important protective factor for both psychosis and suicidal behaviour. Carers, many of whom are those closest to people experiencing mental health problems, are well place to provide this support. However, results of this interview study illuminate how they face unique challenges in developing caregiving self-efficacy in the context of psychosis and co-occurring suicidal behaviour. Service improvements should involve offering support to carers in developing detailed understandings of the mental health of those they support, as well as improved knowledge of how to access professional assistance in suicidal crises.

6.7 Methodological reflection

Interpretive limitations

Critical realism as a philosophy of the social sciences encourages researchers to engage with the task of developing explanations of complex social phenomena (Cruickshank, 2012). Interpretation of data at the level of the empirical provides an indication of the multitude of interacting psychological and social forces that give rise to these observations at the level of the real and actual. Therefore, looking beyond the surface level meaning of the data itself is necessary for articulating these rich explanations of social phenomena. One of the challenges I experienced in this regard relates to the fact that this chapter attempts to articulate carers' understandings of someone else's experience of psychosis, which itself represents a highly idiosyncratic set of phenomena that may hold a range of personal meanings. In some sense, the double-hermeneutic procedure inherent to the process of qualitative interpretation is here infused with an additional hermeneutic challenge, whereby participants in this study necessarily make sense of the nature of psychosis experienced by those they support. This awareness made me more hesitant in making deeper interpretive claims about the data I was analysing.

This hesitation was exacerbated by the realisation of the limitations of my own interpretive perspective. Having little knowledge of key aspects of participant experiences, central to the narratives they had shared with me such as being a parent or from a particular social background, I felt tentative about making firm claims about how these clearly important contextual factors influenced my characterisation of participant experiences. Furthermore, it should be noted that many voices are not represented here, limiting the transferability of my interpretations across diverse communities. Of particular significance is the underrepresentation of people from black ethic groups, known to experience psychosis and negative interactions with services, especially crisis care, at disproportionately higher rates than other groups in the UK (Kirkbride et al., 2012; Barnett et al., 2018; Staniszewska et al., 2019). These are potentially highly significant issues directly related to the overarching research aim which are not elucidated in this research.

Though I did make efforts to draw on the advice and support of a range of other people, including experienced researchers and experts by experience, on reflection, I would if doing this research again and with sufficient resource, attempt to draw more extensively on carers' lived experience perspectives, and earlier in the analytic process. This may have assisted with generating a more nuanced and explanatory account, especially of elements of participant experience that do not overlap with my own.

Chapter 7. Thesis discussion

7.1 Chapter introduction

This chapter will provide an overview of key findings across the four previous chapters and attempt to integrate these insights with existing related literature. The relevance of these findings to the CMCP will be outlined and suggestions for further research and theoretical advances made. Implications of this research for service provision with respect to primary care, secondary care, the voluntary sector, and public health will be considered. Strengths and limitations of the methodological approach taken here will then be reviewed, concluding with a reflection on the overarching methodological approach taken.

7.2 Overview of key thesis findings

7.2.1 Summary of research findings

The preceding chapters present findings related to the research aim of understanding how carers experience supporting a friend or family member with psychosis who has also experienced suicidal behaviour. As each chapter includes a detailed discussion of results, and in the interest of conciseness, this section will outline only key findings from across the preceding chapters. Chapter aims and themes are presented in table 8. For brevity, previous chapters are referred to in this discussion chapter as follows:

- Chapter 3 is referred to as the ‘systematic review’
- Chapter 4 is referred to as the ‘forum paper’
- Chapter 5 is referred to as ‘interview paper 1’
- Chapter 6 is referred to as ‘interview paper 2’

Table 8. Overview of thesis themes by study aim

Chapter	Aim	Themes
3 ('systematic review')	Understand carers' experiences of supporting friends or family members with suicidal behaviour	1. Experiencing suicidal situations: 'Your whole life comes to a halt' 2. Seeking safety in professional support: 'I had no choice' 3. Learning to manage risk: 'what am I supposed to do?'
4 ('forum paper')	Understand the experience of supporting a family member with psychosis or bipolar disorder and suicidal behaviour as expressed in the context of online peer support	1. Suicide as the 'ultimate threat' 2. 'Bouncing from one crisis to another’ 3. 'It definitely needs to be easier to get help'
5 ('interview paper 1')	Understand the personal psychosocial impact of caring for a friend or family member with psychosis and suicidal behaviour of suicidal behaviour	1. Meeting the responsibilities of care: 'it's like juggling knives' 2. Working with (or against) others to manage safety
6 (interview paper 2')	Explore carers' understanding of the relationship between psychosis and suicidal behaviour amongst those they support	1. 'Why do it? Why think that?': Making sense of the desire to die 2. Caring 'doesn't come with a guidebook': Developing the ‘toolbox’ to manage psychosis

The overarching research aim of understanding carers’ experiences of supporting friends or family members with psychosis and suicidal behaviour was addressed within four chapters with distinct objectives:

1. The systematic review chapter synthesised nineteen qualitative studies investigating the experience of caring for a friend or family member with suicidal behaviour. Thematic synthesis emphasised three central aspects to carers' experiences: the challenge of adjusting to a context of ongoing stress and uncertainty; the need for responsive and accessible professional support to manage suicidal behaviour; and carers' own attempts to build an understanding of suicidal behaviour to inform the help they provided to their friend or family member.
2. The forum paper used data from an online, moderated peer support forum for carers of people with psychosis and bipolar disorder to explore comments related to caregiving and suicidal behaviour. Overarching themes elucidated carers' ongoing fears of the 'threat' of further suicidal behaviour, the characteristic cyclical and disruptive nature of mental health crises involving suicidal behaviour, and the challenge of drawing on emergency support during these periods, with particular focus on crisis support and its limitations.
3. Interview paper 1 was informed by twenty in-depth semi-structured interviews with carers who had supported friends or family members with psychosis and suicidal behaviour. Carers reflected on how the personal psychosocial impact of this experience relates to an ongoing tension between the necessity of providing vital, time-sensitive support to someone experiencing psychosis and suicidal behaviour, and the need to identify and prioritise their own interpersonal boundaries in order to maintain their own wellbeing. A parallel tension between the value of help seeking and the

challenges this provoke is explored, with focus on carers interactions with mental health services.

4. Interview paper two focused on carers' understandings of how psychosis and suicidal behaviour interact and inform caregiving behaviours. The difficult but necessary process of developing caregiving self-efficacy involved building an in-depth understanding of the mental states of those they supported, often made challenging by the unusual or hidden nature of psychosis. This facilitated the identification of support and help-seeking strategies that could mitigate an escalation in distress caused by psychotic experiences, which for some, was essential to reducing the likelihood of further suicidal behaviour.

7.2.2 Integration of research findings

This section integrates findings from across the preceding four chapters with prior research. It is based on three 'meta-themes', or key thematic threads running throughout this thesis. These themes were developed by the author through reflection on results from preceding chapters, reviewing relevant literature, considering reflexive notes generated across the thesis, and discussion with the project's primary supervisor. The most prominent and meaningful patterns of experience are emphasised. It is noted that other points are necessarily omitted but are discussed in depth within each chapter. These dominant thematic threads relate to carers' interrelated experiences of personal emotional impacts characterised by fear and uncertainty; the challenge of developing caregiving self-efficacy due to barriers in making sense of the mental health difficulties of those they supported; and the need for professional collaboration to promote safety.

Figure 7. Thesis meta-themes

Figure 7 highlights how carers experience an understandable and profound sense of fear in the periods that follow suicidal behaviour. The disturbing and often pervasive feeling that suicidal behaviour may reoccur leaves carers hypervigilant to signs of increased risk, leading to ongoing periods of stress and uncertainty. Often unable to develop an understanding of why suicidal behaviour had occurred, carers struggled with developing interpersonal support strategies to manage the mental health of the person they care for and ultimately reduce risk of suicide. This appeared particularly challenging in the early and more acute periods of psychosis. Amongst carers of people with psychosis, recurrent crises compounded carers' feelings of exasperation and fatigue, as did the feeling of not being sufficiently supported in the periods that follow discharge from health services. During periods in which carers were in contact with health services, carers' priorities were to keep their loved ones safe. They sought to develop collaborative relationships with healthcare staff to achieve this aim, who were perceived as most effective when accommodating of the carers' expertise and the evident difficulties of carers' circumstances. Conversely, health services who were unable to recognise and relieve carers of the heavy burden of keeping a family member safe from suicide exacerbated their already intense feelings of fatigue and frustration.

7.3 Integration with existing literature

7.3.1 Fear and uncertainty

Fear, apprehension, uncertainty, and anxiety were common responses to carers' anticipation of further suicidal behaviour (systematic review; forum paper; interview paper 1). This is consistent with other related research. Indeed, carers' fears of further self-injury and the associated overwhelming nature of uncertainty have been described as leading to feelings of 'impending doom' and being 'held to ransom' by the situation (Lindgren et al., 2010; Rose et al., 2011). In the research in this thesis, these reactions were often most prominent immediately following suicidal crises. Yet carers also identified a feeling of anticipatory anxiety in the periods that followed crisis situations, described as "emotional limbo" (P13, interview study 2) and evident in comments such as "I really know that feeling of 'as soon as I start to relax something kicks off again' as we lived with that for so long" (P27, forum paper). Difficulties with understanding of what had caused the suicidal behaviour impeded carers' sense of how to respond appropriately and therefore how to reduce this ongoing uncertainty. A feeling of being "left living in terror, not knowing why this had occurred" (P12, forum paper) appeared at the root of carers' reflexive and exhausting reliance on physically monitoring their loved ones for signs of suicidal behaviour.

As indicated by the systematic review, fear and anxiety are prominent themes across research involving carers of people who have experienced suicidal behaviour. In the additional context of psychosis, difficulties understanding, predicting, and intervening effectively are exacerbated by the unpredictable and often hidden nature of psychotic experiences. In this situation, "…for people all around to try to understand what's going on underneath all of that, make sense of it and do something that will work, you know, erm, it is difficult" (P7, interview study 2). This seemed to be linked to the sense that "you never know what's gonna happen, and it will kill you. We'd develop trauma and anxiety" (P13, interview study 1). As noted in prior qualitative research, carers sense-making, especially in early period of psychosis, is especially challenging (Onwumere et al., 2016; Wainwright et al., 2015). In the context of suicide risk, this appeared to take on an additional emotional impact, adding to carers' sense of ongoing uncertainty and fatigue: "somebody's after him, he owes somebody money, somebody's gonna kill him, erm, you're never quite sure in the end whether they are, or he made it up, or he thinks it's true. You just can't, you haven't got the energy to follow it through…it is quite exhausting*" (P10, interview study 1)*.

As in prior research with carers of people with psychosis (Mui et al., 2019) and separately in research with families affected by suicidal behaviour (McLaughlin et al., 2014), ongoing stress and fatigue against a background of emotional and physical support tasks have significant impacts on carer wellbeing. It should be noted that for many people, their experience of psychosis extends across extended periods of time. While estimates of duration of psychosis vary by study design, longitudinal research suggest that only a minority of people experiencing nonaffective psychosis or schizophrenia will experience clinical recovery (Taylor & Jauhar, 2019), while between 25 and 50% of those diagnosed with schizophrenia will attempt suicide (Cassidy et al., 2018). Indeed, in the forum study, participants had on average supported their family member for almost a decade when they entered the REACT study and were reporting high levels of distress and were actively seeking help. Therefore, experiencing sustained periods of “being on the edge of a precipice all the time” (P3, interview study 1) may be particularly likely amongst carers of people with psychosis. Throughout these periods, the need to remain aware of potential signs of suicidal behaviour may impede carers’ self-care strategies, especially where coping strategies such as taking time away from caregiving are viewed as unfeasible due to the possibility that the risk of mental health crises may increase if they do so. It may be that the opportunity for respite is therefore limited in this specific context.

7.3.1 Barriers to sense-making and action

Carers’ priorities focused around developing an understanding of suicidal behaviour which could allow them “to take the second step…being able to cope with the behaviour” (Nosek, 2008, p. 40). Where those being supported were experiencing psychosis, learning how to mitigate or avoid the distress associated with psychotic experiences represented a necessary component of understanding how to reduce the likelihood of further suicidal behaviour. Over time, and in combination with carers’ knowledge of those they supported, some were able to identify and implement interpersonal support strategies to effectively moderate this distress. This can be understood as a transition from families feeling “at a loss themselves, clueless how to help” (P12, forum paper) to helping their loved one to develop a “toolbox of things to call on when he’s struggling” (P3, interview study 2). As identified elsewhere, a distressing sense of ‘not knowing’ (Cairns et al., 2015) how to meet carers’ personal responsibilities for the safety of those they supported was evident throughout the research presented here. In the context of suicidal behaviour in psychosis, the pressure to act combined with low perceived caregiving self-efficacy creates a particularly disempowering interpersonal environment. Indeed, psychosis was considered at times to be hidden and opaque. This appeared to exacerbate carers' sense of frustration and even desperation, evident in comments such as "…everything I do/say is wrong. She is again now telling me she wants to kill herself. I am so emotionally exhausted I don't know what to do" (P23, forum study).

For some carers, the challenge of providing support in this context contributed to a reflection on the nature of their caregiving relationship. This included attempts to determine the extent or limit of their caregiving responsibilities. Navigating the responsibilities of care became particularly challenging as the severity of the distress experienced by their loved one increased. At its most intense, one carer considered the extent to which their support was ethical: "things cannot get much worse and maybe the kinder option would have been to not interrupt his plan to die, at least he would be at peace but then I doubt I could live with that" (P10, forum study). As indicated by other qualitative research (Nygaard et al., 2019), those in the most traditionally intensive caregiving roles, especially parents, are uniquely impacted by this challenge . Notwithstanding, interview studies 1 and 2 indicated that friends also often took on significant caregiving responsibilities. Indeed, the majority of those participating in interview studies 1 and 2 were friends, suggesting that the significance of this role may have been previously overlooked in carer research which has typically focused to a greater extent on family carers.

7.3.2 The need for professional collaboration and safety

In the context of suicidal crises, professional services were called upon by carers primarily to assist with keeping their friend or family member physically safe. This occurred most frequently during crisis situations where managing safety in the community appeared untenable. Consequently, services were considered most helpful when they were perceived as accessible and responsive and took robust steps to manage suicide risk at the first point of contact. In doing so, services relieved the responsibility of preventing suicidal behaviour, and thus helped carers to manage the immediate challenges of knowing "…what do we do? How do we do this? Where do we go? Who do we turn to?" (P19, interview study 2). Indeed, where services were able to ensure service users' safety, this "…created a moment of rest, to take some time off for myself. Because I knew: they will take care of him" (Nygaard et al., 2019). Conversely, being unable to quickly access appropriately trained healthcare staff able to take proactive steps to reduce risk of suicide, or support carers in doing so, left carers feeling disempowered and unsure of how to respond (systematic review, forum study, interview study 1). Particularly important points of interaction occurred at admission to health services and transition back to the community setting. Crucially, these periods are points at which carers require information about the care their family member will receive, and their own role in the process (Clibbens et al., 2019). Yet as described here, carers do not always receive this information and, as identified in previous research, can be left feeling excluded by health services despite their vital roles in supporting their loved ones in the community (Dransart & Guerry, 2017).

Challenges interacting productively with healthcare staff have been highlighted in previous research with carers of people with psychosis (McCann et al., 2012; Wainwright et al., 2015) and suicidal behaviour (Sellin et al., 2017; Talseth et al., 2001). This was also reflected in the systematic review chapter and again amongst participants in both forum and interview studies. This experiential thread is exemplified by the comment of a participant with 30 years of caregiving experience: "the most important support would be to be treated as a member, a valid member of the team...and actually listened to, rather than just being seen as ‘oh, that’s Mark’s mum, she’s just a mum’…” (P11, interview study 1). What collaboration meant for carers varied across contexts but typically involved working towards making the situation safe for the person being supported. For some, collaboration therefore meant sharing their caregiving responsibility with health services. Others sought advice from the perceived expert authority of health services about how to manage their loved one’s mental health. In the context of psychosis specifically, some also wanted staff to listen and make use of carers’ often intimate understandings of the nature of their friend or family member’s situation to improve the support they received from services. In line with prior research (Cree et al., 2015; Dransart & Guerry, 2017), data presented here shows that the absence of interpersonally accommodating healthcare services extends carers’ feelings of disorientation and uncertainty in already highly stressful situations. This takes on an additional significance in the context of suicidal behaviour, where carers report having no choice but to reach out for help to avoid the potential suicide of their friends and family members (systematic review).

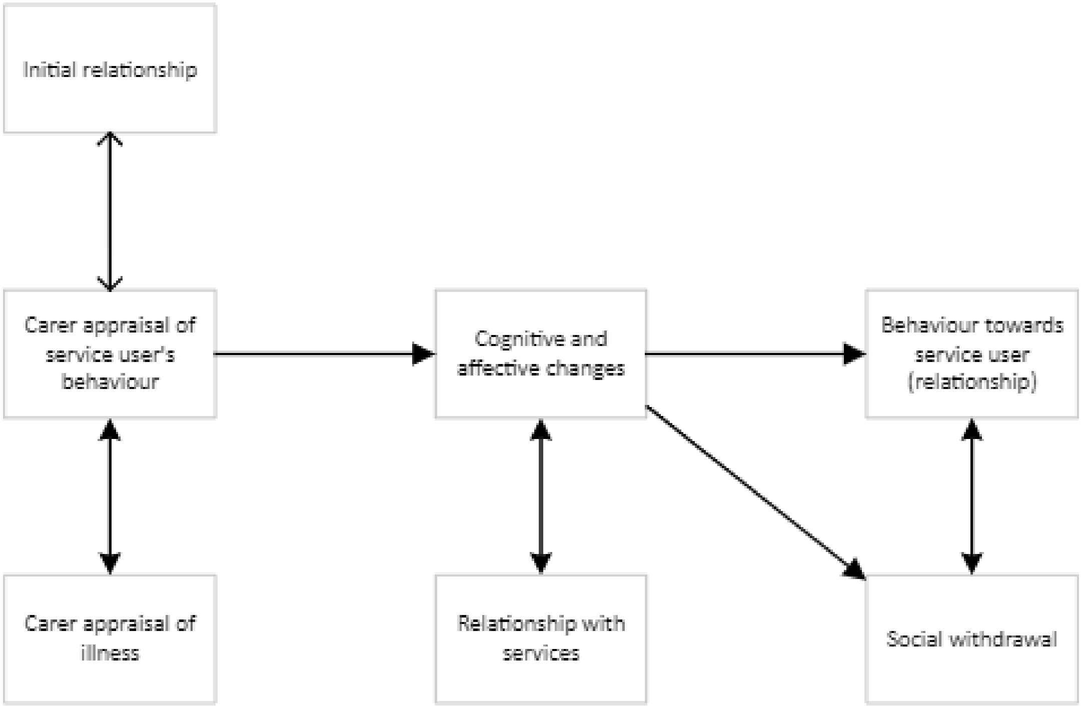
7.4 Implications for further research

7.4.1 Theoretical implications

The cognitive model of caregiving in psychosis

The CMCP is used in this thesis to situate the research presented here in the context of important theoretical concepts and prior empirical evidence. In doing so, this thesis builds on and contributes to the established body of conceptual work in this area. This qualitative investigation was inductive and thus did not seek to understand carers’ experiences with specific reference to constructs within the CMCP. However, this section highlights findings of relevance to the CMCP and is used to suggest theoretically informed avenues of further research.

Figure 1. The Cognitive Model of Caregiving in Psychosis (Kuipers et al., 2010) (reproduced with consent from the publisher).



The initial relationship

As per the CMCP (Kuipers et al., 2010), the initial relationship between carer and service user has important implications for factors such as expressed emotion, carers' appraisals, and their subsequent personal and interpersonal reactions. The interview sample recruited for the research presented in this thesis included a higher-than-expected proportion of friends, raising the question of how this relationship type may influence the cognitive pathways identified by the CMCP. Given the voluntary and typically mutually beneficial nature of friendships (and partnerships), it may be that these types of relationships are characterised by more positive initial relationships in which the responsibility of caregiving is more readily renegotiated to prioritise carers’ own wellbeing. It is notable that that while carer distress was prominent throughout the research presented here, one carer in particular represented a ‘negative case’, in that they were able to clearly identify personal boundaries as part of their caregiving role. This included recognising the limit of their own responsibly for their friend’s possible suicide, with an anticipatory acceptance of this outcome seemingly offering protection from future distress: “…if she did kill herself, I wouldn’t be totally hysterical because I’m kind of expecting it” (P4, Interview paper 1). Similarly, a conversation between carers reported by the forum paper highlighted how mothers and partners may negotiate their caregiving responsibilities differently, with the latter relationship affording the opportunity to more readily re-define interpersonal expectations about who was to blame for the service user’s mental health: “My husband and I separated for a time when he was at his most ill, he made several suicide attempts during this time and I realised that this was not my fault, it was his illness. One of my conditions for getting back together was that he engaged with mental health services and another was that he took responsibility for his own mental health” (P27, forum paper).

Further research may seek to investigate whether relationship type influences carer appraisals/attributions of psychosis and suicidal behaviour in ways that may impact subsequent caregiving behaviours and distress. For example, the systematic review chapter highlighted some carers’ experiences of guilt for their family member’s suicidal behaviour, while the forum study noted one carer’s guilt at initiating involuntary hospital admission within the context of a suicidal crisis. Indeed, guilt and blame have been identified as forms of attribution associated with carer distress (Kuipers et al., 2010), yet it is unclear whether the likelihood of these attributions vary by relationship type and/or how the additional context of suicidal behaviour influences these experiences. Better understanding the role of relationship type may be important in determining the kinds of support most appropriate for carers at this time. As per the CMCP, different interventions may be more suitable given the individual psychological characteristics of the carer (Kuipers et al., 2010). If it is the case that friendships are more likely to be characterised by low expressed emotion, for example, then as per the CMCP, targeted interventions focused on information provision, contact with other carers, and ongoing practical and emotional support may be appropriate. Where other relationships feature experiences such as limited opportunity for respite and loss of social networks, as indicated by mothers’ experiences described in this thesis, interventions to support autonomy and participation in wider life activities may be appropriate following recovery from suicidal experiences within the family.

Carer appraisals and cognitive/affective change

The CMCP focuses to a significant extent on factors that underpin carer reactions, including carers’ appraisals of psychosis and its impacts (Kuipers et al., 2010). As suggested in the forum paper and interview papers, appraisals of low controllability and high illness severity are mirrored in carers’ experiences described in this thesis. Specifically, carers reported feeling disempowered and experienced an often devasting impact on personal and family life that contributed to ongoing feelings of hopelessness. Empirical evidence suggests that carers who appraise psychosis as severe, difficult to control, likely to contribute to negative future outcomes are at increased risk of personal distress (Jansen et al., 2015a; Jansen et al., 2015b; Kuipers et al., 2010). It is suggested here that these appraisals may occur to a greater degree in the context of suicidal behaviour. This may to some extent explain the relationship between suicidal behaviour in psychosis and poorer quality of life, negative experiences of caregiving, and family burden observed, in prior research (Bowman et al., 2014, 2017; Hsiao et al., 2020; Hsiao & Tsai, 2015). This link represents a directly testable hypothesis that could advance the conceptual understanding of mechanisms underpinning caregiver reactions to suicidal behaviour in psychosis.

Relationship with services

The CMCP highlights how carers' perceptions of the involvement of services can be important determinants of their own wellbeing (Kuipers et al., 2010). The model states that frustration with services and a sense that other family members are also not coping can leave families 'stuck' – especially in the early stages of psychosis – and with feelings of defeat that exacerbate rather than mitigate the self-reinforcing cycles of difficulties experienced within the family. This appears to mirror the experience of initial suicidal crises described by some studies in the systematic review chapter, and by individual carers in the forum study and interview study 1. The additional context of suicidal behaviour requires many carers take on significant responsibility for the safety of their loved one, and the period that follows may involve loss of autonomy as they struggle to define the boundaries of their caregiving relationship. Returning a sense of autonomy (and thus reducing stress associated with this situation) to carers involves taking practical steps to reduce the likelihood of further suicidal behaviour. As per the CMCP, what is likely to help carers in this situation will vary depending on relationship type and involvement in care. In 'overinvolved' relationships, support should focus on reattributing control and supporting carer independence. For more 'critical' relationships, interventions may be more effective when focusing on stress management, respite, and joint problem solving. Offering (or directing carers to) a broad spectrum of psychosocial support options is therefore necessary to meet the needs these of these varied individual and family circumstances.

Behaviour towards service user

The CMCP suggests that carers’ behaviours towards the service users they support are related to factors including expressed emotion and carers’ attributions (Kuipers et al., 2010). For example, ‘high EE critical’ relationships may contribute to carers attributing blame for psychosis to service users themselves. These behaviours have important consequences for service users, with critical comments associated with increased likelihood of relapse (Ma et al., 2021). This takes on additional significance in the context of suicidal behaviour. A recent study by Lopez and Weisman de Mamani (2020) reported that families’ critical comments, but not other aspects of EE, were associated with suicidal ideation amongst people with psychosis. Indeed, in interview study 2, one carer reflected on the need to protect their family member from the critical comments of wider family members out of concern that they could “tip her over the fence”. This raises important implications for further research. If the association reported by Lopez and colleagues (2020) reflects a causal link between critical comments and suicidal ideation, interventions to promote constructive communication within families should be prioritised.

Research presented here focuses firmly on participants’ caregiving behaviours, including interpersonal support strategies and help-seeking. This reflects a dominant theme in this thesis related to carers’ focus on caregiving self-efficacy in reducing the likelihood of suicidal behaviour. Understandably, a central concern for carers lies in seeking immediate physical safety for their loved ones. Carer-directed support should therefore focus on promoting knowledge of how to reduce the likelihood of suicidal behaviour and where to go when this is not possible in the community. Relatedly, there is some evidence to suggest that caregiving self-efficacy in psychosis is associated with lower caregiver burden (Durmaz & Okanli, 2014; Ramzani et al., 2019). Further research may seek to investigate caregiver self-efficacy in the context of suicidal behaviour to more clearly understand how it relates to important determinants of caregiving highlighted by the CMCP. For example, on the basis of evidence presented here, it would be expected that for carers of people experiencing psychosis and suicidal behaviour, low caregiving self-efficacy would be associated with appraisals of low controllability of psychosis and therefore carer distress.

Social withdrawal

Social withdrawal has been highlighted as a significant factor in the lives of people with psychosis and their families. As per the CMCP, the impact of factors such as stigma can serve to limit access to social support for some carers (Kuipers et al., 2010). Both the systematic review and forum paper highlight how the presence of suicidal behaviour can contribute to perceived stigma and may impede carers' help-seeking behaviours. A feeling that carers have failed to protect their loved one, that others may not understand their situation, and sociocultural conceptions of the meaning of suicide may exacerbate the sense of isolation felt by carers of people who are suicidal (systematic review). Whether social withdrawal and its psychological consequences, such as poorer carer wellbeing, are more likely in the presence of suicidal behaviour amongst carers of people with psychosis remains unclear and could represent a focus for future research. This is important for the provision of appropriate support. For example, it may be that services such as online forums, which can be accessed anonymously and thus provide a somewhat safe space for the discussion of caregiving experiences, and/or digital psychoeducation, are helpful for providing access to support to carers who are socially withdrawn and may otherwise not feel able to seek help.

7.4.2 Differing needs of specific carer sub-groups

Studies in this thesis did not sample on the basis of demographic or clinical characteristics. This was done partly because this is a relatively under researched area and the aim was to understand a broad range of related carer experiences, and partly because of concerns about being able to recruit sufficient participants, particularly in the context of national lockdown due to Covid-19. However, future research may benefit from focussing on the needs of more homogenous carer groups to understand how their experiences differ. The forum study and interview studies emphasise that carers' experiences of supporting people with psychosis and suicidal behaviour can extend over many years. There appeared a chronological pattern to carers' experiences, from emergence of suicidal behaviour, escalation in distress necessitating contact with healthcare services, and periods of (sometimes partial) recovery. Better understanding how these important periods are reflected within carers' lived experiences could inform how to meet carers' varying needs over time. Needs of carers of people experiencing early psychosis are likely to be different to those whose family member is receiving more long-term inpatient mental health care (Lavis et al., 2015; Wood et al., 2021), and different still to those in contact with emergency and crisis services (Lavoie, 2018). Of particular importance is the experiences of transition between services, which, as highlighted here, is likely to be difficult to manage in the context of ongoing concerns about suicidal behaviour, where responsibility for service user safety is passed between informal and formal caregivers.

The systematic review chapter and interview paper 2 highlight how carers' experiences were to some extent shaped by socio-cultural factors. In the UK, there is evidence that members of ethnic minority groups experiencing psychosis face barriers to collaborative tailored support, which may emerge from a lack of culturally-informed mental health services (Islam et al., 2015). Patterns of service use amongst people with psychosis also vary by ethnic background. For example, in the UK, ethnic minority groups, specifically people from black ethnics groups not represented in the research reported here, are more likely to experience involuntary inpatient admission and describe coercive experiences of care (Barnett et al., 2019; Staniszewska et al., 2019). It is currently unclear if and how carers' experiences of service use in the context of psychosis and suicidal behaviour are influenced by these factors. Furthermore, understanding how specific cultural beliefs around psychosis, known to vary across ethnic backgrounds (Mirza et al., 2019), may influence carers' experiences of suicidal behaviour in psychosis is important in developing a more nuanced evidence base. Indeed, qualitative research with family caregivers of people with psychosis, and separate research with carers of people experiencing suicidal behaviour, highlight how culture shapes important aspect of the caregiving experience including the meaning of recovery, expressed emotion, experience of mental health-related stigma, and coping behaviours (Doyle et al., 2021; Sun et al., 2008). A greater emphasis on the experience of different cultural groups and these specific concepts may therefore facilitate identification of contextual factors impacting on carers in these contexts.

7.4.3 Carers' and other stakeholders' experiences

This research was conducted exclusively with carers. However, related qualitative research has sought to integrate the perspectives of other stakeholders, including service users and professionals (Lachal et al., 2015). Multi-stakeholder research is advantageous in the context of this research topic, given that all stakeholder groups play mutually influential roles in each other's outcomes. Opportunities for further multi-stakeholder research include dyadic study designs with carers and service users that explores how carers behaviours (including appraisals and expressed emotion) influence suicidal behaviour in psychosis over time, and how suicidal behaviour impacts carer outcomes prospectively. It may also be beneficial to involve health professionals in research exploring and co-designing ways in which the suggested changes to practice, such as greater caregiver communication and involvement, can be implemented into mainstream practice.

7.4.4 Longitudinal research

The introduction chapter of this thesis highlights how research into the impact of caring in the context of psychosis and suicidal behaviour is dominated by cross-sectional study designs. This is also reflected in the wider literature investigating carer experiences of psychosis (Jansen et al., 2015a), and is a limitation of the interview studies reported in this thesis. It is therefore unclear how carers' experiences change over time in the additional context of suicidal behaviour. As noted, opportunities for further research include investigation of how carer and service user experiences influence one another over extended periods. This could, for example, investigate how aspects of carer experience, including communication styles, subsequently influence the likelihood of service user suicidal behaviour. A range of methods are appropriate for understanding the temporal aspects of these experiences. These include longitudinal survey designs, experience sampling methodology, and longitudinal qualitative research using repeated interviews or diary methods.

7.4.5 Co-design and intervention research

While family interventions for psychosis have been evaluated, to date, research has not typically assessed the impact of these interventions on suicidal behaviour (Bucci et al., 2016). Furthermore, as highlighted by Krysinska and colleagues (Krysinska et al., 2021), there have been few large, high-quality evaluations of interventions to support family members following suicide attempts. There is therefore an outstanding need to develop and evaluate psychosocial interventions to support carers of people with psychosis who also experience suicidal behaviour. Research presented in this thesis highlights several areas of priority in this regard. The systematic review chapter suggests carers require support with understanding suicidal behaviour, how to respond to a family member in severe distress, and signposting to services that are equipped to help in this scenario; the forum paper suggest carers may benefit from increased access to peer support, particularly in an easily accessible and anonymous context and more structured approaches to carer-inclusive crisis care; the systematic review, in combination with the forum paper and interview paper 1, stresses the importance of developing interventions to support carers with managing their own wellbeing at periods of crisis and on an ongoing basis; and interview paper 2 highlights carers' desires for support with understanding psychosis, its link to suicidal behaviour, and associated interpersonal support strategies.

All of these support needs represent valid targets for intervention development. According to Medical Research Council and NIHR guidance, intervention development should ideally involve substantial involvement from experts by experience in order to ensure that services are sensitive to the needs of user groups (Skivington et al., 2021). Recent relevant examples demonstrate the feasibility of embedding lived experience perspectives in intervention development research in psychosis. For example, the culturally adapted family intervention study, which aims to develop family intervention for schizophrenia culturally adapted for African and Caribbean communities in the UK, was developed with extensive input from lived experience experts (Edge et al., 2018). Intervention development guidance also recommends that theory development should form a central thread in intervention design and testing (Skivington et al., 2021) on the basis that well-resourced theory development can assist with understanding why an intervention works, why it may work for some people and not others, and critical contextual factors impacting on its successful implementation. Realist theory offers an important ontological and epistemological foundation for this task, and realist methods including realist synthesis and evaluation are increasingly used to understand mechanisms that underpin mental health interventions (Pearson et al., 2015). Theory development methodologies combined with stakeholder engagement represent a promising angle on intervention design, that may assist research with meeting guidance recommendations for both of these aspects of service development (Law et al., 2021).

7.5 Implications for service provision

7.5.1 Primary care

Primary care services, such as GPs surgeries, are well placed to provide support to carers of people with psychosis experiencing suicidal behaviour. As noted in research presented throughout this thesis, many carers will be with those they support when accessing primary care. Primary care practitioners may therefore wish to consider how they can accommodate carers’ needs for information about psychosis and suicidal behaviour, and ongoing support for their own wellbeing. As noted by many carers in interview studies 1 and 2, not understanding psychosis, nor where to seek support, represented significant barriers to help-seeking and caregiving. As a point of first contact with the health and social care system, primary care providers should ensure that carers have access to informative and up-to-date signposting resources. This could direct carers to support services such as local carer groups in the community, recovery colleges, or crisis phone services hosted by mental health services. High quality psychosis and suicidal behaviour-specific information, including that provided by third sector organisations such as Mind, Rethink Mental Illness, and the Samaritans (Mind, 2017; Rethink Mental Illness, 2019; Samaritans, 2022), may help meet carers' make sense of their circumstances, and where they can go for additional support beyond the primary care setting.

A UK-based study reporting the development and evaluation of a leaflet for family members and friends concerned about suicide demonstrates the feasibility and potential of this approach (Owens & Charles, 2017). The 'it's safe to talk about suicide' leaflet was developed in consultation with key stakeholders and distributed to community settings across England, including GPs surgeries. Subsequent interviews highlighted how frontline providers of health and social care services were often apprehensive about providing advice to carers related to their concerns about suicide, with this leaflet representing a welcomed tool for professionals wishing to help concerned carers understand a complex and often under-discussed issue. This is consistent with other primary carer practitioners' needs for increased support with suicide prevention. GPs, for example, report needing specific training tailored for how to interact effectively with people experiencing suicidal thoughts, in order to assess suicidal behaviour effectively (Michail & Tait, 2016). Comprehensive, evidenced informed signposting resources are therefore likely to represent valuable tools for clinicians, as well as service users and carers.

7.5.2 Secondary care services

Emergency and crisis services

The systematic review chapter, forum paper, and interview paper 1 suggest that emergency and crisis services are common sources of support for carers of people with psychosis who are suicidal. An important implication of this thesis for emergency and crisis services relates to carers' experiences of feeling unsupported and uncertain following interactions with these services. As noted in the forum paper, structured crisis care planning, which integrates carers' views and perspectives, would be welcomed in this context. These interventions provide service users and carers with actions to mitigate the possibility of further crises, and steps to take should a crisis occur (Ferguson et al., 2021). Other brief suicide-prevention interventions may also be appropriate including, telephone-follow ups, caring letters, and crisis cards (Milner et al., 2015). Many of these interventions can be delivered by non-specialist staff, making them appropriate for a range of settings. Even where such interventions do not directly involve carers, they may go some way to help carers feel that those they care for are being supported by services and indirectly alleviate carer distress by reducing the likelihood of further suicidal behaviour. Crisis services could also offer support directly to carers without any reference to service users or sharing of any personal information. Generic information about mental health and how to support a friend or family member in a crisis does not risk breaking confidentiality in any way and needs to be routinely available.

As per research reported here, carers desire interactions with staff that are safety-focused, yet also interpersonally accommodating. As noted by one participant in the forum study, a crisis team member who was able to identify with and validate the carers' distress was highly valued. Similarly, interview studies 1 emphasised the importance of emergency and crisis services' interpersonal warmth and collaborative demeanour. Yet carers also experienced poor communication and a lack of empathy during this highly distressing time. Overcoming challenges with building more productive relationships with families during suicidal crisis has been recognised as a health service development need (Littlewood et al., 2019). In one survey of mental healthcare staff, closer contact with family members was rated as the second most important of 10 suicide prevention strategies, behind closer service user supervision by staff (Appleby et al., 2019). Engaging with carers to incorporate their unique perspectives into the situation, as desired by serval carers here, is therefore also likely to help staff understand suicidal behaviour in its social and familial context.

Specialist mental health services

This research suggests that mental health services in secondary care may come into contact with carers of people with psychosis experiencing suicidal behaviour. Psychological intervention for psychosis involving families and friends, as recommended by clinical guidelines (NICE, 2014b), is likely to meet carers' needs for developing an understanding of factors that underly suicidal behaviour in psychosis and the ability to identify concrete, personalised steps towards recovery. Family intervention may serve the dual function of improving outcomes for both carers and service users (Claxton et al., 2017; Rodolico et al., 2022). UK service evaluation shows that access to family intervention in first episode psychosis remains suboptimal and varies by region (Royal College of Psychiatrists, 2021). Efforts should therefore be made to improve service availability, including increasing resources and training for therapists to meet service needs.

The forum study highlighted how peer-support may be particularly valuable for carers, given the often-isolating experience, which may be exacerbated by stigma linked to both psychosis and suicidal behaviour. Peer support may also help meet carers needs for specific caregiving and coping strategies, consistently reported in research presented here. However, while evidence suggest that online peer support and psychoeducation for carers of people with psychosis can be implemented in a safe and acceptable manner, evidence of its effectiveness is mixed and mechanisms underpinning the impacts of these services require further investigation, as do ways of successfully implementing online services for carers into routine clinical practice (Lobban et al., 2020; Sin et al., 2022).

Evidence of carers' challenges with being considered partners in care justifies further efforts to better integrate the role of carers into health services. This includes greater uptake of initiatives such as the NHS carers' passport, increasing representation of carers in structures such as NHS patient and carer councils, and the recognition of carers' expertise by experience in staff training. Approaches that centralise the role of carers in healthcare delivery are also likely to meet this need. One example is the Open Dialogue approach to intervention in psychosis (Gromer, 2012). Open Dialogue views the service user and their social network as the target of intervention. Its relational therapeutic focus emphasises the important of listening to and integrating the perspective of service users, professionals, and carers. It can be applied in crisis services and in more longer-term support environments. These factors suggest that this approach may align with many of the preferences described by carers in this thesis. This includes the need for more substantive involvement in care, the recognition of the expertise they bring to understanding the situations of those they support, and tools to improve communication around psychosis and recovery within families. However, while some evidence of positive outcomes following open dialogue are promising, further large scale evaluation is required to determine its effectiveness (Freeman et al., 2019).

7.5.3 Voluntary sector

Voluntary sector services have important roles to play in providing support to carers of people with psychosis. Organisations such as Rethink Mental Illness host a range of relevant online and in-person services, including peer-support groups (Rethink Mental Illness, 2022). Other organisations, such as Bipolar UK, host online peer support forums which may help some participants connect with others going through similar challenges, as described by participants in the forum study (Bipolar UK, 2022). Internationally, there are a range of online resources, such as the previously mentioned ‘You are not alone’ psychoeducation platform for carers of people who are suicidal (Coker et al., 2019).Yet crucially, carers need to know that these services are available and how to access them. Initiatives such as the Hub of Hope bring together links to voluntary and public sector resources in a single online space and highlight their specific geographic locations (Chasing the Stigma, 2022). This form of signposting is likely to assist carers with finding voluntary sector support that meets their needs. It is important that other service providers who signpost to local voluntary sector services remain appraised of their service offer, availability, and contact details, and provide this information in varied and accessible formats likely to promote use by service users and carers.

A key focus for voluntary sector support lies in supporting carers with understanding how to interact with someone experiencing suicidal behaviour, a prominent support need across the research presented in this thesis. Suicide prevention charities already provide a wide range of resources in support of this form of psychoeducation. For example, health talk, PAPYRUS, and Samaritans host multi-media resources focused on interpersonal support for friends and family members experiencing suicidal behaviour, including advice with noticing warning signs, how to have difficult conversations, and how to develop a safety plan (PAPYRUS, 2022; Samaritans, 2022). Many of these initiatives are evidence-based, integrated with ongoing research, and developed alongside experts by experience. It is important that these services continue to develop and are made visible by statutory providers to broaden the reach and impact of support for carers.

7.5.4 Public health

Public health campaigns have the potential to create impact at scale, which could address wider systemic issues highlighted in this thesis. For example, Samaritan's recent campaign encouraging people to initiate small talk, and ultimately have conversations that could limit suicidal behaviour, reached over 17 million people via social media (Samaritans, 2018). However, more broadly, stigma remains a feature of the lives of people with psychosis (Mestdagh & Hansen, 2014) and those who experience suicidal behaviour (Carpiniello & Pinna, 2017). As noted in the systematic review chapter and interview study 2, this form of prejudice also influences family members. Evidence-based initiatives, such as mental health first aid training, have attempted to promote public understanding of mental health, with some evidence to suggest that this form of brief psychoeducation can promote mental health literacy and reduce prejudice (Hadlaczky et al., 2014). However, as noted by a participants interviewed for this thesis, the nature of psychosis remains hidden for many. Public health campaigns with a greater emphasis on often underdiscussed topics including psychosis are necessary to challenge this prejudice. This could focus on communicating humanising and normalising accounts of psychosis, reflecting evidence that psychosis is understood by some to represent an understandable response to life challenges which takes on a range of meanings for people across settings (Cooke, 2017).

Given the often highly detrimental impact of psychosis on those personally affected and their families, addressing factors linked to the emergence of psychosis should represent a primary public health aim. This involves addressing growing evidence for social determinants of poorer mental health, including psychosis. Risk factors include exposure to early adverse experiences, including physical and emotional abuse, poverty and economic insecurity, and stigma (Alegría et al., 2018). Public health interventions designed to prevent the emergence of mental health challenges likely to involve friends, family members and partners include parenting interventions, employment-related stress prevention, and action to prevent fuel and food insecurity (Campion et al., 2022). Public health strategies specifically related to suicide prevention should also be advanced, including responsible coverage of suicide related news and reducing public access to lethal means of self-injury (Arensman, 2017). A significant barrier to implementation of interventions that take a systemic, long-term, life course perspective on mental health include poor policy implementation, insufficient political will to allocate necessary resources, and insufficient appreciation of cultural differences in critical factors impacting on intervention acceptability (Campion et al., 2022).

7.6 Implications for policy

The WHO Comprehensive Mental Health Action Plan 2013-2030 calls for the involvement of families and carers in two primary areas of service development (World Health Organization, 2021). The first relates to the need to widen stakeholder collaboration in the design and implementation of mental health services, and related legal and policy frameworks. The second relates to the important role families and carers should play in the development of holistic and integrated health systems that promote recovery from mental ill-health. The results of this thesis suggest that further work is required at a policy level in the UK to achieve these aims. A notable limitation of existing UK policy is the lack of specific action to promote carer involvement in health service provision. Relevant programmes and strategies highlighted by the NHS long term plan are likely to support improvement in this area, including NHS ‘involvement hub’ resources designed to facilitate improvements in carer’s service development (NHS, 2019a). Yet this policy does not support targeted, objective driven, measurable change for carers. Similarly, suicide prevention policy makes important suggestions for actionable changes to key areas likely to reduce suicide, including reducing access to lethal means and targeting support at high-risk groups (Department of Health and Social Care, 2021). However, as highlighted by research presented in this thesis, families of people with psychosis (and bipolar disorder), who are at increased risk of suicide, often struggle to access sufficient assistance with managing suicidal behaviour in the community. Given that local suicide prevention policies are now mandatory in England, local authorities should seek to formalise, communicate, and assess the progress of specific measures to involve and support family members of people experiencing suicidal behaviour. Following suggestions reported here, and NICE guidance for suicide prevention (NICE, 2019), this may fruitfully include clear guidance (and regular training) for healthcare professionals on information sharing with families, implementable strategies for substantive carer involvement in service user care should where appropriate (such as templates for care plans involving family members), and ongoing support planning for carers.

7.7 Strengths and limitations

7.7.1 Design

This thesis took a critical realist approach to experiential qualitative research. An advantage of this approach is its focus on generating in-depth understandings of participants' experiences underpinned by an ontological and epistemological position that foregrounds the complex nature of social reality. In doing so, this research addressed a gap in research evidence for detailed lived experience accounts of caring in the context of psychosis and suicidal behaviour, as highlighted by chapter 1. However, critical realism, and other pragmatic mixed methods methodologies, do provide theoretical foundation for other forms of more quantitively oriented research appropriate for building on the existing evidence base. Quantitative approaches could have been suitable to more directly test specific hypotheses or theoretical explanations, such as roles of coping behaviours or cognitive appraisals, highlighted by the CMCP. Research of this kind is necessary to build a more comprehensive and more transferable understanding of carer experiences in this context.

The overarching research question was broad and informed the data collection strategies for each study. This led to a wide-ranging understanding of carers experiences, using a range of data sources, and ensured that the issues important to the participants were foregrounded in the findings. This approach also allowed the studies to occur in parallel, without requiring the findings of one to be finalised before another started. This was pragmatically important in ensuring the research occurred within the time constraints of the PhD, and especially given the additional challenges of managing Covid-19 restrictions on data collection. However, a more sequential design in which key issues identified in the review, or the forum analysis, were then used to inform the design of the interview studies, may have allowed a deeper analysis of specific issues. For example, the forum data study suggested that the nature of the familial relationship may play a crucial role in carers experiences. This could have been explored more fully in the interviews by sampling specifically for parents of people with psychosis and suicidal behaviour and understanding their specific needs.

7.7.2 Sampling

The systematic review chapter focused on caregiving in the context of suicidal behaviour, but not specifically related to psychosis. This pragmatic decision was made based on the lack of psychosis related literature combined with a desire to conduct a novel literature review that could assist with developing an understanding of lived experiences in an overlapping context. This was further justified by the presence of recent reviews focused on psychosis in existing literature (Mui et al., 2019; Shiraishi & Reilly, 2019). However, a limitation of this approach is that this research question is less directly related to the thesis research question than other studies presented here.

The REACT paper drew on a sample recruited during 2016 and 2017 for an online randomised controlled trial of an online peer support intervention (Lobban et al., 2020). A strength of the sampling strategy in this trial was its broad use of recruitment strategies. Recruitment materials were hosted on both online services, including social media and charity websites, and in-person health and voluntary services. On entry into the study, participants were both highly distressed and help-seeking. This may have represented an advantage in directing the resource to those most likely to access services. However, in the paper in this thesis, this may have limited the voices present in the dataset by excluding those managing well in the community without formal support. As noted, the sample itself is largely white, female, had access to technology to support their participation in the trial, and sufficient English language ability to understand written and video content hosted on the REACT website. This may again have influenced the perspectives reflected in the REACT paper presented here by underrepresenting those who experience barriers to English-language online services.

The interview studies described in this thesis set intentionally broad inclusion criteria to maximise participation. Participants were not required to evidence supporting someone with psychosis/suicidal behaviour and no time restriction was placed on the time between interview and their caregiving experiences. Participants were not sampled on any specific demographic or clinical characteristics. It is possible that the challenge of identifying people with this experience who are also willing to participate in research is partially responsible for the limited number of existing studies in this area. This pragmatic approach had the advantage of widening the pool of potential participants. This also contributed to a heterogenous sample, with notable differences in time spent caring and relationship type.

Broadening inclusion criteria in this way did, however, limit the analysis in other ways. As carers were not recruited within a given time following the experience of psychosis and suicidal behaviour, nor was this information collected, key aspects of the temporality of their experience were unable to be explored. For example, it may be that carers recruited much closer to this experience report quite different emotional reactions and support needs and suffer less from recall bias than those whose experiences were some time ago. Moreover, collecting information about the mental health of the person they supported may have helped contextualise their caregiving experiences. Indeed, previous qualitative research has investigated more specific aspects of psychosis from the perspective of friends and family members, such as their support needs during early psychosis (Wainwright et al., 2015). The approach to sampling taken here precluded this type of specificity of analysis. While the inclusion criteria were broad, it is notable that the final sample did not include fathers, which is problematic in the broader context of fathers' underrepresentation in this literature. Furthermore, there is consistent evidence that ethnic minority communities are disproportionately impacted by psychosis and negative experiences with services (Barnett et al., 2019; Staniszewska et al., 2019). The related lack of representation in both the REACT paper and interview papers limits the transferability of these results and implies barriers to participation in research not successfully overcome by the recruitment strategies used here. Moreover, the demographic details collected did not include the option to self-define gender and sexual identity. This is a significant limitation given that LGBT communities experience significant physical and mental health inequalities in the UK (Kneale, Henley, Thomas, & French, 2019) and the extent to which these challenges impact caregiving experiences in psychosis remain unclear.

7.7.3 Data collection

A key strength of this qualitative investigation is the inclusion of different forms of qualitative data. The systematic review chapter drew on a range of qualitative methodologies applied in different national, health service, and relational contexts, and the REACT and interview papers used methods of data collection whose strengths and weaknesses were complimentary. More specifically, the naturalistic forum data offered insights collected during an active peer-support context but were limited in depth due to the nature of online forum interaction. Interviews facilitated more in-depth narrative exploration but took place in a qualitatively different interpersonal context defined by the boundaries of the participant-researcher relationship. More specifically, carers were producing reflective accounts of past experiences, in the context of demand characteristics that may have included a desire to convey positive coping for reasons of social desirability, or conversely the desire to improve services by highlighting specific challenges. These different data sources facilitated a form of triangulation in which divergent research characteristics converged to facilitate a more comprehensive answer to the research question.

7.7.4 Analysis

A strength of the application of inductive thematic analysis and synthesis is that these approaches facilitate the generation of novel, or ‘bottom-up’ analyses. This is important where existing research is limited and does not provide a clear a-priori framework to facilitate more deductive approaches. A further strength of the use of thematic analysis and thematic lies in their theoretical congruence, with both approaches being approached from realist perspective. This avoided the potentially challenging integration of methods drawn from different philosophical perspectives. It also situates the findings in a realist ontological context that frames these analyses as highlighting potential mechanisms that may explain social phenomena that are mind-independent (Wiltshire, 2018). This adds weight to associated suggested changes to practice by the implication that psychosocial phenomena described here exist to some extent outside of the immediate research context.

The application of these methods necessarily excluded others that may have provided valuable insight into the research topic. For example, realist methods that draw much more directly on realist theory are valuable for articulating contextual factors that influence participants’ experiences of phenomena of interest here, such as views and experiences of specific health services, or ‘programmes’ in realist terms (Pawson, 2006). Furthermore, on reflection, many participant accounts described here naturally took the form of a chronological narrative, describing changes in caregiving relationships and service user experience over time, including important contextual factors impacting on the emergence and recovery from psychotic and suicidal experiences. Qualitative methodologies that are more naturally applicable to drawing out these narratives, such as biographical narrative interviewing approaches (Corbally & O’Neill, 2014), may have facilitated research outputs with greater emphasis on these temporal aspect of caregiving.

7.7.5 Public and patient involvement

Strengths and limitations of PPI in this thesis are presented (table 9) with reference to items on Guidance for Reporting Involvement of Patients and the Public (GRIPP) 2 short form checklist (Staniszewska et al., 2017):

GRIPP item 1. Aim of PPI

The aims of PPI in this thesis were to facilitate research practices appropriate for and sensitive to the context of mental health research with carers and to enhance the credibility of research outputs through feedback on developing analyses.

Table 9. Thesis PPI activities

GRIPP item 2. Methods of PPI	GRIPP items 3 and 4. Results of PPI and its influence on studies (these items are combined as answers overlap significantly in the context of this thesis)
The interview study concept was presented to and reviewed by a PPI group at Lancaster University.	The PPI group helped develop a more comprehensive set of questions for the topic guide, reflecting the impact of caring on wider life experiences. Written and verbal feedback on the initial topic guide and advertisements helped amend the wording of these documents to be more acceptable to the likely sample, for example by changing the word 'care' to 'support' in order to connect with those who do not see their role as one of a formal caregiver.
A service user researcher took part in a practice interview and provided feedback on interview technique.	The practice interview represented an extremely valuable opportunity for a novice researcher to experience a one-to-one interview setting before conducting 'live' data collection. Running through the entire interview study procedure and exploring personal mental health difficulties assisted with developing interview fluency, general professionalism in a research context, and acquaintance with the personal emotional impact of engaging in mental health research.
A service user researcher provided guidance on recruitment strategies	A service user researcher provided contacts at local mental health charities that the author would otherwise not have made and which ultimately contributed to recruitment into the interview studies.
Service users were consulted to review candidate thematic frameworks in each of the studies in this thesis.	Two valuable aspects of sharing the candidate thematic framework with service user researchers relate to their exploratory questioning of aspects of the analysis and research as a whole, not previously considered by the author. A second important point relates to assistance with understanding divergent views on the use of relevant terminology and how it is perceived (including phrases such as 'patient', 'cared for person', and 'schizophrenia') much of this language was changed on the basis of this feedback.
Three of these service user researchers discussed the meaning of the results of the interview studies with reference to ongoing research prioritises and the wider context of services available for carers and people with psychosis.	Conversations with service user researchers helped to contextualise discussions sections in this thesis with reference to services that are already available for carers and people with psychosis. This helped to address a notable limitation in the author's own perspective as a non-user of mental health services in this context.

GRIPP item 5. Critical reflection

These PPI activities were invaluable in conducting this research, especially for a novice researcher unfamiliar with issues and debates raised by PPI group members and service user researchers. As noted in the methodological reflection in chapter 6, more extensive PPI involvement in the analytic process may have helped integrate lived experience perspectives to a greater extent than was done in this thesis. While methodological critiques of practices such as member checking have been made, especially from a constructionist epistemological perspective, others argue that it is possible to integrate participant views into qualitative analyses in a way that is consistent with realist philosophy of science (Birt et al., 2016). Indeed, there are examples of lived experience being embedded within qualitative research, including through peer researchers involvement in co-producing analyses (Greenwood et al., 2022). This would, however, require significant planning and resources (including payment consistent with involvement guidance) to ensure these approaches are conducted ethically.

7.7.6 Ethical considerations

A strength of this research was its focus on mitigating the potential for distress amongst research participants. This was particularly appropriate given the subject of this research. Several strategies were implemented to achieve this. First, practice interviews with two experienced interviewers and clinical psychologists assisted with developing interview techniques appropriate for this setting. Second, the interview procedure clearly communicated that participants were not required to answer any questions they did not want to, could take breaks if needed, and had the right to re-schedule or end the interview at any time. Third, a list of carer support resources was provided on the participants information sheet and debrief sheet, including a link to the REACT website. Fourth, participants were offered a phone call 24 hours after the interview in which they could check-in with the researcher and share any concerns about their participation. Fifth, the interviewer had a clearly defined procedure for raising any issues during the interview with the supervisory team, or if necessary, emergency services.

Furthermore, participants were able to engage with the interview in ways that felt appropriate for them. Most participants took part by phone, while a minority used online video call. In the latter scenario, participants could choose whether to have their webcam on and were asked if they wanted the researcher to do the same. A potential limitation of this approach is that those less able to access online communication services or who were unable or uncomfortable with telephone conversations may have faced barriers to participation. A related limitation is that this research did not have resources to support the participation of those who were unable to communicate in English. This ethical challenge is significant, given the need to address ethnic minority underrepresentation in UK-based health research (Redwood & Gill, 2013).

7.7.7 Dissemination

The primary method of dissemination for this research will be the publication of results as research articles and presentations at mental health-related conferences. The author will aim to target journals with readership including academics and practitioners positioned to advance the implications for research and practice described in this thesis. A limitation of this dissemination strategy is its limited reach to those less likely to access research literature. However, all research outputs associated with this thesis will be made freely available online, consistent with principles of open access.

7.8 Methodological reflection

The rationale for combining different sources of qualitative data in this thesis was to develop a more nuanced understanding of carer experiences than could be generated from any one data collection method. The systematic review drew qualitative data from a range of contexts, but with no focus on psychosis; the online forum represented a unique peer-support environment related to psychosis and bipolar disorder, yet data were retrospectively collected and so limited in depth; and semi-structured interviews complemented these methods with a focused exploration of carers' experiences of suicidal behaviour in psychosis. One thing I reflected upon throughout the period of data collection was how aspects of carers' experiences quite consistently reoccur across contexts. Experiences including challenges with health services, difficulties with knowing how to provide care and ongoing stress, are evident in the research presented in each chapter in this thesis. These thematic threads also feature prominently in prior research with carers of people with psychosis (Mui et al., 2019) and, in separate research with those supporting people who are or have been suicidal (Juel et al., 2021). A question I repeatedly asked myself when conducting these analyses was: 'am I reflecting what's actually happening in the 'real' world or am I just repeating what's been said (and what I've read) before?'.

The answer, I think, is both. It's quite possible that my exposure to the literature had built an expectation around the kinds of issues carers were likely to experience surrounding their interactions with services, the people they support, and subsequent impacts on their own wellbeing. It is striking how consistently carers report the above-mentioned challenges, across different health service contexts, nations, and with respect to different mental health experiences. It is quite possible that this may have biased my attention towards these issues, contributing to my highlighting aspects of carers' experiences that are consistent with these expectations. Yet I also feel that the reason I was motivated to draw out these experiences is because they do indeed represent the most meaningful and prominent patters of personal experience within the datasets I analysed. At times, the necessity of producing research with novel insights that significantly add to the research literature felt at odds with the straightforwardly consistent evidence I had generated. While psychosis and suicidal behaviour are experienced in vastly different ways from the carers' perspective, carers are, by-and-large, in clear need of support with making their loved one as safe possible and with managing the ongoing stress of their situation. This thesis builds on a robust body of evidence highlighting that this is the case for carers of people with psychosis. Where suicidal behaviour is present, it serves to exacerbate and deepen the challenges many carers describe, necessitating a greater degree of attention to the support that should be offered to those in this situation.

7.8.1 Reflection on conducting research during the coronavirus pandemic

Research reported in this thesis was conducted during the coronavirus pandemic. Its primary impact on this research relates to delays in recruiting participants for interviews. Recruitment was delayed from its planned start date around March 2019 to July 2019, owing to the first period of lockdown and related disruption to existing research plans. While this context seemed to justify the decision not to recruit directly from increasingly strained NHS services, recruitment took longer than expected even with broad inclusion criteria. A blanket 6-month extension was provided to PhD students in my cohort, which ultimately was highly valuable. Practically speaking, travel and meeting restrictions meant I had to conduct all interviews by phone or online. As noted in an earlier reflection on conducting interviews this way, I did not personally feel that this impeded rapport building or the depth of data collected, though it is difficult to know for certain how this context impacted participant disclosure. Following an exploratory approach to semi-structured interviews, I decided to allow participants to raise the issue of the pandemic themselves rather than inquire directly, primarily because I was aware that not all people were likely to be talking about current caregiving experiences, so the pandemic may not have been particularly relevant. Others may not have felt prepared for this line of questioning given the research advert and information sheet did not mention them. On reflection, this topic was notably and surprisingly absent from the interview dataset. It is possible that lockdown dissuaded some people from participating, such as those who could not feasibly have a private conversation in their home environment and/or those for whom lockdown was a particularly challenging time for them and their family member or friend experiencing psychosis, though it is also possible it allowed others who would usually be busy with other commitments, more time to take part. My sense is that interview participants welcomed the opportunity to share their experiences and have a focused discussion of a topic of importance to them that was not focused on the ongoing pandemic.

7.9 Thesis conclusion

This thesis presents a qualitative investigation of caring for someone with psychosis who has experienced suicidal behaviour. Findings highlight carers’ challenges with understanding how to provide effective support in this context, difficulties managing their own wellbeing, and consistent barriers to accessing appropriate professional support. The additional context of suicidal behaviour intensifies these challenges and makes carers’ perceived inabilities in meeting their caregiving responsibilities particularly emotionally demanding. Improving access to information about psychosis and suicidal behaviour and how to care for someone going through these experiences, tools to help carers manage their own wellbeing, and resources to support services with meeting demands on healthcare provision are vital to improving carers’ experiences in this specific context.

Appendices

8.1 Appendix A: Narrative review (chapter 1) search strategy

Search title OR abstract. Combine free text and subject terms using OR. Combine concepts (care/psychosis/suicide) using AND. Select English language and published article filters.

Free text terms (all databases)

((famil* OR friend* OR parent* OR partner* OR relative* OR "significant other*" OR sibling* OR caregiver* OR carer* OR informal OR unpaid) NEAR/5 (care* OR support*))

AND

psychosis OR schizophreni* OR schizoaffective OR psychotic OR “psychotic disorder” OR hallucination* OR delusion*

AND

suicid*

PsychINFO index terms

DE "Caregivers" OR DE "Caregiving" OR DE "Social Support" OR DE "Couples" OR DE "Family Relations" OR DE "Friendship" OR DE "Partners" OR DE "Family" OR DE "Marital Relations" OR DE "Parent Child Relations" OR DE "Parental Role" OR DE "Sibling Relations"

AND

DE "Psychosis" OR DE "Acute Psychosis" OR DE "Affective Psychosis" OR DE "Hallucinosis" OR DE "Paranoia (Psychosis)" OR DE "Schizophrenia" OR DE "Paranoid Schizophrenia” OR DE "Chronic Psychosis" OR DE "Acute Schizophrenia" OR DE "Schizoaffective Disorder" OR DE "Schizophrenia (Disorganized Type)" OR DE "Schizophreniform Disorder" OR DE "Undifferentiated Schizophrenia” OR DE "Positive and Negative Symptoms"

AND

DE "Attempted Suicide" OR DE "Suicidality" OR DE "Suicidal Ideation" OR DE "Suicide Prevention” OR DE "Suicidology"

CINAHL Subject headings

MH "Caregivers" OR MH "Spouses" OR MH "Family" OR MH "Adult Children" OR MH "Extended Family" OR MH "Family Relations" OR (MH "Daughters" OR MH "Parents" OR MH "Siblings" OR MH "Sons" OR MH Family Coping OR MH Caregiver Support OR MH Caregiver Burden OR MH "Support, Psychosocial" OR MH "Caregiver Support"

AND

(MH "Schizophrenia Spectrum and Other Psychotic Disorders") OR (MH "Psychotic Disorders") OR (MH "Schizophrenia") OR (MH "Paranoid Disorders") OR (MH "Affective Disorders, Psychotic")

AND

(MH "Suicide") OR (MH "Suicide, Attempted") OR (MH "Suicidal Ideation")

Medline MeSH

(MH "Social Support") OR (MH "Psychosocial Support Systems") OR (MH "Caregivers") OR (MH "Friends") OR (MH "Parents") OR (MH "Siblings") OR (MH "Spouses") OR (MH "Family")

AND

(MH "Schizophrenia Spectrum and Other Psychotic Disorders") OR (MH "Psychotic Disorders") OR (MH "Schizophrenia") OR (MH "Paranoid Disorders") OR (MH "Affective Disorders, Psychotic")

AND

(MH "Suicide") OR (MH "Suicide, Attempted") OR (MH "Suicidal Ideation")

SocINDEX Subject terms

DE "SOCIAL support" OR DE "CAREGIVERS" OR DE "PARENT-adult child relationships" OR DE "PARENT-child relationships" OR DE "HUSBANDS" OR DE "WIVES" OR DE "SIGNIFICANT others" OR DE "SIBLINGS" OR DE "FRIENDSHIP"

AND

DE "PSYCHOSES" OR DE "PARANOIA" OR DE "SCHIZOPHRENIA"

AND

DE "SUICIDE" OR DE "SUICIDE risk factors" OR DE "SUICIDAL ideation” OR DE "SUICIDE -- Psychological aspects"

EMBASE subject headings

family OR friend OR relative OR care behavior OR care giving OR caring OR caregiver OR parental behavior OR social support OR spouse OR sibling

AND

psychosis OR affective psychosis OR paranoid psychosis OR first episode psychosis OR psychotic disorders OR schizophrenia OR paranoid schizophrenia OR schizophrenia spectrum disorder

AND

suicidal behavior OR suicide OR suicidality OR suicidal thought OR suicidal thoughts OR suicide attempt

8.2 Appendix B: Systematic review (chapter 3) search strategy

Search title OR abstract (OR where available, keywords). Combine free text and subject terms using OR. Combine concepts (suicide/care/qualitative) using AND. Select English language and published article filters.

Free text terms (all databases)

suicid* OR self-harm* OR self-injur*

AND

carer* OR caregiv* OR famil* OR friend*

AND

qualitative OR mixed method* OR focus group* OR interview*

PsychInfo DE term

(DE "Suicide" OR DE "Attempted Suicide" OR DE "Suicidality" OR DE "Self-Injurious Behavior)

AND

DE " Caregivers" OR "Family Members" OR DE "Family" OR DE "Adult Offspring" OR DE "Daughters" OR DE "Grandchildren" OR DE "Grandparents" OR DE "Parents" OR DE "Siblings" OR DE "Sons" OR DE "Spouses" OR DE "Offspring" OR DE "Significant Others"

AND

DE "Qualitative Methods" OR DE "Focus Group" OR DE "Grounded Theory" OR DE "Interpretative Phenomenological Analysis" OR DE "Narrative Analysis" OR DE "Semi-Structured Interview" OR DE "Thematic Analysis" OR DE "Interviews" OR DE "Mixed Methods Research" OR DE "Phenomenology" OR DE "Qualitative Measures"

Medline MeSH 2019

(MH "Suicide") OR (MH "Self-Injurious Behavior") OR (MH "Suicide, Attempted") OR (MH "Suicidal Ideation") OR (MH "Self Mutilation")

AND

(MH "Spouses") OR (MH "Siblings") OR (MH "Grandparents") OR (MH "Friends") OR (MH "Caregivers") OR (MH "Adult Children") OR (MH "Parents") (MH "Family") OR (MH "Family Relations") (MH "Nuclear Family") OR (MH "Mothers") OR (MH "Fathers") OR (MH "Group Processes")

AND

(MH "Qualitative Research") OR (MH "Interview") OR (MH "Personal Narrative") OR (MH "Grounded Theory") OR (MH "Hermeneutics") OR (MH "Focus Groups")

CINAHL subject headings

(MH "Suicide") OR (MH "Suicide, Attempted") OR (MH "Suicidal Ideation") OR (MH "Injuries, Self-Inflicted") OR (MH "Self-Injurious Behavior")

AND

(MH "Caregivers") OR (MH "Spouses") OR (MH "Family") OR (MH "Adult Children") OR (MH "Extended Family") OR (MH "Family Relations") OR (MH "Group Processes") OR (MH "Daughters") OR (MH "Parents") OR (MH "Siblings") OR (MH "Sons")

AND

(MH "Qualitative Studies") OR (MH "Ethnographic Research") OR (MH "Grounded Theory") OR (MH "Phenomenological Research") OR (MH "Semi-Structured Interview") OR (MH "Interviews") OR (MH "Unstructured Interview") OR (MH "Focus Groups") OR (MH "Thematic Analysis")

SocIndex subject terms

(DE "SUICIDE" OR DE "SUICIDAL behavior" OR DE "SUICIDAL ideation" OR DE "SELF-mutilation" OR DE "SELF-destructive behavior")

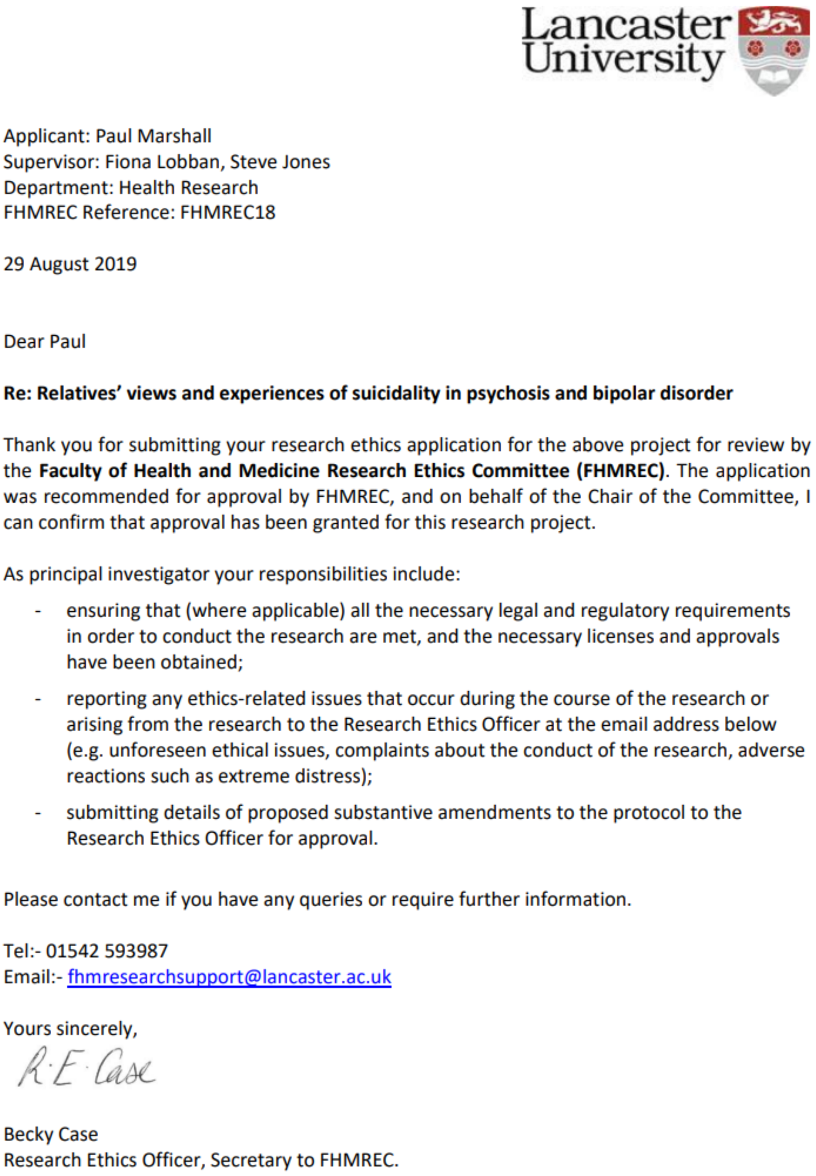
AND

(DE "FAMILIES" OR DE "AUNTS" OR DE "CHILDREN" OR DE "COUSINS" OR DE "DAUGHTERS" OR DE "DAUGHTERS-in-law" OR DE "DEPENDENTS" OR DE "EXTENDED families" OR DE "FATHERS" OR DE "FATHERS-in-law" OR DE "GRANDPARENT & child" OR DE "MOTHERS" OR DE "NEPHEWS" OR DE "NIECES" OR DE "PARENT & child" OR DE "PARENTHOOD" OR DE "PARENTS" OR DE "PARENTS-in-law" OR DE "SIBLINGS" OR DE "SISTERS-in-law" OR DE "SONS" OR DE "SONS-in-law" OR DE "STEPFAMILIES")

AND

(DE "QUALITATIVE research" OR DE "FOCUS groups" OR DE "PARTICIPANT observation" OR DE "ETHNOLOGY" OR DE "INTERVIEWING" OR DE "SOCIAL sciences fieldwork")

8.3 Appendix C: REACT forum study (chapter 4) ethical approval letter



Lancaster University

Applicant: Paul Marshall
Supervisor: Fiona Lobban, Steve Jones
Department: Health Research
FHMREC Reference: FHMREC18

29 August 2019

Dear Paul

Re: Relatives' views and experiences of suicidality in psychosis and bipolar disorder

Thank you for submitting your research ethics application for the above project for review by the **Faculty of Health and Medicine Research Ethics Committee (FHMREC)**. The application was recommended for approval by FHMREC, and on behalf of the Chair of the Committee, I can confirm that approval has been granted for this research project.

As principal investigator your responsibilities include:

- ensuring that (where applicable) all the necessary legal and regulatory requirements in order to conduct the research are met, and the necessary licenses and approvals have been obtained;
- reporting any ethics-related issues that occur during the course of the research or arising from the research to the Research Ethics Officer at the email address below (e.g. unforeseen ethical issues, complaints about the conduct of the research, adverse reactions such as extreme distress);
- submitting details of proposed substantive amendments to the protocol to the Research Ethics Officer for approval.

Please contact me if you have any queries or require further information.

Tel:- 01542 593987
Email:- fhmresearchsupport@lancaster.ac.uk

Yours sincerely,

R·E·Case

Becky Case
Research Ethics Officer, Secretary to FHMREC.

8.4 Appendix D: Interview study (chapters 5 and 6) materials

8.4.1 Ethical approval letter

Lancaster University

Applicant: Paul Marshall
Supervisor: Fiona Lobban & Steve Jones
Department: Health Research
FHMREC Reference: FHMREC19059

25 March 2020

Dear Paul

Re: Understanding the experience of supporting someone with psychosis who is suicidal

Thank you for submitting your research ethics application for the above project for review by the **Faculty of Health and Medicine Research Ethics Committee (FHMREC)**. The application was recommended for approval by FHMREC, and on behalf of the Chair of the Committee, I can confirm that approval has been granted for this research project.

As principal investigator your responsibilities include:

- ensuring that (where applicable) all the necessary legal and regulatory requirements in order to conduct the research are met, and the necessary licenses and approvals have been obtained;
- reporting any ethics-related issues that occur during the course of the research or arising from the research to the Research Ethics Officer at the email address below (e.g. unforeseen ethical issues, complaints about the conduct of the research, adverse reactions such as extreme distress);
- submitting details of proposed substantive amendments to the protocol to the Research Ethics Officer for approval.

Please contact me if you have any queries or require further information.

Tel:- 01542 593987
Email:- fhmresearchsupport@lancaster.ac.uk

Yours sincerely,

R.E. Case

Becky Case
Research Ethics Officer, Secretary to FHMREC.

8.4.2 Study advertisement

THE SPECTRUM CENTRE

Health & Medicine | Lancaster University

E·S·R·C ECONOMIC & SOCIAL RESEARCH COUNCIL

Do you support or care for someone with psychosis?

Has the person you support ever experienced suicidal thoughts or attempted suicide?

Are you over 18 years of age?

We would like to speak to you to better understand the support needs and experiences of people who have supported someone with psychosis at a time of increased suicide risk.

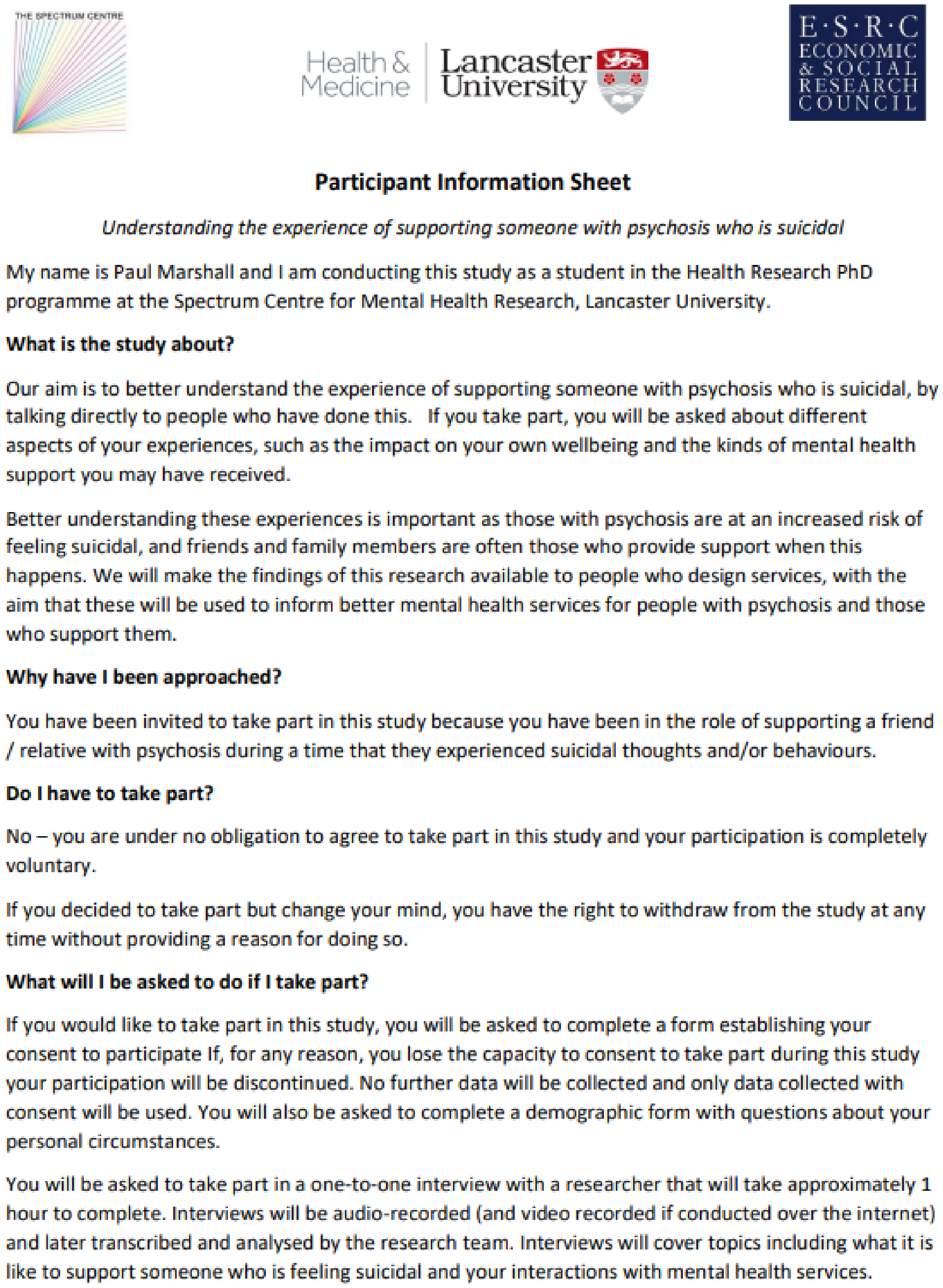
If you would like to find out more about this interview study, please contact Paul Marshall:

Tel: XXXXXXXXXXX

e-mail: p.marshall4@lancaster.ac.uk

twitter: @PaulG_Marshall

8.4.3 Information sheet



Participant Information Sheet

Understanding the experience of supporting someone with psychosis who is suicidal

My name is Paul Marshall and I am conducting this study as a student in the Health Research PhD programme at the Spectrum Centre for Mental Health Research, Lancaster University.

What is the study about?

Our aim is to better understand the experience of supporting someone with psychosis who is suicidal, by talking directly to people who have done this. If you take part, you will be asked about different aspects of your experiences, such as the impact on your own wellbeing and the kinds of mental health support you may have received.

Better understanding these experiences is important as those with psychosis are at an increased risk of feeling suicidal, and friends and family members are often those who provide support when this happens. We will make the findings of this research available to people who design services, with the aim that these will be used to inform better mental health services for people with psychosis and those who support them.

Why have I been approached?

You have been invited to take part in this study because you have been in the role of supporting a friend / relative with psychosis during a time that they experienced suicidal thoughts and/or behaviours.

Do I have to take part?

No – you are under no obligation to agree to take part in this study and your participation is completely voluntary.

If you decided to take part but change your mind, you have the right to withdraw from the study at any time without providing a reason for doing so.

What will I be asked to do if I take part?

If you would like to take part in this study, you will be asked to complete a form establishing your consent to participate If, for any reason, you lose the capacity to consent to take part during this study your participation will be discontinued. No further data will be collected and only data collected with consent will be used. You will also be asked to complete a demographic form with questions about your personal circumstances.

You will be asked to take part in a one-to-one interview with a researcher that will take approximately 1 hour to complete. Interviews will be audio-recorded (and video recorded if conducted over the internet) and later transcribed and analysed by the research team. Interviews will cover topics including what it is like to support someone who is feeling suicidal and your interactions with mental health services.

You will be contacted by the research team to arrange a one-to-one interview at a time that is convenient for you. You will be asked to choose how you would like to complete the interview. This could be in person at your home or in a private interview room at Lancaster University, over the phone, or through an online video conversation. Participants using online video software should be aware that the internet cannot be guaranteed to be a completely secure means of communication.

Will my data be identifiable?

Audio-video files, written transcriptions and documents containing personal information will be securely stored in a locked cabinet at Lancaster University or on a secure research drive that is encrypted and GDPR compliant. This drive is password protected and accessible only by members of the research team.

Any identifying information within written interview transcripts, such as names, will be replaced. While direct quotations may be used as part of the final study publication, they will not contain any information that could be used to identify you. Anonymous transcripts will be saved securely at Lancaster University for a period of up to 10 years consistent with University policy.

While information discussed during the interviews will remain confidential, we will inform relevant emergency services if we are told of any immediate risks of harm to you or someone else during this study.

Following data collection, you will have a one-week window to withdraw your data entirely from the study. After this, anonymised data will be incorporated into themes and it may not be possible to remove their data completely from the analysis, however, every attempt will be made to extract their data, up to the point of publication.

What will happen to the results?

You will be provided with a summary of the results at the end of the study. We intend to share the findings with key stakeholders through conferences, and written reports, to ensure that this research informs the development of better services. The results will form part of the lead researcher's PhD thesis.

Are there any risks?

Discussing personal experiences of supporting a suicidal friend or relative can be difficult and there is a risk that you may experience emotional distress during the interview. The interviewer conducting the study will be mindful of this and encourage you to take breaks where necessary. You will be offered an optional phone call 24-hours after your interview to address any concerns you have following the interview. We will also provide you with a list of support resources available local and nationally that you may find useful. You will be reminded of your right to withdraw from the study at any time.

Are there any benefits

You will receive £10 for participation in this study.

Who has reviewed this project?

This study has been developed as part of the lead researcher's doctoral studies and went through rigorous peer review to secure research funding. This study has undergone ethical review by Lancaster University.

Where can I obtain further information about the study if I need it?

If you would like further information about participation in this study, please contact:

Paul Marshall – Lead researcher

Spectrum Centre for Mental Health Research, Lancaster University

Email: p.marshall4@lancaster.ac.uk

Tel: 07xxxxxxxxx

Twitter: @PaulG_Marshall

Who do I speak to if I have any concerns or complaints?

If you have any concerns or complaints about this study, please contact:

Professor Fiona Lobban
Professor of Clinical Psychology & PhD Supervisor
Spectrum Centre for Mental Health Research, Lancaster University
Email: f.lobban@lancaster.ac.uk

Professor Roger Pickup
Associate Dean for Research
Tel: +44 (0)1524 593746
Faculty of Health and Medicine, Lancaster University
Email: r.pickup@lancaster.ac.uk

Resource Sheet

The following resource list has been copied from the Relatives Education and Coping Toolkit (REACT), an online resource developed for, and in consultation with, relatives of people with psychosis and bipolar disorder. In addition to the contact details below, the REACT toolkit includes other information you may find helpful, such as information to help recognise and manage psychosis, advice for how to deal with crisis situations, and help with understanding mental health services. You can access the free toolkit by registering at reacttoolkit.uk.

If you need more urgent help and are already in contact with mental health services, please contact them directly. If you are not in contact with mental health services the following might be helpful:

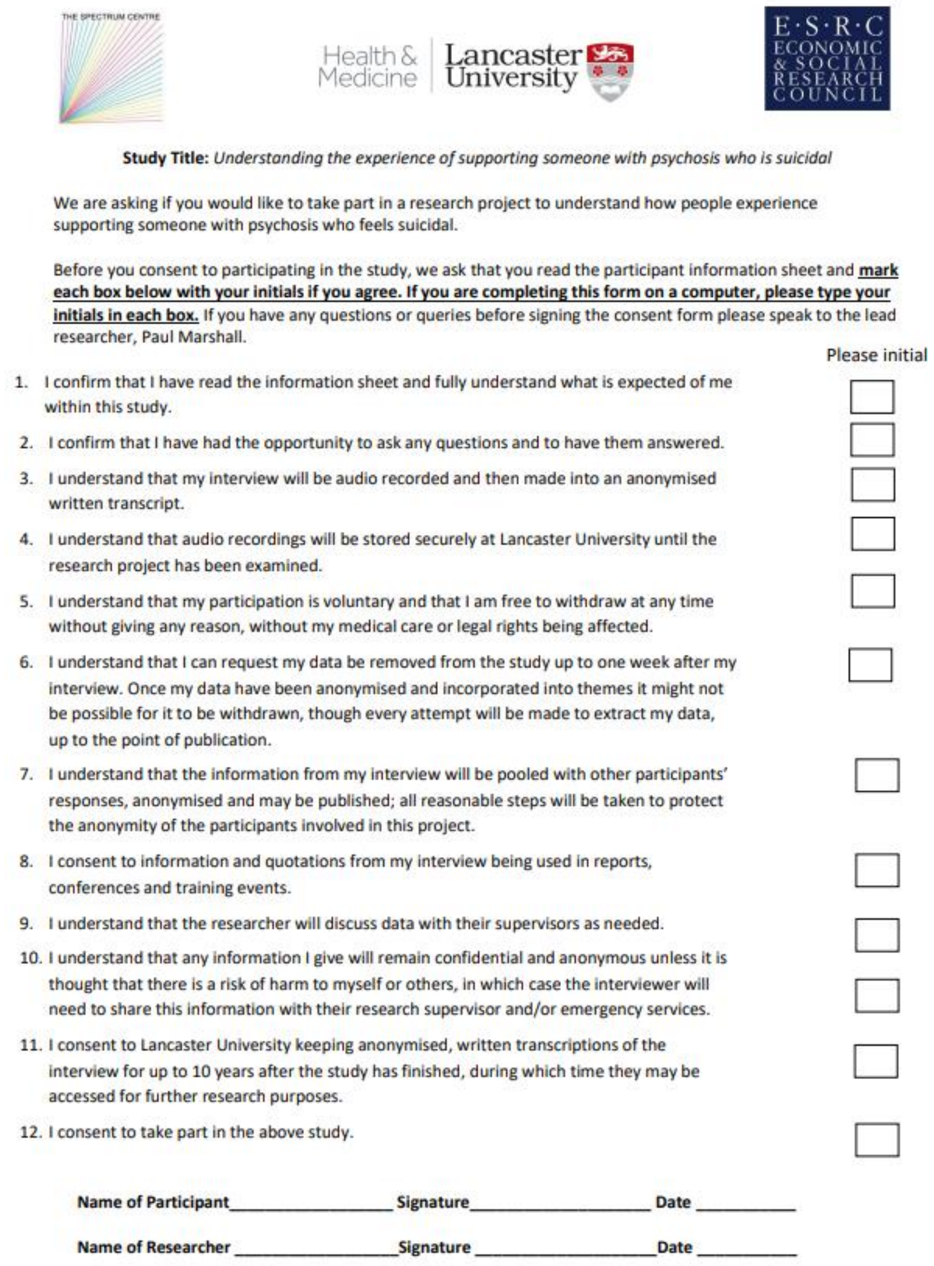
- Your own GP practice
- Your local out of hours GP or A+E. Visit www.nhs.uk if you're unsure where to find the services
- If you are unsure of what help you need, call 111 for the NHS telephone advice service
- For someone to talk to over the phone call Samaritans on 116 123 or email jo@samaritans.org
- If you feel there is a serious and immediate risk please call the emergency services on 999

National Directory

Mental Health Support
Bipolar UK - www.bipolaruk.org
Hearing Voices - www.hearing-voices.org
Making Space - www.makingspace.co.uk
Mind - www.mind.org.uk
Rethink - www.rethink.org
Sane - www.sane.org.uk
Young Minds - www.youngminds.org.uk

General Carer Support:
Carers Federation - www.carersfederation.co.uk
The Carers Trust - www.carers.org
Carers UK - www.carersuk.org
Chill4 Us Carers - www.chill4uscarers.co.uk

8.4.4 Consent form



THE SPECTRUM CENTRE

Health & Medicine | Lancaster University

E·S·R·C ECONOMIC & SOCIAL RESEARCH COUNCIL

Study Title: *Understanding the experience of supporting someone with psychosis who is suicidal*

We are asking if you would like to take part in a research project to understand how people experience supporting someone with psychosis who feels suicidal.

Before you consent to participating in the study, we ask that you read the participant information sheet and **<u>mark each box below with your initials if you agree. If you are completing this form on a computer, please type your initials in each box.</u>** If you have any questions or queries before signing the consent form please speak to the lead researcher, Paul Marshall.

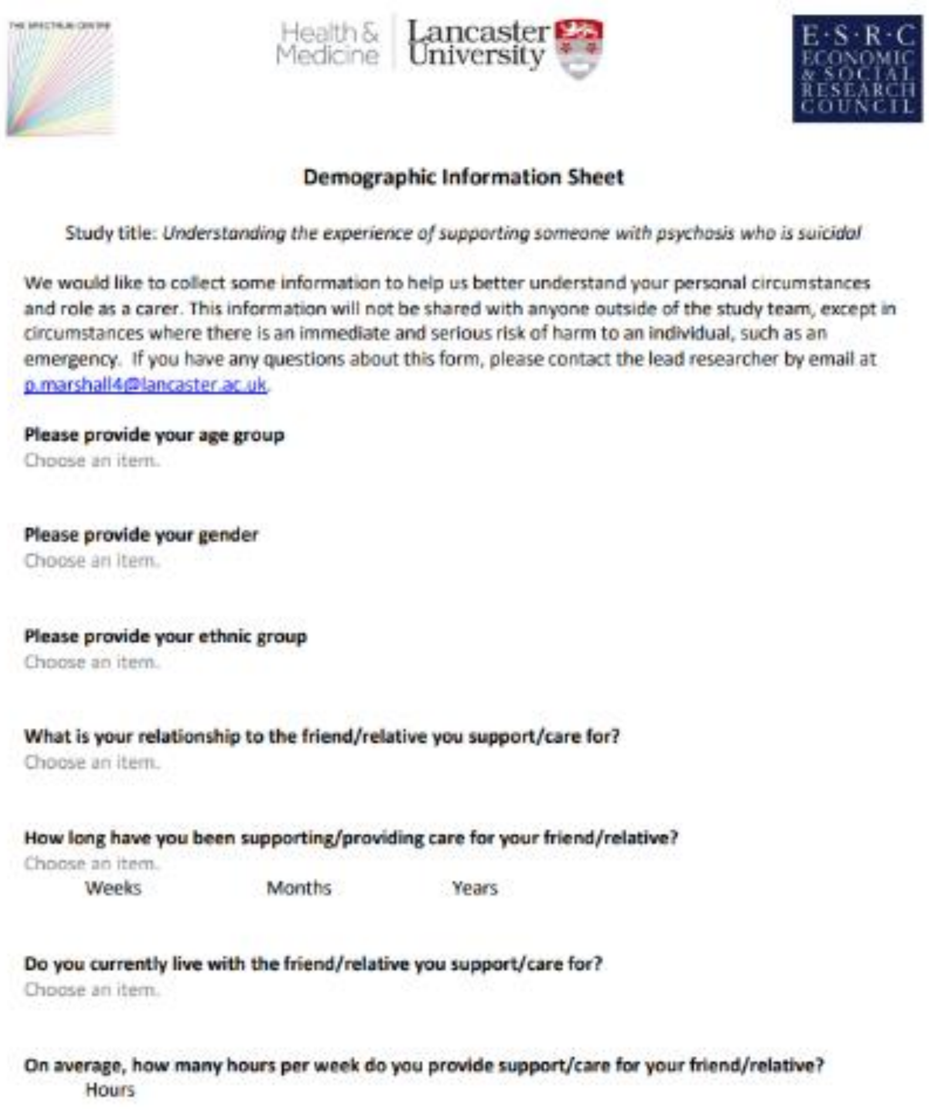
Please initial

1. I confirm that I have read the information sheet and fully understand what is expected of me within this study. ☐
2. I confirm that I have had the opportunity to ask any questions and to have them answered. ☐
3. I understand that my interview will be audio recorded and then made into an anonymised written transcript. ☐
4. I understand that audio recordings will be stored securely at Lancaster University until the research project has been examined. ☐
5. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected. ☐
6. I understand that I can request my data be removed from the study up to one week after my interview. Once my data have been anonymised and incorporated into themes it might not be possible for it to be withdrawn, though every attempt will be made to extract my data, up to the point of publication. ☐
7. I understand that the information from my interview will be pooled with other participants' responses, anonymised and may be published; all reasonable steps will be taken to protect the anonymity of the participants involved in this project. ☐
8. I consent to information and quotations from my interview being used in reports, conferences and training events. ☐
9. I understand that the researcher will discuss data with their supervisors as needed. ☐
10. I understand that any information I give will remain confidential and anonymous unless it is thought that there is a risk of harm to myself or others, in which case the interviewer will need to share this information with their research supervisor and/or emergency services. ☐
11. I consent to Lancaster University keeping anonymised, written transcriptions of the interview for up to 10 years after the study has finished, during which time they may be accessed for further research purposes. ☐
12. I consent to take part in the above study. ☐

Name of Participant__________________ **Signature**____________________ **Date** ___________

Name of Researcher __________________**Signature** ____________________**Date** ___________

8.4.5 Demographics form



Health & Medicine | Lancaster University

E·S·R·C ECONOMIC & SOCIAL RESEARCH COUNCIL

Demographic Information Sheet

Study title: *Understanding the experience of supporting someone with psychosis who is suicidal*

We would like to collect some information to help us better understand your personal circumstances and role as a carer. This information will not be shared with anyone outside of the study team, except in circumstances where there is an immediate and serious risk of harm to an individual, such as an emergency. If you have any questions about this form, please contact the lead researcher by email at p.marshall4@lancaster.ac.uk.

Please provide your age group
Choose an item.

Please provide your gender
Choose an item.

Please provide your ethnic group
Choose an item.

What is your relationship to the friend/relative you support/care for?
Choose an item.

How long have you been supporting/providing care for your friend/relative?
Choose an item.
Weeks Months Years

Do you currently live with the friend/relative you support/care for?
Choose an item.

On average, how many hours per week do you provide support/care for your friend/relative?
Hours

8.4.6 Interview topic guide

Please note, these are example questions and consistent with qualitative methods, may evolve during the project depending on the responses of the participants. The focus of the interview will not change without seeking further consent from the ethics committee.

Initial actions: personal introduction, check audio

equipment, check participant information sheet, check consent, remind participant of right to confidentiality and researcher's legal obligation to break confidentiality if risk of harm is present. Highlight risk of emotional distress and the right to take breaks and/or withdraw for any reason.

If the interview is online, remind participants that you cannot ensure the security of internet communications.

Topic 1: *Understanding the supportive relationship*

This introductory topic will establish who it is the participant provides support to and the nature of their mental health problems.

Questions:

"could we start by going over how you know your friend?"

"your partner has experienced psychosis/hallucinations/delusions, what has your experience of that been?"

Example probes:

"when did your relative begin to experience psychosis"?

"can you tell me a bit more about what that was like for you?"

Topic 2: *Understanding suicidal experiences*

A second topic will move to the participants' experiences of suicidal thoughts/behaviours of the person they have supported.

Questions:

"as part of this research we are trying to understand what it is like for carers/family members when the person they support feels suicidal. Would you be happy to talk about your own experience of that?"

"can you tell me about how your relative's voice hearing/unusual beliefs impacted on you at the time they were feeling suicidal?"

Example probes:

"what concerns did you have following the (suicidal) experience?"

"how did the experience of psychosis impact on their suicidal thinking/behaviour?"

Topic 3: *Health service interactions.*

This topic will address the kinds of mental health support participants and those they support for have received.

Questions:

“what have your interactions with your daughter’s mental health team been like?”

“can you tell me about the crisis support you received?”

Example probes:

“how did (the GP/crisis team/A&E) respond when you contacted them?”

“can you tell about what it is like being involved in your relative’s appointments?”

Topics 4: *Personal impact*

This topic will address the ways in which supporting someone with psychosis impacted upon participants’ own wellbeing.

Example questions:

“did supporting your family member at this time have an influence on your other relationships?”

“in what way did your life change after this happened?”

Example probes:

Can you tell me more about the impact on e.g. work life balance/relationship with other family members?

How did your friend(s), acquaintances, partner respond?

Topic 5: *Coping and self-care.*

The interviewer will ask about the kinds of strategies participants use to maintain their own health and wellbeing.

Questions:

“do you find that there are certain things that help when you feel stressed/upset/anxious about your relative?”

“Have you accessed support services? Have you found them helpful?”

Example probes:

“if no – why?” or “if yes – what about the service/technique was helpful?”

“where did you look for support/was information easy/hard to find?”

Topic 6: *Improving support*

The interview will end with a topic discussing the kinds of changes that might help improve outcomes for families and friends of people with psychosis

Questions:

"I'd like to end by asking about ways in which support for people in a similar situation could be improved"

"how could partners be better supported during a crisis?"

Example probes:

"can you tell me more about how you think crisis team/GP/A&E might better include relatives?"

"What did services do well/could more of this be done?"

At the end of the interview, stop any recording devices and follow debrief procedure.

References

Addington, J., Coldham, E., Jones, B., Ko, T., & Addington, D. (2003). The first episode of psychosis: the experience of relatives. *Acta Psychiatrica Scandinavica*, *108*(4), 285-289.

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