Entering and adjusting to a different and uncertain world: experiences and support needs of adult family members, partners and friends in England who care for an adult at risk of suicide.

By

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A thesis submitted in partial fulfilment of the requirements for the degree of Doctor of Nursing, Oxford Institute of Nursing, Midwifery and Allied Health Research, Faculty of Health and Life Sciences, Oxford Brookes University

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Statement of the contribution of others

This thesis has been made possible through the support of the following people:

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Abstract

Background: Mental health services in England are dependent on family and friends to support patients who may be at risk of suicide. However, support for these informal caregivers is lacking despite evidence of caregiver burden, poor health outcomes, and difficult encounters with mental health services. Stigmatising experiences have been unearthed in qualitative studies although perceived stigma relating to suicidal behaviour has not been formally assessed in carers. To date, minimal research specifically investigating carers of adults at risk of suicide has been conducted in England and there is a dearth of mixed methods inquiry in the field.

Aim: This exploratory mixed methods research aimed to develop an understanding of the experiences and support needs of adult informal caregivers of adults at risk of suicide.

Methods: An online survey of 101 self-selecting adult carers of an adult at risk of suicide assessed perceived stigma of suicide attempt, quality of life and helpfulness of support services, as well as obtaining qualitative data on experiences and support needs. Semi structured interviews were carried out with 15 of the survey participants. Statistical analyses were conducted with quantitative data, summative content analysis was used for qualitative survey data and reflexive thematic analysis for interview data. The three data sets were integrated, and, through a process of abduction, mixed methods interpretations were achieved.

Results: The overarching theme of ‘entering and adjusting to a different and uncertain world’ was generated, with uncertainty being the main response of carers. The finding of uncertainty is explained by the Uncertainty in Illness Theory. Carer uncertainty was acute on entry to the different world, enduring in the longer term, and inherent in perspectives on the future. Uncertainty manifested emotionally, psychologically, interpersonally and behaviourally, was perpetuated by difficult encounters with healthcare providers, and had detrimental effects on mental and physical wellbeing. Stress was propagated by lack of support from mental health services, which were the least helpful support agency. Perceived stigma was inversely associated with carer support, caring choice and carer stress, and accounts indicated experiences of provider-based stigma. Carers demonstrated an adept ability to balance uncertainty with hope, which helped them to tolerate uncertainty and sustain their caring role. Identified support needs included recognition, information and education, authentic collaboration and tailored peer support and psychosocial interventions.

Conclusion. The Uncertainty in Illness Theory provides a helpful framework for caregivers and clinicians to make sense of carers experiences including how uncertainty can be perpetuated by healthcare providers. This understanding should be used to inform coproduced resources and interventions for carers and education for mental health clinicians. There is a need for further research with this population of carers, particularly longitudinal studies, with a view to developing and evaluating tailored psychosocial interventions to help carers tolerate the longstanding uncertainty caring for someone at risk of suicide entails.

Dissemination outcomes

Published articles

Lascelles, K.M., (2022) Might informal carers of adults with enduring suicidality experience anticipatory loss?. *Crisis*, 43(3): 215-219

Lascelles, K.M., Davey, Z., Jackson, D. and Aveyard, H. (2023) Experiences and needs of adult informal carers of adults at risk of suicide: A systematic review with mixed methods analysis. *Journal of Advanced Nursing*; 00:1-33

Learning resources

Making Families Count Life Beyond the Cubicle eLearning resource for involving families during a mental health crisis. https://www.makingfamiliescount.org.uk/life-beyond-the-cubicle/ (contributed research experience and findings as part of a coproduction team)

Conference Presentations

Lascelles K, Davey Z, Jackson D, Hawton, K., Appleton A, Aveyard H (2022) *Experiences and support needs of adult informal caregivers of adults at risk of suicide in England: The impact of the COVID-19 pandemic on carers experiences.* Early and mid career researchers in suicide research conference, University of Glasgow

Lascelles, K., Davey, Z., Jackson, D., Hawton, K., Appleton, A., Aveyard, H (2022) *How did the COVID-19 pandemic effect adult informal carers of adults at risk of suicide: A qualitative content analysis of survey data.* Harmless suicide prevention conference (online)

Lascelles, K., Davey, Z., Jackson, D., Aveyard H. (2022) *Experiences and needs of adult informal carers of adults at risk of suicide: A systematic review with mixed methods analysis.* International Mental Health Nursing Research Conference, Oxford.

Lascelles, K., Davey, Z., Jackson, D., Aveyard H. (2023) *Experiences and needs of adult informal carers of adults at risk of suicide: A systematic review with mixed methods analysis*. Early and mid career researchers in suicide research conference, University of Glasgow

Lascelles, K., Groves, S. (2023) *How are staff and informal carers affected by repeated exposure to self-harm and suicidal behaviour?* Harmless Suicide and Self-harm Prevention Conference, Nottingham

Lascelles, K., Davey, Z., Jackson, D., Aveyard H. (2024) *Entering and adjusting to a different and uncertain world: Experiences and needs of adults who care for an adult family member, partner or friend they consider to be at risk of suicide.* University of Manchester Division of Psychology and Mental Health (online)

Lascelles, K. (2024) *Entering and adjusting to a different and uncertain world: Experiences and needs of adults who care for an adult family member, partner or friend they consider to be at risk of suicide.* South West Yorkshire NHS Trust Suicide Prevention Conference, Wakefield.

Local Presentations

Lascelles, K. (2023) *The experiences and needs of adults who care for an adult family member or friend at risk of suicide: A mixed methods doctoral research study*. Oxford Brookes University (online)

Lascelles, K. (2024) *The Carers' voice*. International Womens Day, Inspire and Inclusion webinar. Oxford Health NHS FT (online)

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List of abbreviations

AC-QoL – adult carer quality of life (scale)

FREC – Faculty research ethics committee

HCP – healthcare professional

MHN – mental health nurse

IV – interviewer

P - participant

PIS – participant information sheet

QoL – quality of life

RUIT – Reconceptualised uncertainty in illness theory

R/UIT – both above theories combined

STOSA – stigma of suicide attempt (scale)

UIT – Uncertainty in illness theory

CHAPTER ONE: INTRODUCTION

1.0 Introduction

The overarching research question underpinning this doctorate asked, ‘what are the experiences and support needs of adult carers (family members, partners and friends) in England who care for adults they consider to be at risk of suicide?’. To help answer this question the aim was to gather accounts of the subjective experiences of caring and obtain an understanding of carers quality of life and perceptions of stigma. As the research was conducted in the COVID-19 era, it was considered important to include inquiry about the impact of restrictions associated with the pandemic, such as lockdown. A mixed methods approach was adopted for this research guided by a pragmatism worldview.

The aim of this introductory chapter is to present the rationale for the doctoral research discussed throughout this thesis. To achieve this, it is important to share the professional and experiential reasoning that led to the research question. Because the said reasoning involved personal professional experiences, parts of this chapter will be written in the first person. Researcher positioning is discussed before presenting the clinical rationale for the research. The main constructs of the research topic are then considered and defined, these being: suicide; caregiving and carers; the impact of caring on quality of life; stigma associated with caring for someone at risk of suicide; and caring during the pandemic. The nursing role in supporting carers will be deliberated and the research rationale summarised before the research aims and objectives are presented. Finally, an overview of the organisation of the thesis will be provided.

1.1 Researcher positioning

This research has been conducted as part of a professional doctorate in nursing. Professional doctorates are characterised by proximity to professional practice and emphasis on change and improvement (Rolfe and Davies, 2009, p. 120; Maxwell, 2019). Professional doctorates produce ‘mode 1’ knowledge (Gibbons, 2003). Mode 1 knowledge informs evidence-based practice and generates ‘mode 2’ knowledge (Gibbons, 2003), which is concerned with the context of application. The aim of this research was to achieve mode 1 and contribute to mode 2 knowledge.

The research interest arose from practice experience, which Flood (2011, cited in Maxwell 2019, p. 8.), influenced by Aristotle, terms ‘phronesis’, defined as ethical and rational practical wisdom. Maxwell (2019) views phronesis as a prerequisite to mode 2 knowledge generation and claims that professional doctorates result from ‘practitioner agency and/or reflection and/or research in practice’ (p.7). The research has been carried out in accord with the clinical, strategic, educational, and research components of my professional nurse consultant role. I will have a key role in translating the outcomes of the research (mode 1 knowledge) to the practice context with the ultimate aim of improvements in care (mode 2 knowledge). To that end, my nurse self is implicit within my researcher ego, and I approached my doctoral research with a dual-role identity (Hay-Smith *et al.*, 2016). I made no attempt to transcend a dual role but embraced it, mindful of the fact that in suicide research the clinical background of researchers is largely valued (Lakeman and FitzGerald, 2009; Lakeman *et al.*, 2013). Notwithstanding the value of dual-roles identities, challenges are recognised in the context of nurse researchers (Arber, 2006; Larkin *et al.*, 2019). For example, feeling torn between the research objectives and protocol and attending to clinical needs or practice problems.

Reflexivity is central to recognising and making sense of role related tensions, and I afforded my duality a sophisticated level of reflexivity throughout the research process to avoid confusion of the nurse/researcher roles, ensure non-maleficence to participants, maintain researcher integrity, and demonstrate research rigour. Braun and Clarke (2022) highlight the need for reflexivity from the moment an idea for research starts to form and view it as a ‘journey not a destination’ (p15). They advocate personal, functional and disciplinary reflexivity to ensure that researchers attend to their assumptions, experiences, choices, and actions. They encourage researchers to reflect on who they are as a researcher at the outset of their journey by situating themselves in their research and wider context. This involved me reflecting on more than my professional nursing role and consider limitations as well as strengths that my social positioning might bring. I am a white, middle class, middle aged professional woman living in the South East of England. I am a mother of daughters, a daughter, sister, wife, aunt, and friend. Whilst I recognise benefits from my nurse persona, I am in a position of privilege due to my social background and ethnicity and a limitation of this might be recruitment of or engagement with a diverse group of participants.

I am a mother of a neurodivergent daughter who has a background of serious mental health problems. Importantly, these mental health problems started in the early stages of my doctoral journey and whilst my daughter was not, at that point, an adult, I was for a while grappling with caring for her whilst investigating the caring experiences of others. Braun and Clarke (2022) recognise that researchers can be both insider and outsider researchers. I did not feel that my experience with my daughter made me an insider researcher because of her age and presentation, but neither did I feel a true outsider researcher anymore. Reflexivity became all the more important as I found myself moving on from a dual role to a 'triune' role as a researcher, nurse and parent carer. My motives for the research, however, remained unchanged and these were driven by my clinical experiences.

1.2 Clinical reasoning for the research

As a student and junior mental health nurse in the early 1990s, I was socialised into mental health teams wherein families were valued as fundamental to the care and wellbeing of patients. The safety of the patient was paramount but where relationships were safe and adaptive, the accepted stance was to involve and support family members in the care and recovery of the patient. Accordingly, I developed a collaborative attitude towards families, and carer involvement and support has long been a core professional value for me. As I advanced my career and specialised in the area of self-harm and suicide, I gained additional insights into the extent of the family/carer role in supporting patients at risk of suicide and realised the importance of supporting carers to undertake this delicate and taxing task. Sadly, through my contacts with family members and carers I also became increasingly aware that they often felt they were not involved or supported by healthcare services. I carried this uncomfortable knowledge for some years, trying to counter my discomfort by ensuring that I myself practiced in a family focused way. Then I experienced a critical clinical experience with parents of an adult who had survived a near fatal suicide attempt, which I describe in appendix 1. This experience prompted critical reflection on my rather singular approach to familial support and led me to challenge more assertively the lack of attention to families and carers who support those at risk of suicide. I started to raise my professional voice to advocate for better recognition of carers and I collaborated with like-minded colleagues to improve carer support within my organisation. I also worked more closely with carers in relation to provision of support and coproduction.

The relationships I developed with carers offered me insights into the ongoing nature of caring and the impact this can have in terms of expectancy. These insights came from disclosures of a sense of anticipation of loss by suicide through phases such as ‘I’m just waiting for it to happen’. Examples of disclosures, which were donated to this thesis with the carers consent, are shown in appendix 2.

When I progressed my academic development to doctoral level, I decided to focus on the area of families and carers of people at risk of suicide to gain a deeper understanding of the experience and needs of this population with a view to improving support and interventions. My focus is on adult carers of adults as this is my area of professional practice and I believe that these carers may experience particular challenges that differ to those encountered by parent carers of young people.

The next part of this chapter discusses the key constructs relevant to the research presented in this thesis.

1.3 Main constructs relevant to the research topic

1.3.1 Suicide

It is important to note that different families or carers will interpret suicidality in different ways. This research did not seek to challenge perceptions of suicide risk. However, clinically and academically there is much literature which informs suicide related lexicon. It is important therefore to consider how suicide is understood and how I interpreted it in this research.

Suicide is a global public health concern accounting for over 703,000 deaths each year (World Health Organisation, 2021). In the United Kingdom (UK) the National Confidential Inquiry into Suicide and Safety in Mental Health (NCISH) reports there are around 6,214 deaths by suicide annually (NCISH, 2023), with over 5000 of these occurring in England (Office of NationalStatistics, 2023). For every completed suicide it is estimated there are 20 suicide attempts (World Health Organisation, 2014). Still more people experience suicide ideation and estimates indicate about a third of these go on to engage in suicidal behaviour within 12 months of onset of suicidal thoughts (Nock *et al.*, 2008).

The nomenclature of suicide, suicide ideation, suicidal behaviour and suicide risk is complex. Silverman (2013) highlights the many challenges with definition such as difficulty determining intent, acceptable and unacceptable terminology, and consensus with regard to interpretation. He notes the varying definitions used within international academia and clinical practice. Recent research to review suicide lexicon undertaken with members (academics, clinicians and experts by experience working in the field) of the International Association for Suicide Prevention (De Leo *et al.*, 2021) canvased views around the definition of suicide related terms. Consensus defined the following:

- suicide is ‘an act resulting in death which is initiated and carried out by an individual to the end of the action, with the knowledge of a potentially fatal result, and in which intent may be ambiguous or unclear, may involve the risk of dying, or may not involve explicit intent to die’
- suicide attempt is when ‘a person harms himself or herself, with the intention to die, and survives
- suicide ideation is thinking of suicide ‘with or without suicidal intent, or hope for death by killing oneself, or state suicidal intention without engaging in behaviour’

(De Leo *et al.*, 2021, p. 8)

There was less unity around a definition for suicide intent, leading the authors to suggest that intent should be guided by patient narrative. Silverman (2011), however, cautions that intent may be denied by patients when ambivalence is present. Indeed, it is known that many people who end their lives by suicide deny thoughts of suicide at their last contact with a clinician (Hawton *et al.*, 2022).

Determining who may be at risk of suicide is complicated. Whilst there is a plethora of evidence on suicide risk factors, such as mental illness, previous self-harm, childhood adversity and unemployment, suicide is multifaceted and it is virtually impossible to predict who will and who will not end their life (Knipe *et al.*, 2022). Most people who think about suicide do not end their lives, some because of an absence or cessation of intent and others due to preventative intervention and care. Therefore, there are many more people who could be considered at risk of suicide than will actually attempt or complete the act. Moreover, suicide is not a phenomenon that can be solely attributed to individuals; suicide is influenced by context and historic, political and social factors (Standley, 2022). A useful lens to consider suicide prevention through is that of Social Ecological Theory (Bronfenbrenner, 1979). Social ecology embraces systems thinking and takes into account the intrapersonal, interpersonal and wider macro factors that might influence individual suicidality. Over recent years, an adapted social ecological approach has been incorporated into suicide prevention (Cramer and Kapusta, 2017; Standley, 2022), with risk factors and interventions being considered at individual, relational, community and societal levels.

For the purposes of this doctoral study, the above definitions of suicide related behaviour are presented to situate suicidality as it is understood academically and clinically. However, the research is concerned with the perspectives of adults who care for adults they consider to be at risk of suicide. These perspectives will subjective and influenced by context. In England, public understanding of suicide is generally that it is a self-inflicted death. Googling ‘what is suicide’ indicates that suicide is ‘when someone ends their own life’. It is likely that the definitions recommended by De Leo *et al.* (2021) would be easily comprehended by the general public, but the current research did not impose a definition, rather participants were asked to base their judgement of suicide risk on past, current or recent behaviour of care recipients. The definition of suicide risk used for this research is outlined below:

Where the carer (family member, partner, friend) judges the care recipient to be at risk of suicide based on past, current or anticipated behaviour.

1.3.2 Caregiving and carers

Family members, partners and friends who care for another family member, partner or friend in the context of illness are usually referred to as caregivers or carers. Hermanns and Mastel-Smith (2012) discuss the etymology of the word ‘caregiving’ noting that ‘care’ and ‘give’ derive from Old English language relating to ‘mental suffering, mourning, sorrow or trouble’ and ‘to bestow gratuitously’ (p. 1). These authors state that the assimilation of the words ‘care’ and ‘giver’ and their underlying meanings convey caregiving as an action orientated term related to helping those who are suffering.

A concept analysis of caregiving by family members was conducted by Swanson *et al.* (1997) who identified caregiving as a process comprising a myriad of tasks and roles, which can be direct (provision of care) or indirect (arrangement of care). They propose that caregiving is characterised by a sense of responsibility and filial obligation, relational history, role acceptance and a sense of competency. Hermanns and Mastel-Smith (2012) expanded on this work and carried out a hybrid concept analysis of caregiving, which, similarly to Swanson *et al.* (1997), highlighted the importance of emotional connection between the caregiver and care recipient and identified essential elements of ability to care and communicate, and adaptability. They defined caregiving as:

> ‘the process of helping another person who is unable to do for themselves in a “holistic” (physically, mentally, emotionally, and socially) manner. Caregiving is facilitated by certain character traits, emotions, skills, knowledge, time, and an emotional connection with the care recipient.’ (Hermanns and Mastel-Smith, 2012, p. 15)

The word informal is usually added to the term caregiver or carer to distinguish family or friend caregivers from paid and professional carers. This use of ‘informal’ has been criticised by (Stall *et al.*, 2019) who consider the term to be disrespectful because it infers caring is a casual and non-essential task, which is at great odds with the reality of caregiving. These authors argue the informal label may mediate nonchalant assumptions about caregiving within health and political discourse, which will impede recognition of caregivers and thus negate the support and education they need to equip them to sustain their caring roles.

Notwithstanding dissent with the term, ‘informal caregiver’ is frequently used within nursing and wider literature when discussing and researching the caregiver population. A recent concept analysis of ‘informal carer’ (Castro *et al.*, 2023) largely echoed findings from the concept analyses discussed above, but emphasised more strongly the negative consequences ongoing caring can have on caregivers, such as self-sacrifice, identity loss, exhaustion, difficult emotions, and stigma. These authors acknowledged the evolution of the caregiver role over the time their review spanned (1986 – 2021), noting key societal and healthcare changes, particularly the aging population and the shift from hospital to community care. These changes may account for the weight of the negative aspects of the caregiver role in their concept analysis as more recent studies might have involved long-term caregivers and reflected the lack of resources in contemporary healthcare.

In the UK the term 'carer' is commonly used to describe a member of this population, with the NHS defining a carer as:

'anybody who looks after a family member, partner or friend who needs help because of their illness, frailty or disability. All the care they give is unpaid.' (NHS England, 2014)

The expression carer has been contested, however. Molyneaux *et al.* (2011) reviewed literature from various health and social care settings and concluded that the term 'carer' is ineffective and should be replaced by retaining a focus on the primary relationship i.e., parent, partner, friend. They argue that interpretation of the term does not take into account the complexity of interpersonal relationships or carers own needs. Furthermore, they reason that the label assumes blame toward carers for causing or maintaining problems and toward the person in need of care for causing carer burden. Their review refers to research wherein the term carer has been rejected by people with health conditions and those who care for them.

Despite the dispute surrounding the term carer, it is still widely accepted within UK policy, practice and research. With regard to mental health, the Triangle of Care: Carers Included (Worthington, 2013) is a longstanding best practice guide developed by carers organisations and informed by carers, which has been adopted by many NHS Trusts in England. In addition, assessments of support needs and benefits are dependent on criteria which identify one as a carer. The current term as defined by NHS England does ensure a degree of shared understanding between those in receipt of care, those who provide support and care at home, and professional health and social care providers. In addition, it does at least acknowledge the primary relationship of family member, partner or friend. Therefore, until an acceptable alternative is achieved, there will likely be a continued reliance on the word carer within UK healthcare parlance.

From my professional perspective I have approached this research as a nurse familiar with the term carer. I work with family members, partners and friends in various capacities from clinician to coproduction and I collaborate with a shared understanding of carer in line with the NHS definition. Whilst I feel and hear some contention with the carer terminology, my experience suggests that it is the relationship which matters most; if the relationship is authentic, collaborative and equal it can overcome uncomfortable jargon. Thus, in the absence of an ideal word, throughout this thesis I use the term carer interchangeably with family member, partner, friend and caregiver, with my underpinning beliefs and values being centred on the person and their relationship with the care recipient. The definition for carer used within the research is based on the NHS England (2014) definition and shown below.

Anyone aged 18 or over who looks after, on a non-professional basis, a family member, partner or friend aged 18 or over who needs help and support because they are considered to be, or have previously been, at risk of suicide.

1.3.3 Carers of those at risk of suicide

In the UK around a quarter of people who die by suicide have received care from psychiatric services within the year before their death (NCISH, 2023) . Mental health services are often heavily reliant on carers to support vulnerable individuals at home, including when they are actively struggling with suicidal thoughts and behaviours (Grant, Ballard and Olson-Madden, 2015). Given most individuals who die by suicide are not in touch with mental health services at the time of their death (NCISH, 2023), many people will be supporting someone at risk of suicide without any professional support or contact at all. The number of people who are caring for someone at risk of suicide, however, is unknown. The closest estimation suggests there are over a million informal carers supporting a person with a mental health condition in the UK (Rethink, 2021). Of course, not all of these will be dealing with suicidality and there may be others who are caring for individuals at risk of suicide who are not considered to have a mental health condition.

Carers of people at risk of suicide are not adequately recognised in global or national suicide prevention strategy. The World Health Organisation (2014) asserts the need for carers to be involved in mental health care design and delivery, but their suicide prevention emphasis is on people who attempt suicide, or are bereaved by suicide, with carers receiving minimal attention. The National Institute for Clinical Guidance (NICE) guidance for preventing suicide in community and custodial settings (NICE, 2018) does not reference carers at all, although more recent guidance for the assessment, management and prevention of recurrence of self-harm (NICE, 2022) does stipulate the importance of informing and involving carers, suggesting that recognition of this population is growing. The Suicide Prevention Strategy for England (Department of Health and Social Care, 2023) has a key objective pertaining to people bereaved by suicide but mention of carers of those at risk of suicide, whilst present, is scant and not prioritised or linked to any specific action.

The low level of attention on the needs of carers of people at risk of suicide likely explains the rather weak provision of support for this population. Various non statutory support agencies provide information for family and friends of people at risk of suicide but, with some exceptions, this is largely focused on what they can do to support the individual rather than support for carers themselves (Maple *et al.*, 2021), despite the fact that research suggests considerable trauma and stress to carers (Buus *et al.*, 2014).

Research interest in this area has increased considerably in the last decade. For example, a recent large mixed methods study commissioned by SANE Australia (Coker *et al.*, 2019) investigated the experiences of carers who support care recipients after a suicide attempt and their perspectives of what resources and interventions would support people in their caring role. A total of 758 participants completed an online a survey and 30 also took part in semi structured interviews. The study has not been published in peer reviewed journals in its entirety but has resulted in two peer reviewed publications (Maple *et al.*, 2021; Wayland, Coker and Maple, 2021), which are included in the literature review (chapter 2). The research concluded that there is a need for improved understanding of carers roles and better recognition and involvement of carers by the healthcare sector. Additionally, it was identified that resources for carers required improvement.

With regard to peer reviewed research papers, three recent systematic reviews appraise the evidence. Juel *et al.* (2021) conducted a meta-ethnography of 11 qualitative studies to develop a theoretical understanding of the experiences of family members of individuals at risk of suicide. Four of the studies reviewed defined the condition of interest as self-harm, with one of these focusing specifically on non-suicidal self-harm. This highlights the difficulties with definition of suicidality; people who self-harm are known to be a group at risk of suicide (Knipe *et al.*, 2022) although self-harm can equally be non-suicidal in nature

(Nock and Favazza, 2009). Juel *et al.* (2021) were concerned with ‘non-fatal’ suicidal behaviour, thus arguably non-suicidal self-harm does not fit with their original definition and aim. Moreover, five of the 11 studies reviewed comprised participants who exclusively or predominantly cared for under 18-year-olds and experiences of carers of adults were not extrapolated from those of younger people.

Juel *et al.* (2021) highlighted a ‘moral career’ trajectory, spanning an initial phase of shifting from ‘normal to abnormal’ when self-harm first occurs through to a gaining sense of a new and different normality which might include living with self-harm and suicidality. Tensions with healthcare services were uncovered but so was professional support that facilitated carers insights into their helpfulness or unhelpfulness in their relatives’ care. The authors recommend that professionals try and make sense of where carers are in their ‘moral career’ in order to assist progression, and that family members should have opportunities for peer support.

A mixed method systematic review was conducted by Lavers, Andriessen and Krysinska (2022). This included 21 studies, six of which included participants who exclusively or predominantly cared for under 18-year-olds. The authors established that supporting someone at risk of suicide can have a detrimental psychological impact on carers and cause disruption to family dynamics. They identified difficult experiences with healthcare services and recommend improved carer involvement and support, including respite care, psychological counselling and mental health screening. In addition, they advocate guidelines for professionals to educate and prepare caregivers for assessing and managing suicide risk at home. However, although both qualitative and quantitative studies were included in this review, minimal qualitative data (i.e., quotes) were used to illustrate the reviewers’ judgements and no themes were developed.

The most recent review (Marshall *et al.*, 2023) is a thematic synthesis of 19 qualitative studies investigating experiences of family members or friends of people at risk at suicide. Ten of these studies involved adult carers of adults, six studies had samples comprising carers of young people, and two involved participants predominantly caring for young people. In one study, ages of the suicidal individuals were unreported but as the participant sample were undergraduate college students who were asked if they had ever responded to a family member or friend in a suicidal crisis, it is likely a sizable proportion would have responded in relation to a young person. Moreover, the college student participants would, in all likelihood, not have been undertaking day to day caring of individuals at risk of suicide. Three analytical themes were developed relating to, the impact of experiencing suicidal situations, seeking safety in professional support, and learning to manage risk. Difficulty accessing support was revealed along with the need for support and education around managing suicidality and associated emotional and familial responses. Recommendations emphasise the importance of supporting and involving carers in care and safety planning and attending to carer wellbeing. This qualitative synthesis sought to answer the same question as the current doctoral research and provides essential information for clinicians. However, the emphasis appears to be somewhat weighted towards parents. Also, the addition of quantitative literature might have expanded understanding.

All of these reviews provide consistent and valuable insights into experiences of carers of people who may be at risk of suicide. However, because nearly half of the studies in the Juel *et al.* (2021) and (Marshall *et al.*, 2023) reviews and almost a third in that by Lavers, Andriessen and Krysinska (2022) involved carers of either predominantly or exclusively under 18 year olds, issues especially salient for adults who care for other adults may not have been elucidated. The present doctoral research addressed experiences of those caring specifically for adults at risk of suicide as it is feasible there are differences in experiences due to the adult/adult dynamic as opposed to the adult/child relationship.

1.3.4 Carers quality of life

Carers generally are known to have poor health and social outcomes. A review by Cottagiri and Sykes (2019) identified both physical and mental health problems related to the stress of caring; isolation of carers; economic impacts; and due to disrupted sleep, poor diet and lack of exercise secondary to the demands of caring or the mental health consequences. They found some positive aspects of caring as well, associated with good relationships with the care recipient, robust social support systems and effective relationships with healthcare professionals (HCPs). With regard to caring for people with mental illness, Shah, Wadoo and Latoo (2010) reviewed research investigating the relationship between caring and psychological distress, finding that behavioural disturbance of the care recipient and carers concern that they may make a suicide attempt were considerable sources of distress.

In the literature, poor health and social outcomes are often encapsulated as caregiver burden, a frequently used term and a phenomenon that has received considerable research attention over many years. However, problems with the term and the academic study thereof have been identified. Bastawrous (2013) suggests the multifaceted nature of caregiver burden results in varying definitions and interpretations of the concept depending on the focus and interest of the researcher. A concept analysis of caregiver burden (Liu, Heffernan and Tan, 2020) resulted in a definition of caregiver burden as ‘the level of multifaceted strain perceived by the caregiver from caring for a family member and/or loved one over time’ (p. 442). Definitions such as this one have been criticised because of the negative messaging. Brown and Brown (2014) argue for more balanced appraisals of caring that account for the potential positive outcomes, such as relationship satisfaction and positive affective responses resulting from giving to others. Similarly, Joseph *et al.* (2012) suggest a shift from measuring negative outcomes in the context of burden to understanding carers quality of life more holistically, including positive components.
It will be interesting to understand if carers of adults at risk of suicide experience satisfaction in their role, as satisfying aspects of caring in this context do not appear to have been studied in any depth as will be seen in the literature review in chapter 2. The research carried out by SANE Australia (Coker *et al.*, 2019) did not indicate elicitation of positive appraisals of caring. This may be because measures and questions were more geared toward finding out about the negative aspects of caring, or that carers did not have positive experiences. The current doctoral research will seek to attend to the absence of information about positive aspects of caring by exploring quality of life rather than caregiver burden, including questions around satisfaction with the caring role.

1.3.5 Stigma associated with caring

The word stigma originated from the Greek language and means ‘sore mark’ (Eilers and Kasten, 2022). Much of today’s understanding of stigma is underpinned by Goffman (1963) who presented stigma as a relationship between visible and concealable attributes (at an individual level) and stereotypes (at a public level). Link and Phelan (2001) built on Goffman and took into account critical views from stigmatised populations based on their assertion that the original concept of stigma victimises and avoids the issue of discrimination. These authors conceptualise stigma as a convergence of interrelated components, these being: the labelling of human differences; the creation of negative stereotypes through dominant cultural beliefs; the categorisation of labelled people leading to an 'us and them' separation; the discrimination of labelled individuals; and the social, economic and political power that enables stigma to occur (Link and Phelan, 2001, p. 367).

The social process of stigmatisation is emphasised by Pescosolido and Martin (2015) who highlight that stigmas are 'shaped and reshaped' (p. 91) in somewhat of a reciprocal fashion in line with the fluidity of cultural and societal circumstances. Pescosolido and Martin (2015) note confusion around the term stigma in research due to the differing and often vague definitions of the concept. To address this, they advocate defining stigma through experiential and action categories with variants in each. Experiential variants include perceived stigma (agreement that stigma exists toward a labelled group whether or not one individually agrees with the stigma), anticipated stigma (the expectation of stigmatised behaviour and discrimination from others), endorsed stigma (agreement with stereotypical beliefs), received stigma (personally experiencing discrimination), and enacted stigma (discriminatory behaviour towards a labelled group). Action variants relate to self-stigma (labelled individuals self-assessing and accepting their lower worth), public stigma (within the general population) and courtesy stigma, or stigma by association (experienced by those who have a relationship with labelled groups or individuals). At a macro level, structural stigma involves organisations, government and policy restricting rights of certain labelled groups.

Structural stigma in relation to suicide is noted by Eilers and Kastan (2022) to exist within religious, legal and historic cultural norms. For example, Hinduism considers that punishment will occur in the next life if someone ends their life; Christianity espouses that life that was given by God and can only be ended by God; and, according to Islam, suicide is a sin. From a legal perspective, until 1961 suicide and attempted suicide were illegal in the UK, and, culturally, some insurance policies continue to refuse payments following death by suicide.

Public stigma toward suicide and received or self-stigma within labelled groups has been investigated in several studies. Sheehan, Dubke and Corrigan (2017) surveyed adults, asking them to complete a suicide specific stigma measure for various vignettes describing cases involving histories of depression, suicide attempt, death by suicide and a control in which no such history was described. Findings indicated that participants were more pessimistic about recovery in the case involving suicide attempt than they were the one describing depression, suggesting that there may be differences in stigma between mental illness and suicide, or that stigma is increased where suicidality is involved. Another study (Sheehan, Corrigan and Al-Khouja, 2017) examined public stigma using separate focus groups with suicide attempt survivors, relatives bereaved by suicide and service providers. The most commonly endorsed stereotypes of suicide attempters were negative, including perceptions of them being considered as attention seeking and malingerers. The authors identified assumptions around contagion and perceptions of the impossibility of recovery. Although helpfulness of healthcare providers was identified by participants in this study, so was discrimination, which was also experienced from employers and within personal relationships. Unfortunately, this study did not include carers of suicide attempt survivors, only those bereaved by suicide, who may have different perspectives.

Perceived stigma has been found to be present toward people who attempt suicide by Scocco *et al.* (2012), who studied samples of suicide attempt survivors, people bereaved by suicide and the general public. Again, samples did not knowingly include carers and therefore cannot be uncritically attributed to that population. Comparisons of perceived stigma from treatment providers and social networks were examined by Frey, Hans and Cerel (2016) via an online survey completed by suicide ideators and attempt survivors. It was found that individuals were more likely to experience stigma from their social networks, including family and friends, than they were from healthcare providers. This is concerning given that most support comes from social networks and stigma has been shown to obstruct help-seeking. However, the study did not include any perspectives from carers, which would have helped to understand whether the perceived stigma of the person at risk of suicide was in any way mediated by carers own perceived stigma, including stigma by association.

Public stigma, perceived stigma and stigma by association are of particular relevance to the carer population but are understudied. Ostman and Kjellin (2002) interviewed 162 relatives of patients in acute psychiatric wards and found evidence of psychological factors of stigma by association, which manifested through feelings of inferiority with staff, reduced opportunities for social interaction and, for some participants, thoughts of wishing the patient had never been born or that they would be better off dead. Findings also indicated a relationship between stigma by association and relative's mental health, with 40% of the sample believing that their own mental health problems had been caused by patients' ill health. This was not substantiated by mental health history or objective measurement and did not account for independent predisposing factors, however. Whether or not suicidality was a factor in how carer participants were managing was not discussed in this study, which looked at differences based on diagnoses rather than behaviours and found few.

There is a definite lack of research investigating stigma within carers of people at risk of suicide. The studies by Frey, Hans and Cerel (2016) and Sheehan, Corrigan and Al-Khouja (2017) have in cases been taken to mean that stigma is experienced by carers, which is rather unfounded given the absence of identified carers in the study samples. Where carer specific research does identify stigma, it is related to their cultural beliefs (Sun *et al.*, 2008; Asare-Doku, Osafo and Akotia, 2017), gender and cultural norms (Owens *et al.*, 2011), a sense of shame (McLaughlin *et al.*, 2014) and concern about the possible responses of others (Spillane *et al.*, 2020), although these studies did not attempt to measure stigma. The limited research that does involve measurement of stigma includes a Taiwanese study (Chiang *et al.*, 2015), which investigated the association between caring stress, suicidal attitude and suicide care ability among family caregivers of suicidal individuals. These authors found an association between stigmatising attitudes towards suicide and lower care ability. In addition, an Australian study by (Maple *et al.*, 2021) found that stigmatising attitudes towards suicide were not predictive of caregiver burden. The current doctoral study adds to this evidence by addressing stigma that is perceived and experienced by carers.

1.3.6 Caring in the COVID-19 pandemic

Following the onset of COVID-19 and commencement of related restrictions in many countries, including the UK, in March 2020, concerns were expressed regarding population mental health, including risk of self-harm and suicide (Paul and Fancourt, 2022). Particular concerns were raised in relation to people with existing mental health problems (Batteux, Taylor and Carter, 2021), and it was correctly predicted that reliance on carers would escalate following the onset of the pandemic (Onwumere, 2021; Onwumere *et al.*, 2021).

The charity Carers UK reported a notable increase in the intensity of caring provision alongside, and often due to, reduced support from services (Carers UK, 2020).
Over the pandemic period caregivers in the UK experienced higher rates of depression and anxiety (Mak, Bu and Fancourt, 2021; Whitley, Reeve and Benzeval, 2021), as well as increased loneliness and isolation (Gallagher and Wetherell, 2020), and social consequences such as financial strain (Lorenz-Dant and Comas-Herrera, 2022). Whilst undoubtedly carers of people at risk of suicide were included in this population-level research, they do not appear to have been specifically studied during this period. A condition-specific approach to studying carers needs has been advocated by Onwumere *et al.* (2021), and pandemic-related studies investigating the experiences of caregivers of people with dementia (Giebel *et al.*, 2021a; Giebel *et al.*, 2021b), eating disorders (Maunder and McNicholas, 2021) and intellectual disability (Sideropoulos *et al.*, 2022) have identified issues salient to those populations. It is important to understand the experiences of caregivers who were trying to manage suicide risk in the community during the COVID-19 pandemic, particularly when social restrictions were in place, in order to develop effective supportive interventions in the aftermath of the pandemic and to inform future policy and practice. This doctoral research aimed to understand if and how the COVID-19 pandemic influenced the caregiving experience of adult informal caregivers of adults at risk of suicide in England.

1.4 The role of nurses and healthcare providers in supporting informal carers

Nurses and other healthcare providers (HCPs) in all clinical settings are likely to encounter carers supporting adults at risk of suicide. These contacts are opportunities to offer supportive interventions. To understand experiences of working with family members of patients at risk of suicide, Vatne, Lohne and Nåden (2021) interviewed 12 HCPs, including eight mental health nurses (MHNs). They found acknowledgement, validation, instilling hope, and providing reassurance and support as core components of carer support. These elements were also expressed as needs by carer participants in the Coker et al (2019) study, and the synergy here is encouraging. Unfortunately, many carers do not experience these approaches; most participants in the Coker et al (2019) study conveyed dissatisfaction with healthcare services and professionals. The HCPs in the Vatne, Lohne and Nåden (2021) study were highly skilled clinicians with ample experience working with families and are not therefore representative of clinicians generally. However, these studies can inform the learning of others, which is of value given there is a lack of guidance on working with carers in the context of suicidality. Evidence based interventions are few; a systematic review by Krysinska *et al.* (2021) found only limited evidence for just three interventions for adult carers of adults at risk of suicide. One of these was a programme for family members of people with a diagnosis of borderline personality disorder originally developed in North America, one was a brief psychoeducational intervention developed for carers in Taiwan, and one was a suicide prevention plan intervention carried out with families in Korea. The same review identified a few joint interventions targeting family members and individuals at risk of suicide, but these involved young people and their (predominantly parent) carers. These findings indicate a need for further development of interventions targeting adult carers of adults at risk of suicide. To ensure such interventions are appropriately tailored it is important to understand the needs and experiences of this population. The current research aims to achieve this understanding in relation to carers in England.

1.5 Significance and relevance of study

As noted in the discussion above, it is unknown how many people in England care for adults at risk of suicide but given in the UK there are well over a million carers of people with known mental health conditions alone, the figure is likely substantial. Carers generally experience higher rates of mental and physical ill health than the general population (Berglund, Lytsy and Westerling, 2015) and are thus a population deserving of tailored support. Barriers to support might include a lack of understanding of what is needed and perceived stigma. It is known that stigma can result in social isolation and a lack of help seeking, and suicidality can add to the public stigma already attached to mental illness (Sheehan, Dubke and Corrigan, 2017).

In England there are a number of national organisations tailored to supporting people bereaved by suicide and the government expects local authorities to ensure service provision for people bereaved in this way (NHS England, 2019). There are also national and local organisations that provide support to carers of people with mental health problems and local commissioning arrangements generally ensure community access to carer support. Whilst some of these latter organisations no doubt offer support and education to help carers manage suicidality, there is no standardised or accepted evidence-based provision for this population. This absence suggests a lack of recognition of carers who manage suicide risk at home, which might lead to a sense of invisibility, in turn potentially increasing self and perceived stigma. If this is the case, it is conceivable that tailored support for this population may help to reduce stigma. As healthcare services are so dependent on family members, partners and friends in the care of patients, there is a fundamental need to care for the carer. This includes developing effective mechanisms for support which are mindful of the stigma that may be experienced.

The primary aim of this research was to address the knowledge gaps discussed above by gaining an understanding of the support experiences and needs of adult carers of adults at risk of suicide in England. The mixed methods approach used enabled qualitative interview and survey data to be considered alongside quantitative data specific to perceived stigma and quality of life. As a result, a more complete understanding of the experiences and needs of carers has been achieved than either qualitative or quantitative research alone would have attained. No prior mixed methods studies with this population have previously been conducted in the UK and studies of any type in England are sparse. In addition, very few studies internationally have looked specifically at suicide related stigma amongst carers. The current research is worthy because it provides new knowledge about the experiences and needs of carers of adults at risk of suicide in England. This knowledge will help enhance HCPs understanding of the context of informal caregiving, which will assist practice improvement. In addition, research outcomes will contribute to the development of tailored interventions for carers. More broadly, it is anticipated that the outcomes of this research will contribute to the development of supportive resources for carers. From a policy perspective it is expected that the research will have the potential to influence a call for more explicit attention to the needs of carers of those at risk of suicide in national policy, strategy and research.

The research question, aims and objectives are set out below.

1.6 Research question, aims and objectives

Research Question

What are the experiences and support needs of adult carers (family members, partners and friends) in England who care for adults they consider to be at risk of suicide?

Research Aim

To develop an understanding of experiences and perspectives of adults who care for adults they consider to be at risk of suicide, including impact on quality of life and perceptions of stigma.

Objectives

- To carry out a comprehensive review of literature reporting experiences and support needs of adult carers of adults at risk of suicide.
- To use qualitative research methods to describe the caring experience, experiences of support received, and perspectives on support required by adult carers who currently care for adults they consider to be at risk of suicide.
- To use quantitative research methods to rate support, determine quality of life and elicit perceptions of stigma among adult carers of adults at risk of suicide, and establish whether associations between these two latter constructs exist.
- To synthesise qualitative and quantitative data to expand understanding of the research topic
- To evaluate the experience of participation in this research.

The methods by which the objectives were achieved are discussed in chapter three. The organisation of the remainder of the thesis is presented below.

1.7 Organisation of thesis

This thesis has seven chapters. This first chapter has provided the background to the research that is presented throughout the remainder of the thesis. Chapter 2 presents the literature review completed for the study and chapter 3 covers the methodological approach and the methods used. Chapter 4 presents the results of the research. Integration and mixed methods interpretations of the results are included in chapter 5, and chapter 6 offers a discussion of the main findings alongside extant literature and theory. Finally, the thesis is concluded in chapter 7 and recommendations for practice and future research are presented.

1.8 Chapter summary

This chapter has introduced the research question underpinning the research presented throughout this thesis. The clinical reasoning behind the study has been provided along with a discussion of key constructs and research relevant to the topic of carers of adults at risk of suicide. An argument for the relevance of the research to practice and policy has been made. In addition, my positioning as a nurse researcher has been discussed. Finally, the aims and objectives of the research have been summarised and the organisation of the thesis has been outlined. The next chapter presents the literature review.

CHAPTER TWO: LITERATURE REVIEW

2.0 Introduction

This chapter presents the systematic literature review conducted in line with the research question of the current research. This review was published in the *Journal of Advanced Nursing* on 27th November 2023 (Lascelles *et al.*, 2023) but elements of the introduction and discussion have been adapted for this thesis chapter and the methods have been expanded upon. Reference to the first author is to me as the researcher and 'other authors' refers to the supervisory team. The publication reference is:

Lascelles, K.M., Davey, Z., Jackson, D. and Aveyard, H., (2023) Experiences and needs of adult informal carers of adults at risk of suicide: A systematic review with mixed methods analysis. *Journal of Advanced Nursing*, 00, pp. 1–33. Available at https://onlinelibrary.wiley.com/doi/pdfdirect/10.1111/jan.15940

2.1 Abstract

Aim

To systematically review and synthesise primary research on experiences and needs of adult informal caregivers of adults at risk of suicide.

Design

Systematic review with a data based convergent synthesis.

Data Sources

MEDLINE, PsychINFO and CINAHL were searched in April 2022 and February 2023. English language research focusing on experiences of adult carers of adults was included.

Methods

Articles were screened by title (n=9077) and abstract (n=132) with additional articles (n=6) obtained via citation and hand searching. 31 included studies were quality assessed using the Mixed Methods Appraisal Tool and study data was systematically extracted prior to thematic synthesis.

Results

Five interconnected themes resulted: transitions; living with fear and uncertainty; changing relationships; interface with HCPs and services; what carers need and want. Caring impacts mental, physical and social wellbeing. Relationships are affected in ways which might not be evident when caring for a minor. Repeated suicidal behaviour is particularly challenging with ongoing hypervigilance contributing to burden, burnout and interpersonal strain. Poor carer support exacerbates negative effects; carers need to feel informed, educated, involved and holistically supported.

Conclusion

Timely support for carers is essential. Interventions should address emotional responses, relational changes and effective care recipient support. Longitudinal research is required to understand effects of ongoing caring where there are multiple suicide attempts.

Implications

Nurses can provide carers with early support and information and longer-term psychosocial interventions. If carers are adequately equipped and supported patient safety and wellbeing will be improved.

Impact

Findings of this systematic review include relational changes due to carer hypervigilance reducing autonomy and living with the possibility of suicide. Clinician awareness of the potential for relational shifts will help them prepare and support carers.

There was no patient or public contribution.

2.2 Background and aim

As highlighted in the previous chapter mental health services rely on informal carers to provide support to adults who are assessed to be at risk of suicide but support for these carers is deficient. The lack of recognition of this informal caregiver population in suicide prevention strategy, along with the fact that research interest in this area is relatively recent, suggests that the experiences and needs of carers of adults at risk of suicide are not yet clearly understood. This may contribute to the low level of support offered and received. That said, despite the wealth of research investigating carers' experiences of caring for people with mental health problems more generally, reports of lack of

involvement and support still abound. The topic of 'mental health problems' is very broad and even research related to certain diagnoses might struggle to highlight salient issues pertaining to specific aspects of caring. It may be helpful therefore to home in on the particular issue of caring for adults at risk of suicide to reach understandings which can inform strategy and clinical practice and contribute to the development of tailored interventions. This is the aim of the research presented in this thesis.
When embarking on research endeavour it is standard practice to conduct a literature review related to the research question to understand what it and what isn't currently known about the question identified (Aveyard, Payne and Preston, 2021). The aim of this systematic review therefore was to understand what is known about the experiences and needs of adults who care for another adult they consider to be at risk of suicide.

2.3 Design

In this systematic review the intention was to include both quantitative and qualitative research to achieve a comprehensive overview and synthesis of current evidence relevant to the research question. It is argued that mixed methods systematic reviews provide clearer direction for policy makers and practitioners than single method reviews because they avoid confusion stemming from trying to understand multiple syntheses of different orientations about the same topic (Pearson *et al.*, 2015). Two main types of synthesis designs in mixed methods have been identified by (Hong *et al.*, 2017): convergent and sequential. In convergent synthesis designs quantitative and qualitative evidence is collected and analysed concurrently whereas sequential designs involve two phases with one being informed by the other. The most common designs are convergent, of which there are three approaches: data based, results based and parallel results (Hong *et al.*, 2017). In data-based designs all included studies are analysed using the same method of synthesis, which involves either transforming quantitative data to qualitative or vice versa. Results are then presented together. Results-based designs involve synthesising separate analyses of quantitative and qualitative evidence. Finally, parallel-results designs comprise separate analyses and presentations of the qualitative and quantitative evidence with synthesis occurring during the discussion.

A data-based convergent synthesis design (Hong *et al.*, 2017) was adopted for this systematic review. Thematic synthesis (Thomas and Harden, 2008) was used for data transformation of the relevant textual quantitative data (numerical results of quantitative studies are not included in the analysis) and for analysis and synthesis of transformed quantitative data and qualitative data. Thematic synthesis involves both the aggregation of descriptive themes and the development of analytical themes within a framework that encompasses three stages to synthesis: line by line coding of individual study findings; organising codes into descriptive themes; and developing analytical themes.

This systematic review was adherent to relevant EQUATOR guidance and PRISMA reporting (Page *et al.*, 2021) (see appendix 3). It was not registered on Prospero because at the time of writing the review COVID-19 related work was being prioritised.

2.4 Search strategy

Search terms were established using the PICo (population, phenomenon of interest, context) framework (Lockwood, Munn and Porritt, 2015), with the assistance of a specialist health librarian. Main key words were ‘informal caregivers’, ‘experience’ and ‘suicide’. Because the focus was on risk of suicide, self-harm was not included as a key word because it would have highlighted studies including non-suicidal self-harm. Search terms are shown in Table 1.

Table 1: Search terms and inclusion/exclusion criteria

Population: Adult carers of adults at risk of suicide	Phenomenon of Interest	Context
“Informal caregiver*(s)”	Experience* (s)	Suicid* (suicide, suicidality, suicided, suicidal, suicide attempt, suicidal behaviour)
“Informal carer*(s)”	Feeling* (s)	
“Significant other* (s)”	Perspective* (s)	
Famil*	View* (s)	
“Next of kin”	Support	
Relative*(s)	Need* (s)	
Partner* (s)		
Spouse		
Wife		
Husband		
Daughter*		
Son*		
Parent*		
Mother		
Father		

Boolean operators

("informal caregiver*" OR "informal carer*" OR "significant other*" OR famil* OR "next of kin" OR relative* OR partner* OR spouse OR wife OR husband OR daughter* OR son* OR parent* Or mother OR father) AND (feeling* OR perspective* OR view* OR support OR need*) AND suicid* NOT (assisted suicide or euthanasia or right to die or death with dignity) NOT (children or adolescents or youth or child) NOT suicide bereavement

Inclusion and Exclusion criteria

Inclusion criteria: peer reviewed empirical qualitative, quantitative or mixed methods studies that included a focus on the experiences and needs of adult informal caregivers of adults at risk of suicide. Reports from the same research study were included if they reported new or additional findings.

Exclusion criteria: Non empirical papers, literature reviews and grey literature, research exclusively studying paid carers, young carers, carers of children and adolescents, and people bereaved by suicide. Studies investigating experiences around euthanasia or assisted dying.

2.5 Information sources

The data bases MEDLINE, PsychINFO and CINAHL were searched on 19th April 2022 with a repeat search on 28th February 2023 to identify any relevant new articles (none were identified). Database limits were English language, adult (age 18 and over) and, date of publication from 1990 onwards. Citation and hand searching were carried out to retrieve additional studies.

2.6 Eligibility criteria

Inclusion and exclusion criteria are listed in Table 1. Where studies involved adult carers of mixed age groups or populations (i.e., children/adolescents and adults; carers and people bereaved), they were excluded if it was clear that over half of care recipients were under the age of 18 or over half of participants were bereaved. In the few cases where ages of care recipients were not reported, the study team discussed the likelihood of half or more being adult based on the relationships with the caregiver participant (e.g., if the carer was an adult partner or friend it was assumed the carer recipient would also be adult).
Studies were identified, screened and selected or otherwise by the first author. Selection decisions were reviewed with the other authors and disagreements resolved through discussion. Citations of papers that were excluded after full assessment for eligibility are provided in appendix 4.

2.7 Quality appraisal

There are many critical appraisal tools available to judge the quality of reported research but no gold standard tool (Katrak *et al.*, 2004). This creates confusion for novice researchers, which is amplified by the differing views in the literature regarding relevance of critical appraisal to systematic reviews. Even recent literature asks the question ‘how should the critical appraisal of quantitative, qualitative and mixed methods studies be performed?’ (Hong and Pluye, 2019). Notwithstanding this debate, there is an expectation that quality assessment of studies included in reviews is conducted. The Mixed Methods Appraisal Tool MMAT (Hong *et al.*, 2018) was used to assess the quality of included studies in the current review. The MMAT consists of tools to assess quantitative, qualitative and mixed methods studies, including quantitative non-randomised and descriptive studies. The current version has resulted from comprehensive testing and evaluation of previous versions (Pace *et al.*, 2012; Souto *et al.*, 2015). As most of the quantitative studies in this review were descriptive, the MMAT was considered to be an appropriate tool. Scoring of quality appraisal is not supported by MMAT and responses to appraisal questions are 'yes/not clear/no', with descriptions to defend decisions. In this review, 'not clear' was also used to denote 'somewhat'. Quality appraisal was conducted to determine strengths and weaknesses of studies rather than for exclusion purposes. Assessment was carried out by the first author and discussed with the remaining authors to achieve consensus. Assessment was somewhat challenging with the descriptive quantitative reviews. For example, cross sectional surveys involving self-selection and including only non-validated questionnaires could automatically be deemed as low quality due to the limitations around validity and generalisability. However, where limitations were candidly acknowledged, the target population was relevant to the research question, the sampling strategy comprehensive and analysis transparent and appropriate for the methodology such studies were judged to meet criteria set out by the MMAT. Therefore, the subjectivity of the quality appraisal is acknowledged as a limitation.

2.8 Extraction of Data items

Data relevant to the review question were extracted in line with Aveyard, Payne and Preston (2021) guidance to develop data extraction tables unique to individual reviews. Data extracted included study characteristics of location, research aim and design, sample size, basic demographics, relationship of caregivers to care recipients, validated measures used, and key themes and results (see appendices 5 and 6). Data not relevant to the review question were not extracted, for example where studies investigated both carer and care recipient experiences, only data specific to carers were included.

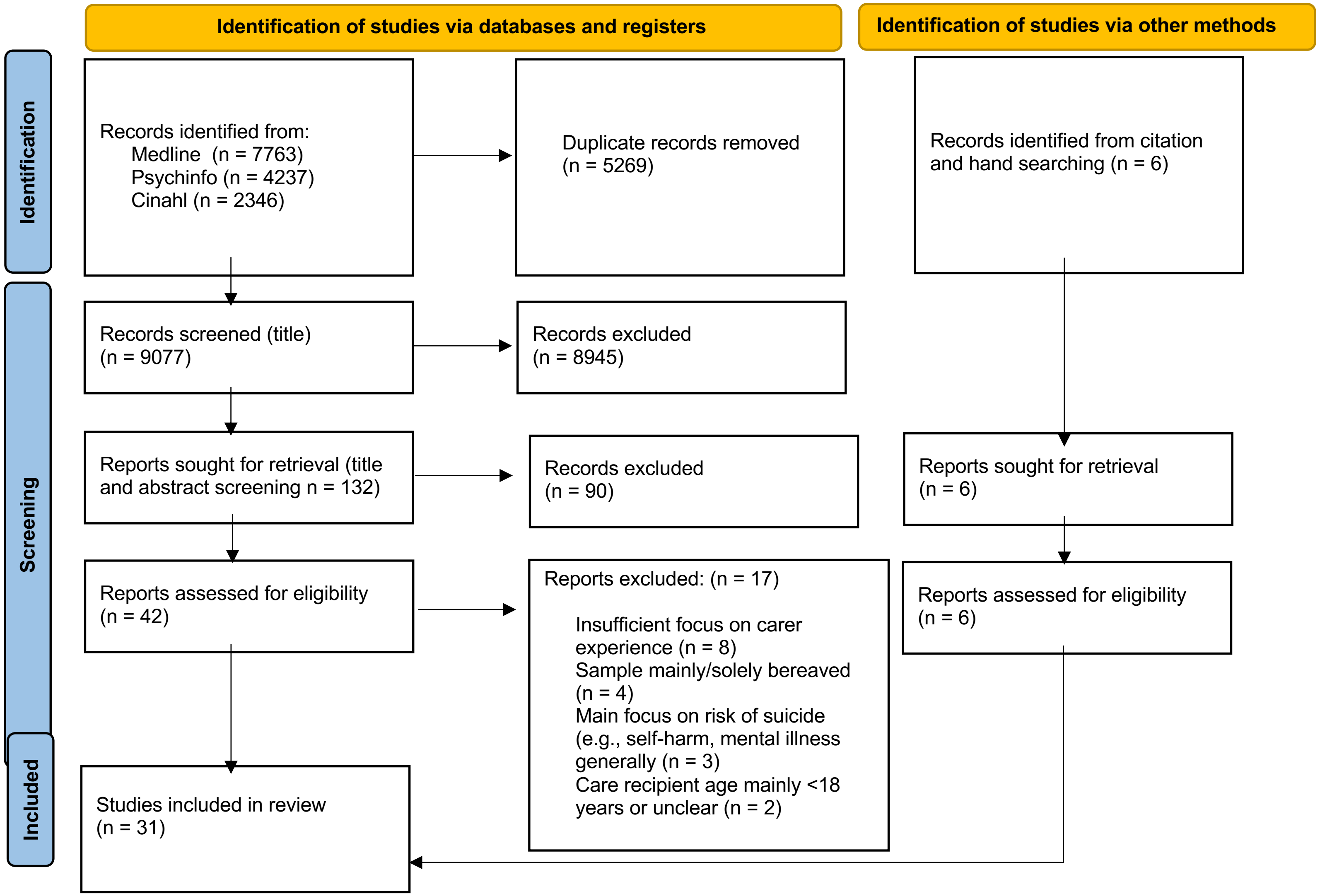
2.9 Data synthesis

Line by line coding was carried out in relevant sections of all selected papers to develop descriptive themes as the first phase of thematic synthesis (Thomas and Harden, 2008). NVIVO version 12 (QRS International, 2018) was used to assist with data storage and coding in the development of the descriptive themes. Analytical themes were then developed from the descriptive themes to answer the review question. Synthesis was carried out by the first author and themes developed in discussion with the other authors.

2.10 Results

The outcome of the systematic search and screening is shown in Figure 1 below.

Figure 1: Process of study selection (Page *et al.*, 2021)



2.10.1 Study characteristics

Quantitative papers

Fourteen quantitative studies involving 12 cohorts were included (Magne-Ingvar and Ojehagen, 1999; Magne-Ingvar and Öjehagen, 1999a; McDonell *et al.*, 2003; Kjellin and Östman, 2005; Cerel, Currier and Conwell, 2006; Chessick *et al.*, 2007; Chessick *et al.*, 2009; Chiang *et al.*, 2015; Katz *et al.*, 2015; Lawn and McMahon, 2015; Borisonik 2018; Crasta *et al.*, 2021; Jaffe *et al.*, 2021; Maple *et al.*, 2021). Study designs included descriptive and analytical cross-sectional studies with samples totalling 3,705 carer participants (14 were bereaved by suicide). Areas examined related to caregiver or family burden, health outcomes of carers, and coping ability. Various validated measures were used in nine studies and five studies devised questionnaires based on clinical experience and relevant literature. Characteristics of quantitative studies are presented in Appendix 5.

Qualitative papers

Seventeen qualitative papers reporting 16 studies comprising 282 carer participants (14 bereaved by suicide) were included (Talseth, Gilje and Norberg, 2001; Giffin, 2008; Nosek, 2008; Sun and Long, 2008; McLaughlin *et al.*, 2014; McLaughlin *et al.*, 2016; Asare-Doku, Osafo and Akotia, 2017; Castelli Dransart and Guerry, 2017; Sellin *et al.*, 2017; Fogarty *et al.*, 2018; Dempsey *et al.*, 2019; Nygaard, Fleischer and Buus, 2019; Wand *et al.*, 2019; Spillane *et al.*, 2020; Rheinberger *et al.*, 2021; Vandewalle *et al.*, 2021; Wayland, Coker and Maple, 2021). Studies investigated experiences and perspectives related to caring for a suicidal individual, and experiences of help seeking and service provision. One study used focus groups and the remaining used interviews. Qualitative study characteristics are presented in Appendix 6.

2.10.2 Quality appraisal

Quality appraisal is outlined in Appendix 7. Of the quantitative papers, 9/14 were assessed to be of moderate or moderate to low quality, two were high quality and three were judged to be of low quality. Stronger studies were those which used validated measures and used probability sampling, and weaker studies were those which involved self-selected samples, used non validated questionnaires and/or had not addressed non-response bias.

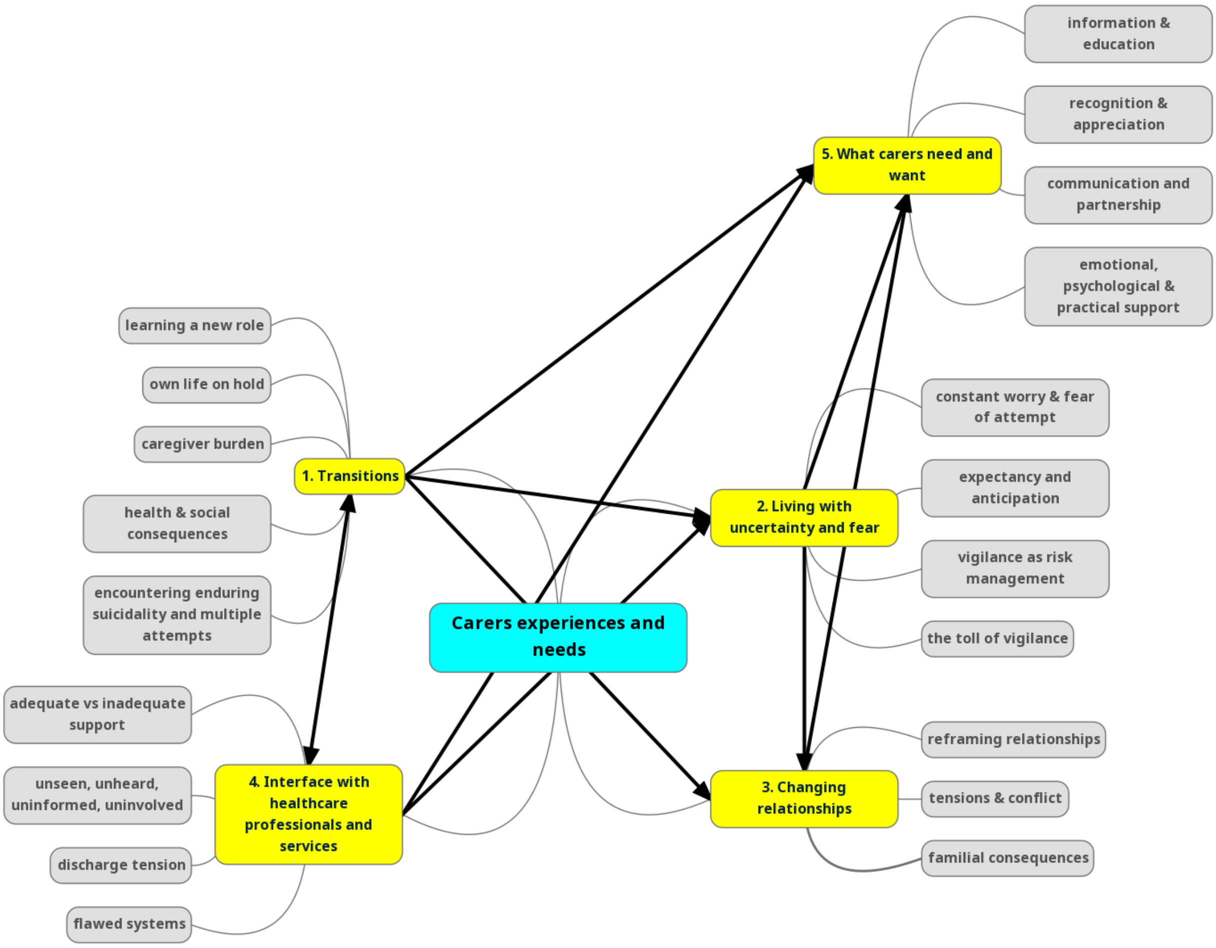
Qualitative studies were mainly moderate (15/17) with two being assessed as high quality. Some studies gave limited detail of the sample. High quality papers reported coherent methodologies, attended to researcher reflexivity and presented robust ethical procedures.

2.10.3 Themes

Five key themes and 20 subthemes reflecting carers experiences and needs were derived from the thematic synthesis (Figure 2): transitions; living with fear and uncertainty; changing relationships; interface with HCPs and services; and what carers need and want. The themes are interrelated, as depicted by the black arrows in Figure 2, reflecting the simultaneous intrapersonal, interpersonal, external and systemic factors that influence the caregiver experience. For example, the transition into the caregiver role was both influenced by and influenced interface with healthcare services and led on to living with fear and uncertainty and changing relationships with care recipients, all of which shaped carers wants and needs. Articles linked to the themes and subthemes are presented in Appendix 8.

Figure 2: Five themes and 20 sub themes reflecting carers experiences and support needs

The black arrows denote the interconnected nature of the themes to illustrate the transition into caring, which influences and is influenced by interface with HCPs and services and leads on to living with fear and uncertainty and changing relationships, all of which shape what carers need and want.



2.10.3.1 Theme 1: Transitions

Transitions associated with caring and the consequences of these transitions were described in 23 studies. The length of time participants had been in a caring role varied between studies; some had a more acute recollection of onset, such as ‘*being thrown into it*’ (Vandewalle *et al.*, 2021 p1143), others talked in the context of longevity e.g., ‘*he’s been like* *that for 27 years*' (McLaughlin *et al.*, 2014 p3). Initial emotional responses such as shock, guilt and anger were cited along with helplessness and powerlessness, quickly followed by a realisation that there was a need to take on a carer role to support the individual and keep them safe. For some, this occurred alongside sensemaking, which involved revisiting belief systems and reflecting on lives before suicidality:

it made me question more about my parenting than anything else … it really made me sit down and go through the way I brought him up (Spillane *et al.*, 2020 p293)

Participants reported feeling ill equipped for this new role:

well, I think I still feel like I—a little bit all at sea … I'm not really sure I would know what to do, to be honest (Dempsey *et al.*, 2019 p107)

although over time some carers had worked things out for themselves:

OK, let's not try that again, let's try this approach…and a lot of it was hit and miss (Nosek, 2008 p40)

Common caregiver tasks included providing emotional or practical support. This involved talking, being available and conveying love, advocacy and general support such as organising appointments. Taking on the caring role and learning to meet care recipients' needs along with balancing other family and work demands, meant that carers often had to put their own life on hold:

the first thing I said is forget about myself (Wand *et al.*, 2019 p597)

Caregiver burden was measured in seven studies. Two of these (McDonell *et al.*, 2003; Katz *et al.*, 2015) suggested that perceived presence of suicide ideation increased burden even if actual ideation wasn't always present. Chiang *et al.* (2015) and (Maple *et al.*, 2021) found burden to be higher in females and suggested that relational closeness could result in higher burden due to the level of emotional investment. Related, Crasta *et al.* (2021) proposed that caregiver burden reduced when the care recipient's perceived burdensomeness was higher because individuals asked for less support when they felt a burden on people they loved. Subjective reports of caregiver burden were either in response to direct questions, through quotes e.g., '*the burden for the carer support person is heavy*' (Wayland, Coker and Maple, 2021 p669) or through interpretation and analysis such as the theme of 'family burden' derived by McLaughlin *et al.* (2014).

All studies referred to the caring experience being stressful, and 16 indicated physical, and/or psychological consequences, such as psychological distress, including carers feeling traumatised; deteriorating general and mental health; and poor wellbeing. Participant narratives gave reports of feeing generally run down, exhausted, anxious and low in mood.

I'm a bit run down at the moment, I have a cold and an enormous cold sore (Spillane et al., 2020 p293),

you can't believe how tired, you know, how tired you feel (Giffin, 2008 p134)

Are you kidding? Of course I am depressed. You know, what kind of parent wouldn't be, if they had been living with what I have been living with for two years? (Dempsey et al., 2019 p107)

One study examined suicide ideation in carers (Maple *et al.*, 2021) and found evidence in participants who had high psychological distress, particularly when carer support was perceived as inadequate. However, these authors also found a negative association between suicide ideation and caregiver burden and postulated that this may be due to them seeking professional help, informed by their awareness of the need for support and how to access such.

Social consequences of caring for someone at risk of suicide largely arose from shame, stigma, and living with the ongoing threat of suicide, which led to avoidance and withdrawal:

I was ashamed, when it happened. …. I have never ever told any of my family people (Asare-Doku, Osafo and Akotia, 2017 p3)

I've just no desire for actual social interaction…like if the person that you think loves you, tries to kill herself, like so many times, it does have an effect on your opinion of yourself (Spillane et al., 2020 p288)

McLaughlin *et al.* (2014) noted that perceived stigma could be a barrier to help seeking:

she (the nurse) was very nice and I know she would have felt like talking to me but I didn't want to tell people (McLaughlin et al., 2014 p4)

Participants experiences with healthcare services (see theme 4) influenced transitions within the caring role. For example, when carers felt they were not recognised as being instrumental to the support of the care recipient, were not informed about what was going on and how they could help, were not advised regarding crisis contacts, and were not offered kindness or support for themselves, feelings of frustration, despair, helplessness and powerlessness appeared to be even more overwhelming.

Borisonik (2018) examined differences between carers of people who had made a single suicide attempt verses multiple attempts, and another 16 studies referred to carers encountering enduring suicidality and/or multiple attempts. Suicide attempts were not always considered to be undertaken with high intent:

She has been pumped a few times because she took an overdose of medicine. I've felt she has never tried 100% to take her own life. Because every time she has taken an overdose she has phoned and told me. It is a way of asking for help, I feel (Talseth, Gilje and Norberg, 2001)

There was consistent indication that negative effects of caring increased with persistent suicidal behaviour. Sun and Long (2008) and Nosek (2008) presented theories illustrating the cyclical nature of suicidal crises and caregiver responses, with each model highlighting caregiver burnout as a result of responding to repeated episodes. Some studies indicated a transition toward a sense of reluctant acceptance of living with the ongoing possibility of suicide (Giffin, 2008; Nosek, 2008; Asare-Doku, Osafo and Akotia, 2017; Sellin *et al.*, 2017; Spillane *et al.*, 2020) although reflecting on this acceptance could be painful for carers and did not necessarily reduce emotional turmoil:

I imagine that I've come to terms with the fact that if anything, now, did happen to her, we've done all we can, but we haven't lived through it, have we ... but have I really [come to terms with it], while there's a little nagging doubt in my mind? (Giffin, 2008)

2.10.3.2 Theme 2: Living with fear and uncertainty

This theme was highlighted in 20 papers. Fear of suicide attempt was common, resulting in constant worry and rumination about care recipients' safety:

is she safe today? Will she cut her wrist? Does she want to die? (Sun and Long, 2008 p1946)

Constant worry could become an '*unrelenting burden*' (McLaughlin *et al.*, 2014 p3) and for carers in some studies, this led to expectancy of suicide attempts or completed suicide: '*when's it gonna happen*' (Nosek, 2008 p40); *'is this another suicide attempt*' (Giffin, 2008 p134). Worry and anticipation frequently resulted in hypervigilant behaviour in an attempt to maintain care recipients' safety and manage carers' fear and uncertainty. Hypervigilance was underpinned by fear and a sense of responsibility e.g., *'my only responsibility was to keep him alive'* (Vandewalle *et al.*, 2021 p1140), and feelings of helplessness and powerlessness. Vigilance ranged from regular telephone calls and check-ins: *'and then I'll send a text 'all ok*?'' (Spillane *et al.*, 2020 p290) to reducing access to means: '*I'm not gonna leave tablets for her like that*' (Wand *et al.*, 2019 p598), and being '*on guard day and night*' (Sun and Long, 2008 p1943). Carers who lived with care recipients often didn't leave the house in case of a suicide attempt or, if they did, they experienced anticipatory fear about what they might find when they arrived back home.

You feel guilty almost about going out of the house, you feel frightened about coming home again because you think what are you going to come home to? (McLaughlin et al., 2014, p. 3)

'Suicide watch' was a term used by participants in several studies (Nosek, 2008; Sun and Long, 2008; McLaughlin *et al.*, 2014; Castelli Dransart and Guerry, 2017; Spillane *et al.*, 2020; Wayland, Coker and Maple, 2021) who had either been advised it by healthcare providers or self-prescribed it to try and achieve a semblance of control.

They (the hospital) actually said take her home, you're on suicide watch. I had her actually sleep in my bed that night, I just couldn't even leave her in her own bedroom (Wayland, Coker and Maple, 2021, p. 666)

Carers in some studies expressed experiences of, or concerns about, relational tension when they tried to balance care recipient safety and autonomy (Giffin, 2008; Fogarty *et al.*, 2018; Vandewalle *et al.*, 2021; Wayland, Coker and Maple, 2021). Some studies showed that carers often existed within a stasis of 24-hour high alert, with the ongoing vigilance taking a toll on sleep e.g., '*I lay the whole time with one eye open*' (Talseth, Gilje and Norberg, 2001 p253). This contributed to burnout, which was identified by (Nosek, 2008; Sun and Long, 2008; McLaughlin *et al.*, 2014). Linked to burnout, some narratives or outcomes were interpreted to indicate detachment and avoidance, either as a coping strategy (Sun and Long, 2008; Borisonik 2018; Wand *et al.*, 2019) or a way of self-preservation (Nosek, 2008; Fogarty *et al.*, 2018).

2.10.3.3 Theme 3 Changing relationships

Effects on individual or familial relationships were identified in 21 papers.
Relationships were often reframed as a result of suicide attempts; the very fact that a suicide attempt had occurred meant that the relationship could not go back to how it was before the attempt (Nosek, 2008; Sellin *et al.*, 2017; Wayland, Coker and Maple, 2021). This was illustrated by participants who articulated a sense of living with the possibility of eventual suicide (Giffin, 2008; Nosek, 2008; Asare-Doku, Osafo and Akotia, 2017; Sellin *et al.*, 2017; Spillane *et al.*, 2020). Becoming a sort of 'case manager' (Castelli Dransart and Guerry, 2017; Wayland, Coker and Maple, 2021) whereby carers sorted things out for and took care of the person's mental health and safety, meant that the emphasis of some relationships shifted from '*equal to advocate*' (Wayland, Coker and Maple, 2021 p670).
Some parents of adult children found that their parental roles were forced to revert backward from an adult-adult dynamic to adult-child relationship (Spillane *et al.*, 2020; Wayland, Coker and Maple, 2021) and some partners experienced a need to become somewhat parental in order to maintain safety (Fogarty *et al.*, 2018; Spillane *et al.*, 2020).
Kjellin and Östman (2005) found that many relationships between their caregiver participants and suicidal individuals deteriorated, and negative feelings towards the care recipient, or their suicidal behaviour, were evident in other studies, which in certain cases resulted in invalidating exchanges or tensions (Nosek, 2008; Asare-Doku, Osafo and Akotia, 2017; Fogarty *et al.*, 2018; Wand *et al.*, 2019). Participants in a few studies reported difficult feelings associated with '*treading on eggshells*' (eg., Wayland, Coker and Maple,

2021 p667) and feeling controlled by the care recipient's state of mind, (Nosek, 2008; McLaughlin *et al.*, 2016). Chiang *et al.* (2015) found that older caregivers held more negative attitudes and suggested that this may be due to stigma or long-term caring. However, they also found that caring ability was high in older carers and surmised that long-term caring made them adept. Conflicting positive and negative emotions experienced by carers such as love or sympathy alongside anger were noted (Giffin, 2008; Asare-Doku, Osafo and Akotia, 2017), while Sellin *et al.* (2017) highlighted the increased intimacy experienced within the relationship, and carers' realisation of their importance to the care recipient, suggesting that not all relationship changes were negative. Similarly, while Katz *et al.* (2015) found negative appraisals of the effects on family, they also noted a focus on good aspects of relationships with care recipients, which they linked to fear of loss.

The deleterious impact on the family was shown in several studies, particularly when suicidality was ongoing. This was due to strained relationships with the care recipient or the family having to reconcile themselves with their own sense of stigma:

they are ruining the family from within the family (Dempsey *et al.*, 2019 p107)

the incident has put us in a very difficult situation in the vicinity where we live and we have still not recovered much yet. It has changed our family course and I know that it will take us several years to recover very little (Asare-Doku, Osafo and Akotia, 2017 p5)

Crasta *et al.* (2021) suggested that good social coping was associated with less negative appraisals of the relationship with the care recipient and Sun and Long (2008) noted that families with strong coping strategies were more able to provide effective care. Chessick *et al.* (2007) indicated differences in the effects of caring for a person at risk of suicide on parental and partner relationships, with the former experiencing higher levels of burden and depression when there was a history of suicide attempt but not necessarily current ideation, and the latter when there was no history, but suicide ideation was present. These authors suggested that this might be to do with parents not being able to relinquish parental tasks as anticipated and partners' expectations of their partner's role in the relationship being somewhat thwarted. Giffin (2008) and Nygaard, Fleischer and Buus (2019) identified that tension within parental partnerships could occur, and two studies noted differences in responses and coping between male and female parents (Asare-Doku, Osafo and Akotia, 2017; Nygaard, Fleischer and Buus, 2019) although Nygaard, Fleischer and Buus (2019) also found that the experience could bring the parent partnerships together in a sense of solidarity. Magne-Ingvar and Öjehagen (1999a) found that parents had worried about the patient more frequently than partners, but partners less often had a confidant(e). This study also found that nearly half of participants had not talked to care recipients about the suicide attempt, suggesting possible relational tensions or communication difficulties. There was minimal attention to the experiences of siblings and effects of this on carers, but Giffin (2008) and Spillane *et al.* (2020) noted the anger of siblings due to the focus of attention on the care recipient and Spillane *et al.* (2020) described the isolation of the sibling caregivers in their study.

2.10.3.4 Theme 4 Interface with HCPs and services

Nineteen papers included information about carers experiences and perspectives of healthcare systems and professionals. Carer satisfaction was largely dependent on perceptions of the mental health care the care recipient received. Participants perceived both adequate and inadequate care, but the latter was more common. Care was considered adequate when the care recipient was safe, supported, treated with kindness, had time with staff and received psychological interventions. Continuity of care and good communication between professionals were also important factors for participants. Maple *et al.* (2021) found that caregiver burden was lower when care was experienced as adequate.

Care was viewed as inadequate when the aforementioned features of adequate care were lacking. In addition, superficial, brief, insensitive and impersonal care was considered to be poor.

Participants in 14 studies reported a lack of support for themselves as carers. Unsupported carers reported being unseen, unheard and uninformed.

I said to the doctors 'but me, I need help, I need help', and I was crying and I didn't have any tissues and nobody offered me any, and then, everybody was watching me cry, nobody said anything (Castelli Dransart and Guerry, 2017 p8)

one doctor I spoke to … he was really dismissive … dismissing with a wave of the hand the observation of someone who'd known him [patient] for a long time (Wand et al., 2019 p598)

I got a bunch of photocopied brochures that's it (Wayland, Coker and Maple, 2021 p668)

Uppermost for many participants in these studies was the experience of being uninvolved in the patients care, be that when they sought information or tried to provide it, with some studies identifying confidentiality as a barrier. Participants stressed that they could not be expected to safely manage the care recipient at home without an understanding of their needs and some preparation to help meet these needs.

We [as parents] do not always understand what is happening. But all they do is give vague answers and refer to confidentially boundaries. That is very confronting, because we are the ones who are stuck in this situation (Vandewalle et al., 2021, p. 1143)

Good carer support described involved practical and educational support and information, being listened to, treated with kindness and respect, and not made to feel blamed.

'*she gave us coping skills*' (McLaughlin *et al.*, 2016 p2)

'[we were] *informed about what has been happening the whole time*' (Talseth, Gilje and Norberg, 2001 p251)

'*... the mental health person ... he had a chat with me as well for about half an hour, to get a read on the situation*' (Rheinberger *et al.*, 2021 p6)

Maple *et al.* (2021) found that caregivers who felt adequately supported experienced less psychological distress, suicide ideation and caregiver burden. Good support could have a profound positive effect in understanding a loved one's presentation:

'*Now it is easier for me to understand and empathize with her situation because I know why she has suicidal thoughts. I used to have no context, so her expressions were just, yeah, really crazy. I used to say that I was married to a psychiatric patient. Now I am able to see it in a much more positive way.*' (Vandewalle *et al.*, 2021 p1143)

There was discontent with healthcare services overreliance on carers to support the person at home. Discharge tension was expressed in 12 studies, with carers being of the view that risk would intensify once the individual was back at home and away from hospital support.

Participants reported a lack of involvement in discharge planning despite being key to supporting this plan at home. Some felt they had no choice with regard to taking the care recipient back into their care, even if they had reservations about the individual's safety:

'*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'* (Castelli Dransart and Guerry, 2017, p. 6)

Difficulties experienced by participants in 10 studies were perpetuated by healthcare systems that were experienced as flawed and complex, meaning that carers did not always know how or where to access support. Common problems were long waiting times (e.g., in the emergency department, a psychiatric bed or for psychological therapy) and insufficient resources (e.g., staff, psychological interventions, carer support). Problems with services were considered by some participants to contribute to poorer outcomes:

'*there's nothing there for us, do you understand, there's been nothing there over the years, as a carer there's nothing there for you but had there been at the start I reckon, some sort of support for us, we could have had a better life as a family'* (McLaughlin et al., 2016 p2)

2.10.3.5 Theme 5: What carers need and want

Needs of caregivers were identified either by study participants themselves or by the authors from their data analyses in 29 papers. 16 studies noted that carers need practical information and education, including about mental health problems and suicide; strategies to help manage the person at home; how to seek help during a crisis; and how mental healthcare systems function.

'*Which solution? How to react? This is how I feel that relatives, they need help in these situations*.' (Castelli Dransart and Guerry, 2017 p9)

'… more information about what mom is going through and what I could do about it' (Vandewalle et al., 2021 p1143)

Eight studies identified that carers wanted to be appreciated as fundamental providers of care for the person at risk of suicide, and recognised as people in their own right, with their own needs. They wanted to be valued as possessors of salient and crucial information:

‘family member(s) must be taken seriously. They need to be listened to. They are the ones who live with the individual on a daily basis and they are more aware of what is going on with the individual than any other person’ (Cerel, Currier and Conwell, 2006 p346)

Related, twelve studies found participants wanted healthcare providers to communicate and work in partnership with them to meet care recipients needs and keep them safe:

‘*So I think it would be a good idea [that] the GP can coordinate into this and keep contact with the family member. … So if some issue is happening I can reach him at least*.’ (Wand *et al.*, 2019 p597)

Support for carers was identified in 19 studies which endorsed psychological interventions to address the emotional, relational and mental health impact of caring, interventions to help develop coping strategies, and the need for couple or family therapy to help reconcile with the relational changes associated with caring. The importance of having the opportunity to talk about what was happening for them was clear across all of these studies.

‘*Families need a place to talk and acknowledge the impact that it has on the family. The offer to speak to someone would have been appreciated. It has had a devastating effect on my family’* (McLaughlin et al., 2016 p3)

In addition to emotional and psychological support, practical support such as respite was considered as a need in a minority of studies. Asare-Doku et al (2017) and Sun and Long (2008) highlighted the importance of acknowledging cultural needs when considering support for carers, particularly due to the stigma that may be attached to suicide in certain cultures.

2.11 The Gap in knowledge identified by this systematic review

In this systematic review we identified 31 primary research papers investigating experiences and needs of adult informal caregivers of adults at risk of suicide. Five interrelated themes related to caregiver experiences were identified: transitions; living with fear and uncertainty; changing relationships; interface with HCPs and services; and what carers want and need.

From this review, we know that transitions spanned the experience of being thrown into or gradually entering the caregiver role through to long term caring. Studies consistently identified negative emotional and health related consequences of caring for suicidal individuals, with positive associations being few. Problematic encounters with healthcare services increased caregiver stress, with discharge being a time of particular tension due to the lack of involvement or opportunity to express concerns. Communication with HCPs was obstructed when clinicians displayed concrete interpretation of confidentiality boundaries, which tested relationships with professionals. However, none of the studies reviewed were carried out in England. Therefore, whilst results across studies are fairly consistent it cannot be assumed that they represent the experiences and needs of carers of adults at risk of suicide in England.

Insights from this review largely reflect previous systematic reviews (Juel *et al.*, 2021; Lavers, Andriessen and Krysinska, 2022), although an additional outcome is the suggestion that negative consequences of caring are experienced as increasingly severe with ongoing suicidality and multiple suicide attempts. This appears to be mediated somewhat by persistent and repeated cycles of hypervigilant behaviour acted out in the context of fear and uncertainty. Hypervigilance was demonstrated through strategies such as suicide watch, constant alert, and persistent checking. Fear and associated hypervigilance resulted in disturbed sleep, which in turn had a detrimental impact on mental and physical wellbeing. In some cases impaired wellbeing led to caregiver burden and burnout, which are known to be associated with poor health and social outcomes (Gérain and Zech, 2019). Notwithstanding the possible association between worsening outcomes for carers and repeated cycles of hypervigilance, we do not know what overall effect hypervigilance has on the person undertaking it.

The studies included in this review had a focus on the past and present, with little attention on future perspectives beyond fear of suicide attempt and living with the possibility of suicide, both of which were largely described in the here and now. Specific questions on participants thoughts about the future in terms of their caring role were not apparent. A future orientated perspective would be a helpful addition to research with this population to elicit deeper insights into caregiver expectations, which could in turn inform clinician understanding and carer interventions.

The majority of participants in the studies reviewed were parents, followed by partners. Relational changes included parents having to take back a level of parental control which had previously been relinquished. Some studies proposed that partners may experience caregiving differently to parents, particularly interpersonal aspects such as shifting from equal to advocate, adopting an authoritarian role, and reconciling with the fact that a partner's wish to die may at times surpass their wish for the relationship. This reflects broader research, for example Lewis (2015) noted distinctive characteristics in partners of people with mental illness in relation to loss; loss of the true partnership; loss of the anticipated future of the partnership; loss of a sexual relationship. However, living with the knowledge that the relationship may not be, or was not, sufficient to prevent a suicide attempt is an experience unique to a caring context which involves suicidality. McGivern (2021) suggests that partners can experience ambiguous loss following their partner's suicide attempt, whereby they exist in the aftermath with a partner who is physically present but psychologically absent. Psychological absence is related, in part, to the suicidal decision making, which by its nature, involved exiting the partnership.

Interventions focusing on the practical, relational and emotional effects of living with a family member at risk of suicide are clearly required. The current systematic review has identified a need for psychological interventions targeting the carer/family and care recipient together, such as couple or family therapy. These interventions should be tailored to context and needs, with family interventions being flexible enough to attend to the various roles within the family, the adult-adult dynamic, and differing experiences and perspectives. Research aiming to develop effective couple interventions which incorporate these elements is beginning to emerge (Khalifian *et al.*, 2020; Khalifian *et al.*, 2022), however current family-based interventions are predominantly tailored to families where the suicidal individual is an adolescent (Ougrin *et al.*, 2015).

Additional carer needs identified in this systematic review included information and education, collaboration and various forms of carer support. These findings are not novel; most have been identified by previous reviews of carers of people with mental illness and/or who are at risk of suicide (Doody *et al.*, 2017; Juel *et al.*, 2021; Lavers, Andriessen and Krysinska, 2022). This replication underlines the need for policy makers, commissioners, managers and clinical leaders to review systems and practice to improve the caregiver experience. There is a strong need for improved interventions involving education and skills training specifically for adult carers of adults (Krysinska *et al.*, 2021). However, to date, perspectives of carers of adults at risk of suicide in England have not been obtained. The research presented in this thesis will contribute an understanding of the caring experience in England to the wider body of literature.

In terms of research methodology, the studies reviewed in this chapter were reported as either quantitative or qualitative. Two papers (one quantitative and one qualitative) were both drawn from a large mixed methods study (Coker *et al.*, 2019), which has not been peer reviewed and published in its entirety. The quantitative and qualitative strands were published as two separate projects and no integration or synthesis was presented. This highlights a gap in mixed methods research in this field which has been identified previously in relation to suicide research (Kral, Links and Bergmans, 2012). The research presented in this thesis helps to address this gap.

2.12 Strengths and limitations

Strengths of this systematic review include the mixed method approach and the relatively large number of studies compared to previous reviews. In addition, the focus on adult carers of adults brings additional insights to the experiences of carers which will be of benefit to clinical practice.

A primary limitation is the screening, selection, appraisal and synthesis of studies being carried out by the first author only, although oversight through discussion was provided by the other authors. Most of the quantitative studies were cross sectional and involved online or interview-based questionnaires meaning there were no comparison groups, not all used validated measures and there was some risk of non-response bias. However, the questionnaires were all relevant to the research question.

Lastly, a small number of the studies reviewed included a minority of bereaved individuals or carers of young people, although the vast majority of study participants were adult carers of over 18-year olds. Most studies were conducted in western countries with participants predominantly white, female and middle aged. This highlights a need for research that adequately targets global majority populations and a wider adult age range, which may require revisiting normative western definitions of caring and considering novel recruitment and data collection strategies.

2.13 Chapter summary

This chapter has presented the systematic review conducted to inform the current research. The review provides insights into the challenging and frightening experiences encountered by carers of adults at risk of suicide and highlights support and involvement needs. Although outcomes of this review largely reflect those of previous reviews it has also identified gaps in knowledge.

The next chapter presents the chosen research methodology and associated research methods.

CHAPTER 3: METHODOLOGIES AND METHODS

3.0 Introduction

This chapter outlines the philosophical assumptions and methodological principles that informed the current research. A brief definition and discussion of worldviews is discussed before focusing on pragmatism and mixed methods methodology. Research methods, including ethical issues and data analysis are presented and researcher reflexivity is considered throughout. To assist readability, research methods associated with the survey are presented first followed by a separate discussion of methods relating to the qualitative semi structured interviews. Ethical issues are then considered before providing an explanation of the approach to integration.

3.1 Philosophical Assumptions

It is generally acknowledged that the approach taken to research should be dictated by the research question and not merely reflect the researcher's preferences (Al-Hamdan and Anthony, 2010; Lacey, 2015), but also that researcher worldviews shape the research questions posed and the ways in which research is conducted (Hanson *et al.*, 2005; Morgan, 2007; Tashakkori and Creswell, 2007). (Creswell and Creswell, 2018) define worldview as 'a basic set of beliefs that guide action' (p5), noting that the word 'worldview' is used interchangeably with 'paradigm', which is defined by Morgan (2007) as being a 'consensual set of beliefs and practice that guide a field' (p. 49). There is some debate around use of paradigm, however: Biesta (2010) observes that research students often perceive a need to select an off the peg paradigm before feeling able to identify as a researcher and undertake research. He argues that preoccupation with paradigm can force indiscriminate acceptance or otherwise of overarching views at the expense of adequate attention to the underlying components of ontology (beliefs about truth and reality), epistemology (perspectives on knowledge and knowing), and methodological assumptions, which may be more fluid than the overarching view suggests. Similarly, Costley (2019) suggests that the term paradigm may not fit with contemporary professional doctorates and proposes the term 'approach' to reflect the complexity of the practice context, where people are exposed to and may possess different perspectives on knowledge and reality at the same time. This view aligns with that of pragmatism which is a worldview concerned with addressing real world problems without the constraints of a fixed paradigmatic stance, but based on defensible beliefs about the prospective consequences of actions related to one research design over another (Morgan, 2014b). Pragmatism transcends the dualistic attitude that has fuelled past paradigm wars (Oakley, 1999) between opposing positivist and constructivist perspectives and offers somewhat of a middle ground. A pragmatist stance requires an understanding of the more extreme ends of the paradigmatic continuum. To demonstrate this understanding and situate the present research within a pragmatist approach, positivism/post positivism and constructivism are briefly discussed below.

3.1.1 Positivism/Post positivism

Positivism is concerned with absolute singular truth, which can be externally measured and observed. Positivists argue that objective empirical knowledge is the only valid form of knowledge (Corry, Porter and McKenna, 2019). Post positivism is a deterministic philosophy wherein theories are scientifically tested in the pursuit of objective, but not universal knowledge. Post positivism differs from the preceding positivistic belief in an absolute external truth because it is accepted that unobservable phenomena exist and thus there are interpretations and unknowns. Post positivist research seeks an 'approximation of truth' (Clark, 1998, p. 1245). According to Clark (1998) the post positivist worldview comprehends the humanness of researchers and, whilst valuing objectivity, accepts the inevitability of biases. This stance has largely superseded the positivist notion that researchers can be value free although other positivist beliefs are retained such as reductionism, which involves reducing experience into distinct and testable concepts. Phillips and Burbules (2000) explain the aim of post positivist research as the quest to explain situations of concern or describe causal relationships of interest. These authors view post positivist knowledge as being shaped by data, evidence and rational consideration via objective research processes. Post positivist research is generally concerned with collecting quantitative data and involves systematic processes wherein theories are tested by examining the relationships among variables. However, some methodologies more aligned with subjective experiences such as experimental or descriptive phenomenology, can align with the post positivism (Kelly, Dowling and Millar, 2018). Research methods typically associated with post positivist research include controlled experiments, controlled observations and use of measurement scales and that have been scientifically validated. Statistical procedures are employed to describe data (descriptive statistics) and draw conclusions and predictions from data (inferential statistics).

3.1.2 Constructivism

A contrasting worldview to positivism and post positivism is constructivism. This standpoint rejects the notion of a single truth and is concerned with multiple subjective realities that are created by individual interpretations of those that live them. A leading theorist in the field is Crotty (1998) who identified constructivist assumptions that humans construct meaning from their historic, cultural and social engagement with the world and direct these meanings onto objects or things. As such, researchers must attend carefully to varying, sometimes conflicting realities and consider the context surrounding these realities (Appleton and King, 2002). Research linked to constructivism is qualitative in nature and designed to collect rich experiential data that illustrates and illuminates the meanings participants hold. Data collection methods might include semi structured or unstructured interviews, focus groups, or participative or non-participative observations. Depending on the research methodology adopted, qualitative data analysis involves varying levels of coding, theme generation, interpretation and theorising of lived experiences to develop new understandings. The researcher who is guided by a constructivist worldview is intertwined with the research and it is understood that their presence and interpretations will be part of, or indeed a purpose of, the research (Stewart, 2010).

3.1.3 Pragmatism

Pragmatism provides a middle ground in the paradigm continuum because it values positivist and constructivist worldviews but rejects the central declarations of each. Pragmatists claim that truth is neither absolute/discovered nor arbitrary/invented (Neubert, 2009) but both real and socially constructed (Morgan, 2014b; Morgan, 2014a); that is, reality exists outside of experience but can only be accessed through experience. Pragmatic ontology, therefore, is pluralist and respectful of singular and multiple realities and shared meanings (Kelly, Dowling and Millar, 2018). Pragmatists carry a healthy scepticism of reality because they cannot really know when they have reached it (Cherryholmes, 1992), so doubt is ever-present and truth is understood in the context of fallibilism (Biesta, 2010); that is, nothing is conclusive. John Dewey, one of the founders of pragmatism, evolved an epistemology of warranted assertibility (Boyles, 2006). Warranted assertibility transcends *knowledge* due to it being a static representation of an end to inquiry and espouses *knowing* as rolling inquiry appertaining to human experience. Warranted assertions are derived from anticipated and experienced consequences of actions (Talisse and Aikin, 2008) and are changeable in response to ongoing lines of action/inquiry stimulated by 'problematic situations' (Talisse and Aikin, 2008, p. 120). Problematic situations occur when a situation is encountered that is outside of current experience (Morgan, 2014a). Dewey refers to this as primary experience (Neubert, 2009). Secondary experience is generated through reflective lines of action (e,g., research) and tested in primary experience for 'workability' (Morgan, 2007), thus warranted assertions are always ultimately understood through human experience.

With regards to the current research, the problematic situation stemmed from clinical practice observations that family members and carers do not receive sufficient support and clinicians do not know what the right kind of support is. In simple terms, lines of action in response to the research question will seek to gain an understanding of carers experiences and needs to develop warranted assertions, which can inform clinical practice wherein experiences of carers and clinicians will test workability.

In pragmatist research, methods are selected in accordance with the research question, guided by the premise of experience, consequence and workability i.e., which design and what methods will best answer the question (Kelly, Dowling and Millar, 2018). Consequently, enforced choice between positivist and constructivist extremes is relieved, and researchers are free to use both quantitative and qualitative methods. The value of using both methods is optimised through abductive reasoning. According to Gilbert (2006), abductive reasoning involves moving back and forth between individual accounts of day to day experiences and the concepts therein to develop social scientific explanation of these concepts in order to enhance understanding. Abduction is a core component of the pragmatist lines of action because it facilitates movement between quantitative and qualitative data with an 'if-then' formulation (Morgan 2014b p29).

There are conflicting perspectives on pragmatism. Giddings and Grant (2007) contend that pragmatism is aligned to post positivism and not therefore equally respecting of the influences of other paradigms, whereas Bressan *et al.* (2017) argue that pragmatism rejects the scientific stance associated with post positivism. Notwithstanding conflicting interpretations of pragmatism, researchers are drawn to it because of the emphasis on using 'what works' to answer research questions and solve problems. Workability and practical selection of methods to achieve such is an important feature of the paradigm, but the 'what works' labelling should not undermine the core principles of pragmatism which are experience, context and shared meanings (Morgan, 2014b; Morgan, 2014a) Pragmatism is appropriate for the research question underlying the current research because the focus of inquiry is carers' experiences and perspectives, including an assessment of the relationship between perceived stigma and carer quality of life. The constructs of stigma and quality of life are recognised concepts that through previous research have become externally measurable, but they are experientially rooted concepts. This befits the epistemological perspective of pragmatism that all knowledge stems from human experience, which is inherently social and informed by socially shared experiences (Morgan, 2014a). A research methodology frequently aligned with pragmatism is mixed methods methodology (Morgan, 2007; Yvonne Feilzer, 2010), which will now be discussed below.

3.2 Mixed Methods Methodology

A mixed methods approach was employed for this research because it enables utilisation of both quantitative and qualitative data collection methods to answer the research question in line with a guiding pragmatist worldview. Johnson and Onwuegbuzie (2004, p. 14) define mixed methods research (MMR) as 'the class of research where the researcher mixes or combines qualitative and quantitative research techniques, methods, approaches, concepts or language into a single study'. MMR is a popular methodology in healthcare because the advantages achieved by combining methods are helpful in investigating complex issues and populations (Curry and Nunez-Smith, 2014), such as informal caregivers of those at risk of suicide. There has been a call for more mixed methods research in the field of suicide research to develop enhanced understandings of the multifaceted phenomenon of suicidality (Kral, Links and Bergmans, 2012). Furthermore, MMR is conducive to influencing local and national policy because the breadth of data reaches a wider audience (Plowright, 2019). Lomas (2005) asserts that policy makers ask additional experiential and contextual questions to those of purist scientific researchers whose motives are purely to determine effectiveness. Given the lack of national attention to carers of adults at risk of suicide it is anticipated that a MMR approach will result in outcomes more likely to influence the policy agenda.

MMR encompasses three core designs (Creswell and Plano Clark, 2018): explanatory sequential design, exploratory sequential design and concurrent design. The sequential designs are carried out in phases. In explanatory sequential MMR, collection and analysis of quantitative data is carried out to inform the secondary qualitative phase, the aim of which is to explain or expand upon the quantitative results. A sequential exploratory approach involves a qualitative phase from which a quantitative element is designed and implemented or tested. In sequential approaches the research questions allied to the second phase are finalised in accordance with the outcomes of phase one. MMR involving a convergent design collects quantitative and qualitative data concurrently and analyses it separately before merging or synthesising it to elicit whether outcomes converge (agree) or diverge (disagree).

Concurrent designs are often used to enhance understanding of a phenomenon which has not previously been explored in depth (Morgan, 2014b), which is why the approach was selected for this study. Whilst the literature review found a lot of studies investigating experiences of carers of people at risk of suicide, none of these were conducted in England. Since completion of the literature review a research study carried out in England has been published (Marshall *et al.*, 2022) although the context differed somewhat to the current study as it concerned carers of people who experience suicidality and psychosis.

A convergent MMR design was selected for this research because of the exploratory motive and the research question, which aimed to gain a better understanding of the phenomenon of informal caring for adults in the context of suicidality (regardless of diagnosis/mental health problems) in England.

In a convergent design, where qualitative and quantitative data are collected concurrently, research questions are predetermined, and the mixed methods objective stresses the integration of the qualitative and quantitative data. Convergent MMR designs can be qualitatively or quantitatively dominant, or equal status can be offered to both components. This decision is guided by the dominant epistemological and ontological perspective. In keeping with the pragmatist stance discussed above, the current study can be categorised as ‘equivalently driven mixed-methods research’ (Moseholm and Fetters, 2017). Tashakkori and Creswell (2007) advocate the presentation of qualitative, quantitative and mixed methods objectives when presenting a mixed methods study in order to convey a comprehensive reasoning of the research approach. The research question, aim and relevant objectives discussed in chapter one are shown again below to demonstrate the mixed methods reasoning.

Research Question

What are the experiences and support needs of adult carers (family members, partners and friends) in England who care for adults they consider to be at risk of suicide?

Research Aim

To develop an understanding of experiences and perspectives of adults in England who care for adults they consider to be at risk of suicide, including impact on quality of life and perceptions of stigma.

Objectives

- To use qualitative research methods to describe the caring experience, experiences of support received, and perspectives on support required by adult carers who currently care for adults they consider to be at risk of suicide.

- To use quantitative research methods to rate support, determine quality of life and elicit perceptions of stigma among adult carers of adults at risk of suicide, and establish whether associations between these two latter constructs exist.

- To synthesise qualitative and quantitative data to expand understanding of the research topic.

- To evaluate the experience of participation in this research.

The mixed methods objective is to understand the extent to which quantitative and qualitative results converge or diverge and how integration of both findings expand understanding of the research topic. Integration is the defining characteristic of mixed methods research (Bazeley, 2016) and must be considered from design onwards (Moseholm and Fetters, 2017). The approach taken with the current research design fits the 'matching approach' discussed by Moseholm and Fetters (2017), whereby data collection instruments (survey and interview schedule) were designed to elucidate data about the same variables. This approach enabled a simultaneous bidirectional approach (Moseholm and Fetters, 2017) to integration which will be discussed later in this chapter.

3.3 Methods

The data collection methods utilised in this research were an online survey (quantitative and qualitative) and semi structured interviews (qualitative). These methods are commonly associated with MMR convergent designs (Creswell and Creswell, 2018). The types of questions Creswell and Creswell (2018) suggest can be answered by surveys include descriptive questions and questions about the relationship between variables, both of which align with the quantitative questions discussed above. Surveys tend to sit within the quantitative domain, although can be considered 'mixed methods light' (Creswell and Plano Clark, 2018, p. 73) if there are an adequate number of open-ended questions that provide qualitative data. The survey used for this research could be considered as mixed methods light due to the inclusion of free text questions asking participants to provide descriptions of their experiences. However, it was the combination of survey and semi structured interviews that characterised this study as robust mixed methods research.

Below the survey is discussed first before moving onto the semi structured interviews

3.4 Survey

A cross sectional online 70- item survey (appendix 9) was designed using the survey software Qualtrics (Qualtrics, Provo, UT). The survey included two validated questionnaires: five of eight domains from the Adult Carer Quality of Life scale (AC-QoL) (Elwick *et al.*, 2010; Joseph *et al.*, 2012), and the Stigma of Suicide Attempt (STOSA) scale (Scocco *et al.*, 2012).

Additional items included demographic questions and closed and open questions specific to the overarching research question.

3.4.1 Selection of Quality of Life questionnaire

When considering which measure for carer quality of life to use, scales used in the research reviewed in chapter 2 were first deliberated. Carer specific outcome measures used in the reviewed studies were the Caregiver Burden Inventory (Novak and Guest, 1989), the Caregiver Burden Scale (Zarit, Reever and Bach-Peterson, 1980) and the Experience of Caregiving Inventory (ECI) (Szmukler *et al.*, 1996). The two caregiver burden scales were developed for carers of elderly individuals including those with Alzheimer's and dementia. Although it was possible that some survey respondents in the current research would be caring for older adults who they thought may be at risk of suicide, the target population was not limited to carers of older adults. Furthermore, caregiver burden scales are concerned with negative aspects of caring and do not seek to measure satisfaction, which is required to understand quality of life. For these two reasons caregiver burden scales were not considered appropriate for this study. The ECI (Szmukler *et al.*, 1996) was developed to elicit experiences of caregivers of individuals with severe mental illness such as schizophrenia. Questions in this scale are very specific to severe and enduring mental illness and as such it was not judged to be suitable for this research which had a broader target population than carers of people with severe mental illness. A health-related quality of life scale was used in one study in the literature review (Jaffe *et al.*, 2021) but this was not specific to carers and therefore was not considered for this research.

3.4.1.2 Adult Carer Quality of Life Scale (AC-QoL) (Elwick et al., 2010)

The Adult Carer Quality of Life scale (AC-QoL) was used to measure quality of life of survey participants in this research. This scale was developed specifically for adult carers of people with a variety of physical and mental health conditions rather than only those caring for elderly individuals. The scale has 40 items covering eight five-item domains: support for caring, caring choice, caring stress, money matters, personal growth, sense of value, ability to care and carer satisfaction. Four-point frequency questions are used for each item; never, some of the time, a lot of the time, and always. Some items are scored inversely.

The AC-QoL can be completed as a whole or by single domains. When completed as a whole, scores range from 0 – 120, with 0 - 40 indicating low reported quality of life, 41 – 80 mid-range reported quality of life and 81 – 120 high reported quality of life. When domains are scored individually 0 – 5 indicates a low reported quality of life, 6-10 mid-range and 11+ high reported quality of life.

The AC-QoL was considered for the current research because it was developed in the UK, is targeted at carers of adults of all ages presenting with a variety of conditions, and carers were involved in the development of the scale. In addition, it is relatively recent compared to caregiver burden scales that are frequently used in research with carers, and it attends to positive as well as negative aspects of caring. Weaknesses associated with using the AC-QoL are that it has not been widely used and there are no comparable studies using it with carers of adults at risk of suicide. Final selection of the scale was based on evidence that it is well validated with a sample of 385 carers from 12 carers organisations across the UK, achieving good internal consistency (Joseph *et al.*, 2012). The validation process is discussed at length in appendix 10.

Five of the eight AC-QoL domains were included in the survey for research; support for caring, caring choice, caring stress, ability to care and carer satisfaction. The omitted domains were money matters, personal growth and sense of value. The main reason for selecting only five elements of the scale was practical; the survey included another validated measure and additional closed and open questions, and it was considered important not to produce a very lengthy questionnaire that might put participants off. To optimise online survey completion, length of time for completion should be a maximum of 20 minutes (Revilla and Ochoa, 2017). Including all eight domains on top of other elements of the survey risked exceeding this. It was reasoned that the carer satisfaction domain would provide data about satisfying experiences of caring to answer the research question and therefore the personal growth and sense of value aspects could be left out. Money matters was not deemed to be essential information for answering the research question because of its specificity. As the survey included open free text questions, participants had the opportunity to highlight key areas of concern above and beyond the included domains of the AC-QoL. Previous studies have excluded certain domains of the AC-QoL and conducted analyses using domains individually rather than as a whole, e.g., Brand, Barry and Gallagher (2016).

3.4.2 Selection of Stigma questionnaire

Stigma in relation to suicide is a phenomenon of interest demonstrated by a scoping review which found 23 measures of suicide stigma (Nicholas *et al.*, 2022). Of these, three were repeatedly used with good evidence of validity and reliability; the Suicide Opinion Questionnaire (SOC) (Domino *et al.*, 1980) the Stigma of Suicide Scale (SoSS) (Batterham, Calear and Christensen, 2013) and the Grief Experience Scale (GES) (Barrett and Scott, 1989). The SOC was not developed specifically to measure stigma but includes some questions relevant to stigma. It is a 100-item questionnaire about general attitudes towards suicide. Due to its age some of the language is rather old fashioned and may not sit easily with contemporary parlance and due to this, along with the number of items, it was not considered appropriate for this study. The SoSS was developed to measure stigma towards people who have died by suicide and the GES asks about grief stigma including related to suicide. Neither of these scales were considered appropriate because of their emphasis on completed suicide which was not in line with the research question of the current study.

3.4.2.1 Stigma of Suicide Attempt Scale (STOSA) (Scocco et al., 2012)

The 12 item Stigma of Suicide Attempt Scale (STOSA) was selected for this research because it aims to gauge perceived stigma of suicide attempts. This is relevant to the research question because of the interest in participants' perceptions of their care recipients' risk of suicide, which may be due to past, threatened or anticipated suicide attempts. The STOSA was developed from the 12-item Perceived Devaluation Discrimination scale (PDD) (Link *et al.*, 1989), which was designed to measure social attitudes about mental illness and has strong psychometric properties (Chronbach alpha = 0.76). The STOSA questions are the same in structure to those on the PDD but tailored to suicide attempt rather than mental illness. Respondents are asked to answer questions based on what they think most people think, rather than what they themselves think, with the aim of reducing social desirability (Scocco *et al.*, 2012). This was considered fitting because the current research question relates to stigma experienced by carers due to their care recipients' suicidality and this might stem from perceptions of how others view care recipients. Indeed, Scocco *et al.* (2012) acknowledge that personal experience of suicide attempt may result in increased awareness of stigma related to suicidality.

In addition to the 12 items derived from the PDD a control item is included in the STOSA, which asks for participants perceptions on people's association between mental illness and suicide attempt. This item is included to elicit whether more stigmatising attitudes are perceived based on the association between mental illness and suicidality. The control item (item 13) is scored separately from the main STOSA scale.

The 12 STOSA items are rated on a four-point scale ranging from strongly agree (score 4) to strongly disagree (score 1) with six items being scored inversely. All items are given equal weighting. Scores are calculated as the sum of all items divided by 12 with higher scores indicating higher levels of perceived stigma. No cut off scores are provided to determine low, moderate or high perceived stigma.

The STOSA scale was validated with participants representing the general population, (n = 282), patients diagnosed with mental disorders (n = 113) and suicide attempt survivors. (n = 57). HCPs were excluded due to the possibility of them skewing results due to their theoretical and practical knowledge of suicide. Although informal carers were not specifically included in validation, the involvement of both general public and people affected by suicide attempts indicates applicability to carers of people at risk of suicide. The scale was well validated with good internal consistency (Scocco *et al.*, 2012). The validation is discussed in appendix 11.

A limitation of measuring perceived stigma is the lack of attention to personal stigma, i.e., that personally experienced by participants. However, available measures that attend to personal stigma are concerned with suicide attempt survivors rather than carers and therefore would not be suitable to the target population of this research. In addition, the qualitative component of the study provided opportunities to ask about personal stigma.

3.4.3 Additional survey questions related to the research question

For the reasons outlined above, the AC-QOL and STOSA scales were identified as appropriate to use in this study. In addition, it was agreed to add some open and closed questions relevant to the research question. These comprised one closed and one open question about support received and helpfulness of said support, and four open ended questions pertaining to participants experiences of caring, perspectives on support required for carers, thoughts on their future caring role, and the impact of the COVID-19 pandemic on their caring experience. The question about perspectives on participants future caring role was included to address the gap identified in the literature review, which indicated that to date most research has a focus on the past and present and less on future focused thinking.

3.4.3.1 Demographic questions

The demographic components of the AC-QoL scale were included in the survey. These were related to gender and ethnicity but also hours spent caring a week and years caring. With permission from the authors (see appendix 12) the introductory paragraph was adapted to invite participants to answer based on their experiences over the last few weeks rather than the original terminology of the last two weeks. The reason for this was that it was anticipated carer intensity related to caring for someone with mental health needs and suicidality would fluctuate more than that related to caring for someone with physical health needs or dementia. It was considered that changing 'two' to 'few' would accommodate this fluctuation.

Additional demographic questions asked about age, geographic location (first part of postcode), whether or not participants lived with their care recipients, their relationship to the care recipient and care recipients' sex, age, history of past self-harm and whether they had received input from mental health services.

3.4.3.2 Survey evaluation questions

Finally, a survey evaluation was incorporated. This involved a mood rating on a scale of 0-100 (0 being the worst ever and 100 the best ever) both before and after completing the questionnaire. In addition, there were three open questions and four Likert style questions regarding the experience of participating in the survey research. The evaluation was based on that used by Rivlin *et al.* (2012) when conducting suicide research with prisoner participants who had attempted suicide.

The final survey, including demographic and evaluation questions consisted of 70 items.

3.4.4 Patient and Public Involvement and testing of the survey

Three current or past carers of adults at risk of suicide agreed to review the survey and associated participant information. One provided initial feedback around wording of parts of the survey and suggestions regarding the order of inclusion questions. These points were accommodated and improved the survey and participant information. Some queries were raised around the validated questionnaires, which were resolved through discussion and explanation as to why these scales could not be changed. Subsequent feedback from the other two carers was positive and they reported they had found the survey easy to understand and relevant and functionality was sound. Finally, two clinical and research colleagues, one of whom had past experience of caring, were asked to complete the survey to provide additional perspectives. These colleagues completed it on laptop, tablet and mobile phone and fed back that the process of completing the survey went smoothly, they did not spot any typos or errors, and it was relevant to the research question.

3.4.5 Sampling and recruitment

3.4.5.1 Sample

As noted in earlier chapters, it is not known how many people in the UK care for adults at risk of suicide and minimal research has been conducted with this population in England. Accordingly, an exploratory sample (Denscombe, 2014, p. 24) was sought for this research by inviting self-selection by people who identified as meeting the inclusion criteria. Findings from research using exploratory samples cannot be generalised and thus have limited external validity, but it is a reasonable approach to establish a better understanding of the phenomenon under study. Denscombe, (2014) advises purposive and convenience sampling methods for an exploratory approach. Fricker (2016) views unrestricted self-selected online surveys such as the current research survey as convenience sampling due to the openness to the general public. Purposive sampling was also carried out by targeting relevant organisations and contacts to cascade the survey to carers.

To determine an exploratory sample size, Denscombe, (2014) suggests that between 30 and 250 participants is acceptable but recommends reviewing comparable research to assist planning sample size. Three similar studies were identified to assist with consideration of sample size for the current research. An Australian 60-item online survey for carers of people at risk of suicide carried out by (Maple *et al.*, 2021) generated 435 eligible responses. This survey was commissioned and circulated by a well-known national mental health charity. Bailey and Grenyer (2015) conducted an 86-item survey with 287 carers of people with personality disorder, recruited via relevant online networks and mental health and non-statutory organisations, and Lawn and McMahon (2015) carried out an 84-item survey with a similar population via a private health consumer carer network, achieving 121 responses. All of these studies used unrestricted self-selected survey approaches with convenience and purposive sampling via specific networks, and none predetermined a sample size.

Based on these studies and the Denscombe, (2014) guidance, whilst a sample of 200 for the survey was aspired to, it was accepted that the sample size would be unknown until closure of the survey. In addition, from a practical perspective, the survey had to be time limited due to doctoral time constraints and therefore could not continue until an ideal sample size was achieved.

3.4.5.2 Recruitment

The survey was distributed via researcher and employing NHS Trust's Twitter and Facebook accounts. In addition, local carer organisations and local and national professional contacts were approached and asked to distribute the online survey link to relevant individuals and groups via social media or by email. Four moderated Facebook carer and mental health nursing groups also agreed to advertise the survey on their sites.

The survey was launched on 21st May 2021 and closed on 2nd November 2021. The invitation to participate (Appendix 13) was attached to an image and brief advertisement text outlining the purpose of the research and inviting eligible individuals to take part. When respondents clicked on the survey link, they were directed to the participant information sheet (PIS) followed by forced response informed consent questions. Eligibility questions followed consent and again these involved forced responses. If a response indicated non-eligibility the respondent was taken via skip logic to a section of the survey which confirmed the reason they were not eligible and provided information about relevant support agencies.

3.4.5.3 Completion rate

In no restriction self-selected surveys, it is not possible to calculate a response rate because the number of people who had access to the survey is not known. Instead, a completion rate is calculated by subtracting those who complete a survey from those who commence but do not complete it (Toepoel, 2016). In this research, the survey link was clicked for viewing 390 times although in 201 cases no attempt was made to start the survey, and these were not therefore classed as responses. 189 responses were commenced. Of these, 18 (9.52%) participants were ineligible for the study. This was ascertained in 17 cases from the consent questions; nine were not currently caring for an adult family member or friend, five had never considered their adult care recipient to be at risk of suicide, and three were not living in England. The other ineligible respondent completed the survey in full but indicated in the demographic questions that they were a professional carer. A total of 171 eligible respondents commenced the main survey but 70 of these responses were excluded due to incompleteness i.e., they only completed the first section of the survey (AC-QoL and STOSA and did not answer any of the demographic questions, which were an essential requirement for analysis purposes. The final survey sample was 101 respondents, which is 53.44% of the total 189 individuals who commenced the survey. Responses are summarised in table 2.

Table 2: Survey completion rate

Responses and reason for exclusion	**N (%)**
Initial responses	189 (100)
Excluded due to ineligibility	18 (9.52)
Incomplete responses	70 (37.04)
Completed responses	101 (53.44)

3.4.6 Survey reliability and validity

3.4.6.1. Internal reliability

As aforementioned the AC-QoL and STOSA scales had been appropriately validated, which added to the rigour of the survey. Internal reliability (whether responses are consistent between items) of the scales with the current research sample was calculated using Chronbach's alpha. Based on an acceptable range of 0.70 to 0.95 (Tavakol and Dennick, 2011), internal consistency was evident with all AC-QoL domains and the STOSA scale (table 3). External reliability (reproducibility) was not measured in this research as the survey was cross sectional.

Table 3: Internal consistency reliabilities of AC-QoL domains and STOSA

Scale	Chronbach's alpha coefficient (N = 101)
AC-QoL Support for caring domain	0.77
AC-QoL Caring choice domain	0.93
AC-QoL Caring stress domain	0.91
AC-QoL Ability to care domain	0.80
AC-QoL Carer satisfaction domain	0.77
STOSA	0.90

3.4.6.2 Sampling bias

Sampling bias was inevitable due to the self-selection of the sample. That is, those who completed the survey may have differed in various ways from those who did not complete the survey, for example in motives, experiences and demographics.

3.4.6.3 Moderacy bias

Moderacy bias occurs when participants choose the mid or neutral response to questions posed on a scale and extreme response bias results from participants habitually selecting the highest or lowest responses (Bogner and Landrock, 2016). Not all neutral or extreme responses indicate bias but when they are repeatedly used by individual participants it is likely. Moderacy bias of the AC-QoL and STOSA scales was reduced because they were both four-point scales and thus did not have a neutral point. However, the non-validated)survey question asking participants to rate support received was a 5-point scale ranging from very helpful to very unhelpful with a neutral mid-point of neither helpful or unhelpful. This could be viewed as a limitation as response bias can be introduced by selection of a neutral response if participants do not feel genuinely neutral, they feel uncertain about the question, or due to social desirability or satisficing behaviour (Chyung *et al.*, 2017).

However, Chyung *et al.* (2017) also acknowledge that where appropriately worded, a neutral mid-point allows participants to express genuine neutral responses and forcing non-neutral answers may also lead to bias. They suggest a mid-point is less likely to lead to bias when respondents are familiar with the topic. In the survey question asking participants to rate support, respondents were familiar with the topic which was their experiences of support. Furthermore, if carers experience services as 'not helpful' or 'not unhelpful' it does not necessarily equate to experiences being the polar opposite of those responses, i.e., 'unhelpful' or 'helpful'. For this reason, a neutral response was included. In terms of interpretation, if carers experience services as neither helpful nor unhelpful it indicates a need to improve service provision so that it is experienced as helpful.

3.4.6.4 Response and non-response bias

Given the self-selection nature of the survey it was not possible to assess response bias (when answers provided by respondents do not accurately represent their true experiences) or non-response bias (differences between characteristics of those who choose and choose not to respond) (Sedgwick, 2014). However, to try and reduce non-response bias of the validated questionnaire completion among those who did complete the survey, the STOSA and AC-QoL questions had forced responses i.e., participants had to complete all items to continue with the survey. In addition, the gender questions included a 'prefer not to say' option to reduce the chance of respondents choosing not to complete. To further assist with data completeness, only respondents who completed the survey until the end, including the demographic section, were included in analysis.

3.4.7 Data analysis

3.4.7.1 Statistical analysis of quantitative survey data

The quantitative questions in the survey sought to elicit i) whether participants experienced perceived stigma; ii) level of quality of life, and iii) whether there were associations between perceived stigma and quality of life.

Descriptive and inferential statistical analyses were conducted under the supervision of an experienced quantitative research supervisor. Descriptive statistics summarise raw data from a sample or population and inferential statistics are concerned with estimating associations or causation (Kaur, Stoltzfus and Yellapu, 2018). Descriptive statistics were used to summarise the sample and primary outcome measures, including, where possible, frequencies, means and standard deviations. Inferential statistics were used to establish associations between quality of life and perceived stigma.

3.4.7.2 Missing data

The decision to include only respondents who completed the survey to the end reduced the chance of construct level missing data (i.e., respondents responding to more than zero but fewer than all constructs on the survey) (Newman, 2014). However, missing data can also arise from participants intentionally or accidentally missing survey items, technical difficulties or researcher human error (Newman, 2014). There was a risk of item level missing data because apart from the eligibility and consent sections, and the AC-QoL and the STOSA scales, questions within the survey were not compulsory. Item non response was not problematic with the free text questions, which were deliberately optional, but missing demographic data could potentially affect statistical validity or bias results (Dong and Peng, 2013). A missing data rate of 5 % or less is considered inconsequential (Schafer, 1999). In the current study item-level missing data was evident in the pre and post survey mood rating and three demographic questions:

- Pre survey mood rating (N = 2/1.98%)
- Post survey mood rating (N = 2/1.98%)
- The relationship between the participant and care recipient (N = 4/3.96%)
- Years spent caring (N = 3/2.97%)
- Hours spent caring per week (N = 3/2.97%)
- Pre and post mood rating (N = 4/3.96%)

There were no patterns in the missing demographic data i.e., the participants who omitted items were different for each question. Further to discussion with the relevant supervisor it was agreed that given the small amount of missing item level data it was reasonable to acknowledge it as missing but not remove participants from analysis. Missing data was coded in SPSS and as such was excluded from calculations.

In addition to item level missing data due to participant omission, there was missing data due to researcher error. The survey question asking participants if their care recipient had a history of self-harm or suicide attempts was not activated in the first few days of the survey being published. This resulted in 19 missing responses (18.81%). Due to this error, data from this question was excluded from the analysis. However, it is still reported in the results section as the data obtained can inform discussion and recommendations.

3.4.7.3 Inferential statistics

Inferential statistics were used to look for associations between perceived stigma (STOSA scale) and quality of life (AC-QoL scale).

A Spearman's rank order analysis was used to assess the relationship between the STOSA control item and the mean totals of the rest of the scale, and a Pearson's product moment correlation coefficient analysis was conducted to determine if there were associations between perceived stigma and quality of life.

The relationship between perceived stigma and quality of life was further examined using multiple linear regression, controlling for potential confounders including age of participant, sex of care recipient, relationship between participant and care recipient, years and hours spent caring, and whether or not the participant and care recipient lived together. Because the vast majority of participants were female, sex of participant was not included.

Deciding whether to include perceived stigma or quality of life (QoL) as the dependent variable was challenging. It is difficult to know if low QoL leads to increased perceived stigma or vice versa. Some studies have found stigma to be predictive of QoL among carers, albeit not specifically carers of people at risk of suicide. For example, Chou *et al.* (2009) studied perceived stigma and QoL amongst aging female caregivers of people with mental illness and found that perceived stigma had a predictive effect on QoL. Similarly, Hu *et al.* (2023) found affiliate stigma to be a contributory factor to low QoL among family caregivers of people with dementia. These studies were both conducted in Taiwan and experiences of stigma may differ from a Western context. In the USA, Perlick *et al.* (2007) studied caregivers of patients with bipolar disorder and found perceived stigma to be positively associated with caregiver depressive symptoms, with lack of social support and avoidance coping explaining 63% of the relationship. Causal inferences could not be made due to the cross-sectional nature of the study and QoL was not specifically measured, but social support is of relevance to QoL. The literature review conducted for this research identified that some carers experienced various forms of stigma. Maple *et al.* (2021) examined the relationship between stigma and caregiver burden, reporting one weak association between one item of the stigma of suicide scale (Batterham, Calear and Christensen, 2013) (perceptions that those who die by suicide were isolated) but concluding that there was no significant association overall. However, the stigma scale used by Maple *et al.,* (2021) focused on beliefs about people who had died by suicide rather than suicide attempt.

Based on this appraisal of relevant research and practice-based reflection that stigma might contribute to reduced quality of life, it was agreed that multiple linear regression would be carried out with each of the individual AC-QoL domains as dependent variables.
The independent variables entered into the regression model and the associated rationales are outlined in table 4.

Table 4: Independent variables entered into multiple linear regression model

Independent variables entered into multiple regression model	**Rational for inclusion**
Age of participant	Higher perceived stigma has been associated with younger age (Batterham, Calear and Christensen, 2013), however older age was associated with more negative attitudes towards suicide by Chiang *et al.,* (2015).
Sex of care recipient	No evidence was found for inclusion of this variable with regard to suicidality, however, male gender of care recipients with schizophrenia have been found to be associated with caregiver burden ((Papastavrou *et al.*, 2010).
Relationship between carer and care recipient	Kjellin and Östman (2005) found that many relationships between their caregiver participants and suicidal individuals deteriorated. Zauszniewski, Bekhet and Suresky (2008),) found mothers as opposed to other female family caregivers to experience greater caregiver burden and stigma.
Years caring	Borisonik (2018) found low involvement and resilience within relatives of individuals with multiple attempts and avoidance used as a strategy. This might suggest that duration of caring has a negative effect and may influence perceived stigma.

Hours caring	Hours caring were associated with role overload, distress and reduced quality of life amongst carers of people with schizophrenia (Quah, 2014). Maple *et al.,* (2021) found that frequency of contact was positively associated with caregiver burden.
Carer and care recipient living together	Maple *et al.,* (2021) found that high frequency of contact prior to suicide attempts was a significant positive contributor to caregiver burden. McDaid and Park (2022) found that adverse impacts on QoL of carers of people with mental illness were higher for those living with care recipients. Zendjidjian *et al.* (2012) found living with the care recipient to be associated with lower QoL.
STOSA scores	These were included in line with the quantitative research question: STOSA was included as an independent variable with AC-QoL domains as dependent variables.

3.4.8 Analysis of qualitative survey data

3.4.8.1 Summative content analysis

A common data analysis method used to analyse patterns in textual data is content analysis, which can range from quantitative counting to qualitative theming of data (Braun and Clarke, 2022, p. 286). Content analysis can be manifest (describing what is literally present) or latent (interpreting what is hidden within the text) (Kleinheksel *et al.*, 2020). Summative content analysis (Hsieh and Shannon, 2005) involves both manifest and latent analysis by identifying and counting key words or content and eliciting contextual use, followed by interpreting underlying meanings of the words or content. Key words can be identified before and during data analysis and are derived from researcher interest and reviewed literature. This approach has been used effectively in survey analysis (Griffiths, 2016; McKenna, Vanderheide and Brooks, 2016). Summative content analysis was deemed appropriate for the qualitative data from the four open-ended survey questions due to the brevity of responses, the volume of data, and the aim of comparing and synthesising survey qualitative data with the more in-depth and nuanced qualitative analysis of semi-structured interview data.

Each open-ended question (what is life like for you as a carer; what support do you think would help adults who care for adult family members or friends they think may be at risk of suicide; what are your thoughts on your future caring role; what was the impact of the COVID-19 pandemic on your caring role?) was classed as a separate unit of analysis. Guided by the strategy used by Mckenna, Vanderheide and Brooks, (2016), survey responses were read and re-read to identify and count key words and content, which were then organised into subcategories and categories for each unit of analysis. Key words were not identified prior to analysis but relevant literature influenced the naming of categories. For example, one category was named 'reactive affect' which was also a theme identified by Asare-Doku, Osafo and Akotia (2017) in their study investigating carers of suicide attempt survivors, and 'care intensity', which was applied to another category, is a phase frequently used in caregiver literature.

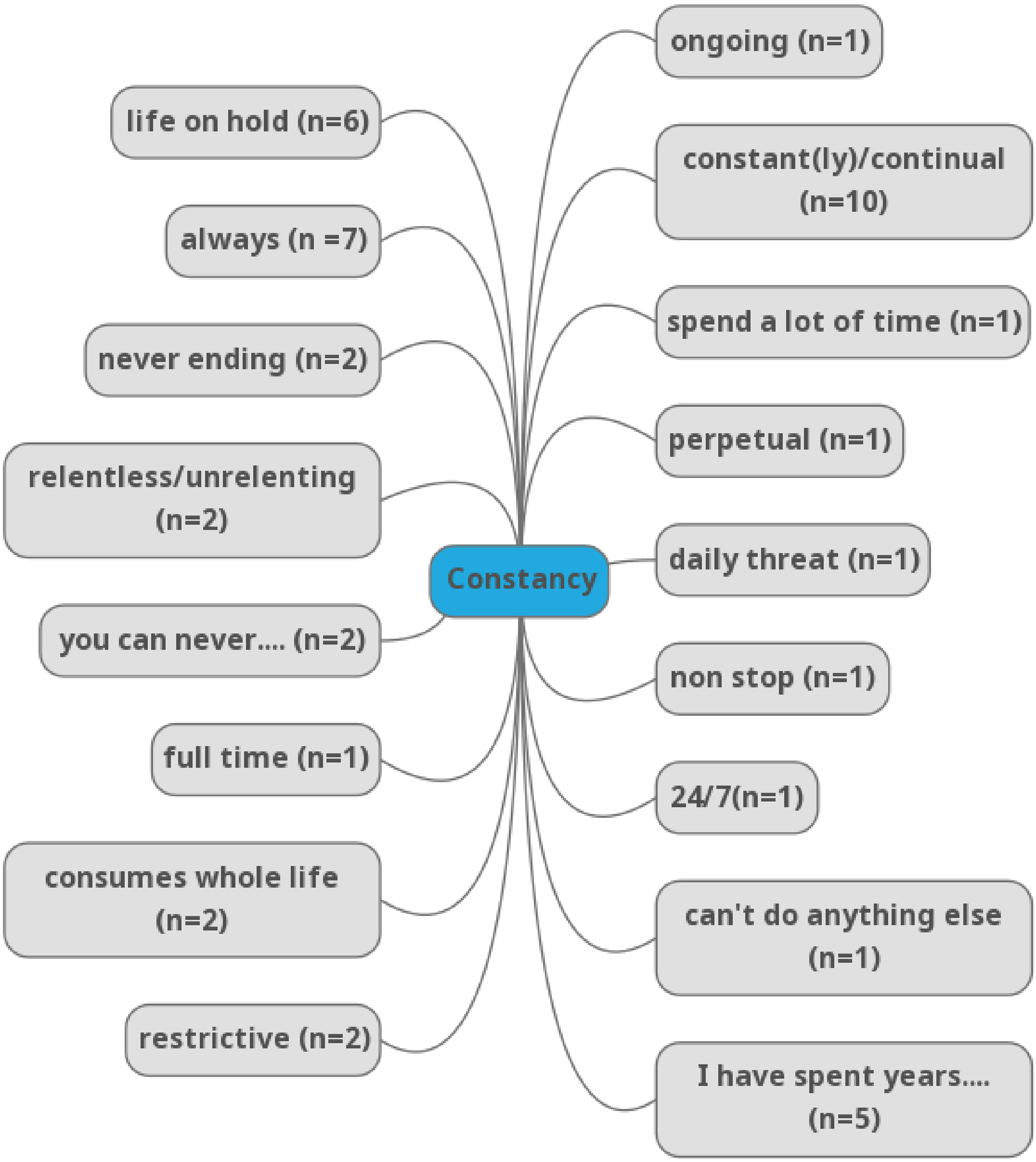
Two examples illustrating coding and category development are shown below. Table 5 shows how responses were initially coded and, in bold and brackets, gives the sub categories or categories that were eventually applied. Figure 3 shows a sub-category named constancy and all of the associated codes.

Table 5: Summative content analysis example of coding and categories

Codes and categories are colour coded with the subcategories and categories bold and in brackets.

Participant response	**Code and category development**
Stressful, sad, lonely. At times happy.	stress/worry, sad **(difficult emotions – reactive affect)** lonely **(loneliness & isolation - unconnected carers)** happy/reward **(positive emotions – reactive affect)**
I've given up my own life. I'm isolated and unhappy, and I no longer have any hope that it will get better.	life on hold **(constancy - care intensity)** isolated **(loneliness & isolation - unconnected carers)** unhappy, hopeless **(difficult emotions – reactive affect)**
Mentally and physically exhausting. Always have to be there to support. Don't get support myself	mentally & physically exhausting **(carer wellbeing)** life on hold **(constancy - care intensity)** lack of support for carer **(lack of support & understanding - unconnected carers)**
Always on edge, exhausted, stressed, financial worries, dreaded call or knock at the door from police or hospital	Hypervigilance **(caring characteristics)** stress/worry, expectancy **(difficult emotions – reactive affect)** exhaustion **(carer wellbeing)** financial worries **(financial & employment concerns - care intensity**)
Life as a carer is exhausting and can be very difficult at times knowing how best to support a granddaughter that has attempted to take her own life	Exhaustion **(carer wellbeing)** Helplessness **(difficult emotions – reactive affect)**
spend a lot of time worrying about 'What if?' Try to work everything around supporting the person. Feel guilty that I can't change how they feel.	Worry **(difficult emotions – reactive affect)** Working things around the person (**balancing competing - demands care intensity)** guilt & helplessness **(difficult emotions – reactive affect)**
At its worst it is having to be hypervigilant and holding the risk, despite how professionals talk endlessly about being the ones who hold risk, I don't think that is true.	Hypervigilance **(caring characteristics)** lack of support for carer (**lack of support & understanding - unconnected carers)**

Figure 3: Subcategory 'constancy' and all of the associated codes



3.4.8.2 Sentiment analysis

For the first open question (what is life like for you as a carer?), a basic sentiment analysis was carried out in addition to the summative content analysis. Sentiment analysis involves using natural language processing, which is a form of machine learning, to automatically classify the sentiment expressed in free text (Zunic, Corcoran and Spasic, 2020). This approach is commonly used for analysing large volumes of online or social media text and can be applied at whole document level, sentence level and text passage level (e.g., single survey responses). At its most basic level, sentiment analysis involves categorising text into positive and negative sentiment polarity (Khoo and Johnkhan, 2018), which is how it was used in this research. The reason for using a simple sentiment analysis with this specific survey question was to help understand the emotional tone underpinning participant responses, therefore providing some emotional context for the categories derived from the content analysis. As the 'what is life like for you as a carer' was the main free text question, which set the scene for the other open questions, it was not considered necessary to complete separate sentiment analyses for every open question.

Qualtrics software uses Text iQ for sentiment analysis (Text iQ. *Qualtrics Web site.* 2023). This facility automates sentiment classifications for each survey response using a range of very negative; negative; mixed; neutral; positive and very positive. It is possible to achieve a sentiment analysis score, which can be useful when conducting time series studies, however in this cross-sectional study proportions (N/%) were used to present classifications rather than scores.

As the sample size in the current research was relatively small (N = 101) it was possible to manually review the Text iQ classifications to pick up inaccuracies or disagreements. Where disagreements were identified justification for these were recorded to illustrate discrepancies and changes to classification. An example of how this was undertaken for four separate sentiment classifications is shown in table 6 below.

Table 6: Manual review of Qualtrics Text IQ sentiment analysis

Participant response	**Qualtrics sentiment classification**	**Researcher review and re-classification (in bold)**
At times challenging	Negative	The 'at times' indicates challenging times are not continuous therefore the category of **mixed** is more appropriate
Full time watching, adapting how I live to reduce risk of them committing suicide. At times thinking it is inevitable one day the attempts will succeed and maybe then they will be at peace and life can move on. Keeping suicide attempts hidden so as not to distress other relatives	Positive	This might have been classified as positive because of the phrase '*one day the attempts will succeed and maybe then they will be at peace and life can move on*'. Given the context of suicide and the remainder of the response indicating negative emotional tone, this statement should be re-categorised as **negative**.
My life was placed on hold whilst I was trying to keep my son safe and prevent him from harming himself and to keep him alive. I could not sleep in fear that he would not be there he following day. My health deteriorated and I had to be admitted to hospital due to shock which caused a hypertensive crisis. I am now on medication for this. I love my son and wanted to make everything better for him but trying to get support from appropriate services was difficult.	Mixed	The phrase '*I love my son and wanted to make everything better for him'* might have resulted in the mixed category, however, in the context of the overall response the emotional tone is **negative**.
Continual walking on eggshells	Neutral	In response to the question this response has a **negative** emotional tone.

3.4.9 Analysis of survey evaluation data

To ascertain statistical significance or otherwise of the pre and post survey mood rating scores a non-parametric related samples Wilcoxin Signed Rank test was computed. This statistical analysis was selected because the 'difference in mood' variable was not normally distributed.

Descriptive statistics with percentages were used to summarise frequencies related to completion rate of this question and the Likert style questions.

Summative content analysis at a manifest level was applied to the free text data.

3.5 Semi structured interviews

Semi structured interviews aim to obtain subjective responses about a particular issue the research participant has experienced (McIntosh and Morse, 2015). They sit between structured interviews in which questions and categories for responses are predefined, and unstructured interviews where the researcher has an overarching topic to explore but responses are largely guided by participants (Braun and Clarke, 2013, p. 78). Semi structured interviews follow an interview schedule comprising open questions and probes, but implicit within this is flexibility in how questions are posed and scope for contained divergence from the script (McIntosh and Morse, 2015). Semi structured interviews were selected for the qualitative data collection method of this MMR because of the experiential emphasis of the research question. In line with the overarching worldview of pragmatism, whereby the motivation was to stay close to participants experiences, a generic approach to interviewing was adopted in which the interview is considered to be a 'professional conversation' (Braun and Clarke, 2013, p. 77), within which the researcher maintains reflexivity and attends to issues of power and participant wellbeing (discussed further below).

3.5.1 Interview schedule

An interview schedule was developed (appendix 14) which reflected the themes covered in the survey with additional prompts to assist acquisition of rich qualitative data. In convergent MMR it is important the quantitative and qualitative methods collect comparable data, albeit separately, because without comparable data integration can be challenging (Morgan, 2014b; Creswell and Plano Clark, 2018). This was addressed in the design stage by adopting a matching approach (Moseholm and Fetters, 2017) as mentioned earlier. The concept of stigma was addressed in the interviews by a specific question whereas quality of life was covered more broadly by asking participants to talk about their caring role with prompts to elicit particular aspects such as satisfaction/reward, emotional and health impacts, and relational changes. Additional information relevant to stigma also arose outside of the specific question as participants told their stories.

To assist evaluation, the interview schedule included the same pre and post interview mood ratings and evaluation questions that were included in the survey.

The interview schedule was reviewed by one individual with lived experience of caring and who had also been involved in review of the survey. Feedback was positive with no suggestions for change, most likely because of the parallels to the survey questions, which this individual had already reviewed. The schedule was piloted with a research nurse colleague who reflected that the questions were acceptable and coherent, and the conduct of the interview was comfortable, supportive and conducive to appropriate disclosure.

3.5.2 Option of informal follow up interview

The option of an informal follow up interview was offered to participants based on past research with carers, which suggests that participants often process their experiences as they talk about them (Funk and Stajduhar, 2009; Lakeman *et al.*, 2013). This this was explained in the participation information sheet (PIS) (appendix 15) as an opportunity for participants to have an additional contact with the researcher to share any reflections or additional information further to the main interview.

3.5.3 Sampling

A nested sampling strategy was used (Collins, Onwuegbuzie and Jiao, 2007), which involved recruiting the interview sample from the survey respondents. This approach to recruitment supports the aim of comparing, corroborating or relating findings in MMR (Creswell and Plano Clark, 2018). With regard to sample size, it is generally acknowledged the sample needs to be adequate to answer the research question (O'reilly and Parker, 2013). Braun and Clarke (2013) note that broad research questions result in shallow data and therefore need larger samples, whereas more focused questions lead to deeper data and need smaller samples. The current research question relates to experiences and needs of adult carers of adults at risk of suicide, which, whilst not a narrow question, is specific and therefore not broad.

One approach to establishing an adequate sample size in qualitative research is data saturation. Data saturation may vary according to study design, but according to Fusch and Ness (2015) it is reached when there is enough information to replicate the study, when the ability to obtain additional new information has been attained, and when further coding is no longer feasible. Various claims have been made as to the correct sample size to achieve data saturation, such as that by Ando, Cousins and Young (2014), who purport that 12 interviews should be an adequate sample for saturation in studies using thematic analysis. Determining sample sizes for exploratory qualitative research a priori, however, is problematic because themes cannot be identified in advance (Sim *et al.*, 2018). Braun and Clarke (2021c) argue that data saturation is poorly operationalised in papers which try to predetermine sample sizes and that an emphasis on codes is inappropriate for thematic analysis, particularly reflexive thematic analysis, whereby theme generation is somewhat evolutionary. Relatedly, there is some consensus that it is not possible to reach a point where one can assume that no new insights will be achieved with ongoing data collection (Low, 2019).

Important issues to consider when contemplating data saturation are the research question and the guiding paradigm or worldview (Saunders *et al.*, 2018). The current research is steered by a pragmatist perspective with the aim of achieving warranted assertions that can be applied to practice. As warranted assertions are not viewed as absolute truths but ways of knowing that grow and moderate as new understandings are realised, arguably a concrete definition of data saturation being 'no new data' does not fit with this research. As an alternative to saturation, Braun and Clarke (2022, p. 28) urge a focus on 'information power', which involves reflecting on the 'information richness' of the dataset and how it is answering the research question. Whilst the notion of information power and richness was considered appropriate for this research, from a practical perspective, the sample size was going to be dependent on how many survey respondents agreed to interview participation. In addition, there needed to be a boundary due to resource availability i.e., doctorate timelines. Braun (Braun and Clarke, 2021c) suggest estimating a lower and higher range of interviews that might achieve adequate information power with the option of 'in situ' decision making to increase sample size if necessary. This approach was adopted and the figure of 12 identified by Ando, Cousins and Young (2014) was a minimum sample size with 15 posited as a maximum. This was a fortunate estimate as 15 survey respondents agreed to the interview, therefore all 15 were included.

3.5.4 Recruitment

Survey respondents were invited to express interest in interview participation by providing their email via a specified box within the survey. Email addresses were separated from the rest of the survey data to preserve anonymity. Twenty-nine respondents expressed interest. These prospective interview participants were emailed to thank them for their interest, provide them with the PIS, invite clarification questions and to request email confirmation if they still wished to participate after reading the relevant information. Fifteen individuals responded and went on to participate in interviews. Arrangements for interviews were made with participants who confirmed their wish to participate. Email addresses of those who did not pursue the option of an interview were deleted.

Interviews took place between 4th October 2021 and 14th January 2022. Fourteen interviews were conducted online using Oxford Brookes Zoom and one was by telephone. Interviews were audio recorded to enable re-listening and transcription. A digital audio recorder was used to record. Interviews lasted between 50 minutes and two hours with most taking 90 minutes.

3.5.5 Remote interviews

Even before the COVID-19 pandemic enforced virtual methods of data collection, the decision had been made to offer a range of interview modes and locations (in person, telephone or videoconferencing) to facilitate participant choice and comfort. Initial feedback from the university's faculty research ethics committee (FREC) indicated that due to the sensitivity of the topic, in person interviews would be preferable. The intention was to challenge this view and argue that videoconferencing or telephone interviews, including for sensitive topics, allow a wider geographic location of participants, support flexibility around interview times, and enable participants to feel more relaxed in their home environments (Novick, 2008; Irani, 2019). In addition, the visual cues observable in videoconferencing interviews can assist with connection, solidarity and validation (Mirick and Wladkowski, 2019), and telephone interviewing is experienced as acceptable, and in some cases preferable (Mealer and Jones, 2014; Ward, Gott and Hoare, 2015). In relation to carers specifically, Mirick and Wladkowski (2019) and Horrell, Stephens and Breheny (2015) highlight the value of online interviews in research because they are less likely to interrupt caring responsibilities and create additional burden, and they enable participation from home. From a researcher perspective, I was confident about conducting online or telephone interviews because I had experience of using these methods for clinical assessments, which explore sensitive topics, and in suicide related research I had previously been part of (Lascelles *et al.*, 2021).

In the event, COVID-19 took the possibility of in person interviews out of the equation and therefore this was no longer a concern for the FREC. Because the intention in the current research had always been to offer remote interview options, I felt prepared for remote interviewing rather than circumstantially forced into an unfamiliar approach. Moreover, by the time of the interviews (2021), all research participants were familiar with videoconferencing, which they had been using throughout the pandemic, and only one participant requested a telephone interview.

3.5.6 Researcher positioning and reflexivity

The researcher's position within qualitative research interviews is influenced by their philosophical worldview. A pragmatist perspective places ultimate value in experience; reality is realised through experience, and the interview itself is an experience. de Gialdino (2009) sees the interview as an exchange between the researcher as a 'knowing subject' and participant as a 'known subject' with this exchange resulting in scientific knowledge. As such it cannot be assumed that the researcher does not influence the interview or analysis of interview data. Nonetheless it was important for me to remain rooted in the participants experience in order to answer the research question. I endeavoured to achieve this by maintaining reflexivity before, during and following interviews to keep participants central and to maintain my own professional and personal identity and integrity. For example, I was open in the PIS and interview about the fact that I was a nurse whilst knowing that participants perceptions of nurses might affect their level of disclosure (Jack, 2008). I couldn't present myself as anything other than a nurse given I was completing a professional doctorate in nursing and I have been a nurse for more of my life than I haven't. It would have compromised my professional and personal integrity to infer a discrete researcher identity. Nevertheless, understanding potential conflicts between my nurse and researcher roles was necessary; Jack (2008) and others caution against falling into a nurse or therapist role when carrying out research interviews. I wrote descriptive participant overviews and initial reflections after each interview (appendix 16) and tried to make sure I attended to my clinical curiosity or assumptions through these reflections. For example, in my reflection following Betty's [pseudonym] interview I contemplated both my clinical and research perspectives. I have learnt that it cannot be possible, nor should it be desirable, to completely extrapolate the clinician from the researcher; if the presence and interpretation of the researcher is an accepted part of interviews and analysis, and that researcher is a clinician, their clinical self, whilst managed through reflexivity, will still have a presence.

I was also aware of the need to contemplate the balance of power within qualitative interviews as this is considered paramount in reflexivity (Rubin and Rubin, 1995; Braun and Clarke, 2013). Power is inevitably weighted towards the researcher who possesses the data, but by structuring and conducting the interview in the context of participant as expert the power dynamic can become more even, providing that empty promises relating to changing practice or systems are not made (Braun and Clarke, 2013).

Reflection in and on the research interviews I carried out enabled me to understand how certain clinical habits had seeped into my interview dialogue and how this may have affected the balance of power. An example of this is my use of paraphrasing (see full reflection in appendix 17), which is a practice I commonly use clinically, but which I needed to adapt in my researcher role. I drew on the de Gialdino (2009) notion of epistemological reflection relating to subjective knowns and subjective knowers, and considered how my clinical approach to paraphrasing in the research context risked distorting participants narratives (Evans *et al.*, 2010) and thus their subjective knowns. This might have occurred when I reflected summarisations back to participants using my own interpretations, which may not have been recognised by the participants. Participants may not have felt able to challenge my summations and this threatened to increase my power as researcher and diminish theirs as participants. Regular reflexivity through journaling, supervision and peer discussion with research colleagues helped me stay mindful of issues such as power and position.

3.5.7 Interview process

The seven stages of interview advocated by Rubin and Rubin (1995) were used to guide, but not rigidly prescribe, the conduct of the semi structured interviews. These authors explain interviews as ‘variants of normal conversations’ (p. 124) within which their seven stages are used fluidly to provide ‘interpersonal scaffolding’ (p. 129) and ensure quality. The stages are outlined below.

1. *Creating natural involvement*

This stage is the entry phase and involves setting the scene, putting the participant at ease, building rapport, conveying interest and outlining the focus of the interviews. During this stage I introduced myself and invited brief social dialogue by asking how participants day had been and by responding to social cues they transmitted. I expressed gratitude to participants, checked for any technical, timing or environmental issues or concerns, revisited informed consent, clarified the purpose of the interview and invited any questions. In addition, I asked participants to rate their mood and explained that I would ask them to do this again at the end of the interview to prepare participants for the evaluation component.

2. *Encouraging conversational competence*

This stage is concerned with reassuring participants that they are competent to answer the interview questions by attending to nervousness, conveying interest and helping participants understand that the interview will be led by their experiences. Rubin and Rubin (1995) advise that initial questioning should be close to the topic but not overly probing. I found it helpful to ask the demographic questions at the beginning of the interview because this information was relatively easy for participants to share. The AC-QoL scale question about the number of hours spent caring was included in this section, which was a difficult question for participants to answer because of the fluctuating nature of suicidality and thus care intensity. Invariably this question involved discussion and was a helpful vehicle for encouraging conversational competence because I could acknowledge the limitation of the framing of the question and show interest in participants accounts of caring as shown in the excerpt below:

IV This next question is quite hard to answer, so just do the best that you can. It's around how many hours do you spend in your caring role, each week. And it's on a rating scale, so 0 to 10, 11 to 20, 21 to 30, and so on. And the highest is 71 plus.

P Yes. I think it varies slightly on how the person I care for is, when he is at his worst then most of the time. But when he's reasonably well then it can be quite as low as maybe 25 actually physically actively caring. The fact that I am caring is never away, it's always at the back of my mind all the time but actually being at the forefront varies from quite low to quite high, depending on him.

IV Yes, of course. So if you were trying to do an average over the last few weeks, what would you say?

P The last couple of weeks have been quite good. Somewhere sort of in the middle I would say.

IV Okay. So that's probably, what 31 to 40?

P Yes.

IV Okay. I do realise that's a difficult one, but because I'm taping, I've got your narrative around it.

3. **Showing understanding**

This stage is characterised by active listening and empathy. Ashton (2014) suggests empathetic distance when the dynamic is one where researchers do not share personal disclosures. Similarly, Braun and Clarke (2013, p. 96) caution researchers not to rely too much on empathy and suggest that 'non-judgemental interest' can be more appropriate and achievable, particularly in situations where the researcher cannot empathise with the participants views. I found my clinical background helpful when balancing empathy, interest and disclosure but reflexivity was essential to help me keep participants experiences foremost, particularly when I identified with them personally. I drew on the concept of radical presence (Harrison, 2017) in my reflexive contemplations (see appendix 18), which helped me develop confidence in my researcher role.

4. **Getting facts and basic descriptions**

This section of the interview is concerned with information gathering through encouraging participants to talk at length and obtain both broad and specific data. In a manner similar to other research with family caregivers (Dempsey *et al.*, 2016), I used a funnelling technique and started by asking participants how they became a carer and followed with probes and subsequently more focused questions from the schedule to ensure participants narratives were central to the interview.

5. Asking difficult questions

Although Rubin and Rubin (1995) present asking difficult questions as a particular interview stage they recognise fluidity. During the interviews this stage intertwined with the phases above and was guided by participants narratives rather than by me as the researcher. The most sensitive points in the interviews where when participants reflected on past suicide attempts of their care recipients. Unsurprisingly some participants became upset. When this occurred, participants were offered the opportunity to stop the interview although none chose to do this. My clinical self was helpful here due to my experience of sitting with distress, which reinforced existing perspectives that clinical expertise is valued in suicide research because of the likelihood of distress (Lakeman and FitzGerald, 2009; Lakeman *et al.*, 2013). I had included an additional measure of a distress protocol (Draucker, Martsolf and Poole, 2009) in case of exceptional distress (appendix 19), although this was not needed in any interview.

6. Toning down the emotional level

This penultimate stage involves directing the interview towards less painful and exposing topics as a prerequisite to ending the interview. Rubin and Rubin (1995) advise asking participants if they have questions or additional insights they would like to share, and participants responded well to this. I also asked participants the evaluation questions which gave them the opportunity to reflect on the interview experience and talk about the feelings they had experienced throughout.

7. Closing while maintaining contact

To achieve a safe ending, I thanked participants for taking the time to speak with me and contribute to the research and reminded them of the support organisations that were outlined in the PIS. I also informed them that I would email the information again. All participants were relatively well informed about available support and did not express much interest in receiving the information but were amenable to me sending it. I asked participants if I could email them to ask if they would like to share any additional reflections and all agreed I could do so.

To help ground participants back into the here and now I went on to ask them what their plans were for the rest of the day or evening and had a short chat about said plans before terminating the interview. All participants were reminded that they could contact me if they had any questions further to the interview.

3.5.8 Interview Data analysis

Thematic analysis (TA) was the approach considered most appropriate for data analysis in this research because of its applicability to experience and emphasis on staying close to the data whilst respecting researcher interpretation (Clarke and Braun, 2017). Boyatzis (1998) defines TA as a process which involves encoding qualitative information, with themes denoting patterns in the data at one level through to organisation and interpretations of the phenomenon under study at a higher level. In 2006, Braun and Clarke elevated TA to the forefront of qualitative research highlighting its theoretical flexibility, asserting that it can be 'a method that works both to reflect reality and to unpick or unravel the surface of 'reality'' (Braun and Clarke, 2006, p. 81). The theoretical flexibility of TA is one of its greatest appeals, but Braun and Clarke (2021b) later reflected that flexibility is often mistaken to mean that it is an atheoretical method. They have since reconceptualised TA as reflexive thematic analysis (RTA) (Braun and Clarke, 2019; Braun and Clarke, 2021b; Braun and Clarke, 2022) and have been explicit about their beliefs that RTA is rooted within qualitative paradigms. They highlight a 'family' of thematic analysis methods (Braun and Clarke, 2021a) which can appeal to various ontological perspectives. These range from coding reliability, which is a structured approach, where codes provide evidence for themes as topic summaries; codebook approaches, which are more reflexive than coding reliability but retain a structure of early theme development, and themes which are topic summaries; and finally RTA where themes are developed from codes later in the process and are seen as patterns of shared meanings surrounded by a central organising concept.

The pragmatist underpinning of the current research values qualitative and quantitative orientated perspectives but ultimately believes that knowing and reality can only be being accessed and realised through experience. The theoretical flexibility originally espoused by Braun and Clarke (2006) fits the pluralistic attitude of pragmatism well, but flexibility is not overruled by RTA, rather the founders urge researchers to thoughtful about how and why the method fits with their guiding paradigm (Braun and Clarke, 2019). RTA was considered appropriate for the current research because of the emphasis on both participant experiences and researcher subjectivity, and recognition that interpretations will evolve from both of these through deep reflection on, and engagement with, data to identify quality codes and generate themes (Braun and Clarke, 2022). This stance complements pragmatism and also professional doctorate nursing research, which stems from nursing practice and is conducted by a nurse researcher wedded to reflexivity in both practice and research.

There are six fluid phases of RTA (Braun and Clarke, 2022); familiarisation; coding; generating initial themes; developing and reviewing themes; refining, defining and naming themes; and writing up.

The process of RTA in this research commenced with transcription. Interviews were transcribed verbatim by the researcher (n = 12) and, with ethical approval, an external transcription company endorsed by Oxford Brookes University (n = 3). Use of an external transcription agency was due to time constraints. Transcription, and subsequent listening, reading and re-reading facilitated intimacy with the data and once familiarisation was achieved, codes were applied to relevant segments of data, although reading and rereading continued.

Data were not approached with pre-formed codes and the approach to analysis was predominantly inductive. This was not an attempt to bracket researcher subjectivity but involved a continuous and conscious internal reflexive dialogue during and following the interviews to stay close to the experiences the research was seeking to understand. Reflexive journaling after the interviews and throughout analysis was essential to help achieve this. Accordingly, coding was mainly semantic in nature by maintaining proximity to participants language and meaning (Braun and Clarke 2022, p. 57). Coding was initially carried out with individual transcripts using the comments function on word. Flip charts and post it notes were then used to extract and cluster codes to generate initial themes. At this point 76 codes and 17 initial themes were transferred to NVIVO version 12 (QRS International 2018) for storage and organisation. Ongoing reflection and clustering of codes continued to review and further develop themes. Themes were then mapped using flip chart and pens to move between them, regularly referring back to the data and identifying central organising concepts, which in turn facilitated the development of more mature themes.

Table 7 shows an example of codes applied to a segment of data followed by (*in italics*) ideas for initial themes. Some initial themes (for example those alluding to uncertainty) were identified very early on and grew in prominence as they were found over and over again within and across transcripts, although they were still refined and redefined throughout the analyses process.

Table 7: Example of coding and generating initial themes

Italics denote initial coding and the bold text the eventual subthemes

Transcript	**Initial coding**
he kind of went under the radar but we said ,look do you want to engage with services here, and he didn't, he was on some antidepressants, I think citalopram, at the time, and then since	Under the radar, not engaging (*can't control/realising limitations*) – **accepting you can't fix it**
then I've kind of sourced a lot of autism focused therapists for him to look at, but you can't, kind of push him to do it and I sort of	Sourcing specialist therapists (*learning the help to look for*) – **learning ways to adjust**
think that really would be a good place for him to start, but he's not engaging with that at the moment so I just say he's safe. I hope he's not too safe and too comfortable, but you know it's	Can't push him to do it (*accepting limitations*) – **accepting you can't fix it**
all these kind of things where you don't quite know if you're doing the right thing	He's safe (*accepting safe is enough*) – **accepting you can't fix it**
	Is he too safe, too comfortable (*questioning self, feeing uncertain*) – **constant and fluctuating worry**
	Not sure if you're doing the right thing (*uncertainty*) – **constant worry and fear in the midst of uncertainty**

Coding and theme development was an immensely iterative process throughout the entire analysis, even though to writing up the results, which conveys the importance of allowing codes to evolve over time as deeper understandings develop (Braun and Clarke 2022, p. 54). As this process continued an overarching theme 'entering and adjusting to a different and uncertain world' was generated with four themes and thirteen subthemes. These will be discussed in depth in the next chapter

3.5.9 Rigour/Trustworthiness

Although various frameworks to assess quality of qualitative research have been proffered over the years (Rolfe, 2006) it is acknowledged that there is no 'golden key' to judging validity or rigour (Porter, 2007). Savin-Baden and Howell Major (2013) argue that the dissent regarding how best to assess quality in qualitative research stems from the lack of consensus as to what it (i.e., quality assessment) is. They note that some scholars consider it to be verification (checking), others see it as evaluation with a focus on documentation to evidence this, and for some it might be both. These authors and others e.g., Bryman (2012) acknowledge the widespread acceptance of the trustworthiness criteria first proposed by Guba (1981) as gold standard quality principles. Trustworthiness comprises four components: credibility, transferability, dependability and confirmability, which are underpinned by the concepts of validity and reliability from quantitative research, leading to some authors such as Morse (2015) to question why qualitative research needs alternative terms to validity and reliability. However, because consensus about the Guba (1981) approach appears to be stronger than dissent, these principles were used to guide the current research. The components of trustworthiness are presented in table 8 below with explanations of how they were achieved in the analysis of the semi structured interviews.

Table 8: Trustworthiness of qualitative research process

Trustworthiness component	**Strategies**
Credibility	Credibility is akin to internal validity in quantitative research, whereby findings are convincing and the researchers account represents a social reality related to the phenomenon studied (Bryman, 2012). This was achieved by closely following Braun and Clarkes six stages of analysis and the use of strong use of quotes to assist 'thick description' (Guba, 1981, p. 81) in the results and through maintaining a reflexive stance throughout all aspects of the research as evidenced by the various examples of reflexive journaling shared in this thesis. Regular discussions with supervisors ensured the process of analysis remained true to the research question and participant accounts. Member

	checking has in the past been considered a strategy to achieve credibility but more recently has not been advised (Morse, 2015). Transcripts were not shared for member checking in the current research because the shared experience of the interview meant that these were generated in a context which cannot be replicated by participants reading back on it. Furthermore, participants reality may have altered between interview and reading transcripts, leading them to change what was salient at the time of interview.
Transferability	Transferability reflects external validity whereby through thick description findings have relevance to and could be transferred to similar contexts or individuals (Morse, 2015). Care was taken to ensure that the presentation of the results (chapter 4) includes prominent quotes to illustrate the themes and demonstrate fidelity to the data. Additionally, I remained alert to any contrary data and was attentive to codes and themes which were less obvious in the data, which included the more positive experiences of caring.
Dependability	Comparable to reliability in quantitative research, dependability refers to transparency to enable replication of the research process. This was achieved by maintaining a clear audit trail through record keeping and reflexive journaling to justify decisions and illuminate reasoning throughout the research process. Field notes were made following interviews (appendix 3.8) and the progression through coding of transcripts and subsequent theme development was recorded by documentation and use of NVIVO software. Discussion with supervisors ensured oversight of the research from conception to completion.
Confirmability	Confirmability refers to the outcomes of the research whereby notwithstanding acceptance of researcher subjectivity, fidelity to the research aims is maintained and reflected in the findings. The triangulation of interview and qualitative survey data strengthened outcomes and confirmability. Again, reflexivity, supervision,

	maintaining a strong audit trail and investment of considerable time to the data analysis throughout the whole of the writing up assisted with confirmability, which involved moving back and forth between interpretation of results and raw data to ensure faithfulness to participants experiences.

3.6 Ethical issues

Cardinal to all research is ethical conduct, particularly when human subjects are involved (Aita and Richer, 2005). Ethical competence is paramount within nursing (Kulju *et al.*, 2016), including within research. Ethical approval for this research was achieved from Oxford Brookes University Faculty Research Ethics Committee (FREC) on 5th November 2020 (reference F.02.2019.15) and the NHS Health Research Authority on 21st April 2021 (Brent NRES REC reference 21/LO/0183). Ethics approval letters can be seen in appendix 20. In the ethical approval process, and throughout the entire research process practice, careful attention was paid to the four pivotal moral principles that guide biomedical practice and research (Beauchamp and Childress, 2009), these being respect for autonomy, beneficence, non-maleficence and justice.

3.6.1 Informed consent

In self-selected online surveys consent is generally assumed by participation (Toepoel, 2016), however, to preserve participant autonomy, particularly given the sensitive topic of the current research, active opt in consent was preferred. Compulsory questions asking respondents to confirm they had read and understood the PIS and wished to proceed with the survey were used, with forced responses meaning participants could not proceed without clicking to confirm their consent.

The interview consent form (appendix 21) was emailed to participants around two days prior to the agreed interview date with a request for it to be signed and returned before the interview (PIS had been sent previously as discussed above). This was to preserve participant autonomy by ensuring that informed consent was agreed as close to the interview as possible whilst giving participants adequate time to digest and complete the forms.

To ensure participants knew they could withdraw from the research up until survey data was submitted and interview data analysis commenced, the PIS clearly stated withdrawal rights. Informed consent was revisited at commencement of semi structured interviews. In line with the principle of beneficence, all participants were signposted to relevant support agencies before and after completion of the online survey and interviews and a distress protocol was prepared to guide response to interview participant distress. Data storage was in line with Oxford Brookes university research governance procedures.

3.6.2 Challenges from the University faculty research ethics committee (FREC)

The first ethics application to FREC was returned with a number of suggestions. One concern, based on the principle of non-maleficence, was that the evaluation of the interview experience might risk highlighting general distress in participants. This concern was successfully challenged on the basis that the purpose of the evaluation was to understand if the interview process, as opposed to the experience of caring per se, caused distress, which is a frequent strategy in suicide research (Rivlin *et al.*, 2012; Biddle *et al.*, 2013; Maple *et al.*, 2020). The aim of the evaluation was in line with autonomy, by providing the opportunity for participants to give real time feedback, and beneficence and non-maleficence by enabling restorative reflection on any difficult experiences. Further, the distress protocol was in place to ensure beneficence and non-maleficence by responding to distress in the moment and facilitating participant autonomy to end the interview at any time. I had also used this approach in previous research (Lascelles *et al.*, 2021) and participants had not found it distressing, rather they valued the opportunity to give feedback. Not asking about impact on mood and level of distress in research does not equate to an absence of such impact, and researchers have a responsibility to assess for detrimental impact of participation *in keeping* with non maleficence. Distress or unmet need relating to the experience of caring would likely be identified in interviews regardless of evaluation questions, and participants would not necessarily find distress harmful; rather it can be cathartic (Alexander, Pillay and Smith, 2018).

Another FREC suggestion was adding additional support agencies to those that had already been carefully identified in the PIS. In addition, signposting to complaints agencies was advised, and it was suggested that I as the researcher follow whistleblowing policies if indicated. Some aspects of this recommendation were challenged. Excessively long lists of support can be overwhelming for individuals and longer PIS are less likely to be read (Ennis and Wykes, 2016). I was confident the agencies I had included were the most salient to the research population and my PPI feedback had indicated appropriateness, therefore the original support agencies were sustained without adding more. In recognition that the addition of PALS (Patient Advice and Liaison Service) would support autonomy and justice, PALS was included in the PIS in response to FREC feedback, but the reference to whistleblowing was contested. This was because as a researcher I would not know the organisations concerned nor be privy to a wider context beyond participants perspectives on a third party's (care recipient) care and treatment. It was considered that by including information about whistleblowing, I would risk giving participants unrealistic expectations as to what I could do to support any claims of substandard care. Arguably this could result in the opposite of the intended non-maleficence. This challenge was accepted by FREC.

The FREC feedback was in line with internationally accepted principles research requirements, especially for a topic such as that investigated in this research, however, it was experienced as somewhat over-cautious. I deduced this to be based on assumptions about the vulnerability of participants this research would attract. Bracken-Roche *et al.* (2017) note that care should be taken not to impose labels of vulnerability and associated protections on those who do not need such status or safeguards. Inflated assumptions about participant safety are not uncommon in suicide research; Maple *et al.* (2020) were driven to investigate carers motivation for and experiences of participating in suicide research as a result of ethics committees over cautiousness around participant safety. Their research found that carers largely found participation in suicide research difficult but manageable and cathartic, which echoes research examining carers experiences in other sensitive contexts such as palliative care (Aoun *et al.*, 2017). Awareness of the research in this area along with my clinical knowledge of the ability of distressed individuals to retain full capacity and gain catharsis through talking about their experiences gave me confidence to intelligently challenge the FREC recommendations and provide them with necessary assurances to proceed with the research.

3.6.3 Ethical moments

An ethics as process approach (Cutcliffe and Ramcharan, 2002) was adopted throughout the research whereby active mindfulness of ethical principles and issues was at the forefront of my researcher consciousness, and ethical moments were attended to as they arose. Guillemin and Gillam (2004) note the potential for unanticipated ethically important moments and emphasise the requirement of researcher alertness and skill to maintain beneficence and participant autonomy. One significant ethical issue arose where a prospective interview participant disclosed her son had ended his life by suicide between her completing the survey and receiving contact regarding interview. She expressed keenness to continue with participation and stressed that this was not out of a desire to honour perceived commitment but due to her strongly felt need to tell her story. Following discussion with supervisors it was agreed that this participant should not be excluded because of her bereavement despite the change in her eligibility for the research. She had not been bereaved when she started participation in the overall study, and it was considered that prohibiting interview participation may do more harm than would be caused by the distress of telling her story. Moreover, it would likely have contravened the principles of justice and autonomy. It is known that people bereaved by suicide benefit from research participation despite finding it challenging (Andriessen *et al.*, 2018) and there is no evidence to suggest that research participation harms those who have been recently bereaved (McCallum *et al.*, 2019). This amendment to protocol was authorised by the Health Research Authority NHS research ethics committee and the participant was interviewed. In the event she did find the interview difficult but fed back that she had found the experience therapeutic and was glad she had taken part and been heard, which is in keeping with the literature.

3.6.4 Changes to planned processes

Regarding the follow up telephone interview, as I had established an email relationship with participants prior to the interview it felt more appropriate in the first instance to ask participants if I could email them within a week of the main interview to see if they had additional thoughts or reflections they would like to share through a second telephone interview. Participants were happy for me to send an email but only six responded, with three either giving a few reflections or to re-emphasise a key point the had made during the interview. No telephone interviews followed because no participant had anything else they wanted to add.

3.6.5 Ethical reflexivity

Reflexivity is crucial to ensure ethical competence in research. From a pragmatist Deweyan perspective, ethical inquiry is continuous, with *moral conduct* involving the development of a *moral imagination* to see the meanings at issue in a situation and address them in a way that is most ethically fulfilling (Thomas, 1993). An example of my developing moral imagination was in relation to my use of pseudonyms, something which I had taken for granted until I was encouraged to reflect on my usage. There are three types of alias's that can be used for participants taking part in a study; pseudonyms, epithets and code names (Heaton, 2022). Pseudonyms are false names that differ from and replace participants true name within research text, epithets are descriptive terms denoting a person or place (e.g., 'doctor', 'superhero' or 'Townsville'), and code names are index terms allocated to participants (e.g., P1, P2 etc). In this study I had used pseudonyms based on Heaton's (2022) point that pseudonyms de-identify participants without depersonalising them. The interviews were in depth, emotional and intimate with participants sharing personal and painful experiences and it felt wrong to assign numerical codes or non-personal terms. Pseudonyms were assigned alphabetically apart from the single non-binary participant where a non-gendered name was selected. Use of alphabetic order is a common approach to identifying pseudonyms (Heaton, 2022). Some researchers offer participants the opportunity to select their own pseudonyms and this is increasingly considered good practice (Allen and Wiles, 2016). The option of giving participants in this study choice was not considered; not because of a conscious decision to retain authority over pseudonym selection, and thus hinder autonomy or justice, but because of a lack of realisation of this good practice in research. Inquiry by supervisors as to my choice of pseudonyms stimulated ethical reflection which led to increased moral imagination and conduct and an ethically fulfilling outcome. This reflection is summarised in appendix 22.

3.7 Integration of the quantitative and qualitative data

The intent of a convergent mixed methods design is to achieve a more complete understanding of the phenomenon of study and to answer the question '*do the quantitative and qualitative results converge or diverge*?' (Cresswell and Plano Clark, 2018). These authors discuss the process of integration as looking for common concepts across both sets of findings. A bidirectional simultaneous approach to integration (Moseholm and Fetters, 2017) was adopted whereby outcomes of quantitative and qualitative data analyses were merged to develop mixed methods interpretations. Integration involved abductive reasoning by moving back and forth between the results of the three datasets (STOSA and AC-QoL scores, survey summative content analysis, qualitative interview thematic analysis) to search for convergence, divergence and ultimately a deeper understanding of the experiences of carers of adults at risk of suicide. Researcher reflexivity continued throughout integration to maintain closeness to the research data whilst acknowledging that findings would resonate with practice experiences (English, Gott and Robinson, 2022). Integration of qualitative data with STOSA and AC-QoL scores was challenging because the summative content analysis of qualitative survey data and thematic analysis of interview data were inductive in nature. The process of abduction helped to make sense of findings that were not explicitly parallel. The outcome of this abductive integration was mixed methods interpretations of the main qualitative and quantitative findings. These are discussed in the results chapter and a joint display table, guided by Stenger *et al.* (2014) and Younas, Pedersen and Durante (2020) is shown in appendix 27. The overarching theme from the interview data analysis (entering and adjusting to a different and uncertain world) was retained as the overarching theme for the research as a whole.

3.8 Chapter summary

This chapter has presented pragmatism as a guiding world view for the current research and provided a rationale for the choice of a convergent mixed methods methodology. The research methods have been detailed along with reasoning for selection of tools and approaches used. Processes of data collection, analysis and integration have been discussed. Key ethical issues have been presented and the importance of researcher reflexivity has been accentuated. The next chapter will present the results from the quantitative and qualitative components of the research along with a summary of the mixed methods integration.

Chapter 4: RESULTS

4.0 Introduction

This chapter presents the findings of the survey and interviews, including the evaluations. The chapter is split into three sections. Section one covers the survey, section two the interviews and section three the evaluation.

4.1 Survey findings

This section presents the quantitative and qualitative findings of the online survey which was distributed via Twitter, certain Facebook pages, nursing and public health fora, and through professional colleagues and contacts over a five-month period. The aim of the survey was to gain an understanding of the experiences and needs of carers of adults at risk of suicide, including information regarding perceived stigma and quality of life. Survey quantitative and qualitative data were analysed separately with a summative content analysis approach taken with the qualitative data to achieve quantification of categories. The characteristics of survey respondents are presented first, followed by the results from the quantitative data analysis and finally the summative content analysis.

4.1.1 Participant characteristics

There were 101 eligible responses to the survey. Characteristics of respondents are presented in table 9. The majority (88.12%) were women, White British (88.12%) and between the ages of 40 and 64 years (78.22%). Most participants (68.32%) lived with the person for whom they cared (care recipient). Half were parents, a quarter were partners, and just over a fifth were classed as other and comprised small numbers of daughters, sisters, friends and grandparents. Hours spent caring each week ranged from 10 or less to more than 70, with over half of respondents (55.45%) caring for more than 30 hours a week. Years spent caring varied from 0-4 years (25.74%) to 20 years or more (18.81%).

Care recipients were fairly evenly distributed by gender and age although only seven were aged 64 years or over. Over half of participants reported that care recipients were under the care of mental health services, with an additional third having previously received mental health care. The majority of participants reported that their care recipients had a history of self-harm or suicide attempts. However, data for this question was missing for nearly a fifth of respondents due to the question being erroneously omitted from the survey for the first few days of it being published.

Table 9: Participant characteristics

Demographic question	Demographic details	N (%)
Gender	Woman Man Other*	89 (88.12) 10 (9.90) 2 (1.98)
Ethnicity:	White British White other Mixed Other	89 (88.12) 7 (6.93) 3 (2.97) 2 (1.98)
Age (years)	18-25 26-39 40-64 65+	2 (1.98) 16 (15.84) 79 (78.22) 4 (3.96)
Relationship with care recipient	Parent Partner Other* Not known/missing	52 (52.49) 23 (22.77) 22 (21.78) 4 (3.96)
Living with care recipient	Yes No	69 (68.32) 32 (31.68)
Years caring:	0-4 5-9 10-14 15-19 20+ Not known/missing	26 (25.74) 29 (28.71) 16 (15.84) 8 (7.92) 19 (18.81) 3 (2.97)
Hours caring per week	0-10 11-20 21-30 31-40 41-50 51-60 61-70 70+ Not known/missing	16 (15.84) 17 (16.83) 9 (8.91) 18 (17.82) 9 (8.91) 6 (5.94) 3 (2.97) 20 (19.80) 3 (2.97)
Gender of care recipient	Woman Man Other/prefer not to say	49 (48.51) 50 (49.50) 2 (1.98)
Age of care recipient (years)	18-25 26-39 40-64 65+	35 (34.65) 30 (29.70) 29 (28.71) 7 (6.93)
Care recipient contact with mental health services	Yes In the past but not currently Never	62 (61.39) 36 (35.64) 3 (2.97)
Care recipient history of self-harm or suicide attempts**	Yes No Not known/missing**	75 (74.26) 7 (6.93) 19 (18.81)

*Other is made up of adult daughters (n = 8), sisters (n = 5), friend (n = 4), grandmother (n = 2), 'family member' (n = 2), aunt (n = 1) ** Data missing due to question being erroneously omitted for first few days of survey

4.1.2 Geographic location of participants

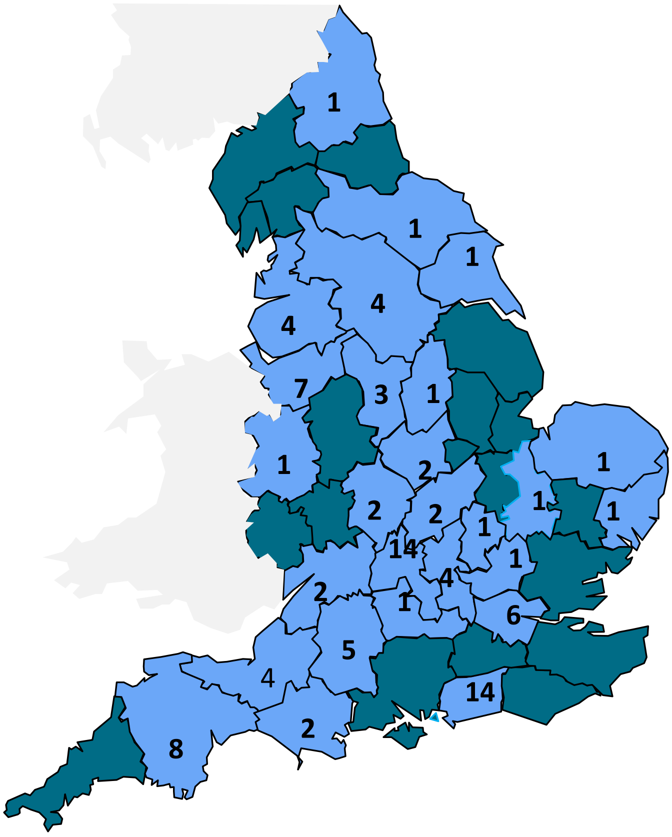
Nearly two thirds of participants were located in the South East or South West of England, with the remaining participants spread across the North of England, the Midlands and the East of England. Six participants did not provide their postcode. A breakdown of participants and their regional geographic locations is provided in table 10 and figure 4 shows the spread of participants across England on a county level.

Table 10: Breakdown of participants and their geographic region

Geographic location	N (%)
South East of England	40 (39.60)
South West of England	21 (20.79)
North of England	18 (17.82)
Midlands	11 (10.90)
East of England	5 (4.95)
Not known	6 (5.94)
Total	101 (100)

Figure 4: Spread of survey participants across England

The blue counties are those from which participants responded. Numbers indicate the number of participants responding from that county (total N = 95)



4.1.3 Quality of life outcomes

The AC-QoL domains were scored individually in accordance with the AC-QoL guidance: scores ranged from 0-15 and were categorised as low QoL = 0-5, mid-range QoL = 6-10, high QoL = 11-15.

Just over three quarters of participants reported low quality of life with regards to support for caring demonstrating a clear lack of support for this population. Scores of the remaining domains indicated that most of participants had mid-range quality of life. However, over a third of participants had low quality of life in the caring choice domain, which tells us that a sizable proportion of carers feel their life is on hold due to caring and they have little choice or control over their caring role. Furthermore, nearly a third of participants reported low quality of life for caring stress, meaning health outcomes in this group are likely to be negatively affected by caring. Over half of participants scored mid-range quality of life for ability to care showing a good overall level of confidence in caring, but a quarter scored low quality of life suggesting they did not feel confident in their abilities. The majority of participants reported mid-range quality of life scores for carer satisfaction signifying that despite the difficulties and stress of caring the role was important to them.

Total and mean scores are presented in table 11.

Table 11: Ac-QoL domain total and mean scores

(total N = 101)

AC-QoL domain	Mean (SD) (range 0-15)	Low QoL N (%)	Mid-range QoL N (%)	High QoL N (%)
Support for caring	4.00 (2.53)	78 (77.23)	21 (20.79)	2 (1.98)
Caring Choice	6.69 (3.80)	38 (37.62)	45 (44.55)	18 (17.82)
Caring Stress	7.08 (3.36)	31 (30.69)	56 (55.45)	14 (13.86)
Ability to care	7.51 (2.58)	25 (24.75)	63 (62.38)	13 (12.87)
Carer satisfaction	7.82 (2.62)	14 (13.86)	73 (72.28)	14 (13.86)

4.1.4 Perceived Stigma outcomes

The overall mean score of the STOSA for this sample was 2.81 (SD, 0.5). Compared to STOSA scores in previous studies, the current results indicate somewhat higher perceived stigma within this study population than that identified in a general (Italian) population (2.58; SD, 0.37), a clinical population (2.72; SD,0.44), suicide attempters (2.69; SD,0.45) (Scocco *et al.*, 2012), and in psychiatric patients who have attempted suicide (2.69; SD, 0.44) (Scocco *et al.*, 2016).

4.1.4.1. Attribution of stigma of suicide attempt to mental disorder

The control question related to perceptions that people who attempt suicide have a mental illness was analysed separately to evaluate participants opinions on the associations between mental illness and suicidal behaviour. The mean score for this question was 3.48 (SD 0.72) with 92/101 participants answering either agree or strongly agree to this question.

To assess the relationship between the STOSA control question and the scores of the main questionnaire a Spearman's rank order correlation was carried out, which showed a significant moderate positive correlation between the control question and the STOSA score r_s (99) = 0.353, $p < 0.001$. In short, the more strongly participants agreed that suicide attempt was associated with mental illness the higher their perceived stigma (see appendix 23). This suggests that perceived stigma may be more to do with mental illness rather than suicide attempt per se.

4.1.5 Relationships between Perceived stigma and quality of life.

Pearson's correlation was carried out to examine the relationship between quality of life and perceived stigma. The relationships between the STOSA and the quality of life variables were linear, and visual inspection of scatter and QQ plots indicated approximate normal distribution and no outliers (see appendix 24). There was a significant moderate negative correlation between caring stress and perceived stigma $r = -0.37$, $p < 0.001$, and significant small negative correlations between caring choice and perceived stigma ($r = -0.30$, $p = 0.002$), and support for caring and perceived stigma ($r = -0.30$, $p = 0.003$) (Cohen 1988). No significant correlations were found between ability to care and perceived stigma ($r = -0.09$, $p = 0.37$) or carer satisfaction and perceived stigma (0.003, $p = 0.98$) These results indicate that perceived stigma is higher in those participants who have lower quality of life in relation to caring stress, caring choice and support for caring.

4.1.6 Multiple Linear Regression with quality of life as dependent variable

Multiple linear regression was conducted with the AC-QoL domains as dependent variables to understand if the associations between perceived stigma and quality of life were explained by other variables. Model fit was assessed based on acceptable R-squared scores guided by (Ozili, 2023) (table 12) guidance that a low R-squared of at least 0.10 is acceptable if some of the explanatory variables are statistically significant. Adequate model fit was achieved in the support for caring domain: $F(10, 81) = 1.979$, $p = 0.046$; caring choice domain $F(10, 81) = 3.693$. $p < 0.001$; and caring stress domain $F(10,81) = 4.017$, $p < 0.001$. The model fit was inadequate in the caring ability and carer satisfaction domains.

Table 12: R, R^2 and R^2 adjusted values for overall models

AC-QoL domain ***(dependant variable)***	**R**	**R^2**	**Adjusted R^2**	**Std Error of the estimate**
Support for caring	.442[a]	.195	.118	2.437
Caring choice	.537[a]	.289	.220	3.344
Caring stress	.529[a]	.280	.210	2.999
Ability to care	.157[a]	.025	-.069	2.688
Carer satisfaction	.269[a]	.073	-0.17	2.591

Models for support for caring, caring choice and caring stress are discussed below. As the model did not fit the caring ability and carer satisfaction domains, coefficients are not presented here but can be seen in appendix 25.

Support for caring domain

The regression coefficients for the support for caring model are presented in table 13. Only perceived stigma was a statistically significant predictor of support for caring such that an increase in perceived stigma was associated with a lower quality of life when other variables in the model were controlled for.

Table 13: Unstandardised regression coefficients for support for caring

Variable	B (S.E)	p	95% CI for B
Sex of care recipient	-0.611 (0.537)	0.258	-1.678 - 0.457
Relationship as parent versus partner*	-0.342 (0.717)	0.634	-1.769 - 1.084
Relationship as parent versus other*	0.229 (0.740)	0.757	-1.242 - 1.701
Living with care recipient	-0.127 (0.717)	0.859	-1.554 - 1.299
Years spent caring	0.003 (0.002)	0.170	-0.001 - 0.008
Hours caring per week	-0.156 (0.117)	0.188	-0.389 - 0.078
Participant age	0.965 (0.589)	0.105	-0.207 - 2.137
Perceived stigma	-1.343 (0.549)	0.017	-2.435 - -0.250

* Relationship = parent is the reference variable

Caring choice domain

Table 14 presents the regression coefficients for the caring choice model. Only the number of hours spent caring per week was a significant predictor of caring choice i.e., an increase in hours spent caring was associated with a lower quality of life (due to lack of choice about caring) when other variables in the model were controlled for. However, it should be noted that years spent caring and perceived stigma were nearing significance suggesting that the length of time spent caring and perceived stigma might contribute somewhat to the level of choice participants felt they had about caring.

Table 14: Unstandardised regression coefficients for caring choice

Variable	B (S.E)	p	95% CI for B
Sex of care recipient	-1.104 (0.736)	0.138	-2.569 - 0.361
Relationship = partner *	-0.414 (0.984)	0.675	-2.372 - 1.543
Relationship = other *	-0.255 (1.015)	0.802	-2.274 - 1.764
Living with care recipient	-0.126 (0.984)	0.898	-2.083 - 1.831
Years spent caring	0.006 (0.003)	0.065	0.000 - 0.013
Hours caring per week	-0.665 (0.161)	<0.001	-0.985- -0.345
Participant age	0.044 (0.809)	0.957	-1.564 - 1.653
Perceived stigma	-1.335 (0.754)	0.080	-2.835 - 0.164

* Relationship = parent is the reference variable

Caring stress

Regression coefficients for the caring stress model are presented in table 15. The number of hours spent caring per week and perceived stigma were significant predictors of caring stress. As with caring choice above, years spent caring neared significance suggesting that the length of time spent caring might contribute somewhat to caring stress.

Table 15: Unstandardised regression coefficients for caring stress

Variable	B (S.E)	p	95% CI for B
Sex of care recipient	-0.285 (0.661)	0.667	-1.599 – 1.029
Relationship = partner *	1.287 (0.883)	0.148	-0.468 – 3.048
Relationship = other *	0.427 (0.910)	0.640	-1.384 – 2.238
Living with care recipient	0.048 (0.882	0.957	-1.707 – 1.803
Years spent caring	0.006 (.003)	0.065	0.000 – 0.012
Hours caring per week	-0.432 (0.144)	0.004	-.720 - -0.145
Participant age	0.685 (0.725)	0.348	-.758 - 2.127
Perceived stigma	-1.714 (0.676)	0.013	-3.059 - -0.370

* Relationship = parent is the reference variable

4.1.7 Helpfulness and unhelpfulness of support

Participants were asked to rate helpfulness of various modes of support they may have accessed (mental health trust, GP, carers support agency, family members, friends) on a Likert scale ranging from 1 (very helpful) to 5 (very unhelpful) with a neutral neither helpful nor unhelpful mid-point. Scores are shown in table 16. The neutral point was the most common response for support services but not for family members or friends. Mental health trusts were the most unhelpful service with two fifths rating them unhelpful or very unhelpful and just over a fifth helpful or very helpful. GPs were experienced as more supportive with two fifths of participants rating then helpful or very helpful, but a quarter rated them unhelpful or very unhelpful. Over a third of the respondents who rated carer support agencies rated them helpful or very helpful and a relatively small number, less than a fifth, unhelpful or very unhelpful. Ninety participants rated helpfulness of support from family members with over half rating this support as helpful or very helpful and a fifth unhelpful or very unhelpful. Friends were the most helpful support with two thirds participants rating them helpful or very helpful and just less than a fifth rating them unhelpful or very unhelpful. These results indicate that overall, mental health trusts are experienced as being of very limited support with GPs and carer support agencies being somewhat more helpful, but family and friends being the most helpful source of support. This finding reinforces the importance of social engagement for carers and the need to retain social networks as much as possible.

Table 16: Participants ratings of helpfulness and unhelpfulness of sources of support

Support provider	**Very helpful N (%)**	**Helpful N (%)**	**Neither helpful nor unhelpful N (%)**	**Unhelpful N (%)**	**Very unhelpful N (%)**	**Total N**
Mental health trust	6 (8.82)	9 (13.23)	25 (36.76)	12 (17.65)	16 (23.53)	68
GP	10 (12.99)	20 (25.97)	27 (35.06)	13 (16.88)	7 (9.09)	77
Carer support agency	12 (19.05)	12 (19.05)	29 (46.03)	8 (12.69)	2 (3.17)	63
Family members	18 (20.00)	35 (38.88)	18 (20.00)	13 (14.44)	6 (6.67)	90
Friends	19 (20.88)	41 (45.05)	20 (21.98)	5 (5.49)	6 (6.59)	91

Participants were invited to report other sources of support they had received. This included private therapy/counselling (n = 7), workplace support (n = 6), charities (n = 6), faith groups (n = 2), social care (n = 2) and the ombudsman (n = 1). Because only some participants rated the ‘other’ support ratings on the Likert scale, ratings are not included in the results.

The survey included an option to provide free text information about the support participants had received, resulting in 89 responses, 46 (51.69%) of which referred to a lack of, or limited, support. Twenty (22.47%) of these referred specifically to lack of support from healthcare services, with five noting the difficulty accessing support when the care recipient refused to engage. An additional seven (7.87%) mentioned inadequate support for the care recipient. The other 19 (21.35%) either just stated 'no support' or referred to limited support available at various community-based carer support agencies. Where responses included particular problems with support, these included a lack of tailored support specific to their context (e.g., caring for an adult; suicidality; outside of working hours) (N=11, 12.36%), negative attitudes from HCPs (N=7, 7.87%), confidentiality being used as a barrier (N=3, 3.7%), and healthcare services having overly high expectations of carers (N=3, 3.7%).

Thirty-four (38.20%) of the free text responses made reference to support being helpful. Where reasons for helpfulness were mentioned, these included listening, empathy and emotional support (N=13, 14.61%), and carer workshops, relevant information and skills training (N=11, 12.36%). Four (4.49%) participants stated that peer support groups were helpful, however, another two (2.25%) referred to them being unhelpful.

4.1.8 Content analysis of qualitative survey data

The survey included four open questions related to the experience of being a carer; what is life like for you as a carer, what support would benefit this population of carers, the impact of the Covid-19 pandemic, and perspectives on the future in terms of the caring role. These questions were classed as separate units of analysis. Using a summative content analysis approach to enable quantification, sub-categories and categories were developed from identification of key words and content in participants responses to each question. Each question is presented in turn below and where appropriate illustrative quotes are included to elucidate the reasoning behind the categories.

Reporting related to the open questions is based on the total number of respondents who answered each question and not the total number of survey participants overall.

4.1.8.1 Open question 1: What is life like for you as a carer?

86 respondents (85.15%) answered this question. The sentiment analysis carried out for this question is reported first, followed by the summative content analysis results.

Sentiment analysis

The Qualtrics sentiment analysis identified the emotional tone of 41 (47.67%) responses as very negative, 18 (20.93%) as negative, 17 (19.77%) as mixed, three (3.49%) as positive, one (1.16%) very positive and six (6.98%) as neutral (table 17). Following researcher review of this analysis there were 13 disagreements (15.11%). Reasons for the disagreements are summarised in table 17 and the full comments and reasoning for differences in interpretation are shown in appendix 26. Reasons for disagreements included the Qualtrics sentiment analysis attributing phases such as 'at peace' and 'considering their needs' as positive, whereas when these were placed into the context of the broader comment it could be seen that the emotional tone was negative. In addition, where there were single or very few words in a response, the Qualtrics analysis tended to categorise as neutral whereas researcher review determined a negative connotation (e.g., tiring, never ending). Disagreements were discussed with a supervisor who concurred with the researcher review and the final sentiment analysis identified the emotional tone of 41 (47.67%) responses as very negative, 27 (31.40%) as negative, 17 (19.77%) mixed and one (1.16%) positive.

Table 17: Results of open question 1 sentiment analysis (N=86)

Sentiment category	**Qualtrics results N(%)**	**Disagreements following researcher review**	**Reasons for disagreement**	**Final results. N(%)**
Very negative	41(47.67)	0	N/A	41(47.67)
Negative	18(20.93)	1	Comment indicated a **mixed** emotional tone	27 (31.40)
Mixed	17(19.77)	3	Comments indicated consistently **negative** emotional tone	17(19.77)
Positive	3(3.49)	2	Comments indicated **negative** emotional tone	1(1.16)
Very positive	1(1.16)	1	Comment indicated **mixed** emotional tone	0
Neutral	6(6.98)	6	5 comments indicated **negative** emotional tone 1 comment indicated a **mixed** emotional tone	0
Total N	86	13	13	86

This simple sentiment analysis shows that the vast majority of participants (N = 68/79.07%) conveyed a very negative or negative tone within their responses suggesting that their life as a carer was challenging and involved difficult emotions. Nearly a fifth (19.77%) of respondents expressed mixed emotions within their responses which infers they experienced both positive and negative experiences and emotions in their caring role. Only

1 participant communicated a wholly positive emotional tone in their response to this question. The results of the sentiment analysis are largely corroborated by the summative content analysis which follows.

Summative content analysis

Five key categories were identified from the content analysis of open question one; reactive affect, care intensity, characteristics of caring, unconnected carers, and carer wellbeing. Table 18 provides a breakdown of the categories and subcategories which are then discussed in turn. Most participant responses (n=72/86, 83.72%) covered multiple categories and/or subcategories and thus the sum of the totals of the categories exceed the total of participants.

Table 18: Categories and subcategories related to the open question 'what is life like for you as a carer'?

Category.	**Total N = 86** N (%)
<u>1.1</u> <u>Reactive affect</u>	65 (75.58)
Difficult emotions	63 (73.26%)
Worry, stress and fear	49 (56.98)
Frustration and helplessness	16 (18.60)
Sadness, emotional pain and grief	9 (10.47)
Difficult familial emotions	7 (8.14)
Stigma and secrecy	5 (5.81)
Expectancy	5 (5.81)
Hopelessness	4 (4.65)
Guilt and lowered self esteem	4 (4.65)
Positive emotions	9 (10.47)
Sense of reward	6
Hope	3 3.49)
<u>1.2 Care intensity</u>	N = 61 (70.93)
Constancy	46 (53.49)
Fluctuation and unpredictability	22 (25.58)
Pressure & responsibility	17 (19.77)
Balancing competing demands	13 (15.12)
Financial and employment concerns	4 (4.65)
<u>1.3 Caring characteristics</u>	N = 24 (27.91)
Walking on eggshells	10 (11.63)
Hypervigilance	14 (16.28)
Self-care & learning	3 (3.49)
<u>1.4 Unconnected carers</u>	N = 33 (38.37)
Lack of support and understanding	26 (30.23)
Loneliness and isolation	16 (18.60)
<u>1.5 Carer wellbeing</u>	N = 33 (38.37)
Exhausting/draining	21 (24.42)
Negative impact on health	11 (12.79)

NB: the sum of the totals of each category exceed the number of participants who answered the question due to responses covering multiple categories and/or sub-categories

Category 1.1: Reactive affect (65, 75.58%)

Responses of 65 (75.58%) participants referred to emotional responses, with several (N=27) of these mentioning multiple emotions, most of which were challenging. Stress and worry related to the care recipient's wellbeing and safety and fear about a future attempt were the most commonly referenced reactions. Additional emotions expressed were frustration, sadness and helplessness. Seven participants responded to this question in the context of themselves and their wider family, highlighting familial as well as individual emotions. The sense of stigma described by a few (5.81%) of participants was related to perceptions that either family members, workplace or others would hold negative views of their situation. Some participants (5.81%) described a sense of expectancy of suicide, which appeared to result from exposure to previous attempts, associated long term worry and anticipation of a future attempt at some point. Both hopelessness and hopefulness were mentioned by a small minority of participants indicating polarised emotions. A low number of participants (10.47%) referred to caring being rewarding at times. The multiple emotions experienced by participants are illustrated by the below quote:

Stressful …., the fear that a personal mistake may have tragic consequences, emotionally difficult to observe a loved one in physical or emotional pain …wary of hope but needing the energy to find it. A sense of pride when things go well that others do not accept/understand or value (Participant 72)

Most respondents to this question reported emotional responses that were concomitant with various of the other categories discussed below.

Category 1.2: Care Intensity (n=61/86, 38.37%)

Sixty-one (70.93%) of participants referred to the intensity of caring. Responses varied in terms of levels of care intensity. The predominant response was related to the constancy of caring (53.49%), for example the experience of participants own life being put on hold due to their caring responsibility with several commenting that their caring role was constant, relentless or never ending. Around a quarter of responses (25.58%) referred to the fluctuating nature of caring depending on the care recipients' mental health and level of suicidality. Unpredictability was commonly described in these responses suggesting that carers were often thrown into a more intense level of caring without warning. Some responses (19.77%) described feelings of pressure and responsibility increasing care intensity. Reasons for this included there being no one else to help with caring, a sense of being responsible because of the primary relationship, or due to the expectations placed on carers by mental health services. Difficulty balancing competing demands such as work and carers own needs with caring was noted by a few respondents (15.12%) and a minority (4.65%) reported that they had encountered work and financial difficulties due to the high intensity of their caring role.

Many responses demonstrated the interrelatedness of care intensity with other categories, for example the quote below indicates that ongoing caring had infringed on the participants life resulting in isolation (see category 4) and subsequently unhappiness and hopelessness (category 1).

I've given up my own life. I'm isolated and unhappy and I no longer have any hope that it will get better (Participant 85)

Category 1.3: Caring characteristics (n = 33/86, 38.37%)

Ten participants (11.63%) reported their caring role was dominated by a sense of walking on eggshells. This was due to the changeability of care recipients' moods and concerns that they might do or say something that would trigger a downturn or even a suicide attempt. Walking on eggshells was in cases linked to unpredictability and constancy highlighted in caring 1.2 above. This is elucidated in the following quote:

Nothing can be planned for certain. I often feel my life is not mine, even down to simple personal possessions and space in the house. I have to "walk on eggshells" quite often, so as not to rock the boat (Participant 76)

Hypervigilance, related to care recipient unpredictability and the emotional response of worry, was highlighted as a characteristic of caring by 14 (16.28%) participants. This was through words and phrases such as 'being constantly on edge', 'unable to relax', 'watching', or text alluding to being on constant alert. The tone in responses categorised as hypervigilance expanded on responses categorised as worry in that whilst they inevitably included worry and fear, the emphasis was on behaviour rather than solely thoughts.

Hypervigilance is a behaviour resulting from worry and fear. The quote below illustrates the behavioural tone of these responses:

*I have learnt that relaxing isn't an option- I am on edge constantly (*Participant 101)

A very small number of participants (n=3) mentioned self-care and learning as being specific to their caring role, that is, learning about their care recipient's condition and recognising the importance of self-care enabled them to sustain their caring role.

Category 1.4: Unconnected carers (n=33, 38.37%)

Thirty-three (38.37) responses described a lack of connection. This was due to a of a lack of support and understanding (26, 30.23%) and/or because of isolation and loneliness (16,18.60%). Lack of support was mainly perceived from mental health or healthcare services; participants reported inadequate support both for care recipients and themselves. The lack of understanding was from HCPs and social networks. Isolation and loneliness resulted from the lack of support and understanding as well as the demands and nature of the caring role. Feeling isolated and lonely was described as a mechanism of poor carer wellbeing (see category 5) as shown in this quote:

There is little or no help. I feel isolated, alone, scared for the future, depressed and pointless (Participant 99)

In addition, where participants had felt a need to put their life on hold, as noted in category 2, loneliness and isolation were also amplified. Two participants reported that the reluctance of the care recipient to engage with services perpetuated their sense of isolation. One response specifically mentioned stigma in relation to isolation and another reported lack of support and understanding from their employer. Overall, responses suggested that loneliness and isolation resulted from feeling alone, unsupported and restricted in the caring role.

Category 1.5: Carer wellbeing 33 (38.37%)

Responses suggested that the health and wellbeing of a sizable proportion of participants (n= 33, 38.37%) was compromised. Participants reported feeling exhausted and drained, either in general, mentally or physically, or sometimes both. Six participants reported mental health conditions that were caused or worsened by their caring roles and four reported the same with their physical health.

Effects on wellbeing were associated with the factors discussed in the categories above as illustrated by the following quote (elements of the quote which are linked to categories 1-5 identified in the content analysis are underlined).

*I feel a lot of <u>pressure to keep my partner safe</u>. It feels like I have to <u>constantly look for potential risks</u> to her mood because I am <u>afraid</u> that <u>anything can be the trigger</u> for a downturn in mood and that <u>could end in suicide</u>. **<u>This is exhausting</u>**. I try to encourage my partner to reach out to other people as well to support her emotionally but she does not trust others with her feelings <u>so this leaves me feeling alone in being responsible for her</u> (*Participant 62)

Summary

In summary the open question on the experience of being a carer yielded many rich responses that enabled quantification of prevalent issues which demonstrate the high demand on carers and the extent of impact caring for someone at risk of suicide can have. Overwhelmingly the experience is difficult with detrimental effects on day-to-day life and wellbeing. Caring for someone at risk of suicide is a huge worry and the intensity of caring can lead to isolation and reduced mental and physical wellbeing. Negative experiences related to caring are perpetuated by lack of support from healthcare services, particularly mental health services. Positive experiences were few but where these were noted they appeared to be linked to relational intimacy and the privilege of caring for someone who is loved.

4.1.8.2 Open question 2: What support do you think would help adults who care for adult family members or friends they think may be at risk of suicide?

96 of the 101 survey participants (95.05%) answered this open question. Responses were categorised into three levels: individual level (carer specific support); healthcare service level; and societal level. Each category is described below and numbers of responses linked to each category and subcategory are provided in table 19.

Table 19: Categories and subcategories related to the open question ‘what support do you think would help adults who care for adult family members or friends they think may be at risk of suicide?’

Categories and Codes	Total N = 96 N (%)
2.1 Individual level	N = 55 (57.29)
Information & education	25 (26.04)
Peer support	20 (20.83)
Listening/emotional support	12 (12.5)
Counselling/therapy	6 (6.25)
Practical support	3 (3.13)
Helpline 24/7	2 (2.08)
2.2 Healthcare services level	N= 49 (47.92)
Recognition & appreciation	29 (30.21)
Improved mental health provision for care recipients	19 (19.80)
Carer involvement in care	13 (13.54)
Respite	7 (7.30)
2.3 Societal level	N = 15 (15.63)
Financial	7 (7.30)
Increased awareness of suicidality and carers	5 (5.21)
Employer support	5 (5.21)

NB: the sum of the totals of each category exceed the number of participants who answered the question (N=96) due to responses covering multiple categories and/or sub-categories.

Category 2.1: Individual level (n = 55/96, 57.29%)

At an individual level, participants indicated that the most helpful support would be information and education, and peer support. Listening and emotional support, and counselling or therapy were also identified as being important. Some participants emphasised that tailored support was imperative i.e., support that is specific to those caring for someone at risk of suicide and geared towards their needs, for example the particular relationship they have with the care recipient. Practical support, (someone to look after care recipient but not necessarily professional respite) was identified by a few participants and two mentioned 24 hour helplines.

Category 2.2: Healthcare services level (n = 49/96, 47.92%)

The most common response in this category related to wanting HCPs and services to recognise and appreciate carers as being an important part of care recipients' life and care, and/or as individuals in their own right who would benefit from attention and support. The importance of involving carers in patient care was highlighted. Several participants reported that improved mental health provision for patients would result in carers feeling more supported. A relatively small number of participants noted that the provision or offer of respite care for care recipients would be beneficial.

Category 2.3: Societal level (n = 15/96, 15.63%)

Fifteen participants identified support needs beyond the scope of the mental health system. These included a combination of financial support namely benefits or funded therapy, increased community/societal awareness of mental health problems, including suicidality and the role of informal carers, and related, employer education to support carers in the workplace.

Summary

Generally, responses to this open question suggest that participants thought a systemic approach to support for carers is important. Responses indicate that individual carer needs are paramount, but to ensure these needs are met consideration of healthcare services attitudes and responses to carers, and wider societal mechanisms to support carers in their roles are required

4.1.8.3 Open question 3: What are your thoughts on your future caring role?

Ninety-five (94.06%) of the 101 survey participants responded to the open question asking how they saw their future caring role. Responses to this question were categorised into three categories; expectations, hopes and fears. The categories are briefly described below and table 20 shows a breakdown of categories and subcategories. Some participant responses (N=22/95, 23.15%) covered multiple categories and/or subcategories and thus the sum of the totals of the categories exceed the total of participants.

Table 20: Categories and subcategories related to the open question 'what are your thoughts on your future caring role?'

Categories and Codes	Total N = 95 Number of times the code was mentioned **N (%)**
3.1 Future expectations	**64 (67.37)**
Continuation (resigned)	22 (23.15)
Continuation (trapped)	15 (15.81)
Continuation (neutral)	12 (12.63)
Continuation (positive)	8 (8.42)
Continuation (increase in care intensity)	3 (3.16)
Continuation (reduction of care intensity)	2 (2.11)
Completed suicide as a possibility	6 (6.32)
Not wanting to look to the future	5 (5.26)
Contribution to healthcare service improvement	3 (3.16)
To end relationship with care recipient	1 (1.05)
3.2 Hopes for the future	**25 (26.32)**
Care recipient to improve/caring role to diminish	19 (20.00)
Primary relationship to become established	5 (5.26)
To end relationship with care recipient	1 (1.05)
3.3 Fears about the future	**N = 20 (21.05)**
Impact on carers health	11 (11.58)
Things won't get better	4 (4.21)
Completed suicide	3 (3.16)
Other	4 (4.21)

NB: the sum of the totals of some categories exceed the number of participants who answered the question due to responses covering multiple categories and/or sub-categories.

Category 3.1: Future expectations (n = 64/95, 67.37%)

Over two thirds of responses described expectations of the future. All but one related to protraction with the majority of participants reporting they expected to continue in their caring role. Of these only two indicated an expectation that the intensity of their caring role would reduce and three specifically stated that they expected intensity to increase. Around a quarter of responses referred to continuation in a resigned fashion, for example *"I do not have a choice"*. Several (15.81%) responses asserted or inferred that participants felt trapped by their ongoing caring role and a slightly smaller number (12.63%) suggested neutrality about continuation with comments such as "*I will always be a carer*". Eight responses (8.42%) implied positivity about the prospect of continued caring with comments indicating a sense of privilege or reward. Six responses included candid remarks about living with the possibility of suicide or expecting suicide to occur. Five participants reported that they chose not to look to the future. This appeared to be a strategy to enable them to carry on; by taking one day at a time. Three participants stated their plans to use their lived experience to contribute to service improvement in mental health services. A single participant reported an expected ending to their caring role because they intended to leave the care recipient, citing that the marriage had been destroyed due to their spouse's mental health problems and associated behaviours.

Category 3.2: Hopes for the future (n=25/95, 26.32)

Just over a quarter of responses to this open question included reference to participants' hopes. Unsurprisingly, most hopes were around the care recipient improving and participants caring responsibilities diminishing. Five (5.26%) participants specifically expressed their desire to relinquish their caring role so that they could re-establish their primary relationship with the care recipient. Three of these respondents were partners and two were friends. One participant reported their hope that they would be able to leave the relationship when the care recipient improved sufficiently (this was a different participant to that identified in the category above).

Category 3.3: Fears about the future (n=20/95, 21.5%)

Twenty (21.05%) responses to this question referenced fears about the future. The most commonly reported fear reported was the impact ongoing caring might have on participants own mental and/or physical health, with a couple of responses including aging as a fear due to the worry about who would then take on the carer role. A minority of responses (4.21%) mentioned fears that things wouldn't get better or that the care recipient would die by suicide. The few 'other' responses comprised single fears around relapse of mental illness, withdrawal of professional support, being the only person to care and being alone if the care recipient completed suicide.

Summary

Overall, the responses to the question regarding participants perspectives on their future caring role indicate that the majority of participants did not anticipate an end to their caring role, and many of these viewed the future with resignation or trepidation. However, nearly a quarter of those who answered this question also articulated hopes, suggesting that hopefulness might be an important enabling factor that mitigates fear and helps carers continue with caring.

4.1.8.4 Open question 4: Do you think the Covid-19 pandemic and the associated restrictions, such as lockdown and social distancing, has influenced your experiences as a carer?

The survey included two questions pertinent to participants' experiences during the COVID-19 pandemic; one closed question asking whether they thought that the pandemic and the associated restrictions, such as lockdown and social distancing, had influenced their experiences as a carer (yes, no, or unsure), and an open question asking participants to give reasons for their answer using free text. Most of the 101 participants (83, 82.18%) indicated that the COVID-19 pandemic and associated restrictions had influenced their experiences as a carer, 14 (13.86%) reported that it had not had an impact, and four (3.96%) were unsure. 93 respondents (92.08%) completed the open free text question asking for details about the impact of the pandemic. Results are presented in table 21.

Table 21: Categories and subcategories related to the question do you think the Covid-19 pandemic and the associated restrictions, such as lockdown and social distancing, has influenced your experiences as a carer?'

Category	Total N = 93 N (%)
Loss/reduction of mental health supports	46 (49.46)
Isolation/Loneliness	25 (26.88)
Increased care intensity	22 (23.67)
New or worsening mental health problem	16 (17.20)
Lack of/reduced contact with family or social network	12 (12.90)
Prohibiting carer respite and lack of carer privacy	8 (8.60)
Made no difference	9 (9.68)
Positive impact	7 (7.53)

NB: the sum of the totals of each category exceed the number of participants who answered the question due to responses covering multiple categories and/or sub-categories

Multiple factors were coded for 38 (40.86%) participants and often these factors were interrelated as shown in the descriptions below.

Category 4.1: Loss or reduction of mental health supports (N=46/93, 49.46%)

Participants reported a loss or reduction of mental health supports both for the person they cared for and themselves. These supports included statutory mental health services, general practitioners (GPs), counselling services and support groups. Some participants referred to reduced visiting to inpatient wards and suspended leave for inpatients. The reduction in support was linked to the remaining categories as seen below.

Category 4.2: Isolation/loneliness (N=25/93, 26.88%)

Most responses highlighting isolation and loneliness reported that this resulted from being alone with their care recipient without access to support from services and because of lack of face-to-face contact with friends and family. Isolation of the care recipient was also noted as a problem for some participants.

Category 4.3: Increased care intensity (N=22/93, 23.67%)

Participants reported that the lack of professional and familial support combined with being alone with their care recipient for greater periods of time, in some cases managing deteriorating mental health, exaggerated existing difficulties and increased pressure.

Category 4.4: New or worsening mental health problems (N= 16/93, 17.20%)

Responses referring to deteriorating mental health related mainly to care recipients, but three respondents wrote about their own emotional or mental health difficulties. Lack of access to support and social networks, and isolation due to COVID-19 restrictions contributed to problems with mental health.

Category 4.5: Lack of/reduced contact with family and social network (N=12/93, 12.90%)

Reduced contact with family members as a result of lockdown restrictions led to some participants finding it difficult to go and see care recipients who did not live with them and others not being able to access practical or emotional support from their family or friends. Some of these responses suggested that family was the main source of support for the carer and lack of contact with them increased care intensity.

Category 4.6: Prohibiting carer respite and lack of carer privacy (N = 8/93, 8.60%)

Prohibiting respite relates to statements that restrictions meant participants got no time away from their care recipient to focus on themselves, and lack of privacy arose from participants noting the difficulty they had talking to family, friends or other supports over video technology or the telephone due to concerns that they may be overheard by the care recipient.

Category 4.7: Made no difference (N = 9/93, 9.68%)

Nine participants stated that the pandemic had made no difference to them, with three of these reporting that services had already been difficult to access prior to the introduction of COVID-19 restrictions.

Category 4.8: Positive impact (N = 7/93, 7.53%)

Seven (7.53%) participants reported that the impact of the pandemic restrictions had been positive because they were more available to their care recipient (n = 5, 5.38%) or due to the fact that their care recipient's mental health improved (n = 2, 2.15%).

Summary

This category shows that the COVID 19 pandemic added to the problems already faced by carers. In particular participants experienced reduced access to healthcare and social support, increased care intensity and isolation due to lockdown restrictions and being more alone in their caring role. New problems faced were reduced opportunities to get time away from care recipients and lack of privacy due to reliance on remote communication with supports.

4.1.9 Section Summary

In this section the survey data analysis has been presented. This has involved a description of the sample, quantitative data analysis of AC-QoL and STOSA data and summative content analysis of qualitative data from the open questions. The next section moves on to the results of the qualitative data analysis of the semi structured interviews.

4.2 Semi-structured interviews

This section presents the themes from the qualitative semi-structured interviews. Fifteen interviews were conducted over a 14-week period. The aim of the interviews was to obtain more in-depth information on the topics that were covered in the online survey. One overarching theme named 'entering and adjusting to a different and uncertain world' was identified, with four additional and interrelated themes; blurred identities and relationships; isolated in an uncertain world; constant worry in the midst of fear and uncertainty; and in for the long haul. In addition to the main themes, participants perspectives on the impact of the COVID-19 pandemic on their caring experience are presented. Data related to the pandemic was analysed separately to understand whether COVID-19 had impacted participants' usual experience of caring and because there was insufficient data to generate a specific theme.

4.2.1 Participant characteristics

Key participant demographics and characteristics are shown in table 22. Of the 15 participants 13 were female, one was male and identified as one non-binary. Ages ranged from 29 to 74 years with a median age of 54 years. Thirteen participants were White British, one mixed White and Asian and one White Irish. Most participants lived in the South of England; six in the South East, five in the South West and one in South Central. One participant lived in the North East, one in the North West and one in the East Midlands. Seven participants were mothers, four of daughters and three of sons. In three of these seven cases the care recipients had developed suicidal behaviours in adulthood with the remaining four having first presented with suicidality during adolescence. Participants who were partners (n=5) had met the care recipient as an adult. One of two daughter caregivers became a carer as an adult whereas the other had been a carer since her teens. The single grandmother participant was caring for her adult granddaughter whose mental health difficulties and suicidal behaviours had started in her early teens.

Eight participants lived with their care recipients and two others had cohabited until fairly recently. The care recipient of one participant had taken his life between her completing the survey and participating in the interview (see the ethics discussion in chapter 3).

All participants stressed that it was very difficult to give a tangible figure for the number of hours spent caring due to the fluctuating levels of care recipient need and thus care intensity. Estimates of hours spent caring over the last few weeks (the bereaved participant was asked to think back to the weeks before her son's death) ranged from under 10 hours to over 71 hours with a median range of 21-30 hours caring. Participants had been caring for between 1 and 18 years with a mean of 7.3 years. An overview of the participants along with reflective notes completed following interviews can be seen in appendix 3.8.

Care recipients, nine female and six male, were between the ages of 18 and 77 years. All had a history of suicidal behaviours (as noted above, one was deceased by suicide). Ten were under current care of mental health services (the deceased care recipient had been in contact at the time of his death) and the remaining five had been in receipt of services in the recent past.

Table 22: Key demographics of interview participants

Participant pseudonym	Age (years)/sex/ethnicity	Relationship to care recipient	Sex/age range of care recipient (years)
Alison	64 - F, WB	Mother of son	Male 8-24
Betty	59 - F, WB	Mother of daughter	Female 25-34
Carol	29 - F, WB	Daughter	Female over 55
Dot	52 - F, WB	Spouse	Male 45-54
Ewan	60 - M, WB	Spouse	Female 45-54
Fiona	74 - F, WB	Grandmother	Female 18-24
Grace	57 - F, Mixed	Mother of daughter	Female 18-24
Hatty	55 - F, WB	Mother of daughter	Female 25-34
Irene	54 - F, WB	Mother of daughter	Female 25-34
Jane	42 - F, WB	Daughter	Female over 55
Kay	49 - F, WB	Mother of son	Male 18-24
Lucy	50 - F, WB	Partner	Male 45-54
Mae	68 - F, WB	Mother of son	Male 35 - 44
Nancy	38 - F, WB	Spouse	Female 35-44
Noah	51 - Non binary, white Irish	Spouse	Male 40-54

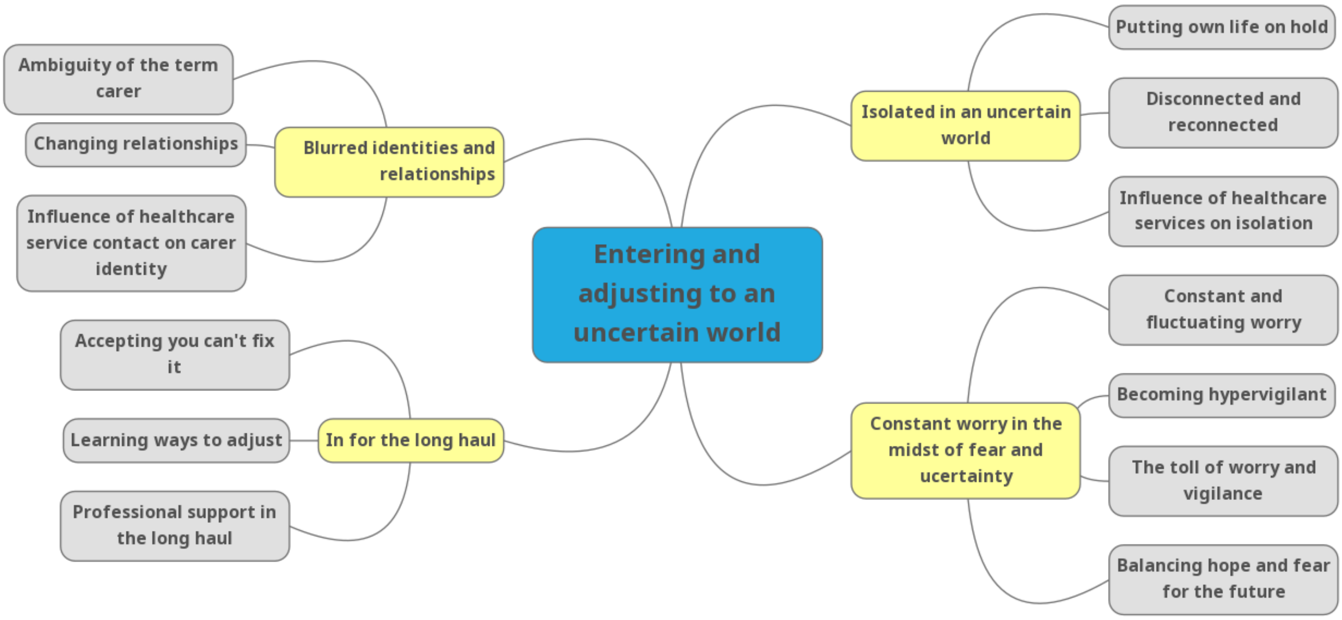
Key: M = male, F = female, WB = white British

4.2.2 Overarching theme generated from reflexive thematic analysis

From the thematic analysis a central overarching theme **'entering and adjusting to a different and uncertain world'** was identified. Participants narratives reflected a sense of being in a different world to the one they had inhabited before their care recipient developed suicidal behaviours; a world which was characterised by uncertainty. Descriptions portrayed this uncertain world as poorly understood by others including healthcare services and professionals.

Four themes depicting the carers trajectory within their uncertain world were derived from interview data: blurred identities and relationships; isolated in an uncertain world; constant worry in the midst of fear and uncertainty; and in for the long haul. The themes are inherently connected, for example, blurred identities and relationships may occur before realisation of living with the long haul, however identity is dynamic and further shaped by and throughout the long haul. Each theme has associated sub-themes as illustrated in figure 5.

Figure 5: Central overarching theme of 'entering and adjusting to a different and uncertain world' with four themes and 13 sub-themes



4.2.3 Theme 1: Blurred identities and relationships

Participants experience of caring and their identification with the carer role was influenced by the quality and intimacy of their relationships with care recipients. At the same time, their relationships were influenced and altered by care recipients' suicidal behaviour and the need for participants to take on a caring role. These influences varied according to the type of relationship. Some commonalities were present across parent, partner and child participants, particularly a difficulty defining, and in cases accepting, the carer role. Experiences with healthcare services contributed to participants perceptions of and reconciliation with their carer identities. Exchanges with service providers were often antagonistic, which resulted in tensions and a somewhat combative informal verses professional carer stasis. Where experiences were more positive, participants felt seen in the context of their relationship with the care recipient rather than through an externally imposed label of carer

This theme has three subthemes; ambiguity of the term carer; changing relationships; and influence of healthcare service contact on carer identity.

Subtheme 1: Ambiguity of the term carer

Although acknowledgement of a caring role was implicit through engagement with this research, the role was difficult for participants to define due to the fluctuation of mental health problems and suicidality and thus the need to provide care. Participants found it difficult to distinguish the role because of the lack of tangible and regular tasks such as those that might be necessary when caring for someone with dementia or physical health issues. Furthermore, not all participants lived with their care recipients, making the role even harder to define. Trying to determine the amount of time spent caring was particularly difficult as the carer role tended to blur into the main relationship. This was illustrated by Irene who found it difficult to delineate her mother and carer identities:

I think it's hard to define what actually what falls under being a carer, what falls under that definition and, you know, I could be doing anything from providing telephone support to picking up the pieces to you know just cooking meals or, I don't know, literally could be anything …. accompanying to appointments or…. So it can sometimes be really hands on, full on, and sometimes it can be what you'd think of just being like another family member so it's hard to pull apart what's my caring role and what's my mum role **Irene, mother**

Even when caring was experienced as constant rather than fluctuating it could be hard to define because it could be merely a presence, but that presence was fundamental to the care recipient's wellbeing and safety. Betty described this as supervising:

Yeah most of my waking hours. It's that funny thing because mostly I'm not actually doing anything, I'm just supervising **Betty, mother**

Some participants expressed dissatisfaction with the term 'carer', finding being seen as a carer rather than by their primary relationship uncomfortable. Lucy seemed to find the term carer somewhat insulting, feeling that it undermined the holistic nature of her relationship wherein she dealt with whatever challenges she encountered as part of that relationship:

I don't feel like I'm his carer I feel like companion-partner. I would do that for any partner, I have done it for any partner regardless of their mental health or physical disability. So when people go oh, you're a carer, I'm like I don't feel like I'm a carer I feel like I'm supporting him like I would my children or my parents **Lucy, partner**

Some participants described a sense of imposition of the carer label. Grace saw it as a reductionist classification rather than one which captures the complexity and nuance of caring for a family member with fluctuating needs. Her narrative suggested a sense of coercion by the NHS system, reflected by her conceded acquiescence to the term carer due to accepted NHS nomenclature despite her dissatisfaction with the label:

I find that the term carer, particularly in mental health, a little bit patronising and, and I only use it because that's the terminology used in the NHS….. I really think there needs to be a huge distinction between mental health, caring and old age care, dementia caring, physical, because it's, it is different **Grace, mother**

Grace's view that the carer role in relation to mental health requires clarification is supported by the experiences of six participants who talked about carer assessments. Five of these reported that carer assessments came to nothing and it was evident that if carers were judged by professionals to be coping well, no support was offered. Irene reflected that judgements of what constituted caring seemed to be based on physical caring demands rather than the more subtle emotional acts of care, or indeed the consequences of caring:

I was deemed not to be doing enough caring hours to be eligible for anything so again it's that ridiculous thing, how do you define caring hours, do you define the hours that I spend worrying or not being able to sleep because of… I don't know, that's why I think it's all a bit just, why it's so much more geared towards supporting someone with a disability or dementia where its more visible **Irene, mother**

Some participants were agreeable with elements of the NHS interpretation of the term carer because it has a certain amount of utility, although this utility was generally unspoken and unrecognised outside of the NHS milieu. For example, Jane's quote below illustrates how being registered as a carer grants certain rights within healthcare, but Noah's shows how the invisibility of caring for someone who isn't obviously disabled or in need means these rights are difficult to express elsewhere.

Because I'm a registered carer now for my mum I will say that recently when we've been going on trips to the hospital, for example, they say only one of you can come in here. But if I say I'm actually a registered care, then they're okay for you to come in so I will use it the, but

I wouldn't describe myself to anyone really as a carer in just general conversation **Jane, daughter**

I do know that if he is going somewhere and I'm going as his carer then I should get in for free, but I've nothing to prove, you know, you walk up as a couple and say well I'm his carer they'd be like you're his wife. It's hard to know how to evidence **Noah, spouse**

One participant linked the ambiguity of the term carer to availability of workplace support, sharing her experiences of the inadequacy of standard workplace carer policies which failed to recognise the complexity of caring.

I think in terms of caring support for any organisation that I've ever been at it's incredibly poor because people … just lump it in with sort of parents, like anything that works with parents will work for carers and it's, it's not the same ……. so I find that very difficult to navigate **Carol, daughter**

Notwithstanding the overall sense of frustration with the term carer, participants could not think of a suitable alternative. In the absence of such an alternative, for some participants the term at least reflected that what they did for care recipients was over and above what would be considered usual:

I don't mind the term because in some respects, you know, yes, I was his mum but actually I was caring, you know, if I wasn't there he relied on me for, for everything **Kay, mother**

In summary, participants narratives strongly conveyed that defining caring in the context of mental health and suicidality is complex and accepted carer labels and norms do not fit with the oft intangible nature of caring for individuals with fluctuating and invisible needs. Indeed, accounts suggest that the current classifications of caring serve professional systems rather than the population they claim to support.

Subtheme 2: Changing relationships

Participants identities and relationships with themselves and their care recipients changed as they experienced behaviours, situations and responses they hadn't previously encountered. Some recalled feeling naive when they were first exposed to suicidal behaviours, experiencing shock and uncertainty. This brought a new dimension to what had been viewed as a familiar relationship as illustrated by Grace's comment:

When she started self-harming that was a shock for me, I hadn't ever experienced that in my life… never in my own personal life had I met anybody who'd self-harmed…. it wasn't in my vocabulary when she started doing it **Grace, mother**

Being confronted with the suicidality of their loved ones resulted in some participants questioning themselves and their previously held assumptions about their primary relationship with the care recipient. Irene for example reflected on how her preconceived ideas around parenting were challenged:

You suddenly realise that this is something that's taken over your life, yeah, something you didn't really ask for, something you didn't really sign up to, it isn't part of the normal parenting process **Irene, mother**

Challenged relational assumptions could be painful for participants. Nancy asked herself why she was not enough for her partner to want to stay alive for but didn't allow herself to dwell on the question because of the underlying hurt. She was even tentative with her disclosure:

You know I don't want to go into the light but, you know, am I not enough, you know, and all that but, you know, I'm always going to get a little bit of that, you know, really **Nancy, spouse**

As well as changes within carer/care recipient relationships, altered dynamics were sometimes present within the wider family. This was particularly evident with the two daughter participants who recalled familial expectations that they adopted the caring role. Jane considered that this was to do with gender-based assumptions about caring being implicit within the female identity:

I think there has always been a bit of an unspoken, unacknowledged assumption that I will deal with it and maybe that it's easier for me because I'm the only girl and that sort of thing **Jane, daughter**

Carol had a similar experience of unspoken expectations of male siblings, which she didn’t specifically attach to her being female, but which may nonetheless have stemmed from gender stereotyping.

…both my brothers have families and I don't have a family. I don't have children and I'm not married but I do have a long-term partner and I think the thing that has sort of altered our relationship is the underlying, like, how we value those things. So sometimes there'll just be an expectation that I can step in and it's, like, well you have, you know, fair enough like you have kids, you have your own family but hang on, like, don't I have people who, you know, I choose to consider my family and equally I didn't, I don’t not have children in order to be able to do this **Carol, daughter**

Notwithstanding changes within relationships there was implicit and explicit acceptance of the carer role amongst participants underpinned by relational values and commitment to the care recipients. Comments such as “*it is what it is*” were relatively common throughout the interviews. The single male participant, Ewan expressed resigned acceptance of his lot:

It’s just one of those things you’ve got to get on with int’it really **Ewan, spouse**

Ewan’s acceptance stemmed from the longevity of his caring role throughout much of his marriage, with his part in the relationship being largely defined by the need to care for his wife. Similarly, Jane grew up caring for her mother and identified that her mother-daughter relationship was re-defined at a young age and had never returned to a conventional dynamic.

It feels as if it’s just grown as I’ve grown up really. It probably started when I was around 13 or 14.……. I think it changed into at points almost doing a complete flip to obviously me being in more of a parental role sometimes. I don't think it’s ever really gone back to what you might call a normal mother-daughter relationship **Jane, daughter**

Thus, long term caring responsibility blurred into the primary relationship and separating caring out was not really possible or necessary for participants who had built their lives around caring. Where participants had been caring for shorter lengths of time, or where they had experienced longer periods of their care recipient before mental ill health and suicidality, they sometimes floundered between their caring role and her original status in the relationship:

I was still really struggling with like, was I a carer or was I, you know, was I just going back to being a daughter? Like, do we just forget that the last, you know, I was, I was struggling with that **Carol, daughter**

This floundering resulted from the fact that once suicidality entered the relational equation it didn't exit, it couldn't unhappen, and participants had to adjust to this reality rather than return to life as it was before. This could be challenging from both intrapersonal and interpersonal perspectives. Mae for example understood her adult son's need for autonomy, but she wasn't able to extend complete trust due to his previous suicidal behaviour and her internal fears that this would reoccur:

He somehow feels that I shouldn't be, which I can see his point in a way, sort of saying you don't trust me but I don't to be honest **Mae, mother**

Parent participants whose children had developed mental health conditions and suicidal behaviours as adolescents or young adults exhibited an air of intransience rather than the floundering described by parents whose care recipients became suicidal later in life. This was perhaps because they hadn't experienced the taken for granted light-hearted aspects of the parent/child relationship as their child grew into adulthood due to the need to prioritise mental health and safety. Where lengthy hospital admissions had been necessitated the relationship was further changed because the parent became a visitor to an environment they did not share with their child and of which they were not custodians. Irene was wistful about her loss of what she perceived a normal mother/daughter relationship to be, but she was also open about her uncertainty as to what such a relationship would be for her.

Sometimes I feel like I would love to just be her mum but its been so long since I've been able to just be her mum that I almost don't know how to do that anymore….. it's not your average mum and 28 year old daughter relationship, it's a very different relationship, because of the nature of what's happened to her….. the more social I suppose friendship or just doing stuff together has not been an option for so many years because she was in hospital for such a long time so it changes the nature of that relationship quite drastically **Irene, mother**

It was important for Irene to accept the difficult idiosyncrasies of her relationship with her daughter so that she could sustain the relationship. Related, for Grace, a core part of her transition to a parent of an adult child was to accept her limitations in preventing her daughter's suicidal behaviours:

I have to learn to accept that my daughter may pass away at any point by her own hand and, that is her choice. And if that is, if that's something she wishes to do, it, it's nothing to do with me. Do you know what I mean? And that, when in one way that puts kind of a, it, it was kind of a severing when I got to that point in my life when I had to accept that, that there was a, okay, it is like the, the invisible, umbilical cord between a mother and child which is how emotionally I had to sever it. I had to go, okay, I had to let her go because I can't hold her in the universe. It's her job now to hold herself in the universe. I have to trust she wants to stay alive and if she doesn't that's her choice too and that's a, a pretty weird place to be as a parent, a hard place to get to. And every now and again that still hurts but, you know, it's, it's a reality I have to live with **Grace, mother**

Grace had to learn to trust that her daughter wanted to stay alive, despite how difficult that was for her, whereas the earlier quote from Mae conveyed that she didn't feel able to trust her son's assertions of the want to live. Grace's ability to pass on responsibility for living was linked to her daughter becoming an adult after numerous suicidal episodes throughout her teenage years. Mae's son became suicidal as an established and independent adult, and thus Mae was faced with a phenomenon completely out of synch with his life up until that point. Mae was struggling with trust because her expectation or aspiration was for her son to return to how he used to be before suicidality, whereas Grace was waiting to see who her daughter would become after her childhood suicidal years.

Partner participants expressed commitment to the standard relationship norms of taking care of their partners in sickness and in health but the need to preserve their partner's safety added a new dynamic. They couldn't unburden to their partners about their own feelings and responses and thus lost their usual confidant[e]. The disintegration of reciprocal partnerships, even when this was not permanent, suggested a somewhat lonely state, indicative of the uncertain world of caring wherein relational dynamics were not conventional:

I couldn't necessarily talk to him about how I was feeling and the impact of his illness ..... we pretty much kind of rubbed along like two strangers but living under the same roof. And I suppose you do detach more as a husband and wife and it then becomes carer and, you know, patient type thing that that's how your roles change **Dot, spouse**

Dot's experience of detaching as husband and wife was echoed by Noah who noted how caring could at times overshadow the rest of the relationship and the equilibrium therein:

Whenever things are really acute for my husband it's really hard to remember that there's a romantic relationship there and a whole other relationship other than caring. **Noah, spouse**

Partner participants were generally more concerned about their caring behaviour threatening relational equity as opposed to the care recipient's suicidal behaviour being the threat. For example, Nancy said *I don't want to imbalance our relationship* and talked of her discomfort when she had needed to implement safety measures. Nancy's internal questioning *am I not enough* [for her partner to stay alive for] suggests that the relationship was already imbalanced by her partners suicidal behaviour, however, Nancy's narrative suggested it was easier to focus on imbalances which could be attributed to her own caring behaviour rather than those which were emotionally situated with her partner. This was perhaps because she was able to exert an element of control by adapting her behaviour, which she couldn't with regard to her partners perception of reasons for living.
Balancing care recipients' autonomy with the need to offer care could cause friction for partner participants both interpersonally as described by Noah, and internally as suggested by Lucy:

He's like, you know, I'm a grown man and I have autonomy over myself and that can be really hard because you're, like, but you didn't yesterday or you didn't this morning, this morning you needed me to come in show you…and select which pot you're going to cook your lunch in and now you're complaining at me for trying to ensure that you've got support in place when you've got to make a difficult phone call **Noah, spouse**

I feel like sometimes I need to be with him 24 hours a day to keep an eye on him. But then I'm, like, he's an adult and he can make these decisions. I do want him to understand and I do want him to be able to manage himself. Sometimes I think maybe he relies on me a little bit too much, so should I step back? **Lucy, partner**

Although some tensions or uncomfortable interpersonal and intrapersonal dynamics were described by participants, there were also expressions of enriched relationships as a result of being together throughout care recipients' suicidality. This was in some cases due to the amount of time spent together and the openness and transparency of the relationship, as illustrated by Carol:

Me and my mum have a better relationship now than we've ever had…… I speak to my mum more now than I ever used to and obviously a big driver of that is there's 90% of my brain that's on those zoom calls looking for any sign of there's something wrong, you know, but the 10% is like, you know, my mum as a person I enjoy speaking to, you know, we have very similar opinions about things and when we can have those conversations that's lovely and actually we didn't, she certainly didn't, I didn't share as much about my life with her before because just because we didn't speak **Carol, daughter**

For some participants, rewards were reaped from caring. For example, Dot talked of enjoying caring when she could see how her support had been of benefit:

I think the most rewarding part is me trying to help [care recipient] *build strategies, build tasks that I knew was helping him, that I knew gave him a purpose that got him up out of bed every day* **Dot, spouse**

Narratives associated with this subtheme inferred patterns, or cycles, which determined whether participants needed to adopt carer or more conventional roles. However, there were no reports of things getting back to what was once 'normal' during phases of care recipient wellness and uncertainty about future suicidal behaviour was ever-present. This emphasises the adjustment to a different and uncertain world, as opposed to leaving it behind. For all participants, regardless of their relationship with their care recipient, once suicidality became part of the equation, it wasn't possible to return to a relationship without it.

Subtheme 3: Influence of healthcare service contact on carer identity

Participants first contact with NHS mental health services generally occurred when (or shortly before) their care recipient first engaged in suicidal behaviour and they first adopted their carer role. In this context, some participants described an initial desperate faith in and reliance on services in response to their own sense of fear and helplessness. They believed that services would help their loved one and help them as carers understand what was happening. Their assumptions and expectations were that services would be supportive to them as carers, but these expectations were frequently unmet as illustrated in Hatty's quote below:

It was my first, her first experience, my first experience of mental health treatment and I fully believed and trusted that what they were doing was the right and allowed even though deep in my heart I could see the treatment that was going on and knew it was wrong, that sixth sense, because I knew nothing about mental health at the time I let it go on because I believed they were the experts and it took six months for me to then stand up and say no this stops now **Hatty, mother**

Negative early encounters such as Hatty's resulted in the initial desperate faith in services morphing into distrust which for some participants, such as Grace, exacerbated their fear and affected their ongoing relationships with professionals

I became very frightened because I didn't trust anybody and that's not how I went, felt going in, I was desperate to trust but the level, the competencies of the staff I met did not make me trust **Grace, mother**

Participants perceptions of themselves as carers were shaped by these early experiences and several used the metaphor of being in battle when describing their interactions with services, particularly when advocating for their care recipients. For some, like Dot, the first battle was trying to get over the threshold of mental health services.

So there was a, you know, a spiralling crisis happening but it was a battle to get to get that help **Dot, spouse**

Mechanisms for diminishing trust included perceived early promises from professionals not materialising:

We both saw a doctor, whoever he was, psychiatrist thing, in July. And that's been it. And he said, oh, we'll get the team together next week and decide whether you stay with my team or we put you into the community with, with the community care team and that's been it, not heard anything, not heard, whether she's with what team or other **Fiona, grandmother**

Even when early engagement with services had been achieved**,** participants voiced frustration due to difficulties getting attention from services outside of fixed appointments, having to repeat their story often multiple times and with each encounter, and because little was forthcoming in terms of actual patient care. Mae, for example found the constant stream of different professionals unhelpful because of the inconsistent approach, with 'good' professionals not being matched by subsequent staff.

And they did come to see him for a few days after that but it was never the same person twice…..some of them were absolutely brilliant and one guy was really, really good but the others were not much use at all **Mae, mother**

Positive experiences of first contacts with healthcare services were not forthcoming from participants in the interviews. This may indicate that they did not occur or that helpful experiences were not recalled because they were overshadowed by more negative encounters. However, it is clear that where participants socialisation into mental health services was negative, the resulting lack of trust and the feeling of going into battle caused relationships with care providers to become strained at an early stage, sometimes irreparably.

Theme Summary

The theme blurred identities and relationships depicts the difficulties with defining the role of a carer of someone at risk of suicide due to the invisibility, complexity and nuance of the role. Difficulties with definition do not mean there isn't a caring role, but that the role is one which blurs into the pre-existing primary relationship, leading to interpersonal and intrapersonal changes within that relationship. Initial interactions with mental health care services contribute to shaping carers understanding of their carer role and where these are problematic carers experience a sense of being in combat to optimise care and safety for their loved ones.

4.2.4 Theme 2: Isolated in an uncertain world

All participants voiced feeling in some way isolated and disconnected in the different and uncertain world of caring for someone at risk of suicide. This was due in part to the allencompassing nature of caring, in part because of difficulty sustaining social networks, and in part as a result of stigmatising or ostracising experiences, particularly with mental health services. Subthemes for this theme are putting own life on hold; disconnected and reconnected; and influence of healthcare services on isolation.

Subtheme 1: Putting own life on hold

Participants frequently had to prioritise the care recipient and put their own lives on hold, which meant they were disconnected from usual routines and people. Those in employment continuously juggled caring and work, sometimes needing to take time off work, and little or no time was left for themselves outside of these two commitments. Activities that participants enjoyed were often not possible as noted by Dot who described her caring situation as a stranglehold:

I became that sole carer, the restriction of not having time to myself, not having a life for myself, having to give up the things that I enjoyed, that was really difficult…… So yeah, a bit a stranglehold for, I would say probably about a year, year and a half **Dot, spouse**

Whilst participants in the main talked of their individual responses and experiences, the lives of other family members were also restricted in some cases, particularly those of other children. Kay and her daughter had to give up things they had previously enjoyed together because her son's needs monopolised Kay's time:

Myself and, and my daughter had quite restricted lives as a result of [care recipient's] *illness. And that was, you know, not having people back, not being able to go, you know, like we used to go to* [city] *and we couldn't do that because* [care recipient] *wouldn't come because he wouldn't leave his room* **Kay, mother**

Some participants alluded to foiled future plans and aspirations. Kay shared her perspective that when she was caring for her son, she believed she was unlikely to travel or have a romantic relationship because she couldn't leave him and no one would want to take her on with the caring responsibilities she came with. Similarly, a number of participants reported that they no longer made plans because of the unpredictability of their care recipients and their past experiences of plans being thwarted. Alison's longstanding plans with her husband were largely put on hold when her son moved home after a suicide attempt:

We had a nice kind of almost retirement nest, you know, where I'm still working but my husband's semi retired so we do what we like with our own time and things like that. And we still do to some degree but if you've got someone in that place mentally 24/7 it does have an impact you know **Alison, mother**

The cyclical nature of caring described by several participants meant that putting life on hold was not permanent as illustrated by Nancy's quote below, although temporality of cycles varied with some participants reporting sustained periods where caring intensity was high.

It takes over and I have to take time off work and I have to cancel everything and I feel as, yeah I suppose it's like a black hole over, you know, certain periods of time **Nancy, spouse**

Most participants asserted that they did not resent their lives being dominated by their caring role because the wellbeing and safety of the care recipient was paramount. This was particularly evident within parent carer/child care recipient dyads wherein participants held an unconditional stance towards their care recipient, especially when onset of suicidality was during adolescence or young adulthood:

I don't really have a life….. I work full-time …… and when I finish work I'm with her and then most of the weekend I'm with her…... I'm not resentful of that, it's the way it is and I would do absolutely anything for her **Hatty, mother**

However, one daughter participant, Jane had over time acknowledged that she did harbour some negative feelings about the restriction caring for her mother had placed on her life over many years.

I only really understood and acknowledged that a couple of years ago that there's quite a lot of anger and resentment and a feeling of not being quite in control of my own life because of various restrictions and things. So, it's been quite difficult at times **Jane, daughter**

Similarly, Noah expressed feeling '*held to ransom*' by their care recipient's vulnerability because they were conscious that by releasing themselves from putting their life on hold and leaving the relationship, they may increase the chances of their care recipient ending their life:

It’s a matter of is it worth staying here because of everything else I get from the relationship or is that fear and the potential of it happening again too much…. And then you also get the ‘well I can’t really make that decision easily’ because if I was to go away he’s in a place where that might be the end of him…. **Noah, spouse**

The sense of putting their own life on hold was experienced by the majority of participants with most being accepting of this outcome but a minority harbouring feelings of frustration and resentment. Putting their lives on hold meant that participants could feel disconnected from the life they once knew and isolated in their caring roles in which they needed to prioritise their care recipient. Isolation and disconnection are explored further in the next sub-theme.

Subtheme 2: Disconnected and reconnected

Some participants shared their view that having a family member or partner who engages in suicidal behaviour is a situation unfathomable to those not in that position. This exacerbated the sense of being in a different world and made it difficult for participants to connect socially with peers who did not share their milieu of uncertainty. Subsequently participants spiralled into an isolated existence as described by Betty:

I mean, it's nothing like anyone would recognise I don't think. It is very hard for friends, I have very few friends left because it's just so boring and so depressing and it's difficult to socialise……. you can't really say so, oh yeah, my daughter's attempted suicide 35 times because it tends to put a bit of a blight on the conversation really……. But yeah, you can't talk about the most important thing in your life **Betty, mother**

Participants had lost friends particularly where their situation had been long term. In cases this appeared to have been self-withdrawal because of a sense of no longer fitting in rather than intentional rejection by social networks. Most participants did have someone they could talk to or at least someone they knew would make themselves available for them should they want to talk, but having access to a possible confidant(e) did not always eradicate isolation. The awareness that peers were unlikely to be able to comprehend the situation or would respond with platitudes resulted in some participants not confiding in family or friends.

I found relationships with family and friends very difficult because, I would get a lot of platitudes or a lot of misunderstanding or a lot of unhelpful advice. So you do, I found myself quite isolated very quickly **Grace, mother**

Some participants also found it difficult to relate to people in supposedly supportive fora such as generic carers groups. To be genuinely helpful, peer support needed to be with peers that inhabited the same uncertain world as participants. When participants were able to meet with others in similar positions, they were able to regain a sense of connection within their uncertain world.

And it is just being able to talk to somebody who knows… I used to go to a coffee morning with the retired people that I used to work with. I could not sit and talk to them in the same way as I can talk to the support group… because they have absolutely no concept of what I'm talking about, whereas the support group know exactly what I'm talking about **Mae, mother**

Generally, participants were very accepting of the fact that those not in their world struggled to understand it and did not automatically equate a lack of awareness or understanding to stigma. For example, Irene reflected that it is reasonable that people who are not grappling with issues such as self-harm don't understand it.

I think it's understandable that people don't understand, why should they? You know, I would have been one of those people who didn't understand. I don't have a problem with that, I don't have a problem with the fact that people don't get it particularly things like self-harm, it's like why would you get it? **Irene, mother**

However, some participants had experienced stigmatised responses from family or friends, either towards themselves or their care recipient. For instance, Lucy detected negative attitudes towards her for making a choice to be with someone who made suicide attempts in the context of mental health problems.

His sister said, are you with him because it's a project? You think you can fix him? My family and friends are a bit like, oh, he's got mental health issues they're never going to go away, why would you want to be with someone like that? **Lucy, partner**

Self-stigmatisation was expressed or inferred by some participants whereby they did not talk to people for fear of judgement. Carol was aware that others in her social network did not have parents who struggled with suicidality and this stopped her from talking about her experiences.

I just didn't talk about what's going on with my mum because I just didn't, I was, I was probably embarrassed and a little bit ashamed and I didn't know how to talk about it, like I didn't, I had this huge black cloud in my head which was what if my mum tries to hurt herself, like what if she dies, and it's, you know, and I had such a stigma around it **Carol, daughter**

These experiences or perceptions of stigma perpetuated participants' sense of isolation and disconnection. In several cases, work was experienced as somewhat of an antidote to isolation because it gave participants an identity different to that of carer and offered a means of socialisation and thus connection:

I think for me, my saving grace was work because I had a different focus **Dot, spouse**

Three participants, at the time of interview, were employed in expert by experience positions, drawing on their experiences as a carer to train clinicians and support other carers. A further participant worked in the voluntary sector as a result of suicide related lived experience, and another had established an online support network specifically for carers in a similar position to their own. Thus, five of the fifteen participants had taken on paid or unpaid roles specific to their experience of being a carer of someone at risk of suicide. This quasi-professionalisation of their lived experience helped participants feel that they were able to help others beyond the person for whom they were caring. This seemed to help them justify their caring role and regain a sense of connection which they had lost when they had first entered the new and different world of suicidality and caring:

And I guess a very selfishly part of setting up that network is to create a very small space where, you know, for people who understand that kind of worry **Carol, daughter**

Furthermore, working in lived experience positions helped participants find a sense of meaning and growth from their circumstances, which helped them to reconcile with their difficult and painful experiences.

I probably over work in terms of doing mental health stuff because it's what I know best now it's become the bit of my life I'm most comfortable with bizarrely, it's strange. But like I say, the work I do gives me some meaning and if I feel like I'm helping other people at least it gives something some meaning to what has fundamentally been just the most negative most traumatic thing I can imagine living through **Irene, mother**

Subtheme 3: Influence of healthcare services on isolation

Mental health services were invariably experienced as problematic with narratives consistently describing a lack of support. Interestingly, those who worked for mental health services reported that they received good support from their employer. This suggests a saddening inequity with services offering better support to employees than the patients and carers they serve. All participants shared experiences whereby mental health services view of their care recipients suicide risk differed significantly from their own which resulted in them feeling alone in their quest to keep their loved one safe from suicide. This isolation was perpetuated by stigmatised responses from mental health services with some participants, particularly mothers, providing accounts of feeling blamed and discredited. The extent of problems with services experienced by mothers was further illuminated by the fact that all of the four participants who disclosed that they had formally complained about healthcare services were mothers.

So you're left in this sort of, you know, this world where the only person who seems worried that your child might kill themselves is you ……. it's parent blaming, it's your fault, you either mollycoddle them too much or not enough or, you know, you ought to go out more, you ought to stop worrying, they need to take responsibility for themselves……. They hate me [because] *I complain about them* **Betty, mother**

Examples of stigmatising attitudes were illustrated through recollections of comments made by staff, which were experienced as being loaded with undertones of blame, for example suggesting that participants should know better:

We had one person that came and she stood in the hall and she said, there's nothing wrong with him, you know, he's just playing you **Mae, mother**

Most participants had felt excluded by the providers of their care recipients care at some point, which further increased isolation. Participants felt excluded due to confidentiality and because their views or questions were not listened to despite often persistent efforts to communicate.

I just didn't feel listened to, you know, with, and I understand, I work for the NHS I understand about confidentiality and people being adults but the amount of times, you know, I tried to phone the GP I tried, you know, with, services and I kept being told he's 18 he needs to phone us. You know, I'm like well he's not going to phone you because he's too ill well we can't talk to you…..and they couldn't tell me the conversations they had with him and that's fine but to me it just felt like they listened to him more than they listened to me….. they'd base their assessment or a decision on 10 minutes with him or a phone call, you know, I was with him all the time and I knew this was going to happen and I told them this was going to happen and I just don't think they took me seriously enough **Kay, mother**

Kay described frustration here because she wasn't heard or taken seriously. Her status as her son's mother was belittled by services because her son had turned 18. No one validated her concerns about her son, who went on to end his life by suicide.

Negative experiences of mental health services were far more common than positive, but several participants volunteered information about at least a few experiences which had facilitated a sense of connection with services. Invariably this involved being listened to and given time, or interventions such as family therapy which a few participants received with care recipients who were engaged with specialist services.

….she's in a trauma service and they are much better and they have involved me much more and I you know I can email them I can ask to talk to them, like, that has been a completely different experience been really helpful for both of us so that you know that has been great, but none of the crisis care has been like that at all and it does it make, you know, it makes a real difference when you feel like, you know, you're either your perspective, you know, is valued or you have something to offer or, you know, literally she's asking me to pass

something on and they're like yeah that's great thank you for telling us that rather than no we have to hear it from her directly **Nancy, spouse**

From interview accounts it was clear that isolation was a common experience for participants. Dynamics within various contexts such as social networks and workplaces could either alleviate or exacerbate these feelings. Invalidating attitudes and responses from healthcare services, along with a lack of care provision invariably intensified isolation but recognition and tailored support reduced it.

4.2.5 Theme 3: Constant worry in the midst of fear and uncertainty

Participants expressed varying degrees of worry and fear about future suicide attempts. This worry was based on evidence as they had all experienced the suicidal behaviour of their care recipient and thus held a reasonable concern that it might reoccur. As noted in theme 1, once they had been confronted with the fact that their loved one wanted to end their life they could not return to a life without this knowledge. They were therefore relentlessly uncertain about their loved one’s safety. Some participants expressed a sense of expectancy that suicidal behaviour would be repeated, although because they were unable to predict if and when this might be it again resulted in uncertainty.
This theme has four subthemes: constant and fluctuating worry; becoming hypervigilant; the toll of worry and vigilance; and balancing hope and fear for the future.

Subtheme 1: Constant and fluctuating worry

Whilst some participants articulated a constant and omnipresent worry, others talked about cycles of suicidal crises wherein their worry was acute and more stable periods when it reduced. Most participants managed to continue with work whilst carrying this constant worry, which often manifested as an active or more latent fear of what they may find when they arrived home.

I think probably the worst thing for me is I never know what I’m going to find when I get home from work **Jane, daughter**

Constant worry was pervasive and generalised, and not limited to worry about the care recipient but also about other family members.

It was just a constant state of anxiety……..I was worried. I was worried for him. I was worried for my daughter. I was always worried about him killing himself. **Kay, mother**

Fluctuations in worry were illustrated by participants describing certain circumstances that triggered or escalated worry rather than the constant generalised worry described above:

If she wants to go and see her friends in [city]*, you know, we've actually got to take her in a, in a wheelchair to the station which scares me because she said obviously jumping off a bridge hasn't worked …… I should have just jumped in front of a train and I thought oh, so it scares me to death when she wants to go off and I don't sleep or rest until she's back* **Fiona, grandmother**

However, even when levels of worry were considered to be low, there was still an air of trepidation in participants' narratives. This suggested that care recipients' safety was always on their minds, but some had become more adept at tolerating the worry:

It's always at the back of my mind and a worry that it's there. I'm not actively concerned at the moment but that fluctuates day to day, week to week. We've had quite a major self-harm incident this week, so yeah, it never goes away it's always there **Hatty, mother**

Even when not acute, worry often resulted in participants changing or stopping engagements or routines just in case something happened.

At one time I could sometimes finish early stop off at a friends who husband died a few years ago, have a cup of tea and just wonder off home but now it's more a case of I get a bit twitchy just sitting there having a cup of tea, I think I'd better get home just to see what state we've got, you feel there's that need not to hang about or stop off so I get home and there's no problem but you wouldn't want to be sitting having a cup of tea while she topped herself **Ewan, spouse**

For some participants, such as Lucy, not living with the care recipient increased their levels of worry because they had less sight of them and less opportunity to assess the situation for themselves.

That worried me because I couldn't be there so when I'd ring him and he didn't answer I'd think, oh my God, here we go, I need to get hold of him because then I can't settle because I'm, like, has he started drinking again? Has he taken his medication? He has only got seven days' worth so then I have to process it all in my head. It's almost worst-case scenario and then he will ring me and go, oh, I'm sorry, I'm asleep. I get incredibly anxious, I worry because I came home from work the day that he went into hospital when he had his overdose **Lucy, partner**

Worry for participants in this study was influenced not only by care recipients expressed suicidal ideation but also circumstances and activities that carers perceived as potential triggers. Worry never disappeared but varied in intensity, with extreme worry leading to hypervigilance as discussed below.

Subtheme 2: Becoming hypervigilant

A common behaviour resulting from worry was hypervigilance, particularly when suicidal behaviour was new to participants, when the care recipient was in crisis or following discharge from hospital. Hypervigilant behaviour such as maintaining a continual presence, excessive checking in or hiding potentially harmful means for suicide was enacted as a means of trying to assure safety. As can be seen from Lucy's statement below, and her quote in the subtheme above, her hypervigilance was often fuelled by her anxiety rather than her partners suicidal assertions. Indeed, this was a pattern throughout most narratives and hypervigilance was clearly linked to participants responses to previous suicidal behaviour.

….. if I sit with him tonight I could go to work tomorrow by five o'clock something might have happened and I think well, hang on a minute I left you well. It's the not knowing, I feel like sometimes I need to be with him 24 hours a day to keep an eye on him **Lucy, partner**

Whilst most participants managed to work despite their worry for some hypervigilance was a strategy which enabled them to function at work. For example, Noah was able to go to work and perform only because they made frequent check-ins on their husband:
I'll phone home frequently to just check **Noah, spouse**

A few participants talked about their sense of relief when their care recipients were taken into some form of staffed environment and they were relinquished of the need to be hypervigilant. Grace described seeking vigilance from services as she felt overwhelmed by fear and did not feel able to maintain her daughter's safety at home:

She had to be hospitalised because I was so scared that she was going to take her life. She did it late at night when I was asleep and so I then asked for her to be admitted into a ward because I was actually overwhelmed, I didn't know how to handle things at home. **Grace, mother**

Discharge from hospital was anxiety provoking because participants no longer had the security of knowing others were taking care of their care recipient, and vigilance was high at these times because of the fear of suicide attempt.

When my mum is discharged from hospital which we have done several times now I find that my anxiety around those weeks is really difficult to manage because I'm just very, I'm very hypervigilant and I'm very sort of like ready for things to go wrong…….. looking for the signs always about is it going the other way, is it going downhill **Carol, daughter**

A minority of participants alluded to their interpretations that mental health services expected they would exercise constant vigilance to ensure their care recipient's safety. Mae had been given vague instructions around safety which she amplified when alone with her son:

I really didn't know whether I was overreacting but like I've said we were advised to lock doors and things and I religiously locked the doors so he was never left alone. I hid big knives, anything. I don't know whether I went over the top or not but I was really really worried that the mood that he was in… **Mae, mother**

Where participants perceived they were expected to sustain constant vigilance in the home it could result in anger towards mental health services:

I think expecting carers to look after people who are suicidal is massively unfair because it takes, it takes moments…. it only takes moments for people to put their plan into action and people aren't told that it only takes moments for people to do it and I think it's wildly unfair to expect relatives to do it, I really do **Betty, mother**

As can be seen from the quotes supporting this theme, the common underlying emotions of hypervigilant behaviour were fear and helplessness. The behaviour was an attempt to ease these difficult emotions and exert control through physical presence or acts.

Subtheme 3: The toll of worry and vigilance

Hypervigilance was exhausting and lifechanging. Participants referred to fatigue or exhaustion due to the constant worry, hypervigilance, or the general toll of caring through suicidal crises. Often, participants' overall physical and mental wellbeing were affected as a result.

It spills into just my general wellbeing in that I find it very difficult to sleep and my appetite reduces and I feel very restless and it's a general sense of sort of insecurity that spills into other things like work. **Carol, daughter**

Participants talked about feeling tired and drained. Impaired sleep was a common complaint, leading to participants feeling increasingly drained over time.

I find it very draining yeah but yeah, I don't think I've ever probably a decent night's sleep because you sort of you've got an ear if you like open in case she needs help……I know it's affected me physically because I'm, you know, I'm constantly tired and it takes a great effort to do things **Fiona, grandmother**

Nancy referenced compromised immunity and low mood indicating the physiological and psychological consequences of caring.

I think when I get run down I'll get a bug or an infection I think I can feel a bit low at times and even been a couple of times where, yeah, it's made me feel very low but, yeah, I think it's more, yeah, I do when I get stressed I get tonsillitis or chest infection or something **Nancy, spouse**

Some participants had experienced extreme emotional responses and detrimental impacts on their mental health, including depression, anxiety, post-traumatic stress symptoms or worsening of pre-existing conditions. These arose from accumulative worry and sadness, as well as the impact of exposure to suicidal behaviour and sense of responsibility of caring. As can be seen from Irene’s quote below, carrying the strain of caring and worrying became unbearable at times:

There were times when I literally felt like I was coming apart like I couldn’t, the strain of what I was trying to hold was so unbearable that I felt like, I don’t know, like when people say they have a breakdown … I literally felt like I was losing my mind, I don’t know how to explain it, I could have ripped my brain out, it was just so, I was just so desperate it was such a desperate feeling **Irene, mother**

Insight into one’s own wellbeing was important as illustrated by Alison who knew she had a propensity to low mood and what might aggravate this and what she needed to do to try and maintain her mental health.

If I’m not careful my own mental health can be affected. If I get too close to how blighted his life has been then that really would take me down so I have to stand back from it a bit **Alison, mother**

In terms of support for their own mental health, a few participants had sourced their own counselling, which they considered to be essential to their wellbeing. Carol shared beneficial outcomes of developing positive perspectives on life, which helped her feel strong enough to continue with her caring role.

I find it much easier to be happier with less now than before my mum was ill because my criteria for what is a good day sometimes has to be really, really low and that's a positive but that's also, that didn't happen accidentally that was, like, I had to work on that **Carol, daughter**

In summary, participants described a continuum of emotional and health consequences of worry and hypervigilance, ranging from fatigue and feeling generally under par through to deterioration of pre-existing conditions or onset of new mental health problems. Self-insight and receipt of tailored support was considered essential for maintaining wellbeing.

Subtheme 4: Balancing hope and fear for the future

When talking about the future, most participants oscillated between sharing their fears and articulating hope that things would improve. Their hopes were for their care recipients to live a happier and more fulfilling life, alongside a wish for their own caring role to be alleviated. The holding of hope was important to mitigate the uncertainty these carers inwardly harboured and to help them persevere in their caring roles. Perhaps unsurprisingly, participants were able to feel more hopeful about the future when they were in a position of relative stability at the time of the interview, suggesting that perspectives on the future may change along with the care recipient’s presentation and in line with suicidal crises.

Well we are hopefully going to move and I'll hopefully not putting too many hopes on moving but I hope that by moving somewhere a bit calmer things will be a bit better yeah I'm hoping that we will to get a calmer pace of life and that will help things calm down…so I'm feeling kind of cautiously, cautiously optimistic **Nancy, spouse**

Some participants found it difficult to feel confident about the future even when improvements were observed but they still urged themselves to remain hopeful.

Of suicide, specifically I would like to think, here's my rational mind, I would like to think that she's done enough work … she's got support the right kind of support and obviously be better equipped so I'd like to think she's not at risk anymore. However, you know, the slightly PTSD version of that is I never thought that would happen in the first place so I don’t know what it would take to trigger… **Grace, mother**

Hatty was able to reflect back to a time she found it very difficult to have hope for the future and had carried a strong sense of expectancy of suicide. Whilst she had been able to shift her outlook due to seeing considerable improvement in her care recipient, she still lived with both hope and uncertainty:

If you'd asked me three years ago, even two years ago, I'd have told you that there was no future, I was absolutely certain that she would leave us at some point ………I don't feel at the moment that risk will ever go away……….I'm hoping things will get better…… I'm hoping by this time next year [care recipient] *will be more stabilised, we just need to get a few other things sorted out in between so I think improvements I'm more positive than I was three years ago* **Hatty, mother**

A minority of participants found it difficult feel hopeful or look too far into the future because their experiences had led them to expect only more of the same cycles of suicidal crises and they couldn’t envisage this changing. Subsequently the constant worry or resignation they experienced spilled over into their thoughts of the future and they preferred to remain rooted in the here and now:

I try not to think about it too much because I don't really have any hope that things will improve. I think for a long time I had said to myself, it's okay, once I go to university it'll be better, once I graduate I'll be able to do this, once I start working I can do this and that will be better. There was always something that I could say actually there's something hopeful about that and each time it's actually been that little bit worse, so now I just try to not live in the moment exactly but just accept where I am and not think too much about the future
Jane, daughter

Hope for some participants enabled them to moderate feelings of despair, which was illustrated by Betty, who shared her pessimistic view that her caring role would end only with her death, but then tried to moderate this with a sense of hope that things would improve for her daughter:

Betty *It sort of ends with death*
IV In what way?
Betty *When I die because there is nothing*.
IV So, you kind of think, well, my caring role will end when I die essentially?
Betty *Yeah.*
IV And what will happen then?
Betty *Who knows? I mean, that might not be for a long time or it might be soon, you know, you just don't know, I suppose, you know, 15 years ago when you start, you sort of hope that you'll have a plan, but as you get on, you find out that there isn't a plan, you know, there is no plan B apart from their older sister. Well, hopefully,* [care recipient] *hopefully will get better, so that'll be good*

Holding hope helped participants to retain an optimistic perspective or at least carry on with their caring role despite the difficult experiences and emotions they dealt with on a daily or regular basis. Those who couldn't feel genuine hope adopted a day-by-day attitude and controlled their expectations of the future to avoid becoming hopeless.

Theme summary

To summarise the theme of constant worry in the midst of fear and uncertainty, worry was a persistent companion for participants in this study although intensity of that worry varied.

High levels of worry and helplessness regarding care recipients' suicidal behaviour were managed by hypervigilant behaviour. Ongoing worry and vigilance had significant emotional, psychological and physiological impacts on participants, which could be alleviated with appropriate support. Several participants were hopeful about their care recipients' futures and thus a reduced caring role for themselves, however this wasn't always the case, and some were resigned to a permanent carer role.

4.2.6 Theme 4: In for the long haul

As participants adjusted to their caring role and care recipients' suicidal behaviour there was a sense of being in it for the long haul, which involved learning ways to live with the possibility of future suicidal behaviour. Central to this learning was carers accepting their limitations with regard to changing their care recipients' behaviours. Some participants reflected on their own personality styles which appeared to facilitate and/or hinder their adjustment to their life as a carer and acceptance of the possibility of suicidal behaviour. A challenge within the long haul was the limitations of mental health services in terms of what they were able to offer and, in several cases, it was specialist and private services participants gained support from, both for themselves and their care recipients. The subthemes attached to this theme are accepting you can't fix it; leaning ways to adjust; and professional support in the long haul.

Subtheme 1: Accepting you can't fix it

Over time most participants reached a reluctant acceptance that they could not fix the situation, that is, they could not prevent care recipients from experiencing suicidal thoughts, nor could they always be on hand to stop suicidal behaviour, even when they anticipated its likely occurrence. This was not resignation and did not mean that participants found suicidal behaviour acceptable, rather it was a necessary acknowledgement of what was and was not in their gift as a carer. Alison framed this as accepting the unacceptable:

I think you can do that when something is ongoing, you know, when you settle into there's nothing I can do you get into a place of well it is what it is, you know, and you get a little bit not hopeless but accepting of something that's not acceptable really and that's where I am *with it because, you know, we’ve tried different things and encouraged but you can’t make someone take a step they’re not ready to take* **Alison, mother**

Hatty’s narrative articulated acceptance that even when suicidal behaviour was anticipated, it couldn’t necessarily be prevented:

I know when she's going to self-harm I can see the signs, I knew it was going to happen this week I can't prevent it, she's 28 she lives on her own I can't stop it **Hatty, mother**

Similarly, Jane had learnt from experience that for her mother certain acts of vigilance such as reducing access to means would not be helpful and, in turn, she had learnt to live with the potential of her mother using said means:

She always has the means there and I don't think it would be either practical or helpful for me to remove that. It’s almost actually I think, a bit of a safety net knowing that that means it’s there if she wants it so I don’t actually do anything on that side **Jane, daughter**

Whilst some participants seemed at times to gain some peace from this acceptance, others also spoke of how challenging it was, conveying emotional pain including frustration, grief, a sense of helplessness and sometimes hopelessness because life was not as they thought it would or should be. Thus, accepting the unfixable was an unfixed state; participants accounts suggested that acceptance was not static but changeable and, accordingly, learning to live with the possibility of suicide was a journey. Intellectual understanding of the unfixability of the situation was not always reconciled with emotional acceptance, because it by necessity involved accepting the possibility of death, which was not something which sat comfortably with any participant:

it’s not something I can fix and that’s really hard…….and I know all the things about it’s his choice, it’s his actions I wouldn't be responsible, you know, but that wouldn’t make it any easier **Noah, spouse**

For some, the strong emotions of grief, sadness, hopeless, frustration could result in a sense of stuckness rather than acceptance, for example Kay described ruminating about her son missing out on the life she saw his friends enjoying:

I'd get frustrated because you know I felt very stuck felt very hopeless, very sad, very angry, you know, I would see his friends who would be getting their license or going into college, you know, and, and [care recipient] *would spend 23 and a half, 24 hours in his room so, yeah, it was tough but the hardest thing was, you know, for him I just felt so sorry for him* **Kay, mother**

In summary, accounts indicated that participants' ability to accept that they could not fix care recipients tendency for suicidal thoughts and behaviours may be influenced by their emotional states and their perspectives on their situation at the time. Furthermore, although acceptance of the unfixable was in ways a survival strategy, it was itself an emotional labour for participants.

Subtheme 2: Learning ways to adjust

Participants perspectives and data analysis suggested that participants pre-caring personality influenced the way they adjusted to their caring role. Self-insights into their personalities helped participants understand their strengths and limitations as well as what support might be helpful or unhelpful. For example, Ewan described himself as flippant and stoic and linked his attitude on life to why peer support groups wouldn't be for him.

[I am] *probably a bit flippant but it's a way of coping….I'm not one of these that get anxious and panicky and start thinking oh this is it rest of my life's going to be misery……. The last thing I want do is sit in a room with a load of others moaning about how life's not very good, I don't think that does you any favours* **Ewan, spouse**

A significant strategy for participants was learning about their care recipient's condition and about suicide and self-harm. Learning styles included active learning through reading and training, learning on receipt of information, and learning on the job. The participants most assertively engaged in learning were those who went on to professionalise their experience through dissemination of their learning to others. Their personality styles were such that they needed understanding and they looked everywhere to achieve this:

I've put myself through training….. I'm just always on the lookout for stuff that helps me understand these things better **Noah, spouse**

Although participants reported largely negative experiences of mental health services, in a few cases their learning was facilitated through information and explanation from these services. For example, one participant talked about the value of receiving a diagnosis for their care recipient because it brought a certain amount of enlightenment and helped their understanding meaning they felt more effective in caring:

I think the diagnosis has helped me to understand and also probably understand the triggers, of why he always goes towards suicidal thoughts when he becomes completely overwhelmed, and as he becomes better, I can sit with him and maybe put some plan in place so that we don't get to that, that stage **Dot, spouse**

However, for others, services seemed unconcerned about facilitating their learning about care recipients' behaviours and needs, perhaps because they assumed carers would know what to do or due to simply not recognising learning as a need:

I think on the one hand people expect that carers will know what to do and on the other hand they just dismiss us as nobody, it's a weird, it's just completely not thought about because if people thought about it they would recognise why on earth would carers know what to do, why on earth would a carer know how to respond or a parent know how to respond to somebody who starts self-harming? Why? **Irene, mother**

Some participants learnt on the job rather than by seeking specific information and knowledge. This involved making sense of the behaviours they observed and testing management strategies out. This was driven by wanting to help the care recipient but enabled carers to cope with their situation by achieving a certain amount of mastery:

What I've started doing is I will give him space, I will give him his time because I've got to let him know that I trust him and he needs to know that he can trust me so when he's low I say to him if you don't want to talk just message me just let me know you're okay, I will be at home if you need me I'll come but I'll stay away and give you some time because I understand that he does need time for himself. Actually, what I've recognised is it gives me a bit of breathing space as well **Lucy, partner**

Some participants coped by burying their own emotions to enable themselves to carry on with daily life or as a way of avoiding their feelings for fear of being overwhelmed by them.

For example, Nancy alluded to experiencing emotion during the interview and talked about feeling overwhelmed at times, but she didn't name individual emotions beyond shock. She talked of not dwelling on emotions but perhaps had not yet faced her emotions:

You know it's a shock, it's horrible and then I try not to think about it too much and move on because I think it yeah it will be too much if you sort of dwell on it….. If I dwelled on what happened in the summer like you know I have got into bed the following weekend I'd still be there so I kind of you know, yeah, I can't really do that **Nancy, spouse**

Alison was able to name her emotions, expressing sadness, anger and frustration but she also identified that she had an ability to bury them, which she considered important because feeling them in their entirety may be overwhelming:

I think I've got a bit of a mechanism where I either don't allow myself to or the situation doesn't allow me to the indulgence of feeling sad all the time about it because that's a floodgate there because of how long it's gone on **Alison, mother**

Interestingly, the participants who buried their emotions did not include those who had professionalised their lived experience. This may suggest that the process of quasi-professionalisation, which involved open identification as a carer and sharing of personal stories, gave participants a sense of permission to express and sit with the emotions caring brought up for them.

One participant spoke about working hard to balance the difficult emotions she experienced, namely sadness, anger and guilt, with reflections on positive aspects of her life and two others highlighted the importance of their faith in helping them cope with their situation.

I try every day to just write some things down that I'm thankful for because it would be very, very easy to just be sad all the time **Carol, daughter**

Family and friends were a valuable resource to the participants who had access to them and the emotional, and in cases practical, support they offered was greatly valued in helping participants to adjust to and live with their situation.

Just that sort of close network of friends … they all know about [care recipient] *and they're all there, supportive and I know that if I was going into a meltdown and needed just a bit of support I could just phone one of them and talk to them and I only need to just message and say can we have a chat?* **Fiona, grandmother**

In summary participants personalities predisposed the way they adjusted to their uncertain world and accordingly strategies deemed helpful were geared towards their natural leanings. Learning was a common beneficial factor in adjustment.

Subtheme 3: Professional support in the long haul

Mental health services were on the whole not experienced as helpful in supporting participants to adjust to and sustain their caring role. This was generally to do with participants not being able to access admission in crises or for respite, poor communication from services, and a lack of professional follow up after suicide attempts or discharge from hospital. This lack of support fuelled feelings of frustration and resulted in participants feeling let down.

When we've had discharges from hospital that's been really difficult to coordinate because the care moves back into the community and it's like there are safety elements like we have to do assessments on the property and all these kind of things that I just often feel like get missed out of the conversation around carers **Carol, daughter**

Securing inpatient care was virtually impossible and some participants found it incredulous that suicidal individuals could be turned away from care unless they had very nearly died.

Basically the criteria for admission seemed to be have you miraculously survived death? And if you had you could get an admission if you hadn't then that, that that was it **Betty, mother**

The lack of contact from services, even when are recipients had nearly died, was a frequent source of frustration for participants. Narratives indicated that services were typically unconcerned about the impact of care recipients’ suicidality on their family members, demonstrated by Irene’s story in which she recalled a complete absence of any communication after her daughters near lethal suicide attempts:

I've had situations where [care recipient*] nearly died and the first person who tells me is* [care recipient], *oh, I nearly died, I've been to A&E and I had to be resuscitated and this happened and that happened and it's like, I'm sorry, what? So when you find out things like that I just don't even know where to start with how that feels and why services can ever say that that's ok to behave like that and work like that and not to pick up the phone and go are you ok, this has happened and we know that you know about it so is there anything you need?* **Irene, mother**

The most helpful professional support often came from specialist agencies, or through tailored interventions for carers.

I think that being involved with the [specialist] *trauma service has been really helpful and actually they really stepped up when she was last in hospital and that was yeah that was great, I felt like I wasn't doing it on my own* **Nancy, spouse**

Therapeutic interventions could be instrumental in supporting participants in their relationships with care recipients. Hatty was able to engage in family therapy when her daughter was in specialist care, and she expressed how it helped their communication:

We had family counselling …. which has helped immensely for us to understand each other….up until a couple of months ago, I never ever let her see how upset or stressed or worried I've been …..it's conversations that we wouldn't have been able to have directly with each other without that intervention so it was really good **Hatty, mother**

Generally, regardless of discipline, helpful professionals were those who listened and offered validation and advice, these human exchanges helped participants to carry on:

He's [GP] *just been very understanding, he knows what the situation is. One of the things when I've been feeling particularly down the few weeks when I've been signed off work, actually, it was him, he suggested that maybe you should take a bit of time off work now rather than pushing and pushing and pushing and then needing six months off or whatever. Really, he listens to what I've got to say, he's made a few helpful suggestions* **Jane, daughter**

Participants had strong views on what support they would like to help them manage their caring role. This varied according to individual personalities but there were some common thoughts. With regards to mental health services, participants were clear that they wanted professionals to identify them as carers, listen to them, appreciate that they knew their care recipients well and were often with them 24/7, therefore had a good level of insight into their problems and needs.

I think that's the big thing is about families being listened to because we know, we know best, we are with this, we are with these people, you know, I was with [care recipient] *every day, every day I saw him* **Kay, mother**

Participants critiqued the current model of service provision, arguing for a more systemic approach that recognised patients exist within family and community contexts and thus the whole family was often affected by the individual's suicidality. There was a plea to see carers as an asset rather than a problem and to move from the medical model which hails professionals as omnipotent and omniscient towards an ethos of collaboration with carers and families:

I really believe the model is faulty and that's kind of where the carers, it's, it's manifested in the way that carers are talked to and carers are dealt with because there is this sense that the professional knows best and, you know, you come to the professional with a problem, then you are the one with the problem and the professional knows how to put that problem right and that, that isn't the way it should be **Grace, mother**

Information and advice about how to navigate the mental health system was identified as a need and participants emphasised the importance of education at an early stage. They wanted to be reached by professionals rather than excluded:

Guidance right at the beginning as to what services are, what you should do to get those services…… I think the first thing people need is that they need to have an understanding of what the heck is happening so some level of psychoeducation ….. and how they can help because fundamentally carers want to help but unless we're told how to help why should we know what to do? **Irene, mother**

Even just simple enquiries as to how carers were would be valued:

….where you've got [professional] *carers coming to the house to help that, that they're there, not just for the person, but to check in on the up on, on the carer* **Fiona, grandmother**

Easier access to services was raised, including hospital admissions when care recipients were actively suicidal.

I think with mental illness, mental health services need to start thinking that sometimes people need to be in hospital for extended periods of time while they get to the, while they actually get some help because you can't do it at home because there's 24 hours in the day **Betty, mother**

Peer support was frequently mentioned as a need but importantly participants voiced that this should not merely be universal carer peer support but specific to the context of caring for someone who engaged in suicidal behaviours, and/or the underlying cause such as certain diagnoses or trauma. Furthermore, some participants were keen for groups to be targeted to, for example, carers in certain age groups or carers in same sex relationships.

Having a group that you could sit round and talk to about how other people are dealing with things that would be really good actually I haven't thought about it before but, yeah, because no one understands like someone who's in it with you do they? You know, it's like there you can open up and say this is how it really is, this is how it's affecting me, and they go well I do this and …. That could be really good **Alison, mother**

Counselling or therapy to help carers process their thoughts and feelings related to their care recipient's suicidality and their caring role was considered important, with trauma therapy being available where indicated.

Access to proper like therapy and support for a start because I feel like living with, consistently managing that level of fear is hard, like that's really hard and it's kind of like, it's a trauma of, of sorts because that's a really big thing to have happened and it's a really big thing to go through and you may be caught in a cycle of that so I feel like it's, it's, it's proper support around that, which is tailored **Carol, daughter**

Practical support to assist carers was identified as a need by a number of participants including financial support, help with chores such as cleaning, and respite care. However, whilst ideas were offered around respite care some of those who suggested respite also reflected that they may not accept such support even if it was offered, either because they would worry too much or because their care recipient would not like it.

…. even if that was available I don't know if I would use it or if mum would. I would really like to be able to just go on holiday for a week without worrying or feeling guilty so some sort of respite care that's easier to access but then I don't know if either of us would actually take advantage of that **Jane, daughter**

Some participants suggested that carer support offers must be flexible enough to enable people who work to attend them and shared their experiences of difficulties attending support in work time.

….there was a group, but it was during the day so I could never attend it and I said, you know, you can't assume that all carers don't have a job to do I said like, you know, I'm a full-time working person who cares full-time for somebody and something like that would've been really helpful to me because I would've been able to have spoken to like-minded people that were maybe struggling the same as I was in the beginning **Dot, spouse**

Employment support was identified as a need by some participants who called for improved culture and policies.

I think carers organisations could work a bit harder to make sure that employers are more aware of how to support carers in their employment **Noah, spouse**

Although participants had slightly differing slants on what support they wanted, there were consistent points raised across interviews, with a strong calling for carers to be heard, involved and supported in the care and treatment of care recipients.

Theme summary

The theme 'in for the long haul' is characterised by carers accepting their limitations in fixing care recipients problems or conditions and the associated acceptance of the possibility of suicidal behaviour and even death by suicide. Adjustment to life in the long haul of the uncertain world was largely dependent on individual personalities and this was reflected in the different support needs articulated. Participants called for tailored rather than standardised support but education was consistently identified as a requirement.

4.2.7 Caring during the COVID-19 pandemic

All participants had been caring during the COVID-19 pandemic. For some, the pandemic made little difference to their caring situation. A few reported that caring became easier due to them being able to work from home, which meant they were on hand for their care recipients and their increased presence was stabilising.

I was still able to take myself off and work from a room that he didn't need to come into so there was still segregation there in some respects, but I think from the caring element it, it helped a little bit because me being there kept his anxiety down as opposed to when he was managing those anxieties when I was going into work **Dot, spouse**

Some participants expressed changes that were not ideal, such as care recipients mental health contact becoming largely remote in nature, but this shift was experienced as manageable for most. However, for one participant this was very problematic as it meant her care recipient was not properly assessed as he was able to avoid certain questions and video calls.

A deterioration in care recipients mental state was noticed by some participants due to the lockdowns restricting access to social networks or activities and/or pandemic related anxiety and thus their levels of care intensity were heightened. In some cases, this was easily manageable as participants were more physically present, however, for others being in lockdown together was stressful, isolation was increased, and restrictions meant getting time to oneself was nigh on impossible:

I was working from home, she was off work at the time we literally have two rooms we have this living room and our bedroom that is it and it was just a slow creep of kind of increasing stress and kind of anxiety in those kinds of things, yeah, and, you know, I, you know, I, we weren't having any separation, I wasn't going to work and we couldn't see people because all of the lockdown rules happened so we were, yeah, we were really isolated **Nancy, spouse**

Initial interruption in support groups or therapy, which was eventually reinstated online, was common. Some participants liked the shift to remote contact whilst others missed face to face support. Virtual means had been essential for those participants whose care recipients were in hospital during the pandemic as it was their only means of contact for a while, but this was dependent on the care recipient's engagement which didn't always happen.

That was the longest I'd ever not seen my mom when she was in hospital and she couldn't have visitors. It's the longest I've ever not seen her and it was awful because I felt like she was disappearing because I couldn't even sit in front of her and so in order for her to engage with me she had to want to engage with me, like she had to want to do a Zoom or a teams call and that didn't happen and so I felt like all the news I was getting about her was second hand and I was like living off scraps basically **Carol, daughter**

In summary the main negative impacts of the COVID-19 pandemic on caring were around reduced contact with support services and care recipients in hospital, the necessary shift to remote interventions, concerns about deteriorating mental health of care recipients and increased isolation. The restrictions associated with the pandemic were not experienced negatively by all participants, however, with some participants experiencing their situation becoming easier as they worked from home.

4.2.8 Section summary

This section has presented the results of the thematic analysis. This included the overarching theme of entering and adjusting to a different and uncertain world and the underlying linked themes of blurred identities and relationships; isolated in an uncertain world; constant worry in the midst of fear and uncertainty; and in for the long haul. In addition, participants' experiences of the impact of the COVID-19 pandemic have been discussed.

This research, both the survey and interviews were addressing a sensitive topic. In order to understand whether the experience was helpful or of detriment to participants an evaluation was carried out which is presented in the next section.

4.3 Evaluation of research participation

In this section participants evaluations of taking part in the survey and interview research are presented. The evaluation involved participants rating their mood on a scale of 0-100 using a sliding scale (0 = worst they've ever felt and 100 =best they've ever felt) both before and after the survey and interview. In addition, participants were asked open questions around the experience of taking part and the best and worst aspects, and finally four Likert scale questions focusing on ease, acceptability, benefits of participation, and how upsetting participants found it to take part.

4.3.1 Survey Evaluation

Pre and post participation mood ratings

98 of the 101 survey participants completed pre and post survey mood ratings. There was a slight reduction in mean scores following completion with a minimal difference in the range of scores (see table 23).

Table 23: Survey participants mood ratings re and post interview (0-100 with 100 being best ever)

N = 98	Median	Mean	Range	SD
Pre survey	60	59.15	9-92	20.130
Post survey	60	55.17	9-90	19.851

To ascertain statistical significance or otherwise a non-parametric related samples Wilcoxin Signed Rank test was computed. This statistical analysis was selected because the ‘difference in mood’ variable was not normally distributed. Of the 98 participants who completed the pre and post survey mood rating, 44 rated their mood as worse on completion of the survey, 27 rated it as better and 27 rated it the same. Completion of the survey elicited a statistically significant decrease in mood compared to pre-survey, $z = -2.88$, $p = .004$. This result indicates that although the median vale of 60 was unchanged, there were changes in distribution of data i.e., individual scores and thus the pattern of distribution changed and demonstrated a statistically significant decrease in mood rating scores.

Open question responses

Participants were asked how they found taking part in the survey. 92 of the 101 survey participants (91.1%) completed this question. Of the 92 responses, 44 (47.83%) gave a neutral response such as *fine, ok, no problem, easy*. 24 participants (26.01%) gave responses indicating that it had been somewhat difficult due recalling painful events and feeling emotional, or in a few cases (N = 3) because of frustration with the questionnaire. Favourable responses were given by 22 (23.91%) participants who stated that completing the survey was cathartic, interesting or that they were pleased to have contributed to research. Two participants conveyed that the experience was both difficult and positive, for example:

Fairly straight forward although some multiple choice questions didn't really have the answer I wanted to give. Felt quite emotional having to think about my son's life experiences and how they have affected him. Pleased that poor mental health and suicide is being taken seriously and being talked about more **(Participant 92)**

Participants were then asked what the best and worst parts of taking part in the research were. 89 /101 (88.12%) respondents reported the best part of participation. The most common responses related to feeling heard and validated and contributing to research. The 'other' category included factors such as distraction from the daily routine. 84 participants (83.17%) reported the worst part of participation. The emotional impact was the worst part for most, although just over a quarter said there were no worst parts. The 'other category' included issues with the questionnaire design, functionality or outcome, for example slide bars, text box size, perceptions about some of the questions and concern that results may not be effectively disseminated. Responses are summarised in table 24.

Table 24: Survey participants perspectives of best and worst parts of participation

Best part of participation in the survey research	**N = 89** **N (%)**
Being heard and validated	45 (50.56)
Contributing to research and hoping for eventual service improvement	33 (37.08)_
Other	7 (7.87)
Unsure/none	4 (4.49)
Worst part of participation in the survey research	**N = 84**
The emotional impact	49 (58.33)
No worst parts	22 (26.19)
Other	13 (15.48)

Likert scale questions

Participants were asked four Likert style questions asking whether they had found the research easy, upsetting, acceptable, and beneficial. The Likert scale had 5 points; strongly agree; agree; neither agree nor disagree; disagree; and strongly disagree. The results are presented in table 25. 98 respondents answered the question asking whether or not they had found the research easy with most (83, 84.69%) agreeing or strongly agreeing that taking part had been easy. 11 (11.22%) were neutral and 4 (4,08%) disagreed that it had been easy. The question asking if respondents had found completing the survey upsetting was answered by 94 participants. Just over a third of these (33, 35.11%) agreed or strongly agreed participation was upsetting, 38 (40.43%) disagreed or strongly disagreed and the remaining 23 (24.47%) gave a neutral response. 96 respondents answered the question asking if they had found taking part in the research to be acceptable. The majority of these (81, 84.37%) agreed or strongly agreed the experience had been acceptable and 15 (15.63%) were neutral. Finally, of the 97 participants who responded to the question asking if they thought taking part had been beneficial, 61 (62.89%) agreed or strongly agreed it had been beneficial, 31 (31.96%) neither agreed nor disagreed, and 5 (5.15%) disagreed or strongly disagreed.

Table 25: Responses to Likert style questions asking if survey participation was easy, upsetting, acceptable and beneficial

Question	Total N	Strongly agree N(%)	Agree N(%)	Neither agree nor disagree N(%)	Disagree N(%)	Strongly disagree (N%)
Taking part in this research was easy	98	45 (45.92%)	38 (38.78)	11 (11.22)	4 (4.08%)	0
Taking part in this research was upsetting	94	8 (8.51%)	25 (26.60%)	23 (24.47%)	24 (25.53%)	14 (14.89%)
Taking part in this research was acceptable	96	36 (37.5%)	45 (46.87%)	15 (15.63%)	0	0
Taking part in this research was beneficial	97	21 (21.65%)	40 (41.24%)	31 (31.96%)	4 (4.12%)	1 (1.03%)

4.3.2 Interview evaluation

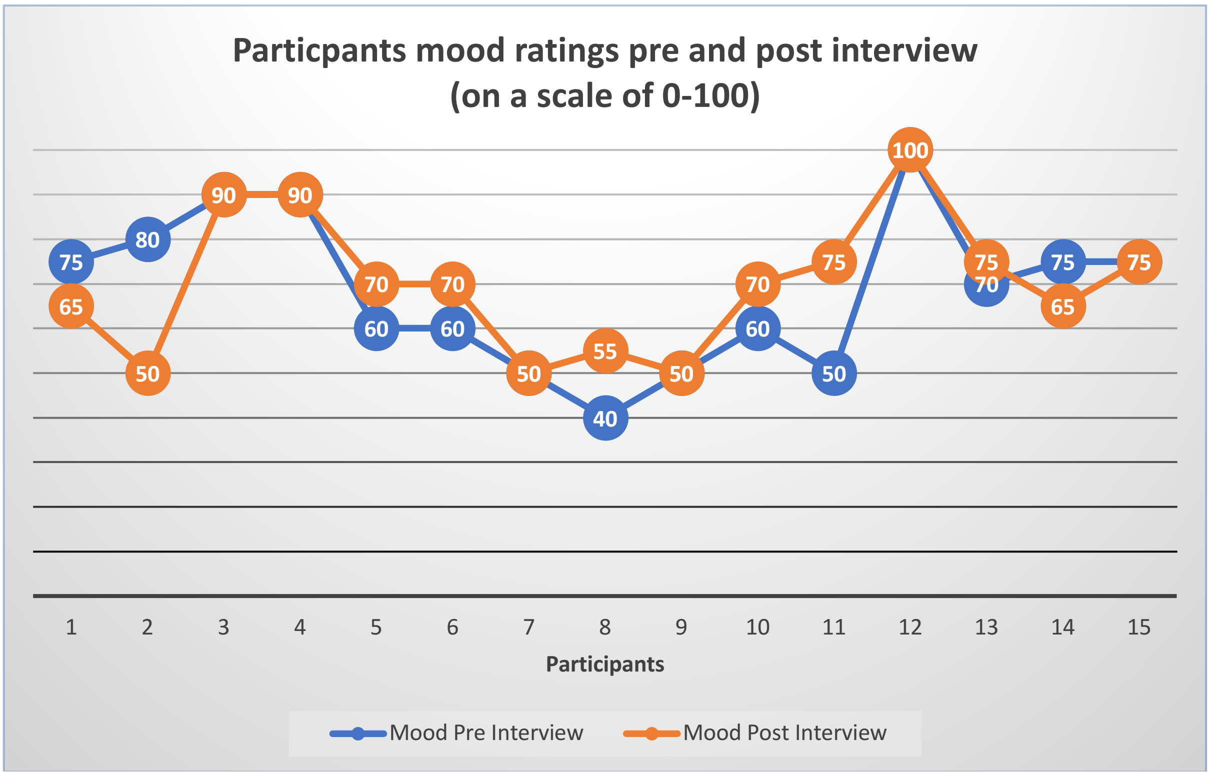
All 15 interview participants completed pre and post mood ratings. Mood remained unchanged for 6 participants, improved for another 6 participants and lowered in three participants (see figure 6). Where mood improved this was because participants felt listened to and that they had appreciated the opportunity to unburden.

Yes, I do feel lighter. Yes. I've unburdened rather a lot on you. So yes, I do feel better than I did at the beginning **(Mae, mother)**

The participants who had experienced a lowering of mood reported that this was to do with talking about an experience, which was at times difficult and painful.

I guess it's around the same maybe a little bit lower because of touching on emotionally where I was. Not because I haven't enjoyed taking part but because I've had to look at things that have been a bit painful **(Alison, mother)**

Figure 6: Interview participants mood ratings pre and post interview



Best and worst parts of interview participation

All 15 interview participants were positive about the interview experience with reasons for this including that they felt passionate about the need for carers to be recognised and wanted to improve both patient and carer support, and that they found the research experience interesting.

It's personal passion of mine. I was very keen to be involved. I wanted to be able to speak freely and, and to participate so it's been a positive experience **(Grace, mother)**

Best parts included being heard, validated and feeling as though they were contributing to potential positive change for other carers. Seven interview participants did not feel there was a worst part and those who did indicated this to be the emotional impact (N=5), anxieties about participation (worrying about talking too much and not meeting expectations) (N=2) and the realisation of the lack of resources (N=1).

The best thing about taking part is taking part really, I mean it’s like someone’s asked, someone actually gives a shit, that’s quite important. It feels like to be asked is that direct *question which is so pertinent to me and my experience feels very validated and that's not something that happens very often so that's a positive* **(Irene, mother)**

I think the negative is that we're talking about hugely emotional stuff. And it's still really difficult. I wouldn't want to be able to talk about it and not have any emotional attachment like that, that would be a little strange. But it's a difficult thing to talk about **(Carol, daughter)**

Likert scale questions

Interview participants were asked to rate their answers from 1-5 with 1 being 'very' and 5 being 'not at all' (see table 26). Most of the 15 interview participants found taking part in the research very easy (n=9) and very acceptable (n=14). One participant (whose son had recently ended his life) found taking part to be very upsetting but reported that she had expected to become very upset and she still found the interview cathartic and beneficial. Three participants were neutral about whether the research had been upsetting and the remaining 11 did not find it to be too upsetting. A third of participants were neutral about whether or not taking part in the research was beneficial with the remaining rating 4 or 5 (very beneficial).

Table 26: Responses to Likert style questions asking if interview participation was easy, upsetting, acceptable and beneficial

Question	Not at all N (%)	N (%)	N (%)	N (%)	Very N(%)
Taking part in this research was easy	0	1 (6.7)	1 (6.7)	4 (26.6)	9 (60)
Taking part in this research was upsetting	5 (33.3)	6 (40.0)	3 (20.0)	0	1 (6.7)
Taking part in this research was acceptable	0	0	0	1 (6.7)	14 (93.3)
Taking part in this research was beneficial	0	0	5 (33.3)	5 (33.3)	5 (33.3)

4.3.3 Section summary and discussion of evaluation

Evaluation of participation in both the survey and interviews show that, overall, while involvement in the research was emotionally challenging, it was not experienced as harmful. Over half of the survey participants found the emotional impact of taking part the most difficult aspect, just over a third found it upsetting or very upsetting and there was a statistically significant decrease in mood after survey completion. This highlights the importance of offering consistent support following online surveys to ensure non maleficence. However, it cannot be concluded that the emotional impact and overall downturn in mood meant it was a negative or harmful experience, nor that participants would have wanted or needed support. Autonomy must be assumed with online surveys in that respondents can choose to stop at any time. Therefore, the participants who continued the survey until the end did so for a reason, which perhaps outweighed the negative consequences.

Nonetheless emotional distress must be acknowledged, and support offered. Of course, this is much harder to achieve with surveys than it is with interviews, demonstrated by the finding that all interviews were experienced as positive despite the emotional impact, which was no doubt due to the human contact. Survey participants were redirected to carer support information following completion, thanks were given and acknowledgements of the possibility of painful recollections causing emotional upset were made. The evaluation suggests that in addition, a more sensitive ending for participants might be helpful. The closing message of a survey is perhaps a way of extending care and humanity despite the lack of physical presence, for example by a short poem, image or statement that conveys validation.

The best parts of survey completion and interviews were recognition, feeling validated, and the feeling of contributing to something positive that might be of help to others. A quarter of survey participants and just under half of interviewees said there was no worst part and the majority found taking part easy, acceptable and beneficial, proving that not all participants were distressed. This finding reinforces the importance of not presupposing that all carers are vulnerable.

The positive feedback given by the interview participants suggests that the opportunity to talk uninterrupted, with discourse being entirely focused on their experiences, was the main ingredient of the good experience. The online nature of interviews was not raised as a problem. As a researcher I found this feedback validating, which underlines the reciprocity of research; I felt that I had been able to give something in return for the stories participants had shared with me. I greatly valued that participants had felt that I cared about their situation and that they had been able to unburden. The evaluation strengthened my belief in the worth nurses bring as researchers because of their human skills. I did not feel burdened by participants' unburdening because of my nursing experience. Thus, my researcher wellbeing was preserved due to my nurse self.

The findings from the participant evaluation of this research are unsurprising. Lowes and Paul (2006) found that family member participants in research investigating a sensitive topic reported altruistic motives for participation and reflected that taking part had been therapeutic. These findings are echoed by Aoun *et al.* (2017) who evaluated research with family caregivers of terminally ill people. Experiences are similar in suicide bereavement research with relatives bereaved by suicide who have reported beneficial participation experiences including positive growth (Andriessen *et al.*, 2018). In relation to previous research with carers of individuals at risk of suicide, Maple *et al.* (2020) included two evaluation questions in their online survey research asking participants why they took part and how they had experienced participation. Motives for participation included a wish to improve awareness of suicide including the role of carers and to improve support for carers. Participation was on the whole considered important despite the elicitation of difficult emotions.

The increasing interest in evaluating suicide research in real time is important to maintain participant safety and wellbeing, but also to challenge over cautious ethics boards who can be nervous about research in this area (Lakeman *et al.*, 2013; Maple *et al.*, 2020). The findings from the current research, which has used an accepted approach to evaluation (Rivlin *et al.*, 2012) contribute to this growing evidence base.

The next chapter presents the integration of the quantitative and qualitative survey and interview findings.

CHAPTER 5: INTEGRATION

5.0 Introduction

The integration stage of this research involved bringing the survey and interview results together and through a process of abduction and reflexivity arriving at mixed methods interpretations of the main qualitative and quantitative findings in order to answer the research question. Findings were further reviewed alongside the social ecological model adapted for suicide prevention by Cramer and Kapusta (2017) to consider them at individual, relational, community and societal levels.

The full integration table is presented in appendix 27 and main findings are aligned with the social ecological model shown in figure 7 beneath the following summary.

5.1 Summary of main findings

Uncertainty related to living with the threat of suicide was a major finding in this research, with a resultant overarching theme of 'entering and adjusting to a different and uncertain world'. All aspects of participants lives were affected by uncertainty. Whether or when a suicidal crisis might occur, or if the care recipient was going to eventually die by suicide, was an ever-present thought. Uncertainty waxed and waned in terms of intensity, but it was a permanent fixture; there was no going back to how life had been before the prospect of suicide had been introduced. Associated reactions of stress, fear and worry were acute and overwhelming in the early stages, later fluctuating as suicidality morphed into unpredictable cyclicity. Uncertainty was propagated by a lack of professional support, which was highlighted by all data sets, and the most helpful support came from family and friends.

The main behavioural response to acute uncertainty was hypervigilance, ranging from overt and restrictive omnipresence to regular check-ins even when participants weren't proximal to care recipients. Hypervigilance restricted participants as much as care recipients, with life often being experienced as 'on hold'. Hypervigilance was experienced as highly stressful with detrimental effects on quality of life and mental and physical wellbeing.

Caring in the context of suicidality brought relational changes and uncertainty as dynamics altered. Non-parent carers became somewhat parental, and parent carers shifted their parental role from adult/adult to adult/child, or vice versa, depending on the timing of onset of their offspring's suicidal behaviour and the level of vigilance required. Care recipients' suicidality invaded family life and affected the quality of partnerships. The obligation rather than choice to become a carer affected quality of life for some individuals.

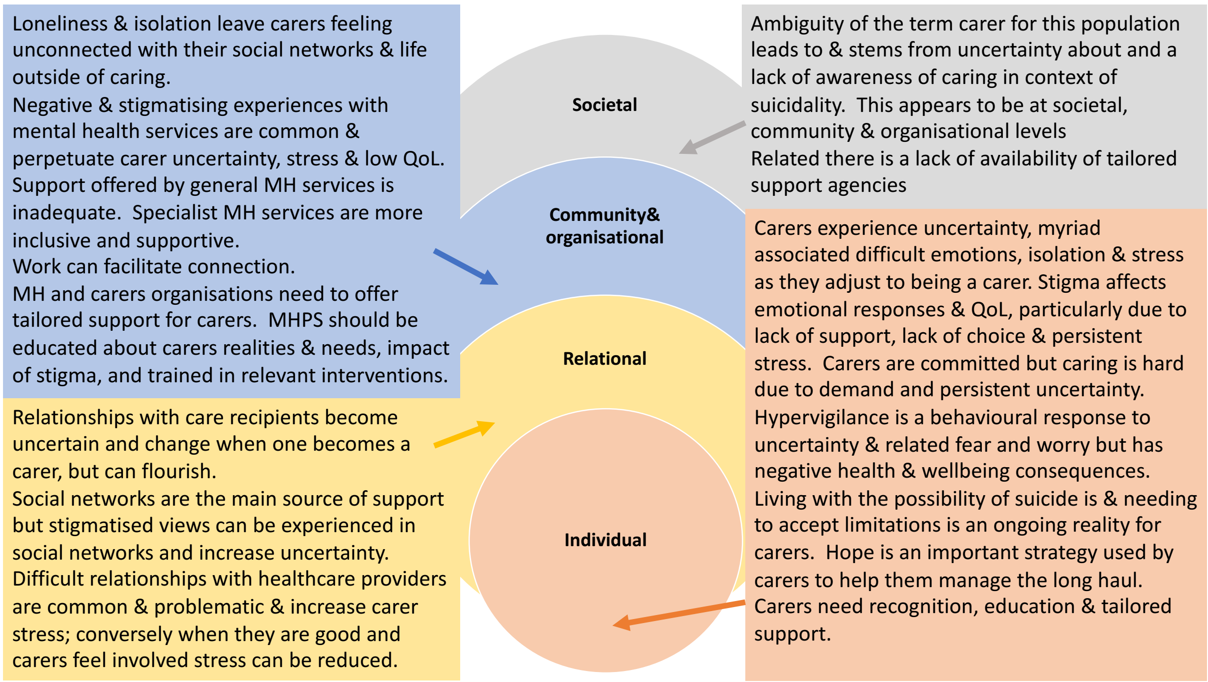
A strong sense of participant isolation and loneliness was evident, which appeared to be due to a combination of all of the factors identified above and resulted in a lowering of quality of life. Loneliness was perpetuated by experiences and perceptions of stigma and lack of, or unhelpful, professional support. Perceived stigma was present amongst the study sample at comparable levels to that identified in clinical psychiatric populations, suicide attempters and patients hospitalised following suicide attempts (Scocco *et al.*, 2012; Scocco *et al.*, 2016), although, given the high attribution to mental disorder, it may have been more to do with mental illness rather than specifically suicidality. Pronounced negative, hostile and stigmatising encounters with mental health professionals and services were relayed and narratives also conveyed a presence of self-stigma. Perceived stigma was associated with lower quality of life and stigmatising experiences resulted in stress and emotional distress.

Longstanding caring led to increased confidence in the 'long haul' of caring and participants demonstrated the ability to tolerate uncertainty and reflect on their experiences. This included deliberation on the term carer which frustrated some participants because it does not reflect the tacit and variable nature of caring in the midst of episodic suicidality. Some participants resisted the 'carer' identity due to their belief that caring was part of their primary relationship, whilst others assumed it despite frustration with the terminology due to their belief that they were functioning over and above, or very differently from, their primary relational role.

Participants perspectives on the future were tinged with sadness at the ongoing uncertainty of life. The challenge became one of acceptance of the possibility of loss rather than eradication of risk. Participants managed ongoing certainty by maintaining hope, both for the recovery of their care recipient and the relinquishment of their caring role. Some affirmative elements of caring were raised, such as increased closeness of relationships, but positive reflections were relatively few. Nonetheless, interview data elicited positive growth with some participants, which enabled them to coexist with uncertainty and find meaning from their experiences for themselves and others, particularly those who engaged in some form of lived experience activity or occupation.

In terms of support needs there was unanimity that improved mental health care provision for care recipients and better recognition and involvement of carers would be of most support. Additionally, there was overall consensus that education and information is paramount and necessary from an early stage. Peer support and therapy were considered helpful by some participants, others expressed that peer support was not for them. Whatever the support offered, participants emphasised the need for it to be tailored to need, underlining the point that there is no one size fits all intervention.

Figure 7: Mixed methods interpretations aligned with the Social Ecological Model



Loneliness & isolation leave carers feeling unconnected with their social networks & life outside of caring.
Negative & stigmatising experiences with mental health services are common & perpetuate carer uncertainty, stress & low QoL.
Support offered by general MH services is inadequate. Specialist MH services are more inclusive and supportive.
Work can facilitate connection.
MH and carers organisations need to offer tailored support for carers. MHPS should be educated about carers realities & needs, impact of stigma, and trained in relevant interventions.

Ambiguity of the term carer for this population leads to & stems from uncertainty about and a lack of awareness of caring in context of suicidality. This appears to be at societal, community & organisational levels
Related there is a lack of availability of tailored support agencies

Relationships with care recipients become uncertain and change when one becomes a carer, but can flourish.
Social networks are the main source of support but stigmatised views can be experienced in social networks and increase uncertainty.
Difficult relationships with healthcare providers are common & problematic & increase carer stress; conversely when they are good and carers feel involved stress can be reduced.

Carers experience uncertainty, myriad associated difficult emotions, isolation & stress as they adjust to being a carer. Stigma affects emotional responses & QoL, particularly due to lack of support, lack of choice & persistent stress. Carers are committed but caring is hard due to demand and persistent uncertainty.
Hypervigilance is a behavioural response to uncertainty & related fear and worry but has negative health & wellbeing consequences.
Living with the possibility of suicide is & needing to accept limitations is an ongoing reality for carers. Hope is an important strategy used by carers to help them manage the long haul.
Carers need recognition, education & tailored support.

5.2 Chapter Summary

This brief chapter has presented the integration of the analyses of three datasets from the research: the survey quantitative data analysis (STOSA, AC-QoL and ratings of helpfulness of support received); survey summative content analysis; and the reflexive thematic analysis of the semi structured interviews. The next chapter discusses the main findings in depth.

CHAPTER SIX: DISCUSSION

6.0 Introduction

This chapter considers some of the main findings of this research alongside the primary research reviewed in chapter two and wider relevant extant literature. To enhance interpretation of the research findings, the concepts of uncertainty and stigma are discussed, drawing on research and theoretical literature to deepen insights. Thereafter, with nursing practice in mind, Peplau's Theory of Interpersonal Relations (Peplau, 1952) is contemplated to help frame the mental health nurse (MHN) role in supporting family members and friends of people at risk of suicide.

6.1 Key research findings with extant literature

The findings from this research support outcomes of the literature review preceding the study and also reflect previous systematic reviews. The experience of uncertainty was universal and articulated in ways that showed it to be acute and overwhelming during suicidal crises and pervasive in the longer term. This finding strongly reflects the Uncertainty in Illness Theory (Mishel, 1988; Mishel, 1990), as will be discussed in section 6.4 below. The sense of traversing a trajectory arising from participants accounts resonates with the theme 'transitions' generated by Lascelles *et al.* (2023) and 'moral career' by Juel *et al.* (2021). Related, a doctoral study involving in depth interviews with partners of people who had attempted suicide (McGivern, 2021) found that even though the average time since the suicide attempt was 10.5 years, all participants viewed the transformative impact on their lives as permanent and ongoing. These findings encapsulate the longevity of caring, termed 'in for the long haul' in the current study. In the midst of this long haul, participants largely lived life in the here and now, with hope being expressed during periods of care recipient stability but also a constant awareness of the possibility of relapse. This constant awareness is comparable to the 'watching and waiting' stasis described by Nosek (2008) and the cyclical care process portrayed by Sun *et al.* (2008) although these authors did not find the sense of hope that was apparent in the present study.

The 'different and uncertain world' identified in this research echoes the 'new normal' described by Juel *et al.* (2023) wherein parents of teenagers and young adults had to reconcile with their inability to control their child's suicidality. However, these parents initially believed that they could resolve the situation for their offspring, with a stage of impasse being reached when they realised that resolution was beyond their control. In the current study, narratives suggested that participants did not experience the same early belief that they could facilitate resolution for their care recipient, rather a sense of helplessness was experienced. This was likely due to the established adult autonomy of the care recipients. Carer participants, even parents, did not have the level of authority parents of younger adults might possess and therefore felt more helpless in the wake of their loved one's wish to die.

Helplessness was also identified in the literature review (Lascelles *et al.*, 2023) resulting in hypervigilant behaviour to try control the uncontrollable (Spillane *et al.*, 2020, p. 5289). Becoming hypervigilant in response to constant worry and fear was a key finding in the current study with participants reporting negative health and social consequences of persistent hypervigilance, supported by evidence of low quality of life. Again, these detrimental consequences parallel findings in previous systematic reviews (Lascelles *et al.,* 2023, Lavers *et al.,* 2022), and strongly indicate a need for reflection on the act of hypervigilance

6.2 Uncertainty

Uncertainty experiences in this research ranged from individual to relational to external, although most data concerned the individual experience. Uncertainty set in when carers either realised or sensed something was wrong, or in direct response to being exposed to suicidal behaviour. Uncertainty was persistent over time, and inherent in participants perspectives on the future. Relational uncertainty was evident within carer and care recipient dyads as participants navigated their caring role and in relationships with mental health care providers when participants expectations were not met. At a wider macro level participant experiences indicated organisational and policy uncertainty about how caring in the context of suicidality is experienced, and subsequently carers received limited support and minimal tailored interventions. Explanations for macro level uncertainty might, in part, be explained by the dissonance participants experienced with regard to accepted language associated with caring and their own lived experience. This issue is expanded on below before moving on to relational and individual level uncertainty.

6.2.1 Macro level uncertainty: the language of caring

Evidence from this study shows that notwithstanding participants ready commitment to provide care in response to suicidality, the lexicon around the term 'carer' is not considered to be representative of their experiences. Previous research has highlighted the invisibility of caring for people at risk of suicide at practice, policy and strategy levels (Onwumere *et al.*, 2021; Lascelles *et al.*, 2023), which was echoed in the current research.   The fluctuating needs of care recipients further blurred comprehension of the caregiver terminology because at times participants did not feel they were caring and at other times it was all consuming. This made it difficult to extrapolate caring activity from the rest of their daily life and they struggled to enumerate the tacit components of caring such as general presence or constant worry.

Difficulties with quantifying informal care has been raised by Bittman *et al.* (2004) who proposed that conventional measures do not capture the true burden of caring such as the need to be on call or difficulties distinguishing care that is embedded into usual domestic activity. One approach to tackle this issue has involved obtaining data on various aspects of care for people with mental health problems, including time in standby and provision of emotional support beyond what would normally be expected in a relationship (Diminic *et al.*, 2021). This author found an average of 37.2 hours caring per week, but difficulties with quantification due to fluctuating demand were still acknowledged. Visual analogue estimations of caring time have also been attempted with a similar population, resulting in estimates of 43.42 hours caring per week (McDaid and Parker, 2022).

Evidence from the current study suggests comparability with the caring hours identified by these aforementioned studies. Despite this high intensity of caring, however, participants did not receive adequate support. Carers assessments were often experienced as somewhat futile and there was a sense from participants that they were not seen as bona fide carers, because of the impalpable nature of their caring role. As a result, participants did not feel recognised or supported.

From a macro perspective, it is plausible that the lack of attention to carers of people at risk of suicide in suicide prevention strategy stems from uncertainty about what their caring role entails, which in turn contributes to ongoing uncertainty about the role at community and organisational levels. From a research perspective, including the present research, this might result in unwitting exclusion of potentially eligible participants because of differing interpretations of caring and being a carer.

6.2.2 Relational uncertainty

Entry into the different and uncertain world involved new behaviours (suicidality) and new dimensions to the dyadic relationship (managing suicidality) which was unsettling. Reflecting the foregoing literature review, this study found that relationships between carers and care recipients had to be reframed. Eifert *et al.* (2015) interpret this relational change as a loss of a shared dyadic identity because the dyad cannot continue to function in the same way when one member becomes a carer. Not only were shared identities shifted, but self-identities were altered as participants put their lives on hold for caring; a common caregiver experience described as 'role engulfment and losing self' by Eifert *et al.* (2015, p. 360).

Reconstruction of identity when exposed to suicidal behaviour of offspring has been addressed in relation to parents of young people (Juel *et al.,* 2023) but is lacking with regards to parents of established adults. The current study shows that identity reconstruction with parents of adults involves a sense of backtracking to relinquished levels of parental authority which brought challenges because of the adulthood of the care recipient. This dynamic is acknowledged as a relational experience by Rolland (1984); (Rolland, 2018), who in his family systems in illness model, recognises uncertainty as being a central feature to familial (including partners) navigation of illness, and advises that pre-illness family functioning, past experiences, belief systems and sense of mastery all influence family members adjustment to the caring context.

Partner participants grappled with questions about themselves, their partner and their relationship status, which resonates with the concept of relational uncertainty posed by Knobloch and Solomon (2005). Three elements of self and partner uncertainty are defined by these authors; desire for the relationship, worthiness of the relationship and goals of the relationship. Some partners in the current research questioned goals of the relationship when the dyad shifted from an equal and intimate partnership to a carer/care recipient dynamic. This was generally not permanent but occurred when suicidality and mental health issues were pronounced. However, repeated cycles led, for some, to reflections as to whether original hopes of the relationship would be fulfilled, and during prolonged suicidal episodes desire for the pre-suicidal relationship could be lost. In some cases, this appeared to erode commitment to the relationship, suggesting goals, worthiness and desire for the relationship were somewhat compromised.

Presence and impact of relational uncertainty demonstrates a need for sensitive interventions that support adjustment and communication. The literature review showed a need for psychological interventions and a few participants in this research indicated that where this had been offered, be that for individuals, couples or parent/adult child dyads, it was beneficial. Mode of therapy was not sought but accounts indicated such interventions had been beneficial in addressing relational uncertainty. Joint psychological interventions linked to adolescent suicidality have been shown to be beneficial with parents of adolescents at risk of suicide (Frey and Hunt, 2018) and it is reasonable to anticipate benefits from tailored interventions for adults, although currently they are lacking (Krysinska *et al.*, 2021). In relation to illness within the family or couple relationship, Rolland (2018) highlights the importance of familial psychosocial interventions to assist adjustment and develop effective ways of managing consequences of illness, relationships and individual wellbeing.

6.2.3 Individual carer uncertainty

At an individual level, carers uncertainty was heightened at times of crisis and receded somewhat when care recipients were more stable, but it was ever-present to some degree. It manifested cognitively (by conscious processing of risk and safety), emotionally (through fear and worry), and behaviourally (by hypervigilance), and was experienced as highly stressful with detrimental effects on mental and physical wellbeing. Participants also experienced considerable existential uncertainty in relation to care recipients' wish to die, their perceptions of their own part in this decision making, and the realisation of their own (and services) limitations with regards to controlling outcomes.

Previous literature has uncovered experiences akin to uncertainty amongst carers (Juel *et al.*, 2021; Lavers, Andriessen and Krysinska, 2022; Lascelles *et al.*, 2023; Marshall *et al.*, 2023). One primary study was specific about the uncertainty experience (Vandewalle *et al.*, 2021) although this not contemplated alongside the uncertainty literature. Uncertainty is a well-studied phenomenon in nursing and healthcare. (Penrod, 2007) explains it as an uncomfortable perception of not knowing, which is stimulated by pre cognitive (e.g., gut feeling) and cognitive (information processing) ways of knowing. The sense of 'not knowing' was certainly felt by participants; they were uncertain about what was happening, how to respond, how to help and where to go to access support. Penrod, (2007) suggests that uncertainty is rooted in the meaning or outcome of a life experience, such as illness, or in the case of this thesis, suicidality. The dynamic and long-term nature of uncertainty uncovered by this research is also highlighted by Penrod, (2007), and she asserts that the aim of uncertainty management strategies should be reduction as opposed to eradication because uncertainty can never be expelled. This reflects the adjustment to the uncertain world wherein suicide was a troublesome possibility that participants lived with.

To expand an understanding of uncertainty in the context of caring for someone at risk of suicide the findings of this research will now be considered against the uncertainty in illness theory (Mishel, 1988; Mishel, 1990).

6.2.4 The uncertainty in illness theory

In her uncertainty in illness theory (UIT), Mishel, (1998) defines uncertainty as the 'inability to determine the meaning of illness related events', which occurs when illness situations are 'ambiguous, complex and unpredictable' (Mishel and Clayton, 2008, p. 53). This definition resounds with the experiences shared by participants in the current research, who co-existed with the possibility of a suicide attempt they were unable to forecast. Furthermore, in the reconceptualised uncertainty in illness theory (RUIT), Mishel (1990) differentiates between uncertainty in acute and chronic stages of illness reflecting the initial and long-haul stages identified in this research. There are three key phrases of the UIT: antecedents to uncertainty, appraisals of uncertainty and coping strategies to manage uncertainty. Antecedents of uncertainty include *stimulus frame*, which involves symptom patterns, familiarity with illness related events and congruency of events to the illness presentation; *cognitive capacity* i.e., one's ability to process illness related information; and *structure providers*, which relates to education and social support provided by appropriate organisations. Where an individual is unfamiliar with symptoms or illness related events, they are unable to process said events, and support and education from healthcare providers is low or absent, uncertainty will be higher.

Appraisals of uncertainty range from danger to opportunity, for example danger to due perceived risk of death, and opportunity related to what one can manage to achieve in the context of illness. Coping and management strategies derive from uncertainty appraisals and have the aim of control in the face of danger appraisals, and facilitation when uncertainty is appraised as opportunity. In the UIT, the ultimate aim of management strategies is to return to a pre illness event level of functioning. The RUIT, however, recognises the need to adjust to chronic or progressive illnesses rather than aspire to pre illness states, and the emphasis is on forming a new life perspective whereby one integrates uncertainty into the 'natural rhythm of life' (Mishel and Clayton, 2008, p. 58). This involves adopting a probabilistic thinking style where the 'expectation of certainty and predictability is abandoned' (Mishel and Clayton, 2008, p. 58). When uncertainty becomes an accepted part of day-to-day life, opportunity appraisals are more likely to develop. In such cases the emotional response of hope is common (Kuang, 2018) and can become a strategy which tempers danger appraisals, even if they cannot be completely eradicated.

The UIT and RUIT are derived from the patient's illness experience and although references are made to carers experiencing uncertainty alongside the patient, and the importance of carers supporting a probabilistic view of life is stressed (Mishel and Clayton 2018), the original theories do not explore carers' own uncertainty in any depth. However, they have been applied to family caregivers in relation to dementia (Unson *et al.*, 2015), Parkinson's disease (Hurt, Cleanthous and Newman, 2017), and schizophrenia (Baier, 1995; Bora and Buldukoğlu, 2020), with findings indicating that the phases of both the UIT and RUIT are applicable to family members and carers. Evidence from the current study also suggests that the UIT and RUIT (hereafter denoted as R/UIT when combined) have direct relevance to the carer experience. Importantly, this relevance is for the carer as a singular entity, as opposed to part of a dyad, because in relation to suicidality the carer uncertainty experience does not mirror the patient experience of uncertainty, rather it is contrary. Participants wanted to preserve life and felt uncertain about whether or not this was possible, while their care recipients contemplated or took steps to end life (where it can perhaps be assumed that any uncertainty was more likely to relate to life or death, or whether or not a chosen method would work). This might differentiate carers of suicidal individuals from counterparts caring for someone with physical illnesses where, although varying experiences of different family members are recognised, there is an overall shared understanding about trying to maintain living whilst the illness allows (Rolland, 2018). The divergent goals of carers and care recipients regarding suicide demarcates the carer experience from the patients and highlights the importance of carers being understood as individuals with their own experiences and responses.

6.2.5 Uncertainty in first and acute phases of suicidality

Uncertainty and associated reactions described by participants were invariably overwhelming when they were first exposed to care recipients' suicidality. Through the UIT lens this related to the absence of symptom patterns or event familiarity and reduced cognitive capacity to process what was going on. Mishel (1988) proposes that uncertainty is a neutral cognitive state until it is appraised as either opportunity or danger and only then is it associated with emotions. However, affective responses to uncertainty are usual (Penrod, 2007), particularly anxiety (Kuang, 2018). Evidence from the current study indicates that for carers, suicidality is always associated with strong emotions, mainly fear and worry, particularly in early and acute stages. Strong emotions result in hot cognition (Robinson *et al.*, 2013) i.e., one's thinking is influenced by emotions. Hot cognitions can result in compromised cognitive capacities (information processing ability), which increase uncertainty (Mishel, 1988; Vander Haegen and Etienne, 2016).

Participants first contact with mental health services was generally in the midst of suicidal crises and therefore their cognitions were likely to have been 'hot'. They approached services in highly charged emotional states with expectations and blind faith that HCPs would treat care recipients and reduce or eradicate suicide risk. These expectations might be explained by the 'powerful others' dimension of health locus of control, whereby participants held beliefs that HCPs could affect health outcomes (Green, 2004). Such a stance is understandable given that carers perceptions of their ability to manage may be compromised by hot cognitions and the underlying emotions of fear and helpfulness.

An important finding of the current study is that HCPs' were commonly experienced as ineffective in reducing uncertainty during suicidal crises, rather their interventions often increased uncertainty and stress. This might be due to the failure of professionals to recognise and attend to carers own crisis responses, including hot cognitions and loci of control, instead putting expectations on them to manage care recipients' safety at home without preparation or assistance.

The possibility that carers might experience hot cognitions and possess a powerful others locus of control is clinically important and awareness of these potential factors should inform the ways in which HCPs approach and interact with carers. If carers' cognitive capacities are compromised by hot cognitions, it might, on the one hand, contradict the call to work in egalitarian partnerships with carers highlighted in the literature review and elsewhere (Van de Bovenkamp and Trappenburg, 2010), at least at points of crisis. At these times carers clearly feel immobilised by fear, worry and helplessness, which may compromise their ability to provide care and they may, therefore, need leadership and direction from HCPs. On the other hand, hot cognitions and powerful others' loci of control do not mean that carers are not in possession of salient information about the patient, nor that they lack perspectives on effective crisis management strategies. However, to engage in collaborative dialogue with carers, hot cognitions must first be attended to and not ignored or misinterpreted (for example by seeing the carer as an angry and unreasonable relative). Clinicians should be educated in the effects of hot cognitions and seek to understand, validate and attend to carers emotions before placing expectations on them to contain and manage patients distress and safety. Whilst HCPs have a responsibility to support patients and families in managing suicidality and they carry expertise in assessment, like carers they cannot predict suicidal acts. It is important, therefore, not to reinforce disproportionate powerful others' loci of control by ensuring transparent and honest communication.

6.2.6 Hypervigilance as an uncertainty management strategy

Findings from this study show that uncertainty related to suicide is appraised as danger, particularly in initial and acute phases. This might be attributable to anticipatory loss (Rolland, 1990), which can be acute or chronic and is defined as living with 'possible, probable or inevitable loss' (Rolland, 2006). The danger is death by suicide, thus loss, and it is anticipated due to past or threatened behaviour.

Danger appraisals result in responsive actions geared toward risk mitigation and emotion regulation (Mishel, 2008), and confidence and control (Penrod, 2007). Hypervigilance was the main responsive action applied in this research. This is a common strategy used by carers experiencing anticipatory loss (Rolland 1990; Rolland 2018) and it is well documented with regards to suicidal behaviour (Lavers, Andriessen and Krysinska, 2022; Lascelles *et al.*, 2023; Marshall *et al.*, 2023). It is both control and emotion focussed because it involves behaviours to increase control (restricting care recipient autonomy to prevent a suicidal act) and accordingly it reduces carers' sense of helplessness and mediates worry and fear. Hypervigilance may be a way of trying to establish an internal locus of control based on the belief that one's own actions can affect health outcomes (Green, 2004). An internal locus of control can be important for one's own emotion regulation, but it might be an unrealistic way of managing the behaviour of others. Gibbons (2021) suggests that sustained hypervigilance might dissociate care recipients from the wish to live as this responsibility becomes increasingly located in others, be that informal carers or staff. In relation to healthcare, Veale *et al.* (2023) argue that the hypervigilant practice of constant observations objectify individuals as 'risks' and prioritise physical safety at the expense of emotional safety. In the context of informal caring, this might suggest that if carers focus solely on behavioural vigilance, open communication between them and care recipients may be stymied and the validating ambiance of loving presence, compromised. This is likely to perpetuate relational uncertainty. Furthermore, constant vigilance is a draining and lonely experience; the current research identified that participants were isolated in their caring roles and had little support with their vigils. In addition, they reported mental and physical health consequences that appeared to be linked to uncertainty and subsequent hypervigilance. These effects are reflected in the literature; negatively appraised uncertainty has been associated with adverse mental health outcomes (Massazza *et al.*, 2023) and hypervigilance has been qualitatively linked with carer burnout (Sun and Young, 2008, Nosek, 2008), which is known to be associated with poor health and social outcomes (Gérain and Zech, 2019). The literature review for this study generated the subtheme 'the toll of vigilance' in which effects on mental and physical health were highlighted, particularly in relation to lack of sleep. Similarly, the thematic analysis derived the theme the 'the toll of worry and vigilance' reflecting the consistent observation of the detrimental consequences that fear and worry, and the behaviour of hypervigilance has on carers.

In summary, the current research, along with relevant extant literature confirm that whilst hypervigilance might alleviate carer distress in the short term, longer term consequences for both the carer and care recipient are likely to be deleterious. Clinicians should take care to understand the familial context and social support available to caregivers before prescribing or endorsing vigilant behaviour. Interventions for carers, should focus on alternative ways of managing uncertainty and offer different, or additional, strategies to hypervigilance that address psychological safety. Clinicians must take time to understand carers' cognitive capabilities, expectations and loci of control, with the aim of developing a collaborative relationship when carers feel able to do so. Safety planning, which is considered an important intervention in reducing suicidal behaviour (Nuij *et al.*, 2021), and should ideally involve carers to promote helpful communication, can help with this aim and support a shift towards a 'safety' emphasis rather than a 'risk' emphasis (Mughal *et al.*, 2023). MHNs in particular are in an ideal position to engage families in safety planning because they are often the clinician with whom patients and carers have the most frequent contact.

6.2.7 Managing uncertainty with Information & education

A key strategy to manage uncertainty is information (Mishel, 1988; Mishel, 1990; Mishel and Clayton, 2008; Kuang, 2018). In the current study information received from HCPs was often perceived as inadequate. One reason for this might be that whilst information related to suicide can provide facts and advice, it cannot offer solid answers. Njå, Solberg and Braut (2017) consider uncertainty related to risk to be ontic in nature because future risk cannot be accurately known even by increasing epistemic knowledge. Similarly, Large *et al.* (2017) assert that uncertainty about suicide risk is principally aleatory and knowing more is of limited help because epistemic uncertainty plays only a minor part. These unknowns mean that mental health clinicians themselves can feel uncertain about how best to support suicidal patients despite perceiving high expectations that they should know what to do (Smith *et al.*, 2015). In addition, clinicians are known to feel uncertain about how to work effectively with carers and family members (Gorman *et al.*, 2023) and thus it is feasible they just do not know what information to give carers of people at risk of suicide. Furthermore, Information alone is considered to be an overly simplistic intervention (Kuang, 2018), unlikely to counter existential uncertainty (Penrod, 2007). Yet, the current research found information to be a key need identified by carers which echoes outcomes of systematic reviews in the field, e.g., Lascelles *et al.* (2023). These findings cannot be ignored, but the fact that carers want information, although at the same time find information to be of limited benefit, poses somewhat of a quandary. It may suggest an information health locus of control (Green, 2004) i.e., the belief that awareness of knowledge and information influences health outcomes.

The type of information is perhaps of significance here. Evidence presented in this thesis underlines the importance of *relevant* information that is conducive to learning. This does not equate with provision of generic leaflets, for example, but must be part of a broader educative intervention. Psychoeducation is posited to be of benefit to carers of people at risk of suicide (Grant, Ballard and Olson-Madden, 2015) and was identified as a need in the current study. To ensure helpful and relevant information giving, outcomes of this study highlight the importance of clinician reflexivity when working with carers of adults at risk of suicide. Effective reflexivity will help professionals remain focused on carers experiences and needs rather than their own uncertainty. Clinicians should listen to carers accounts of their experiences and needs and tailor interactions and information accordingly, ideally as part of a psychosocial intervention. It is beyond the scope of this study to explore the content of information given to carers but from the interpretation of the findings we can conclude that information and education about uncertainty might be usefully received. This would necessitate clinicians helping carers to reconcile with ongoing uncertainty rather than trying to provide certainty and thus raising unrealistic expectations.

6.2.8 Uncertainty in the long haul

As discussed above, the RUIT conceptualises uncertainty as a continuous state for which a probabilistic stance is assumed, based on the belief that it is not possible to be sure of everything or foresee results (Bora and Buldukoglu, 2020). Probabilistic thinking involves contemplating multiple possibilities to address problems in the same way that pragmatist thinking aims for warranted assertions as opposed to concrete truths. Mishel (2008) postulates that through this process, appraisal of uncertainty can shift from danger to opportunity. Opportunity is not a word that fits easily with caring for someone at risk of suicide, although it can perhaps be interpreted as developing skills and strategies over time which are more effective in supporting care recipients than highly charged hypervigilance. This was demonstrated by the ‘in for the long haul’ theme of the current study when less frenetic strategies emerged as participants reached a realisation that they couldn’t fix the situation and therefore had to accept their limitations. Mishel (1990) notes that patterns in presentation and familiarity with illness events develop over time, which can temper uncertainty. In the current study behavioural patterns were recognised by participants as they experienced suicidal cycles. Because they anticipated continuation of these, carers became conditioned to ongoing uncertainty and anticipatory loss, but they also developed tacit ways of knowing as their event familiarity grew, reflecting the aforementioned pre cognitive ways of knowing in uncertainty identified by Penrod (2007). Pre cognitive knowing was evidenced by the common experience of 'walking on eggshells' in response to, or in anticipation of suicidal behaviour when potential warning signs were sensed.

Qualitative data indicated evidence of positive growth with long-term carer participants suggesting that acceptance of limitations enabled them to tolerate existential uncertainty about meaning and survival. Whilst affective responses to uncertainty remained, these were more akin to an implicit sadness about the possibility of suicide rather than acute emotional pain and helplessness. Penrod (2007) recognises positive growth through the experience of uncertainty whereby confidence is bolstered, and previously unconsidered forms of control are realised. Narratives of those who had achieved such growth suggested they had resituated their loci of control by optimising their internal locus of control to enable them to manage their own responses but relinquishing it in terms of managing care recipients' behaviour. Instead, they reluctantly accepted care recipients' internal loci of control. This was not a pessimistic move, rather it was a step taken when they were able to hold hope that care recipients would choose to live.

Most interview participants who had achieved positive growth had engaged in some form of psychological or psychosocial intervention, highlighting the need for effective and tailored therapeutic interventions for this population.

6.2.9 Reasonable hope as an uncertainty management strategy

Hope is intrinsically linked to uncertainty (Duggleby *et al.*, 2010; Kuang, 2018) and findings of this research highlight it as an important enabling factor with regards to ongoing caring for people at risk of suicide. Participants accounts reflected findings by Duggleby *et al.* (2010) that transitional refocusing from a difficult present to a positive future in the context of ongoing uncertainty characterised hope. As in the Duggleby *et al.,* (2010) review, conceptions of hope in the current study were predominantly rooted in the present or near term, specific to certain goals or tasks, or simply related to taking things day by day. Situating oneself in the here and now was a learnt protective strategy developed by participants based on experiences of repeated and unpredictable suicidal cycles. The research findings demonstrate that over time carers became skilled at tolerating uncertainty by balancing hope and fear, which is akin to the concept of reasonable hope (Weingarten 2010). Reasonable hope concerns what might be attainable rather than what may be desirable. (Weingarten, 2010) claims that by referring to reasonable hope the polarities between hope and hopelessness are moderated and thus it is more achievable to reside with both hope and uncertainty. He goes on to note that reasonable hope is a humble hope, at the heart of which is sensemaking of individual experiences and not a focus on positive outcomes that can never be guaranteed. The findings of the current study suggest that concept of reasonable hope may have utility for carers of those at risk of suicide because it does not avoid the possibility of loss. Including reasonable hope in psychosocial interventions for carers may help with acceptance of uncertainty and help to improve carers quality of life.

6.2.10 Summary

In summary, uncertainty is central to the caring experience and also evident at organisational and policy levels. Understanding this prominence is a positive step towards establishing effective responses and interventions for carers. The R/UIT provides a useful theoretical framework to help clinicians understand carers uncertainty, and their own. Related concepts of anticipatory loss, loci of control and reasonable hope offer additional lenses to help carers and clinicians make sense of carers experiences and address their needs.

6.3 Stigma and negative attitudes

In this study, stigma was experienced at individual, relational and community levels. The measure of perceived stigma used indicated that participants did perceive stigma of suicide attempt. They also scored highly on the control item indicating attribution of suicidal behaviour to mental disorders, which was reflective of previous research (Scocco *et al.*, 2012). The high scores might be explained by the fact that nearly all participants reported their care recipients had current or past involvement with mental health services, suggesting a presence of psychiatric pathology. Suicidal behaviour is not in and of itself a diagnosis, therefore where suicidality occurs in the context of a mental disorder it is perhaps unsurprising that it is attributed to the disorder. This also reflects public opinion; (Pescosolido, 2013) found that even in countries where general stigma was low the public stigma towards violence towards the self by mentally ill individuals was high.

The vast majority of participants disclosed that their care recipients had a history of previous suicide attempts or self-harm which might have contributed to higher perceived stigma, self-stigma or courtesy stigma (stigma by association). Perceived stigma is an experiential stigma (Pescosolido and Martin, 2015) based on beliefs which are shaped throughout life (Rao *et al.*, 2009). As such, any stigma, including perceived stigma, is inherently social (Goffman, 1963) and perceived or anticipated stigma can only be made real through social experience (Pescosolido and Martin, 2015). Social interactions participants in the current research had witnessed or experienced in relation to previous suicide attempts or self-harm of their care recipients likely influenced their responses to the STOSA questions. Scocco *et al.* (2016) postulate that previous suicidal episodes and associated experiences of stigmatisation result in higher perceived stigma, which can become internalised to become self-stigma. Moreover, Carpiniello and Pinna (2017) suggest that family members can experience similar stigma processes to suicide attempt survivors, which might include courtesy stigma i.e., carers are stigmatised because of their affiliation with the care recipient. The current research supports these perspectives, with qualitative data elucidating stigmatising attitudes from social networks and self-stigma, for example experiences of peers labelling the care recipient as mentally ill and unhealable, and participants feeling a sense of shame directed toward the self.

By far the most common stigmatising experiences exposed in this research, however, were at the hands of mental health care professionals. This type of stigma is known as provider-based stigma, defined by Pescosolido and Martin (2015) as ‘prejudice and discrimination voiced or exercised, consciously or unconsciously, by occupational groups designated to provide assistance to stigmatized groups’ (p. 92). Findings suggest that negativity and stigma from HCPs contributed to reduced quality of life because participants felt unsupported, expectations of services meant they had little choice but to provide ongoing care even during crisis periods. Consequently, their caring stress was increased. Negative encounters with mental healthcare providers perpetuated isolation and influenced participants perceptions of their identity. Tensions with services continued over time for several participants and whilst these cannot all be put down to stigma it is feasible that stigmatised attitudes played a part in the long as well as short term.

Statistically significant relationships between perceived stigma quality of life were shown in this research. This finding somewhat contradicts results from Maple *et al.* (2021) who found that only beliefs that those who died by suicide were isolated were (weakly) associated with caregiver burden. However, these authors' results are not directly comparable to those of this study because the stigma measure they used asks for participants own views rather than perceived stigma of others, and the focus is on completed as opposed to attempted suicide. It may be that the STOSA emphasis on attempted suicide was more relevant to carers current experiences hence the associations with carer support, stress and choice identified in the present research. The objectives of the Maple *et al*. (2021) study did not include asking about experiences with healthcare services, but they did ask for perceptions of support generally, with 54% of their sample indicating low and inadequate support. So, in fact this might indirectly support the findings of the current research, which suggest that the associations between perceived stigma and quality of life might be explained by negative and stigmatising experiences with mental health services.

The detrimental nature of professional negativity and stigmatisation was confirmed by contrary participant accounts of positive experiences with mental health services, which involved non stigmatised interventions such as recognition, validation and listening without judgement.

These research findings echo outcomes of the literature review which identified that negative and stigmatising experiences with healthcare services resulted in difficulties within the caring role and compounded adverse effects on carers' health and social wellbeing, whereas positive and affirming experiences brought benefits and reduced burden. Findings indicate that stigma was experienced in a variety of ways, which are summarised in figure 8.

Figure 8: Forms of stigma experienced by participants in this research

Perceived Stigma	• Measured by STOSA scale • Attribution to mental illness = high • Perceived stigma associated with low quality of life
Self Stigma	• Blaming self for care recipients' suicidality (mothers) • Shame, embarrassment of situation
Courtesy Stigma	• Negative attitudes towards people who self-harm/attempt suicide/have mental health problems and, by association, carers
Provider based stigma	• Witnessing negative attitudes and hostility towards patients • Mother blaming • Excluded from care, dismissed, talked down to

6.3.1 Mother blaming

In addition to a more generalised perception of stigma, all four interview participants who were mothers of daughters, reported feeling blamed by staff for the suicidal behaviour of their daughters. This sense of feeling blamed was not reported by other interview participants suggesting that mothers of daughters are held responsible for their daughters' conditions and behaviours in ways that other relations are not. Overt accusations from professionals were not disclosed, rather participants described perceptions of blame from staff, suggesting the presence of professional stigmatisation. However, they also talked of their own self-reflection on their parental role, including wondering if they were at fault. They felt the need to challenge previously held assumptions about motherhood, which included questioning their mothering ability. This processing might have involved self-blame, underpinned by a parental sense of responsibility and concern about anything bad happening to their children (Corrigan and Miller, 2004), an attitude which might have been reinforced, or perceived to have been reinforced, by HCPs. Guilt is a frequent early emotional response of carers (Lascelles *et al.,* 2023), and parental self-blame has been shown to be a common initial response to a daughter's self-harm (Giffin, 2008; Lindgren, Åström and Graneheim, 2010; Juel *et al.*, 2023), which can lead to feelings of shame and fear about responses from others, including HCPs (McDonald, O''Brien and Jackson, 2007). It is conceivable that self-stigma and perceived stigma based on these intrapersonal experiences might explain perceptions of blame from professionals rather than tangible evidence of such. On the other hand, mother blaming is a recognised phenomenon which has been highlighted through the tone of journal articles (Caplan (Caplan and Hall-McCorquodale, 1985), raised as a therapist habit (Allan, 2004) and experienced by mothers in a variety of contexts (Jackson and Mannix, 2004), including self-harm (Lindgren, Åström and Graneheim, 2010; O'Keeffe *et al.*, 2021). Historically, psychiatry was quick to hold mothers responsible for mental health conditions of their offspring (Harrington, 2016) and whilst this view is no longer espoused, the aforementioned studies suggest it may still be covertly present. Therefore, a possible explanation for the stigmatised attitudes some participants in this study experienced is conscious or unconscious mother blaming by mental health professionals. Additional possible explanations are discussed below.

6.3.2 Possible explanations for provider-based stigma

This research did not collect data from clinicians about their attitudes towards and perspectives on carers of people at risk of suicide and thus it is not possible to compare narratives to make sense of the dynamics between carers and HCPs. However, as this professional doctorate is concerned with both mode 1 and mode 2 knowledge, with the latter having a focus on application of the evidence generated from the research findings, it is expedient to consider possible explanations for the stigma experienced by carers in order to address its presence in practice effectively. Carer reports of negative healthcare staff attitudes are ubiquitous in the caregiver literature (Lascelles *et al.*, 2023) and numerous studies have found negative attitudes towards patients who self-harm, particularly those who repeat self-harm (Taylor, Hawton and Kapur, 2009; Karman *et al.*, 2015; Murphy, Keogh and Doyle, 2019; Uddin *et al.*, 2023). Whilst these studies have a focus on self-harm, they also include attitudes towards suicidality as many studies do not differentiate between suicidal and non-suicidal self-harm. Participants in the current research were predominantly caring for individuals with a history of self-harm and suicide attempts and the negative attitudes they witnessed from staff may have been towards the phenomenon of repeat self-harm rather than suicide. Nonetheless, it is perhaps logical to conclude that if stigma is witnessed or experienced by carers of those who repeat self-harm without suicidal intent, it will likely be experienced by those who do so with intent. Regardless, given that self-harm, particularly repeat self-harm, is the single biggest risk factor for suicide (Knipe *et* *al.*, 2022), patients who self-harm must be seen to be at potential risk of suicide. Thus, research on attitudes towards self-harm is of relevance when considering the experiences of this population and may have influenced the perceived stigma of participants. Pescosolido and Martin, (2015) note that provider-based stigma is often unconscious. Implicit bias held at a subconscious level is automatically activated during clinical encounters (Merino, Adams and Hall, 2018), and practitioners may not be aware of how they come across to carers, nor of the detrimental impact their interactions can have on carer wellbeing. It is important, therefore, to consider what the mechanisms of the stigma experienced by participants in this study might have been in an attempt to raise clinical consciousness of stigma and inform education. Possible explanations might include clinician anxiety, malignant alienation and countertransference hate.

6.3.3 Clinician anxiety

Clinicians experience considerable anxiety when working with patients who engage in suicidal behaviours (Morrissey and Higgins, 2019; Clua-García, Casanova-Garrigós and Moreno-Poyato, 2021) and feel a strong sense of responsibility for preservation of life (Smith *et al.,* 2015). The seminal work of Menzies (1960) can help with reflection on the role staff anxiety might have on attitudes towards carers. Menzies identified that nurses experienced high levels of anxiety related to the nature of their work, particularly when it involved incurable conditions. She proclaimed that an aspect of the nurse's role is to absorb strong feelings projected on to them by patients and families, for example anxiety and fear related to illness and prognosis. Menzies observed familial projection, whereby family members forced responsibility for the patient on to staff and services so that they could avoid facing it themselves. This might be considered a powerful others locus of control as discussed in 6.4.1 above. Menzies described these projected feelings as being 'psychically added' (Menzies, 1960, p. 99) to the nurses own emotions. Menzies went on to discern that nurses and their organisations had developed defensive task based techniques to manage anxiety and enable detachment and avoidance. Therefore, with Menzies theory in mind, it may be that an exchange of mental defence mechanisms takes place between carers of patients at risk of suicide and clinicians, namely projection [by carers] and avoidance [by clinicians]. Carers might understandably interpret avoidance as rejection or stigmatisation, and clinicians might reinforce this by persistent avoidant behaviour.

6.3.4 Malignant alienation and countertransference hate

Malignant alienation (Morgan, 1979; Watts and Morgan, 1994) occurs when staff are confronted with patients who don't get better, and who therefore challenge clinicians 'narcissistic snares' of know all, heal all, love all (Maltsberger and Buie, 1974). Watts and Morgan (1994) declare that narcistic snares can be compounded by the hopes and expectations of patients at the start of treatment and it is viable that they can also be amplified by the hopes and expectations of carers. Initially clinicians might be seduced by the high expectations and faith of carers thus conveying promises of recovery and reinforcing a 'powerful others' health locus of control. If care recipients don't get better or carers are not appeased by professional interaction, carers may experience malignant alienation, either by their association with the patient (courtesy stigma) or in direct response to their own approaches to staff. Malignant alienation may result in a sense of therapeutic nihilism. Some accounts in the current study suggested therapeutic nihilism might have been present in the negative interactions carers had with professionals, which inferred nothing would change care recipients' suicidality.

One precursor to malignant alienation is countertransference hate (Maltsberger and Buie, 1974), an emotional response triggered by staff/patient interaction in the therapeutic/healthcare milieu which can be triggered by complex patients who present with repeated suicidality and are perceived as difficult to treat. Key components of countertransference hate are malice and avoidance. Malice manifests in antitherapeutic transactions, which might include stigmatisation, and avoidance rejects the patient completely. When HCPs have caseloads with high numbers of 'difficult to treat' patients and are therefore exposed to high numbers of carers whose expectations they cannot meet, the symptoms of countertransference hate might become entrenched and manifest as an overall negative attitude towards all patients and carers linked to repeated suicidality. Consequently, carers experience negative and stigmatising responses from clinicians (malice) or, alternatively, avoidance.

Maltsberger and Buie (1974) stress that countertransference hate is inevitable in therapy and is containable when therapists are conscious of it but can be harmful when it is unconscious. Whilst therapists are trained to understand, detect and reflect on countertransference responses, MHNs and other HCPs are less well educated in or prepared for these psychodynamics. Therefore, countertransference hate is more likely to be unconscious and harmful. Recent research into MHNs countertransference reactions to patients' suicidal behaviour (Caputo, 2021) found evidence of resentment and hostility towards patients and resignation and fatalism about suicide, which the author linked to countertransference hate. Where carers are closely involved with patients it is perhaps inevitable that they will become embroiled in this negative dynamic. Countertransference hate can potentially be influenced by external factors such as dysregulated organisations (Smith *et al.,* 2015), that do not provide staff with clarity or containment regarding care for suicidal patients and their families or carers. The negative experiences described by participants in this study may be related to observed or sensed countertransference hate towards their care recipient or experienced countertransference hate stemming from clinicians seeing them as an extension of the difficult to treat patient.

6.3.5 Applying understandings of anxiety defence mechanisms, malignant alienation and countertransference hate to practice

Using a psychodynamic perspective to frame carers difficult experiences with mental health clinicians is helpful when considering interventions to reduce negative and stigmatising attitudes and improve practice. The automatic response to changing attitudes is education, however, the effectiveness of education is equivocal. Schulze (2007) argues that there is little evidence that knowledge about mental illness and related stigma reduces stigmatised attitudes towards patients. Related, a recent systematic review looking at staff attitudes towards self-harm shows that the problem persists despite awareness of the problem and provision of educational interventions (Uddin *et al.,* 2023). Caputo (2021) advocates reflective practice alongside training to raise emotional awareness and highlights the importance of MHNs to have the opportunity to work on subjective feelings of inadequacy, helplessness and hopelessness. Introducing concepts such as clinician fear and anxiety, malignant alienation and countertransference hate into clinician education and reflective practice might go some way to raise awareness of how carers might be affected by unconscious stigmatising responses.

6.4 Towards a solution for mental health nurses and carers: learning from the Interpersonal Relations in Nursing Theory

MHNs have considerable contact with family members and carers, and given the nature of their roles it is possible they have more contact than many other HCPs within mental healthcare, particularly during times of crisis or hospital admission. They are, therefore, in a prime position to collaborate with carers (Skärsäter *et al.*, 2018) to understand their experiences of uncertainty and their associated needs, and to offer tailored support to facilitate acceptance and tolerance of uncertainty in line with the RUIT (Mishel 1990). The importance of a therapeutic relationship with carers to help achieve this is highlighted by the literature review and research presented in this thesis. Findings show that carers value being recognised as individuals, benefit from having their own responses and fears validated and require support, information and education regarding effective ways to support care recipients. In addition, MHNs should assess for impacts on carers mental and physical health, offer supportive psychosocial interventions conducive to need and provide signposting to community-based resources to support with caring and carer wellbeing.

The concepts of uncertainty and stigma have been discussed thus far in this chapter. The R/UIT provides a framework to help nurses understand carers responses to uncertainty and the psychodynamic concepts discussed in relation to stigma can assist in raising awareness of unconscious stigmatisation. In terms of nursing interventions, the Interpersonal Relations in Nursing Theory (Peplau, 1952) is a useful model to support MHNs in their practice with carers. Peplau heralded the concept of the nurse/patient relationship, which she developed from her nursing experiences, drawing on psychodynamic and interpersonal theory to inform her understandings. Whilst this theory was developed with the nursing of patients in mind, Peplau later espoused her intention to support the nurse/'*client*' relationship, with client being an individual, such as a patient or carer, or a couple or family (Forchuk and Dorsay, 1995). The theory has been shown to have utility when working with family caregivers (Yamashita, 1997; McCarthy and Aquino-Russell, 2009).

Peplau viewed nursing as a therapeutic interpersonal process wherein the nurse works with the client 'to solve a presenting difficulty about which there are common understandings'

(Peplau, 1988, p. 11). The theory outlines an interpersonal process which moves through four phases of orientation (entering into and defining the relationship), identification (gaining clarity about the problem and context, and establishing interpersonal supports), exploitation (using the nurse/client relationship to facilitate agency, skills development and growth), and resolution (closure). Throughout these phases, which can flow in a linear fashion or 'overlap or interlock' (Peplau 1988, p. 17), the nurse adopts various roles according to the client's expressed needs, the cues the nurse detects, and the nurses own responses. The main roles include those of stranger, resource person, teacher, leader, counsellor and surrogate, but Peplau acknowledges there are many other roles and urges nurses to use their 'intelligence and imagination' (Peplau, 1988, p. 70) to decide these. Anxiety is a major construct of Peplau's theory, conceptualised as a truth which is experienced differently by everybody. Anxiety is understood to be linked to illness uncertainty (Simpson, 1991) and influenced by personal characteristics and past experiences (Peplau 1988).

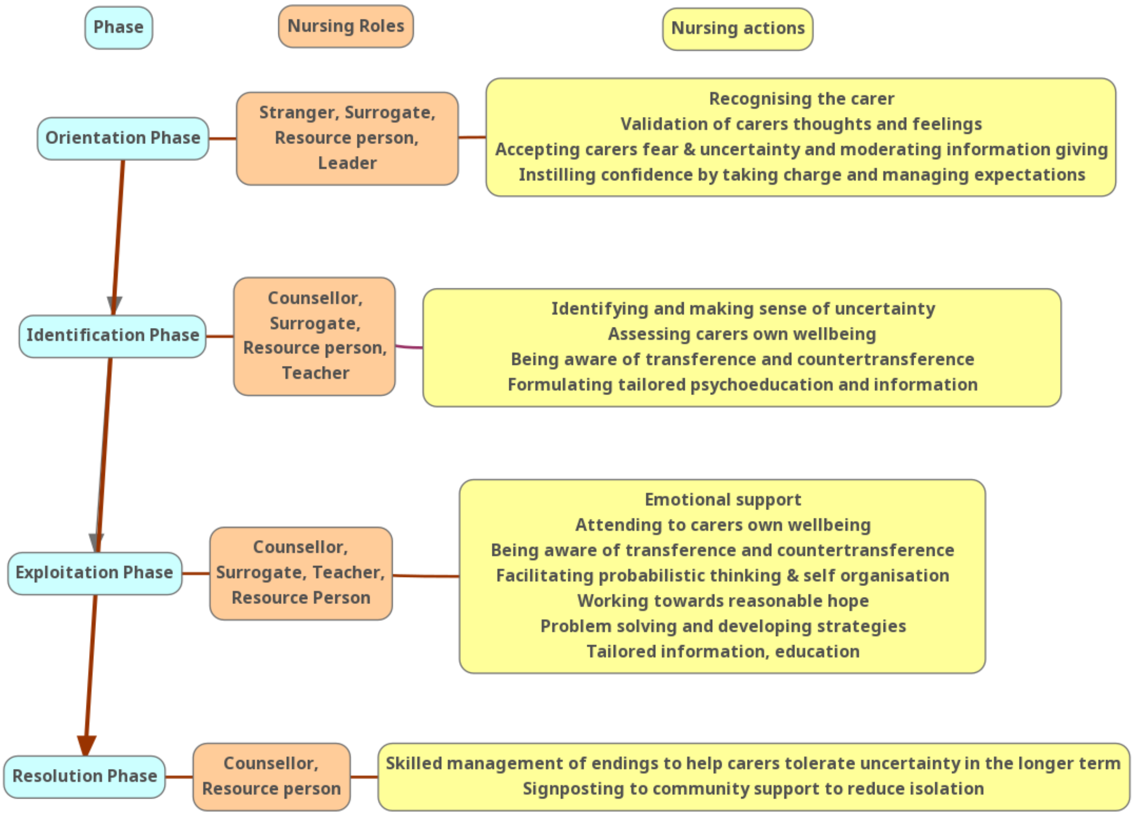
The nurse provides a measure of security through 'thereness' (Peplau ,1988, p. 133) to facilitate expression and sensemaking of the client's anxiety. Participants in the current research described overt anxiety related to fear of suicide but also more subtle anxieties linked to existential and relational uncertainty, and realisation of their limitations. Suicidality, uncertainty and anxiety go hand in hand, and it will never be possible for MHNs to eradicate carers uncertainty, nor their own. Therefore, in keeping with the RUIT (Mishel, 1990), the goal must be the formation of a new life perspective, of which uncertainty is part. Peplau's theory encourages nurses to face uncertainty and anxiety head on (Simpson, 1991). By moving between the various interpersonal roles, nurses can work with carers to convert some of their anxiety it into 'productive activity' (Peplau 1988, p. 135) whilst supporting reconciliation with remaining doubt and uncertainty. This aspect of Peplau's theory lends itself well to the application of the RUIT: Mishel (1990) proposes that adapting to long term illness related uncertainty involves a process of self organisation, probabilistic thinking and formation of a new life perspective. Self-organisation in this context has been defined as 'a transition between psychological instability and psychological adjustment'(Eppel-Meichlinger, Kobleder and Mayer, 2022). By definition, therefore, self organisation must involve conversion of anxiety to productive psychological activity, which MHNs can facilitate. Based on the findings of the current research, this, might involve, for example, helping carers shift from reliance on physical safety through hypervigilance to psychological safety through supportive presence, by modelling 'thereness' with care recipients and using problem solving and perspective taking interventions to work towards carers adopting a stance of reasonable hope.

Evidence from this study indicates that support from mental health professionals is experienced as inadequate and this perpetuates caregiver uncertainty. Bailey and Stewart (2017) observe that the formation of a new life perspective necessitated by ongoing uncertainty in illness can be stymied by structure providers (in this case healthcare professionals) who do not support probabilistic thinking, which is fundamental to self-organisation and achieving a new life perspective. It is suggested in this thesis that reasons participants' anxieties were not attended to by HCPs may include HCP avoidance due to their own discomfort, unconscious provider-based stigma and/or malignant alienation and countertransference hate. These factors prohibit effective and collaborative interactions with carers which are necessary to support development of a probabilistic attitude. The Interpersonal Relations Theory guides nurses to distinguish and attend to their own anxiety in recognition of the fact that if this is not processed it will interfere in the nurse/client relationship and the goals thereof. This level of self-awareness is a vital component of Peplau's theory and of relevance to stigma and countertransference hate; self-awareness has been identified as more likely to reduce stigma than education (Schulze, 2007) and is essential to work effectively with countertransference (Maltsberger and Bui, 1994, Caputo, 2021).

Based on the findings of the current study, all of the key roles Peplau espouses are of potential value when encountering carers and working with their acute and long term uncertainty. For example, poor experiences with mental health services were often from the first contact, when uncertainty is appraised as danger, and expectations of HCPS to mitigate this danger were not met. At this first contact carers and HCPs/MHN's are strangers. Peplau realises the instrumental effect the stranger role can have on the ensuing therapeutic relationship (Peplau, 1988, p. 44) and recognises the conscious and unconscious anxieties that can threaten this rapport. The surrogate role addresses projection, transference and countertransference, helping nurses to recognise and normalise it, thus enabling them to stay present with the carer and tolerate their uncertainty.

Figure 9 describes how, through the phases of the Interpersonal Relations Theory, the various nursing roles can be enacted to effectively support carers.

Figure 9: Use of the Interpersonal Relations in Nursing Theory to support adult carers of adults at risk of suicide



Peplau pronounces that nurses who use her theory will have existing specialist knowledge pertaining to their area of practice (Peplau, 1988). MHN education provides specialist knowledge but this will be enriched by inclusion of nursing theories such as the Interpersonal Relations Theory to support nurses develop effective therapeutic relationships with carers and patient/carer dyads. Of note, Peplau's theory, amongst others, has been found to be 'useful' in guiding practice (Younas and Quennell, 2019). It goes without saying, however, that for MHNs to develop confidence, reflexivity and wisdom in practicing Peplau's theory and its embedded psychodynamic principles, supervision is essential. Consideration of the application of the model to working with carers will necessitate a methodical team approach to ensure psychological safety of both carers and MHNs.

6.4.1 A perspective on Peplau and pragmatism

From a philosophical perspective, Peplau's theory has been judged to be representative of phenomenology because of the human and interpretive character of nursing (Gastmans, 1998). This stance might infer tension between the theory and the pragmatist leanings of the current research as there is debate about the compatibility or otherwise of pragmatism and phenomenology (Chemero and Käufer, 2016). However, Peplau herself did not align herself with phenomenology but with experience, which is not only the domain of phenomenology but is central to pragmatism, as discussed in chapter three. Moreover, Peplau has been hailed as revolutionising nursing because she embraced both medical and aesthetic knowledge and indeed borrowed knowledge from other scientific fields (Adams, 2017). Her theory can be seen to fit well with pragmatist thinking therefore, demonstrated further by the problem focused attitude underlying the theory and its relatability to warranted assertions as the nurse and client work together to increase understandings to address problems.

6.5 Chapter summary

This chapter has presented a discussion of the main findings from the study, drawing on relevant literature related to uncertainty and stigma. It has been suggested that the Uncertainty in Illness theory (Mishel, 1988; 1990) is a helpful lenses through which to understand carers experiences and to educate MHNs, other HCPs, and carers. The concepts of anxiety defence mechanisms, malignant alienation and countertransference hate have been contemplated as a possible explanation for the negative and stigmatising encounters carers experience with HCPs. It is argued that education alone is unlikely to change the current status quo with regard to carer support and involvement, and that these theoretical and psychodynamic understandings may have utility in developing more sophisticated and reflexive ways to support both carers and clinicians. Finally, with a particular emphasis on mental health nursing, the Interpersonal Relations in Nursing theory has been put forward as an ideal framework to assist nurses to implement the R/UIT in practice.

The next chapter discusses strengths and weaknesses of the study before concluding and presenting recommendations.

CHAPTER SEVEN: CONCLUSIONS AND RECOMMENDATIONS

7.0 Introduction

This chapter discusses strengths and weaknesses of the research described throughout this thesis before summarising the conclusions of the study and outlining key recommendations for policy, research, practice and education. The chapter, and this thesis, ends with a final personal reflection.

7.1 Strengths and Limitations of this doctoral research

The current study contributes to a growing evidence base of carers experiences related to caring for a suicidal individual and it is one of only a few to focus solely and specifically on carers of adults at risk of suicide. Findings have enlarged upon previous research by drawing on the Uncertainty in Illness Theory (Mishel, 1988; 1990) to explain carers responses and experiences and to inform nursing practice. In addition, the detrimental effects of hypervigilance have been identified as a behaviour which can be changed rather than solely as a characteristic of caring. By so doing, suggestions for transcending hypervigilance and considering alternate strategies have been made. This research has brought a novel perspective to the field by including carers' future perspectives and highlighting the value of reasonable hope in managing enduring uncertainty. The research appears to be the first in England to use a mixed methods approach when investigating this population, which is a key strength, particularly because it involved integration of three datasets. The convergence of the qualitative and quantitative data analyses adds weight to the overall findings.

Including a survey enabled a larger sample than interviews alone would have allowed, and the national recruitment strategy permitted people from a wide geography to take part. The online nature of the survey afforded complete anonymity and the self-selection enabled participants to self-identify as carers rather than being identified by a third party. A further strength of the survey was the inclusion of recognised and credible questionnaires which supported the validity of the survey. Moreover, PPI ensured acceptability. The semi structured interviews added richness and expanded on the topics covered in the survey.

The attention to reflexivity throughout the research can be seen as a strength and demonstrates authenticity and researcher integrity. From a MHN perspective a strength is the maintenance of proximity to practice from conception of the study to the theories drawn upon for the discussion. As such it is believed that the findings have direct relevance for front line clinicians and can be seen as fertile fodder to inform practice improvement. Another strength of this research is the addition of a real time evaluation of participation, which can be seen as good ethical practice due to the underpinning motive of ensuring non maleficence. Whilst the outcomes of the evaluation did not contribute to the key findings of the study, they do add a meaningful perspective to the evidence base on the impact of suicide related research. In particular, by demonstrating the benefits derived from participation despite the difficult emotions taking part also entailed, the evaluation highlights the value of research with carers, who are frequently viewed by ethics boards as being vulnerable and thus requiring excessive protection (Maple *et al.,* 2020).

There are several limitations, however. Firstly, with regard to survey design, the omission of three domains of the AC-QoL was on reflection rather arbitrary and the findings would likely have been improved by incorporating the full questionnaire. In addition, the cross-sectional design of the survey meant that it was only possible to examine relationships between variables and direction of causal influence could not be determined (Bryman, 2012). Regarding recruitment, as cautioned by Bethlehem (2010) online surveys will only be found by those with a) access to the internet, and b) access to the platforms on which the survey is advertised. In this study only carers connected to the organisations or individuals who distributed the survey, or those who subscribed to the relevant social media platforms or groups will have been made aware of the survey. There was no way of knowing how comprehensive distribution was, but it can be assumed that many potentially eligible participants would not have had the opportunity to participate in the research. This is reflected by the limited number of respondents for a national survey. Moreover, the sampling method employed is associated with low external validity (the extent to which findings can be generalised). The majority of participants were female and white British, therefore carers from other ethnic and gender groups were not adequately represented. Furthermore, most participants' care recipients were under the care of mental health services, thus, experiences of carers not engaged with services were not captured. However, notwithstanding these limitations, the sample was largely homogenous and thus findings might be generalisable to equivalent populations, which might be seen as a strength.

As with the current study, most caregiver research has involved largely female participants (Onwumere *et al.*, 2021; Lorenz-Dant and Comas-Herrera, 2022), including that investigating carers of people at risk of suicide (Maple *et al.,* 2021), so is possible that the majority of recognised carers, or at least those who identify as carers, are from this demographic. Even if this is the case, this pattern still highlights the importance of identifying unrecognised caregivers from male and minority groups. Strategies to increase involvement of under-represented populations in research include directly engaging with participants rather than via a third party, considerable investment of time on pre-engagement to build trust and rapport, multiple and creative efforts to facilitate engagement and transcending research participation to achieve strengths research based partnerships (Gallegos *et al.*, 2023). The present research did not achieve all of these strategies. Although the self-selection of the survey enabled direct engagement, there was still limited access to the survey, as discussed. Also, PPI was limited to consultation regarding research documents and data collection tools, and the individuals who assisted with this were all White British and female. Furthermore, pre-engagement time was not spent directly with potential participants to establish trust. However, given the scope of the doctoral programme there was a limit to how much time could be devoted to these strategies.

Finally, data analysis this was conducted solely by me as the researcher, albeit with oversight from the supervisory team. Inter-rater reliability was not tested, which might have been appropriate for the summative content analysis, although it is accepted that in reflexive thematic analysis individual analysis is acceptable (Braun and Clark, 2022).

7.2 Conclusions

This research has uncovered experiences and needs of 101 carers of adults at risk of suicide. Results indicate that carers are catapulted into a different and uncertain world when they are faced with their care recipient's suicidality which can be explained by Merle Mishel's Uncertainty in Illness Theory. For many caring is all consuming. Carers are not afforded choice: they take on the role out of love, obligation or both. They experience myriad emotions, pervasive uncertainty and associated stress, worry and fear, resulting in reduced quality of life, including impaired health and wellbeing. Inadequate support and stigmatising vibes from mental health services is a major problem, which perpetuates all of the difficult experiences of carers. Outside of the mental health context, recognition of carers of adults at risk of suicide and knowledge about their needs is poor. Provision of tailored support is the exception rather than the rule and this equation needs to be reversed. Despite all of this, carers in this study demonstrated dedication and resilience. They had developed strategies to help them through the long haul, including an ability for reasonable hope which enabled a mindful and present optimism. Additionally, participants volunteered valuable perspectives on what carers need to enable them to sustain their caring roles.

All of the findings from this research must be considered alongside the existing body of research which tells us loudly and clearly that carers are a vital and yet unpaid, marginalised and invisible arm of health and social care. The recommendations below aim to build on calls from previous research to improve carers lives and in turn help to reduce and prevent suicide.

7.3 Recommendations

Four key recommendations have been identified from the research presented in this thesis related to policy, research, clinical practice and education. These are outlined below.

7.3.1 Policy

In June 2008 under the Labour government a national carers strategy was published which espoused the following vision:

"….. by 2018, carers will be universally recognised and valued as being fundamental to strong families and stable communities. Support will be tailored to meet individuals' needs, enabling carers to maintain a balance between their caring responsibilities and a life outside caring, whilst enabling the person they support to be a full and equal citizen." (Department of Health, 2008, p. 9).

Notwithstanding this ambitious aim, a plethora of research has consistently shown that carers of people with mental health problems are not routinely involved in care or adequately supported. Sadly, the current study reinforces these findings and demonstrates that recognition of the specific experiences and needs of those who care for adults at risk of suicide is poor. There is a clear need stronger policy direction regarding support for and involvement of carers, and those who care for individuals at risk of suicide need specific attention in national and local strategy. Before this can be achieved, however, NHS & social care language related to informal caring requires review to ensure inclusivity and avoid perceptions that informal caring is only associated with dementia, disability, and tangible physical health conditions. The following recommendation supports this aim:

Recommendation One

A national (England and Wales) Delphi study should be designed and conducted, taking into account the need to ensure a wide range of views from groups that have yet to be represented in research, to establish consensus on appropriate language for caring in the context of suicidality. Outcomes of this study should be used to influence policy related to carers.

7.3.2 Research

Research with carers of adults at risk of suicide to date is mainly qualitative, based on individual perspectives and, including that presented in this thesis, cross sectional in nature. To increase understanding of carers experiences and needs over time, research needs to move on to longitudinal inquiry. Based on the current research it is recommended that:

Recommendation 2

Longitudinal mixed methods research is conducted to investigate carers experiences and health and social outcomes at various timepoints, from first exposure to care recipient suicidality onwards. Given the finding that uncertainty is central to the caring experience, the Uncertainty in Illness and Growth through Uncertainty scales should be incorporated to expand understanding, which can then inform interventions,

7.3.3 Clinical Practice

Given the lack of evidence based psychosocial interventions for carers of adults at risk of suicide there is a need for development and testing of interventions. Existing models or theory that appear to have relevance to caring in the context of suicidality can inform or be adapted to support intervention development. Based on the current research it is recommended that:

Recommendation 3

Findings from this research and the R/UIT are used to inform co-designed interventions for carers, which should include strategies to develop probabilistic thinking, achieve self-organisation, and create shared understandings to support formation of a new life perspective and attainment of effective coping strategies. Interventions should be evaluated and, accordingly, further developed.

7.3.4 Education

Suicide prevention should be part of all pre-registration training and service based training. As part of this, the experiences and needs of carers must be addressed. Based on the current research it is recommended that:

Recommendation 4

Findings from this research framed within the R/UIT and Theory of Interpersonal Relations are used to inform MHN education and training on family and carer involvement and interventions.

7.4 A final word: personal reflection

This doctoral journey has been a personal, professional and academic challenge, but more than that it has been an honour. The beauty of undertaking a professional doctorate is the nearness to practice. Throughout my nearly seven-year journey I have maintained a co-facilitator role in a carer support group for carers of people who engage in self-harm or suicidal behaviours. I often hear the group members use similar words to those research participants uttered, which reinforces my belief in common humanity. My commitment to improving support and interventions for carers of adults at risk of suicide has gone from strength to strength. But despite this, I have at times felt disappointed in my research because I have pondered that it has only told me what I had already elicited from my practice. My supervisors, mentors and peers have helped me remember that my immersion in the lives of carers privileges me in ways that most mental health nurses are not acquainted with. Therein lies the honour. I wish to end this thesis as I started; with gratitude to those who so generously shared their time and stories. Thank you.

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APPENDICES

Chapter 1: Introduction (Appendices 1 – 2)

Appendix 1: The critical clinical experience which informed the research question underpinning the research presented in this thesis

I worked with an adult patient and their adult family members (hereafter termed carers for anonymity purposes) following a near fatal suicide attempt in which a highly violent and lethal method was used. The carers had feared the patient was going to die as initial chances of survival were not considered to be high. During one of my conversations with the patient and their carers a natural and informal psychological debriefing took place, with each person telling their stories of the night of the suicide attempt. This was an emotional and pivotal moment for them as they shared their thoughts and feelings with me as a silent but mediating presence. I believe that this communication was essential for them to move towards adjustment to life beyond the suicide attempt. I hadn't anticipated this exchange, but through reflection I understood the importance of enabling families to talk about their experiences after suicide attempts and how perhaps we unwittingly inhibit, or avoid, this by focusing on the relief of the patient's survival. I considered support options for this family in the community and they were few; either primary care counselling, which had waiting lists and the counsellor may not have been equipped to deal with the situation, or carer support agencies, which were more geared towards offering advice, information and practical support with less emphasis on adjustment and emotional support. Moreover, the patient was not under the care of mental health services, meaning neither they, nor their carers, were in a position to receive support from a mental health team. So, there was nothing for them. The tragic irony of this situation was that had the patient died, their carers would have had access to specialist and peer support for people bereaved by suicide, but being merely *nearly* bereaved, they got nothing. I was left with a sense of inadequacy and a strong desire to understand the experiences and needs of those who care for adult family members or friends who are at risk of suicide.

Appendix 2: Insights into the ongoing nature of caring that have informed the research question underpinning the research presented in this thesis.

A parent who talked about bracing themselves every time they went home after work due to a longstanding sense of anticipation that their adult child would die as a result of self-harm, either with or without suicidal intent.

A spouse who, in the aftermath of a suicide attempt and anticipating the possibility of future attempts, urged their partner to leave a note for their children so that they were not left with feelings of responsibility.

A parent who had reconciled themself with the very real possibility that their adult child would die by suicide. This stance had been reached after many years of anticipating a lethal episode of self-harm and was a helpful realisation for the parent because it enabled them to accept that they could not control the situation and would not always be able to rescue.

Chapter 2: Literature review (Appendices 3-8)

Appendix 3: PRISMA Checklist

Section and Topic	Item #	Checklist item	Location where item is reported
TITLE			
Title	1	Identify the report as a systematic review.	Title
ABSTRACT			
Abstract	2	See the PRISMA 2020 for Abstracts checklist.	Part met
INTRODUCTION			
Rationale	3	Describe the rationale for the review in the context of existing knowledge.	introduction
Objectives	4	Provide an explicit statement of the objective(s) or question(s) the review addresses.	introduction
METHODS			
Eligibility criteria	5	Specify the inclusion and exclusion criteria for the review and how studies were grouped for the syntheses.	methods
Information sources	6	Specify all databases, registers, websites, organisations, reference lists and other sources searched or consulted to identify studies. Specify the date when each source was last searched or consulted.	methods
Search strategy	7	Present the full search strategies for all databases, registers and websites, including any filters and limits used.	methods
Selection process	8	Specify the methods used to decide whether a study met the inclusion criteria of the review, including how many reviewers screened each record and each report retrieved, whether they worked independently, and if applicable, details of automation tools used in the process.	methods
Data collection process	9	Specify the methods used to collect data from reports, including how many reviewers collected data from each report, whether they worked independently, any processes for obtaining or confirming data from study investigators, and if applicable, details of automation tools used in the process.	methods
Data items	10a	List and define all outcomes for which data were sought. Specify whether all results that were compatible with each outcome domain in each study were sought (e.g. for all measures, time points, analyses), and if not, the methods used to decide which results to collect.	Tables 2,3
	10b	List and define all other variables for which data were sought (e.g. participant and intervention characteristics, funding sources). Describe any assumptions made about any missing or unclear information.	Tables 2,3
Study risk of bias assessment	11	Specify the methods used to assess risk of bias in the included studies, including details of the tool(s) used, how many reviewers assessed each study and whether they worked independently, and if applicable, details of automation tools used in the process.	Methods, Supplementary file
Effect measures	12	Specify for each outcome the effect measure(s) (e.g. risk ratio, mean difference) used in the synthesis or presentation of results.	/
Synthesis methods	13a	Describe the processes used to decide which studies were eligible for each synthesis (e.g. tabulating the study intervention characteristics and comparing against the planned groups for each synthesis (item #5)).	Methods

Section and Topic	Item #	Checklist item	Location where item is reported
	13b	Describe any methods required to prepare the data for presentation or synthesis, such as handling of missing summary statistics, or data conversions.	Methods
	13c	Describe any methods used to tabulate or visually display results of individual studies and syntheses.	Methods
	13d	Describe any methods used to synthesize results and provide a rationale for the choice(s). If meta-analysis was performed, describe the model(s), method(s) to identify the presence and extent of statistical heterogeneity, and software package(s) used.	Methods
	13e	Describe any methods used to explore possible causes of heterogeneity among study results (e.g. subgroup analysis, meta-regression).	/
	13f	Describe any sensitivity analyses conducted to assess robustness of the synthesized results.	/
Reporting bias assessment	14	Describe any methods used to assess risk of bias due to missing results in a synthesis (arising from reporting biases).	/
Certainty assessment	15	Describe any methods used to assess certainty (or confidence) in the body of evidence for an outcome.	/
RESULTS			
Study selection	16a	Describe the results of the search and selection process, from the number of records identified in the search to the number of studies included in the review, ideally using a flow diagram.	Figure 1
	16b	Cite studies that might appear to meet the inclusion criteria, but which were excluded, and explain why they were excluded.	Supplementary file
Study characteristics	17	Cite each included study and present its characteristics.	Tables 2,3
Risk of bias in studies	18	Present assessments of risk of bias for each included study.	Supplementary file
Results of individual studies	19	For all outcomes, present, for each study: (a) summary statistics for each group (where appropriate) and (b) an effect estimate and its precision (e.g. confidence/credible interval), ideally using structured tables or plots.	Tables 2,3
Results of syntheses	20a	For each synthesis, briefly summarise the characteristics and risk of bias among contributing studies.	/
	20b	Present results of all statistical syntheses conducted. If meta-analysis was done, present for each the summary estimate and its precision (e.g. confidence/credible interval) and measures of statistical heterogeneity. If comparing groups, describe the direction of the effect.	/
	20c	Present results of all investigations of possible causes of heterogeneity among study results.	/
	20d	Present results of all sensitivity analyses conducted to assess the robustness of the synthesized results.	/
Reporting biases	21	Present assessments of risk of bias due to missing results (arising from reporting biases) for each synthesis assessed.	/
Certainty of evidence	22	Present assessments of certainty (or confidence) in the body of evidence for each outcome assessed.	/
DISCUSSION			

Section and Topic	Item #	Checklist item	Location where item is reported
Discussion	23a	Provide a general interpretation of the results in the context of other evidence.	Discussion
	23b	Discuss any limitations of the evidence included in the review.	Discussion
	23c	Discuss any limitations of the review processes used.	Discussion
	23d	Discuss implications of the results for practice, policy, and future research.	Discussion
OTHER INFORMATION			
Registration and protocol	24a	Provide registration information for the review, including register name and registration number, or state that the review was not registered.	Not registered
	24b	Indicate where the review protocol can be accessed, or state that a protocol was not prepared.	Methods
	24c	Describe and explain any amendments to information provided at registration or in the protocol.	/
Support	25	Describe sources of financial or non-financial support for the review, and the role of the funders or sponsors in the review.	Abstract
Competing interests	26	Declare any competing interests of review authors.	Title page
Availability of data, code and other materials	27	Report which of the following are publicly available and where they can be found: template data collection forms; data extracted from included studies; data used for all analyses; analytic code; any other materials used in the review.	Methods Supplementary files

Appendix 4: Citations of papers that were excluded after full assessment for eligibility

- **Reason for exclusion: insufficient focus on carer experience (specific to caring for a suicidal individual)**

Buila, S. M. D., & Swanke, J. R. (2010). Patient-centered mental health care: encouraging caregiver participation. *Care Management Journals*, *11*(3), 146-150.

Frey, L. M., Hans, J. D., & Cerel, J. (2017). An interpretive phenomenological inquiry of family and friend reactions to suicide disclosure. *Journal of Marital and Family Therapy*, *43*(1), 159-172.

McGill, K., Hackney, S., & Skehan, J. (2019). Information needs of people after a suicide attempt: A thematic analysis. *Patient education and counseling*, *102*(6), 1119-1124.

Rooney, L., John, M., & Morison, L. (2020). Communication strategies used by women to influence male partners to seek professional help for mental health problems: A qualitative study. *Clinical Psychologist*, *24*(1), 55-63.

Shivers, C., Russon, J., Benson, M. J., King, A., & Textoris, S. (2022). Siblings' Role Positions and Perceptions of Mental Illness. *Contemporary Family Therapy*, 1-11.

Sun, F. K., & Long, A. (2013). A suicidal recovery theory to guide individuals on their healing and recovering process following a suicide attempt. *Journal of Advanced Nursing*, *69*(9), 2030-2040.

Sun, F. K., Ko, C. J., Chang, S. L., & Chiang, C. Y. (2012). Comparison study of postdischarge care provided to suicide patients by family members in east and south Taiwan. *Journal of Nursing Research*, *20*(1), 53-65.

Thapa, P., Lama, S., Pradhan, N., Thapa, K., Kumar, R., & Basnet, M. (2021). Attitude towards suicide among caregivers of patients admitted with suicide attempt in a tertiary care hospital: A descriptive crosssectional study. *JNMA: Journal of the Nepal Medical Association*, *59*(236), 374.

- **Reason for exclusion: sample including predominantly bereaved carers**

Benson, O., Gibson, S., Boden, Z. V., & Owen, G. (2016). Exhausted without trust and inherent worth: A model of the suicide process based on experiential accounts. *Social Science & Medicine*, *163*, 126-134.

Clements, Caroline, Navneet Kapur, Steven H. Jones, Richard Morriss, and Sarah Peters. "Qualitative investigation of relatives' and service users' experience of mental healthcare for suicidal behaviour in bipolar disorder." *BMJ open* 9, no. 11 (2019): e030335.

Owen, G., Belam, J., Lambert, H., Donovan, J., Rapport, F., & Owens, C. (2012). Suicide communication events: Lay interpretation of the communication of suicidal ideation and intent. *Social science & medicine*, *75*(2), 419-428.

Owens, C., Owen, G., Lambert, H., Donovan, J., Belam, J., Rapport, F., & Lloyd, K. (2009). Public involvement in suicide prevention: understanding and strengthening lay responses to distress. *BMC Public Health*, *9*, 1-9.

- **Reason for exclusion: main focus on risk of suicide**

Aitken, M. E., Minster, S. D., Mullins, S. H., Hirsch, H. M., Unni, P., Monroe, K., & Miller, B. K. (2020). Parents' perspectives on safe storage of firearms. *Journal of community health*, *45*, 469-477.

Asare-Doku, W., Osafo, J., & Akotia, C. S. (2019). Comparing the reasons for suicide from attempt survivors and their families in Ghana. *BMC Public Health*, *19*, 1-10.

Hvidkjær, K. L., Ranning, A., Madsen, T., Fleischer, E., Eckardt, J. P., Hjorthøj, C., ... & Erlangsen, A. (2021). People exposed to suicide attempts: Frequency, impact, and the support received. *Suicide and Life-Threatening Behavior*, *51*(3), 467-477.

- **Reason for exclusion: care recipients predominantly 18 years or under**

Buus, N., Caspersen, J., Hansen, R., Stenager, E., & Fleischer, E. (2014). Experiences of parents whose sons or daughters have (had) attempted suicide. *Journal of Advanced Nursing*, *70*(4), 823-832.

Garcia-Williams, A. G., & McGee, R. E. (2016). Responding to a suicidal friend or family member: a qualitative study of college students. *Death studies*, *40*(2), 80-87.

Appendix 5: Characteristics of qualitative studies

Author/year /location	Research aim & design	Sample size (only including carers or bereaved participants)	Demographics: Carers (age/sex/ethnicity) Care recipients (age)	Caregiver relationship to care recipient	Summary of findings related to carers
Borisonik (2018) Russia	**Aim** To study the psychological consequences of suicidal behaviour for relatives of the suicidal person, as well as factors affecting the severity of depressive and anxiety symptoms. **Design** Pilot cross sectional study **Validated Measures** Adapted Beck depression and anxiety scales (Tarabrina 2001) The COPE questionnaire Carver et al adapted by Garanyan and Ivanova (2010) S. Muddy resilience test adapted by Osin and Rasskazova (2013) R. Moos Family Environment scale adapted by Kupriyanov (2009)	N = 40 26 carers 14 bereaved	**Carers (n=26)** 19 female (73.0%) 7 male (27.0%) Mean age 44 years (range 28-60 years) **Bereaved (n=14)** Mean age 40 years (range 18-50 years) 14 female (100%) Ethnicity not reported **Care recipients (n=26)** Mean age 25 (range 16-51 years) **Decedents (n=14)** Mean age 35 years (range 18-50 years)	**Carers**: Parent = 20 (77.0%) Spouse = 6 (23.0%) **Bereaved:** Parent = 8 (57.1%) Spouse = 4 (28.6%) Daughter = 2 (14.3%)	70% of sample exhibited depressive symptoms with 30% severe symptoms Anxiety symptoms present in 30% of sample Resilience reduced in 40% sample. Scores indicated helplessness and a decrease in the ability to influence one's life. Emotional distress negatively associated with use of coping strategies for positive redefinition and personal growth. Depressive symptoms lowest in relatives of individuals with a single suicide attempt. Lowest involvement and resilience with relatives of individuals with multiple attempts Avoidance used as a strategy with relatives of people with repeated behaviours
Cerel et al (2006) USA	**Aim** To explore the experiences of psychiatric consumers and family members in the	N = 254 carers	*Demographic information not available for all participants.	Included parents, partners,	73.9% of sample who answered relevant question reported being treated with respect, 57.1% felt listened to, 53.8% were given information about treatments, 28.8% felt punished or stigmatised, 28.6% felt injury was not taken seriously by ED staff

	ED following a suicide attempt **Design** Online survey 49 questions One open ended question **Validated Measures** None used		**Carers** 156 female (61.4%) 32 male (12.6%) 66 not known (26.0%) Age (years) 18-24 = 9 (3.5%) 25-34 = 21 (8,3%) 35-44 = 40 (15.7%) 45-54 = 71 (28%) 55+ = 46 (18.1%) Not known = 187 (26.4%) Ethnicity - 173 White non Hispanic (68.1%) 12 hispanic, black or ’other’ 12 (4.7%) 69 not known (27.2%) **Care recipients** All over 18 years	friends and ‘other’	31.4% of sample who answered relevant question were not seen in a timely fashion, 28.9% did not feel cultural considerations were addressed, 14.5% thought staff used jargon, 37.6% reported that ED staff did not want to communicate with them about the patient. Positive experiences related to good experiences with staff and being provided with information Negative experiences included perceived unprofessional behaviour by staff, perceiving that suicide attempt was not taken seriously, feeling that waiting time was too long, a need for better communication of discharge plans or instructions
Chiang et al (2015) Taiwan	**Aim** To examine the relationship between caring stress, suicidal attitude and suicide care ability among family carers of suicidal individuals **Design** Cross sectional correlational study with path analysis techniques. **Validated Measures** Caring Stress Scale	164 carers	**Carers** 101 female (61.6%) 63 male (38.4%) Mean age 43.92 years (SD 13.84) Ethnicity not reported **Care recipients** Not reported, author gave	59 parent (36.0%) 33 spouse (20.1%) 28 child (17.0%) 44 other (26.9%)	Caring Stress Scale mean score 80.73 (SD 16.11) indicating mild level. Suicidal Attitudes Scale mean score 75.21 (SD 7.20) indicating relatively positive attitude. Suicidal Caring Ability Scale mean score 104.79 (SD 13.31) indicating high score in suicidal caring ability. Older caregivers had less positive attitudes. Female caregivers had a higher level of stress. Caring stress had direct effect on suicidal attitude (b=.27, P=.01) indicating higher caring stress was associated with a more positive attitude towards suicidal individuals. Caring stress did not have a significant effect on suicide care ability (b=.15, P=.11). Higher holistic caring burden associated with less care ability.

	Suicidal Attitudes Scale Suicidal caring Ability Scale		confirmation that at least half were 18 years or over		Association between suicidal attitude and care ability was significant (r=.65, P<.01) indicating that positive attitudes were associated with better care ability.
Chessick et al (2007) USA	**Aim:** To examine whether caregivers of bipolar patients reporting current suicidal ideation (SI) and/or a history of a suicide attempt (SA) reported higher levels of burden and/or poorer health compared to caregivers of patients without these suicidality indices **Design:** Cross sectional design – validated questionnaires. Part of a larger RCT. **Validated Measures** The Social Behaviour Assessment Scale (SBAS) Centre for Epidemiological Studies of Depression Scale (CES-D) The General Health Scale from the Medical Outcomes Survey (MOS) 36-item Short-Form Health Survey	500 carers	**Carers** 345 females (65.3%) 155 males 34.7% Mean age 50.2 years (SD 13.1) 439 Caucasian (87.8%) Black, Hispanic, Asian or other 12.2% **Care recipients** Mean age 39.9 years (SD 13.5)	Parent 188 (37.6%) Spouse 182 (36.4%) Child 22 (4.4%) Sibling 28 (5.6%) Other 80 (16%)	Significant main effects of positive current SI (F = 4.64, df = 1, p = 0.03) and positive SA history (F = 7.16, df = 1, 456, p<0.01) on caregiver self-reported general health i.e., relatives of patients with current SI and those of patients with lifetime history of SA reported lower general health status. No interactions between SI and SA history were found in predicting caregiver general health status, depression or burden. Parents of patients with positive lifetime SA history had more burden on the role dysfunction scale than spouses of patients with lifetime SA. Spouses of patients with a negative SA history reported more burden on the role dysfunction scale than parents of patients with negative lifetime SA. Parents reported higher levels of depressive symptoms than spouses if patient had lifetime SA and current SI. Spouses reported higher levels of depression than parents if patient had negative lifetime SA but current SI.
Chessick et al (2009) USA	**Aim:** To evaluate whether caregivers' health and depression varied over time in relation to changes in patients' suicide ideation (SI) and depressive symptoms	500 carers	As above – same sample	As above	Caregivers general health status was poorer when the care recipient had higher SI at baseline, 6 and 12 months compared to those caring for people with lower SI at each time point [F(1,764)=5.28, p = 0.02] even after controlling for patient history of SA, education and patient global functioning. This was evident among parent and spousal caregivers. Caregivers of patients whose SI increased from baseline at 6 and/or 12 months also reported poorer health at 6 and 12 months compared to those caring for patients with no increase in SI. Caregiver self-reported health was consistently correlated with patients SI over time.

	Design: Longitudinal naturalistic observational study **Validated Measures** Centre for Epidemiological Studies of Depression Scale (CES-D) The General Health Scale from the Medical Outcomes Survey (MOS) 36-item Short-Form Health Survey				Patient depression scores were not related to caregiver health. SI contributed to caregiver health status, but depression did not. Patients with higher baseline, 6 and 12 month SI were associated with higher depression scores in caregivers [F(1.722) = 4.91, p = 0.03] Increase in patients SI from baseline was not significantly associated with caregiver CES-D depression scores at 6 and 12 months [F(1,301) = 1.35, p = 0.25]
Dev Crasta et al (2022) USA	**Aim** To examine the association between interpersonal perceptions related to suicide and social coping efforts. **Design** Part of a RCT studying joint safety planning between Veterans and their caregivers. Included Hypothesis 1B – caregivers reporting greater family problem solving will report lower burden. **Validated Measures** Problem solving module of the Family Assessment Device (FAD) Caregiver Burden Inventory (CBI)	43 carers	**Carers** 28 female (65.0%) 15 male (35.0%) Age (years) 18-34 = 12 (28.0%) 35-44 = 7 (16.0%) 45-64 = 20 (47.0%) 65+ = 4 (9.0%) Black/African American 19(44.0%) White 7 (16.0%) Native American, multi-racial or other (39%) **Care recipients** All over 18 years	Partner 16 (37.0%) Family members 15 (35.0%) Close non family supports 12 (28%)	Caregivers who reported social coping experienced fewer negative feelings towards Veterans Relationships with lower mutual coping were associated with caregiver negative feelings towards veterans Veteran social coping was associated with higher time demands on caregiver Caregivers reported lower caregiving demand when veteran had high perceived burdensomenesss
Jaffe et al (2020) Europe	**Aim** To assess the additional humanistic and economic burden experienced by persons caring for patients	554 carers depression & suicide ideation	**Carers** **CAUD-SI** Female 298 (53.8%) Male 256 (46.2%)	Not reported	Carers of people with unipolar depression and SI (CAUD-SI) respondents reported higher mental health burden than carers of people with unipolar depression and no SI (CAUD) in terms of self-reported medical diagnosis of

	with depression and suicidal ideation in five major European countries **Design** Retrospective observational study **Validated Measures used** Demographic Health characteristics – self reported BMI, exercise, alcohol consumption, smoking status. Charlson Cormobidity Index (**CCI**) Patient Health Questionnaire (**PHQ-9**) Medical Outcomes Study 12 -Item Short-Form Health Survey version 2 (**SF-12v2**) Mental Component Summary (**MCS**) Physical Component Summary (**PCS**) Short-Form 6 Dimension (**SF-6D**) derived from SFv2 (prior 4 weeks) EuroQol 5-Dimension 5-Level version **EQ-5D-5L**	(CAUD-SI) 837 carers dep only (CAUD)	Mean age 40.7 years (SD 15.2) Ethnicity not reported **CAUD** Female 487 (58.2%) Male 350 (41.8%) Mean age 43.5 (SD 15.2) Ethnicity not reported **Care recipients** All over 18 years		depression (47.8% vs 37.5%, overall distribution p<0.001 and sleep problems (14.8% vs 10.9%, overall distribution p<0.05). PHQ-9 scores indicated significant difference between groups (p<0.001) with more CAUD-SI reporting moderate, moderately severe and severe depression Unadjusted comparison of outcome for CAUD-SI & CAUD – CAUD-SI reported significantly lower scores for physical functioning (44.9 vs 48.7, p < 0.001), bodily pain (41.8 vs 44.3, p <0.001), physical role functioning (40.4 vs 43.7, p<0.001), emotional role functioning (34.2 vs 38.7, p<0.001), & social role functioning (38.1 vs 41.5, p<0.001), and lower PCS (46.2 vs 48.5, p<0.001) and Mental Component Scale (38.4 vs 40.3, p<0.001) scores. CAUS-SI reported lower EQ-5D-5L measured health status (0.63 vs 0.73, p<0.001) and SF-6D health utilities (0.60 vs 0.64, p<0.001). CAUD-SI reported higher absenteeism (24.1 vs 14.6, p<0.001), presenteeism (48.4 vs 34.7, p<0.001), overall work productivity loss (54.7 vs 39.6, p<0.001), and activity impairment (49.0 vs 39.5, p<0.001). A higher percentage of CAUD-SI reported visits to a psychologist or therapist in the last 6 months (12.3% vs 8.5%, p = 0.021), although no difference for visit to psychiatrist. CAUD-SI had higher traditional provider visits (7.9 vs 6.5, p=0.005), ER visits (1.45 vs 0.59, p<0.001) and hospitalisation (0.83 vs 0.32, p<0.001). Adjusted comparison of outcomes for CAUD-SI & CAUD CAUD-SI had lower adjusted means for Mental Component Score (37.5 vs3 8.9, p=0.007) and physical component score (42.7 vs 45.0, p<0.001). Specific domains with statistically significant marginal mean differences between groups included physical functioning (difference = 3.5), bodily pain (difference = 2.4), physical role functioning (difference = 3.0), emotional role functioning (difference = 4.0), and social role functioning (difference = 3.0). CAUD-SI had significantly poorer health status in both measures used - SF-6D (0.57 vs 0.60, p>0.01) and EQ-5D-5L (0.58 vs 0.66, p<0.001).
Katz et al (2015) USA	**Aim** To examine the relationship between the perception of risk of harm and family distress, burden, empowerment,	434 carers in total 104 (24.0%) noted perceived risk of harm.	**N=56 carers** 14 male (25%) Other genders not reported	Not reported	Participants who perceived risk of harm were more likely to report that their ill family member had a hospitalisation for mental health reasons in the previous 6 months and had a greater number of hospitalisations in the previous 6 months than those without a perceived recent risk of harm.

	coping, physical and mental health, appraisal of the caregiving experience, family communication and family functioning **Design** Secondary analysis of baseline data from RCT of the family to family peer driven education programme **Validated Measures** FEIS worry and displeasure scale Family Empowerment Scale (FES) Coping Inventory (COPE) Brief Symptom Inventory (BSI-18) Centre for Epidemiological Studies Depression Scale (CES-D) SF-12 measure of health Family Assessment Device (FAD) Family problem Solving Communication (FPSC) Experience of Caregiving Inventory (ECI)	28 (26.7% of carers noting perceived risk of harm and 6.5% of total sample) reported risk of harm to self (SH) only and the same number Reported risk of SH & harm to others **In total 56 carers of pts at risk of harm to self (SH)**	Mean age harm to self carers 49.8 years (SD 9.5) Mean age harm to self and harm to others carers age 50.2 years (SD 6.7) Ethnicity – 40 (71.42%) white **Care recipients** Mean age 30.8 years (SD 15.1)		Subjective burden was significantly greater in the harm to self and others (BOTH) and harm to others (OTHERS) groups compared with the no perceived recent risk of harm group (NONE) as measured by the FEIS worry and displeasure scales. All perceived recent risk of harm groups (harm to SELF, OTHERS, and BOTH) reported greater objective burden compared with the NONE group as measured by the FEIS daily living assistance and supervision subscales Psychological distress was greater in all perceived risk of harm groups (OTHERS, SELF, and BOTH) compared with the NONE group as measured by the CESD, the BSI, and the SF12 mental health scale. No differences were observed across groups in physical health. OTHERS, SELF, and BOTH groups had more overall negative appraisal of the caregiving experience compared with the NONE group Participants in the SELF group thought more often about the good aspects of their relationship with the ill relative compared with participants in the NONE group.
Kjellin and Ostman (2005) Sweden	**Aim** To investigate family burden and relatives' participation in care in relation to 1) physical	155 carers 27 (17.4%) carers of patients who	**Carers** 79 female (51%) Other genders not reported	Spouses 29% Parents 27% Siblings or other relatives 27%	Of all carers of patients who had exhibited harm to self and/or harm to others (N=155): 28% reported they had to give up leisure time 16% reported they had to give up work 33% reported they were prevented from having their own company

	violence towards others by psychiatric before or at admission, and 2) suicide attempts of psychiatric patients before admission **Design** Cross sectional study involving researcher administered semi structured interviews (95 questions) **Validated measures** None used	had attempted suicide prior to admission according to patient notes 2 (1.3%) carers of patients who had attempted suicide and been physically violent prior to admission according to patient notes	48% aged 40-49yrs Ethnicity not reported **Care recipients** Mean age 43 years (SD 13)	Children 12% Close friends 5%	31% feared patient might attempt suicide 39%experienced mental health problems 25% reported negative effects on relationship with patient Relatives of patients with suicide attempts more often stated they were prevented from having own company (52% vs 29%; chi sq = 5.317, df = 1, p = 0.021), more often worried about suicide attempts (59% vs 25%; chi sq = 12.242, df = 1, p = 0.000), more often had mental health problems themselves (56% vs 35%; chi sq = 3.911, df = 1, p = 0.048), and said they had their own need for care and support from services (74% vs 42%; chi sq = 9.087, df = 1, p = 0.0003).
Lawn and McMahon (2015) Australia	**Aim** To explore experiences of carers of a person diagnosed with BPD (including questions on suicide/self-harm from perspectives of carer) **Design** Cross sectional study - online survey involving 60 multiple choice, 15 open ended and 9 Likert rated questions **Validated measures** None used	121 carers 64 with experience of patient suicidal behaviour	**Carers** 78 /102 female (76.5%) 24/102 male (25.5%) **Age (years)** <18 = 1/119 (0.84%) 18-64 = 110/119 (92.46%) >65 = 8/119 (6.7%) Ethnicity not reported **Care recipients** All over 18 years	Parent 31/103 (30%) Partner/ sibling/child 49/103 (47.6%) Other 23/103 (24.3%)	64/121 participants completed questions relating to suicidal behaviour but response rates across questions was low 45/60 (75%) said the person they cared for had tried to end their life, 9/60 (15%) said they hadn't made an attempt 5/60 (8.3% did not know)* (NB numbers reported do not add up to 60/100%) Concerns expressed included: • Lack of explanation/information • Lack of choice of support services • Difficulty accessing crisis support/responsiveness of support • Not being taken seriously • Need for individualised carer support (group and 1-1)
Magne-Ingvar and	**Aim**	81 carers	**Carers** 49 female (60%)	Partners 31 (38.3%)	30% of SOs said SA was not unexpected

Ojehagen (1999) Sweden	To investigate 1) the significant other's (SO) view on problems and reasons for the suicide attempt and on the patients need for help as well as their ability to perceive suicidal communication 2) whether information from SOs was helpful in the assessment of the patient 3) the wellbeing of the SOs and their need for support **Design** Cross sectional study with interview questionnaire **Validated measures** None used		Other genders not reported Age - all over 18 years Ethnicity not reported **Care recipients** Mean age 39 years (range 18-92 years)	Parents 30 (37.0%) Adult children 12 (14.8%) Friends 6 (7.4%) Siblings 2 (2.5%)	Over 50% SOs perceived themselves to have provided psychological support to the patient 1/3 SOs reported that they had provided help with practical matters 53% reported that the patient did not turn to them with their difficulties 75% SOs said they were upset, worried or shocked after SA 16% reported they felt physically unwell 25% reported sleep, mood and/or appetite problems 41% reported other personal problems mainly relationship or vocational 57% SOs reported that giving psychological and/or instrumental support was a burden to them Most SOs found it helpful to talk to a professional after patient's SA and felt relieved after giving their view on the attempt. 53% expressed a desire for counselling together with patient 37% desires individual counselling themselves 73% reported they had someone else to turn to when difficulties occurred
Magne-Ingvar and Ojehagen (1999a) Sweden	**Aim** To investigate the views of SOs concerning the situation of the patients, their involvement in the patients' treatment and their own wellbeing and need of support 1 year after patient's SA **Design** Cross sectional study with interview questionnaire (68 questions) **Validated measures** None used	84 carers (above sample + 13 participants not reported on in previous study, with 10 dropouts i.e., 81 + 13 – 10 = 84)	**Carers** 50 female (59.5%) 34 men (40.5%) Age not reported but all over 18 Ethnicity not reported **Care recipients** All over 18 years	Parents 37 (44.0%) Partners 28 (33.3%) Adult children 10 (12.0%) Friends 7 (8.3%) Siblings 2 (2.4%)	11 (14%) participants reported repeated SA of care recipient 20% reported perceiving suicidal signals 70% were worried about repeat attempt, more so when patient had history of repeat attempts Worrying about patient was considered stressful Parents worried more often Nearly half of participants had not talked to patient about SA Partners especially still had questions about suicidal behaviour 80% participants had someone to turn to – (parents more than partners) Nearly half would like professional counselling with patient A third wanted individual support – more often partners 45% thought patient treatment was insufficient, 53% wanted more treatment. Higher satisfaction was associated with inpatient care 22% carers thought they had not been treated well by staff 2/3 carers had not received enough information about the patients situation Involvement in care was considered insufficient – carers wanted more 83% thought their general wellbeing was satisfactory – less often with partners 2/3 reported one or more symptoms of worry, tiredness, headache, irritability, downheartedness, epigastric pain, impaired sleep, tension, hopelessness, anxiety. 1/3 reported 4 or more symptoms.

					32% had professional support, another 16% felt they needed it S47% SOs had other worries e.g., financial Poor wellbeing was associated with questions about suicide attempt, less access to social support, desiring better support
Maple et al (2021) Australia	**Aim** To identify predictors of caregiver burden identified as a result of caring **Design** Cross sectional study Online survey **Validated Measures** Stigma of Suicide Scale Suicidal Ideation Attributes Scale Kessler-10 psychological distress scale Caregiver Burden Scale	435 carers	**Carers** 390 Women 89.7% 38 Men 8.7% 7 Other 1.6% Mean age 47.91 years (SD = 12.03) Ethnicity not reported **Care recipients** Not reported but carer relationships to care recipient indicate that most were over 18 years	Not available for final sample but of overall sample of 666 (before exclusion of ineligible participants or incomplete data): Child 168(25.2%) Friend 156(23.4%) Partner Parent 61(9.2%) Other 58(8.7% Family relation 42(6.3%) Sibling 39(5.9%) Colleague 8(1.2%) Missing 63(9.5%)	Being female (B =.11, p<.05, sr^2 = 1%), reported closeness with the supported person (B = .11, p<.05, sr^2 = 1%), high impact of the SA (B = .17, p>.001, sr^2 = 2%), high frequency of contact 6 months prior to SA (B = .12, p<.01, 1%), and high psychological distress (B = .32, p<.001, sr^2 = 5%) contributed significantly to high caregiver burden. Most care recipients had multiple SAs. Participants who had confidence in supporting the person (B = -.14, p<.01, sr^2 = 1%), perceived adequate level of healthcare for patient (B = -.09, p<.05, sr^2 = 1%), and adequate support the carer received (B = -.20, p<.001, sr^2 = 3%, and had higher SI themselves (B = -.11, p<.05, sr^2 = 1%) experienced significantly less caregiver burden. Participants who did not feel well supported reported higher scores on SI, psychological distress and caregiver burden compared to participants who were supported
McDonnell et al (2003) USA	**Aim** To investigate the relationship between burden, its previously established patient and	84 carers	**Carers** 65 Male 77.4% 19 Female 22.6%	Parent 71.4% Sibling 11.9% Partner 9.5% Other 7.2%	Family awareness of patient SI was significantly correlated to family burden r = (82) .49, p<.01 (as are patient age, illness duration and family resource). Young patient age, low family resources and family awareness of suicide all found to be significant predictors of family burden.

	caregiver correlates and other possible correlates such as substance abuse, depressive symptoms and suicidality in outpatients with schizophrenia. **Design** Part of a RCT investigating efficacy of a multiple family group treatment programme **Validated Measures** Revised Ways of Coping Checklist (Vitaliano et al 1985) Social Support Questionnaire (SSQ; Sarason et al 1990) Family Burden Interview Schedule (Tessler et al 2=1992)		Mean age 51.0 (SD 12.8) European-American 90.5% Non-European-American 9.5% **Care recipients** Mean age 33.2 years (SD 9.4)		There was a discrepancy between patient reported and family awareness of SI – 60% patients reported SI but only 17% carers were aware of SI. Awareness of SI appears to have a significant effect on caregiver burden when controlling for other significant variables therefore is an independent risk factor for burden.

SI = suicide ideation, SA = suicide attempt

Appendix 6: Characteristics of qualitative studies

Author/year /location	Research aim & design	Sample size (carers or bereaved participants)	Demographics: Carers (age/sex/ethnicity) Care recipients (age)	Caregiver relationship to care recipient	Summary of key themes/findings
Asare-Doku et al (2017) Ghana	**Aim** To understand the experiences of suicide attempt survivors and how they cope with the aftermath **Design** Interpretative Phenomenological Analysis	10 carers	**Carers** 6 males 4 females Mean age 41 years (range 25-62 years) Ethnicity not reported **Care recipients** All over 18 years	4 fathers 2 mothers 1 brother 1 husband 1 sister 1 aunt	*Experiencing shame & stigma* – intra and extra family stigma, not talking about it, gender dynamics in management of shame, isolation *Reactive affect* – shock, surprise, shock but not surprise (ongoing suicidality), anger, shattered myth *Surviving the stress of attempt* – spiritual coping, social support, avoidance
Castelli-Dransart and Guerry (2017) Switzerland	**Aim** To understand the help-seeking experiences of significant others and their perception of the care their loved one received including carer interactions and collaboration with healthcare providers **Design** Qualitative interview study	18 carers	**Carers** 16 women 2 men Mean age 44 years (range 23-61 years) Ethnicity not reported **Care recipients** All over 18 years	7 partners 3 Child 3 Mothers 3 Sisters 2 friends	*Help seeking process* - Considerable time and energy providing support/preventing acting out suicide ideation/ getting help from third party. Suicidal person refusing care versus need for professional care The help-seeking road was tortuous and difficult – helpless, disillusioned, desperate, angry, not listened to, not understood not helped by those they contacted. Multiple attempts experienced. *Perceptions of patient care for suicidal person* - ¾ expressed dissatisfaction with care, a recurring complaint was the quality of patient care; access to means not restricted, inadequate assessment of suicide risk, inadequate risk management plan, poor information sharing, needing to take on 'care manager' role. Feelings of exhaustion and hopelessness amplified. *Perception of collaboration with professionals* - Nearly half of participants reported positive experiences while the care recipient was an inpatient. More than 1/3 not able to get information on patient's health due to adulthood/confidentiality. Professionals not taking account of information from caregivers, not seen as a valid representative. Leading to anger, having to be persistent, amplification of anxiety, helplessness, contradictory messages

					from professionals. Lack of empathy from professionals. Needing support and education.
Dempsey et al (2019) Australia	**Aim** To explore clinician and caregiver perspectives on service provision for family members of young people (15–25 years, av. 20.5 years) attending a specialist clinic for moderate–severe mood disorder. **Design** Qualitative interview study with thematic analysis	8 carers	7 female 1 male Mean age 52.50 years (SD 3.78) Ethnicity not reported **Care recipients** Mean age 20.5 years (SD 3.01)	Parents	*Initial Needs: information* – needing contact numbers for general and crisis situations; confusion over what to use when; differences in what clinicians believed they provided and what caregivers perceived they had been given; barriers due to wishes of patient; need for shared understanding between caregivers. *Support* – reassurance and emotional support, gaining hope from referral to service, feeling safe due to contact with service, reduced anxiety, value of peer support, want for mentoring *Crisis Needs: information* – needing to know how to get help, initial information 'goes out of the window' in crisis; caregivers' perception of a crisis not necessarily viewed in the same way by clinicians. *Support* – heightened distress, 'roller-coaster' of emotions means need for more intensive support *Discharge Needs: Information;* concerns about 'where to next'; worry/concern about patients' treatment and future in general; needing more information on options available; concerned about difficulties re-referring; feeling unready for discharge *Support* – concerns about how they would cope *Carer Challenges:* *Own emotions* – anxiety, distress, shock/surprise, shame, isolation with burden of care, bewilderment, importance of accessing own support *Family and life* – struggling to balance other responsibilities and leisure time with caring, developing own mental health problems, struggling to take time out of work, concerns about degradation of family relationships *Managing suicide risk* – feeling unskilled, not knowing how to speak to patient, what restrictions to place on patient, needing specific information, feeling as though they were not doing enough, appreciative of help they did get, wanting more time with treating team to help manage time between visits, wanting group information sessions
Fogarty et al (2018) Australia	**Aim** To examine the complexities of and tensions within suicide	47 family & friends	**Carers** 26 female (55%) 21 males (45%)	Not reported	PHQ-9 scores fell within mild depression range GAD scores fell within minimal to normal range *Tension 1*: respect for privacy vs vigilant risk monitoring.

	prevention approaches for at-risk males, and how suicide prevention and interventions for men may be improved. **Design** Secondary analysis of qualitative data from focus groups **This is the only qualitative study to include validated Measures:** Patient Health Questionnaire PHQ-9 General Anxiety Disorder Scale (GAD)		Median age 47 years (range 19-65 years) Ethnicity not reported **Care recipients** All over 18 years		*Tension 2*: differentiating normal vs risky behavioural change. *Tension 3*: familiarity vs anonymity in risk monitoring. *Tension 4:* respecting autonomy vs imposing restraints. *Tension 5*: dependence on vs perceived failures of community services.
Giffin (2008) Australia	**Aim** To hear the voice of a small sample of family members who have an adult daughter or sister receiving treatment for severe personality disorder featuring a chronic pattern of self- harm and suicidality **Design** Qualitative interview study	4 carers	**Carers** 3 female 1 male Age all over 18 years Ethnicity not reported **Care recipients** All over 18 years	Parents	*Chronic and traumatic stress:* due to ongoing worry and repeated witnessing of self-harm and near death; fearful responses to the phone ringing at night; emotional strain & exhaustion through lack of sleep, concerns about their own physical health; finding treatment approaches that discourage hospital admission unhelpful and increasing burden of care *The responsibility and support dilemma:* Torn between wanting to care for/ support and thinking they should step back but fearing the consequences; intensified by mixed messages from professionals; importance of support from professionals and family & friends *Trying to make sense of it all:* Reflecting on own lives and parenting; looking for explanations *Impact of BPD on the broader family:* Intensified mother-daughter bond in context of active caring; mixed feelings of love and anger; strain/distance on couple and other adult children relationships; differing views among family members leading to tension and division

					Mental health system and the family: health professionals providing little support to, but relying on, family; not understanding relationships between multiple services involved in patient's care; faced with inconsistency/contradictory advice; disliking lack of professional empathy but relating to clinician experience; lack of involvement in treatment and discharge planning; needing dialogue to provide knowledge/understanding/support for caring; uncomfortable clinical contacts; lack of collaboration from professionals *BPD, the family and the broader system:* becoming advocates; wanting recognition of the carer burden; wanting respite; feeling like health services regarded them as 'over-anxious'; not feeling listened to so approaching higher authorities
McLaughlin et al (2014) Ireland	**Aim** To investigate the experiences of carers and the impact that the suicidal behaviour of a family member has on them **Design** Qualitative interviews	11 carers 7 bereaved	**Carers** 14 female 4 male Age range 25-78 years Ethnicity not reported **Care recipients** All not reported but where relationships are mentioned in the text and from correspondence with one author it was agreed that half or more were likely to have been 18 years or over	Not reported	*Family burden:* taking responsibility for the safe care of the family member; the potential for actual suicide took over and affected the whole family across a period of time; impact on activities of living and leisure activities for prolonged periods; unrelenting burden of worry and psychological stress; negative effect on physical and emotional health of family members; ongoing hypervigilance *Competing pressures:* usual daily stressful life issues carry on; fear of what will be found on arrival home; anxieties over and above daily chores; effect on personal life, family life, working life; balancing family and work responsibilities *Secrecy and shame:* pressure from family member not to speak to others; perceived stigma; feelings of shame – concerned about what others thought; feigning normality; feeling prevented from obtaining emotional and psychological support *Helplessness and guilt:* helplessness, powerless and alienation; guilt due to feeling unable to help.
McLaughlin et al (2016) Ireland	**Aim** To explore the support needs of voluntary family	11 carers 7 bereaved	Same sample as above	Not reported	*Carers unmet needs:* Having practical support, respite and advice Feeling acknowledged and included Having someone to turn to

	carers of persons at risk of suicide **Design** Qualitative interviews				Consistency of support
Nosek (2008) USA	**Aim** To investigate the experiences of families who manage the care of a depressed and suicidal individual at home **Design** Grounded theory	17 carers	**Carers** Sex not reported Age not reported - all over 18 years Ethnicity not reported **Care recipients** All over 18 years	Partner 7 Parent 8 Sibling 1 Adult daughter 1	Mood down due to loved one's situation, constant worry, not thinking about the future because it is too sad. Theory: From *not knowing* to *identifying* (seeking information and learning) to *gaining awareness* (piecing together the information, recognising patterns, seeking to understand triggers, increased vigilance) to *knowing and understanding* (knowing the signs, knowing the seriousness, how to manage the illness, being able to cope with the behaviour) to *taking action* (taking steps to respond to the depressed and suicidal loved one, repeated attempts to find what works, close monitoring) to *watching and waiting* (always on their minds, checking effectiveness of actions, waiting for signs of improvement) to *reaching limit* (running out of sympathy, being pulled back into the cycle) to in cases *Not wanting to know* (not talking about it, extended family members not talking about it, becoming less involved)
Nygaard et al (2019) Denmark	**Aim** To explore how the parents and their relationship with their partner or ex-partner were affected following their son or daughter's suicide attempt or serious suicide threats. **Design** Qualitative interviews	19 parents	**Carers** 12 female 7 male Age range 42 - 81 years Ethnicity not reported **Care recipients** At least half were 18 years or over (range 14-54 years)	Parents	*Sense of solidarity:* minimised the feelings of isolation, communication and acknowledgement of each other's feelings and ways of coping *Challenges to the relationship:* very stressful, work out, all other issues and plans of less importance than child's situation, more time at home for vigilance, all energy on caring whilst trying to hold on to everyday life, little or no time for each other as a couple, time together not comforting or rewarding, different reactions, doubt about how to support their offspring, not always perceiving offspring's need for support the same way. *Responding to different reactions and coping strategies:* ways of coping based on traditional stereotypical gender roles – mothers had in depth conversations with offspring and contact with professionals, fathers did practical things, mothers needed to talk extensively about SA, fathers tried to unwind by doing things on their own, frustration about partner's coping strategies, one partner being the stronger, stronger partner alternating, conflict meaning finding new ways of managing the situation

Rheinberger et al (2021) Australia	**Aim** To understand the experiences of help seekers and support persons during a suicide related ED presentation to identify from their perspectives what works, what does not work and areas for improvement in the delivery of crisis care for suicide in Australia **Design** Qualitative interviews with grounded theory approach	16 carers	**Carers** 11 female 5 male Age - all over 16 years Ethnicity not reported **Care recipients** All over 16 years	Parent 10 Partner 4 Friend 1 Other 1	*Interpersonal: Roadblocks* – negative interactions with ED staff, reliance on carers initiative to ensure care, patient obstruction of care, discharge when out of crisis, no support for support person *Pathways* – positive interactions with ED staff, support person involved in assessments, presence of support person in ED *Systemic: Roadblocks* – chaotic ED environment, prioritisation of physical presentation, long waiting times, understaffing in ED, poor access to mental health staff in ED, transactional mental health assessments, inadequate discharge plans *Pathways* – detailed mental health assessments, access to mental health staff, involvement in discharge decisions
Sellin et al (2017) Sweden	**Aim** 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. **Design** Reflective lifeworld.	8 carers	**Carers** 5 female 3 male Age range 30-80 years Ethnicity not reported **Care recipients** All over 18 years	Close relatives	Participation as experienced by relatives of persons who are subject to inpatient care due to a risk of suicide means *"being actively involved in the process in which the person regains their desire to live"* *Struggling for being able to be present for the person at risk of suicide:* being present as a helpful resource; creating a space for connectedness; risk of losing the person can involve doubt about ones' ability to contribute in a meaningful way; lacking knowledge about the situation; facilitated when professional caregivers invite relatives to be included; doubt and questioning are balanced by experiences of connectedness *Being able to share everyday life:* relatives search for contact with the person at risk of suicide as a way of being able to participant in what is going on; includes a need for reciprocal communication with professional caregivers; participation is rather about supporting your family member rather than joining forces with the professional caregivers; powerless is evoked when it is not possible to get contact with professional caregivers; dealing with uncertainty concerning what the persons wishes and needs are; holding back one's own needs and adjusting to the other; maintaining contact when the person is emotionally distant.

					Nurturing sources for vitality: dealing with one's awareness of the risk of losing the loved person; holding on to possibilities of life while simultaneously agonizing over the risk of losing the loved person; nurturing and caring presence
Sun and Long (2008) Taiwan	**Aim** To explore family carers and suicidal ex-patients perspectives of caring for someone after a suicide attempt **Design** Grounded theory	15 carers	**Carers** 9 men 6 women Mean age 50 years Ethnicity not reported **Care recipients** Mean age 40 years	Partner 6 Parent 4 Siblings 3 Adult children 2	*On guard day and night* **–** observation and safety *Maintaining activities of daily living* **–** physical care, providing treatment, arranging activities *Creating a nurturing environment* **–** caring and support, fostering tranquillity, re-awakening hope *Effects of caring* – support systems, families coping strategies *Barriers to caring* – lack of support systems, caring difficulties, families caring ability problems *Family environment & Chinese culture* – the family setting, relationship and mood, stigma, folk therapy *Impending burnout* **–** recurrent suicidal thoughts and attempts
Spillane et al (2020) Ireland	**Aim** To explore the overall impact of a family member's high risk self-harm, in terms of psychological, physical and psychosomatic consequences. **Design** Interpretative Phenomenological Analysis	9 carers	**Carers** 6 female 3 male Mean age 44 years (range 33-61) Ethnicity not reported **Care recipients** Age not reported but carer relationships to care recipient suggest at least half are 18 years or over	Partner 3 Sibling 3 Parent 2 Fiend 1	*Implications for health and wellbeing:* *Physical & psychosomatic responses* - shock, breathing, heart rate, nausea. Susceptibility to physical illness. Worse for those who had experienced multiple high-risk self-harm acts. Changes in lifestyle behaviours. Sleep. *Psychological responses* – panic, shock, numbness, disbelief, fear, anxiety. Autopilot, controlled panic, shutdown mode, state of high alert. Low self-esteem, depression, panic attacks in longer term. More pronounced psychological impact amongst participants responding to multiple acts of high-risk self-harm – reduced confidence, self-esteem, shame, rejection, isolation. *Process of meaning making* - increased understanding of mental illness, gaining control of the uncontrollable *Feelings of responsibility* - Caring for the self-harm patient, care for self Caring for self to care for others

					Challenges with support network - Formal aftercare following self-harm, Informal aftercare following self-harm
Talseth et al (2001) Norway	**Aim** 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 suicide **Design** Phenomenological Hermeneutic method, Narrative inquiry	15 relatives	**Carers** 8 Female 7 male Age– all over 18 years Ethnicity not reported **Care recipients** All over 18 years	Not reported	*Helpless and powerless:* Not knowing what to do to meet the needs of a person at risk of suicide In response to personnel and the healthcare system – not being listened to, connected with or supported, dealing with ongoing suicidality *Being met (Norwegian context – commonly used phrase referring to acknowledging and noticing another human being while engaging in dialogue i.e., being aware of the needs of the other):* Being seen as a human being Participating in I-Thou relationship with personnel Trusting personnel, treatment and care, feeling trusted by personnel, being consoled, entering into hope
Vandewalle et al (2021) Belguim	**Aim** To develop an understanding of family members expectations of care and treatment for their relative **Design** Qualitative study based on grounded theory	14 carers	**Carers** 10 female 4 male Mean age 42 years (range 23-66) Ethnicity not reported **Care recipients** All over 18 years	Partner 5 Parent 3 Adult child 3 Sibling 3	*Struggling to remain hopeful while looking through the lens of uncertainty:* Assuming safety as a priority Looking for a healing approach and environment Counting on continuity of care Wanting to be loved and supported
Wand et al (2018) Australia	**Aim** To explore the perspectives of relatives /friends of older people who had self-harmed regarding the reasons for and potential interventions, and the effects on the relatives /friends of the self-harm	32 carers	**Carers** 17 female (53.1%) 15 male (46.9%) Age - all over 18 years Ethnicity not reported	Adult child 24 (75%) Spouse 5 (15.6%) Sibling 1 (3%) Grandchild 1 (3%) Friend 1 (3%)	*Reasons for self-harm* They can't communicate (communication difficulties and difficulty expressing emotion) Suicide and secrets Invalidation by carers *Experiences* Anger Guilt and self-blame It made us ill

	Design Qualitative interviews		**Care recipients** Mean age 86.5 years (range 80-102 years)		Ignoring self-harm Shared shame and stigma Clinicians dismissing the carer Relief and support when patient received good care *Solutions* More practical support and structure Improving communication Removing means of self-harm Advanced care directives
Wayland et al (2020) Australia	**Aim** To understand how carers explain their experiences of caring roles and responsibilities and how they navigate health systems while undertaking these roles **Design** Narrative inquiry	25 carers 7 bereaved	**Carers** Female 24 (75%) Male 8 (25%) Age – all over 18 years 2 Aboriginal Torres Strait Islander (6%) **Care recipients** Age not reported but carer relationships to care recipient suggest at least half are 18 years or over	13 Child (41%) 6 Partner (19%) 4 Friend (12%) 4 Parent (12%) 4 extended family (12%) 1 sibling (4%)	*Living experiences:* *Practical roles* – pseudo care management, financial support travel/transport assistance, keeping them safe, emotional support *Lack of agreed role* – lack of specific conversations, assumptions about stepping into caring role, lack of requisite skills *Hypervigilance* – post discharge suicide watch, most participants reported multiple attempts of care recipient, managing hypervigilance without impacting relationship, strain of ongoing hypervigilance, morphing into the role of advocate *The delicate balancing of the relationship* – emotional implications of making practical decisions about how to respond to personal safety, reframing relationships, no safety net for carers *The human approach to supportive intervention:* navigating the health system, little preparation for the emotional state that accompanies the responsibility *post discharge as a touchpoint for carer distress* – not being involved in discharge decision making, lack of collaboration in discussions regarding risk, uncertainty in time between discharge and follow up appointments, risk assessment tools in hospitals did not provide accurate reflection on risk at home, need for information, fighting the system in advocating *What helped and what didn't help* – kindness, wanting to be asked if they were equipped to manage suicide watch, not to be viewed as a side-line act but a main event, seeking own therapeutic support, having a collaborative relationship with services, role being recognised

Appendix 7: Quality assessment of included studies using Mixed Methods Assessment Tools (MMAT)

Scoring key: No = 0
Partly/not clear = 1
Yes. = 2

High scores were allocated to scores of 9+ (quantitative) and 10 (qualitative). This decision was based on the MMAT questions and the judgement of the study as a whole, taking into account the balance of strengths and weaknesses.

QUANTITATIVE DESCRIPTION MMAT							
Study	Is the sampling strategy relevant to address the research question	Is the sample representative of the target population	Are the measurements appropriate	Is the risk of response bias low	Is the statistical analysis appropriate to answer the research question	total	Outcome
Cerel et al (2006)	1	1	1	0	1	4	Low
Chiang et al (2015)	1	1	2	2	2	8	Moderate
Crasta et al (2021)	1	1	2	2	2	8	Moderate
Jaffe et al (2021)	2	1	2	1	2	8	Moderate
Katz et al (2015)	1	1	2	2	2	8	Moderate
Kjellin and Ostman (2005)	1	1	1	2	2	7	Moderate/low
Lawn and McMahon (2015)	1	1	1	0	2	5	Low
Magne-Ingvar and Oiehagen (1999)	1	1	1	2	2	7	Moderate/Low
Magne-Ingvar and Oiehagen (1999a)	1	1	1	2	2	7	Moderate/low
Maple et al (2021)	1	1	2	1	2	7	Moderate/low
QUANTITATIVE NON RANDOMISED MMAT						Total	Outcome
	Are participants representative of the target population	Are measurements appropriate regarding both the outcome and	Are there complete outcome data?	Are the confounders accounted for in the design and analysis?	During the study period, is the intervention administered (or		

		intervention (or exposure0			exposure occurred as intended)?		
Borisnick (2018)	1	2	1	1	1	6	Low
Chessick et al (2007)	2	2	1	2	2	9	High
Chessick et al (2009)	2	2	1	2	2	9	High
McDonnell et al (2003)	2	2	1	2	1	8	Moderate
QUALITATIVE MMAT							
	Is a qualitative approach appropriate for the research question?	Are data collection methods appropriate for the research question?	Are the findings adequately derived from the data?	Is interpretation of the results sufficiently substantiated by the data?	Is there coherence between data sources, collection, analysis and interpretation?	Total	Outcome
Asare-Doku et al (2017)	2	2	2	2	1	9	Moderate
Castelli-Dransart and Guerry (2017)	1	2	2	2	1	8	Moderate
Dempsey et al (2019)	1	2	2	2	1	8	Moderate
Fogarty (2018)	1	2	2	2	1	8	Moderate
Giffin (2008)	1	2	2	2	1	8	Moderate
McLaughlin et al (2014)	1	2	2	2	1	8	Moderate
McLaughlin et al (2016)	1	2	2	2	1	8	Moderate
Nosek (2008)	2	2	2	2	1	9	Moderate
Nygaard et al (2019)	2	2	2	2	1	9	Moderate
Rheinberger et al (2021)	2	2	2	2	1	9	Moderate
Sellin et al (2017)	2	2	2	2	1	9	Moderate
Spillaine et al (2020)	2	2	2	2	1	9	Moderate
Sun and Long (2008)	2	2	2	2	1	9	Moderate
Talseth et al (2001)	2	2	2	2	1	9	Moderate
Vanderwalle et al (2021)	2	2	2	2	2	10	High
Wand et al (2019)	1	2	2	2	1	8	Moderate
Wayland, Coker and Maple (2021)	2	2	2	2	2	10	High

Appendix 8: Articles linked to themes

Theme	Subtheme	Articles including theme/subtheme
1. Transitions		Asare-Doku et al., 2017; Castelli Dransart & Guerry, 2017; Chessick et al., 2007; Chessick et al., 2009; Dempsey et al., 2019; Fogarty et al., 2018; Giffin, 2008; Jaffe et al., 2021; Katz et al., 2015; Kjellin & Östman, 2005; Magne-Ingvar & Öjehagen, 1999a; Maple et al 2021; McLaughlin et al., 2014; McLaughlin et al., 2016; Nosek, 2008; Nygaard et al., 2019; Sellin et al., 2017; Spillane et al., 2020; Sun and Long 2008; Talseth et al., 2001; Vandewalle et al., 2021; Wand et al., 2019; Wayland et al., 2021
	Learning a new role	Asare-Doku et al., 2017; Castelli Dransart & Guerry, 2017; Dempsey et al., 2019; Fogarty et al., 2018; Giffin, 2008; Magne-Ingvar & Öjehagen, 1999a; Nosek, 2008; Sellin et al., 2017; Spillane et al., 2020; Talseth et al., 2001; Vandewalle et al., 2021; Wand et al., 2019; Wayland et al., 2021
	Own life on hold	Asare-Doku et al., 2017; Castelli Dransart & Guerry, 2017; Dempsey et al., 2019; Fogarty et al., 2018; Giffin, 2008; 2005; Magne-Ingvar & Öjehagen, 1999a; McLaughlin et al., 2014; McLaughlin et al., 2016; Nosek, 2008; Nygaard et al., 2019; Sellin et al., 2017; Spillane et al., 2020; Talseth et al., 2001; Vandewalle et al., 2021; Wand et al., 2019; Wayland et al., 2021
	Caregiver burden	Chessick et al., 2007; Chiang et al., 2015; Crasta et al., 2021; Katz et al., 2015; Kjellin & Östman, 2005; Maple et al., 2021; McDonell et al., 2003; McLaughlin et al 2014; Wayland et al 2021
	Health and social consequences	Borisonik 2018; Chessick et al., 2007; Chessick et al., 2009; Chiang et al., 2015; Crasta et al., 2021; Dempsey et al., 2019; Fogarty et al., 2018; Giffin, 2008; Jaffe et al., 2021; Katz et al., 2015; Magne-Ingvar & Ojehagen, 1999; Magne-Ingvar & Öjehagen, 1999a; Maple et al., 2021; McLaughlin et al., 2014; Nygaard et al., 2019; Spillane et al., 2020
	Encountering enduring suicidality and multiple attempts	Asare-Doku et al., 2017; Borisonik 2018; Castelli Dransart & Guerry, 2017; Chessick et al., 2009; Chessick et al., 2007; Giffin, 2008; Magne-Ingvar & Öjehagen, 1999a; Maple et al., 2021; McLaughlin et al., 2014; McLaughlin et al., 2016; Nosek, 2008; Sellin et al., 2017; Spillane et al., 2020; Sun & Long, 2008; Talseth et al., 2001; Vandewalle et al., 2021; Wayland et al., 2021
2. Living with fear and uncertainty		Asare-Duko et al 2017; Borisonik 2018; Cerel, 2006; Castelli Dransart & Guerry, 2017; Fogarty et al., 2018; Giffin, 2008; Kjellin & Östman, 2005; Magne-Ingvar & Ojehagen, 1999; Magne-Ingvar & Öjehagen, 1999a; McLaughlin et al., 2014; McLaughlin et al., 2016; Nosek, 2008; Nygaard et al., 2019; Sellin et al 2018., Spillane et al., 2020; Sun & Long, 2008; Talseth et al., 2001; Vandewalle et al., 2021; Wand et al., 2019; Wayland et al., 2021

	Constant worry and fear	Cerel, 2006; Giffin, 2008; Kjellin & Östman, 2005; Magne-Ingvar & Ojehagen, 1999; Magne-Ingvar & Öjehagen, 1999a; McLaughlin et al., 2014; McLaughlin et al., 2016; Nosek, 2008; Nygaard et al., 2019; Spillane et al., 2020; Sun & Long, 2008; Talseth et al., 2001; Vandewalle et al., 2021; Wayland et al., 2021
	Expectancy and anticipation	Asare-Duko et al 2017; Giffin, 2008; McLaughlin et al., 2014; Nosek, 2008; Sellin et al 2018., Spillane et al., 2020; Sun & Long, 2008; 2019; Wayland et al., 2021
	Vigilance as risk management	Castilli Dransart & Guerry, 2017; Fogarty et al., 2018; Giffin, 2008; McLaughlin et al., 2014; McLaughlin et al., 2016; Nosek, 2008; Nygaard et al., 2019; Sellin et al., 2018; Spillane et al., 2020; Sun & Long, 2008; Talseth et al., 2001; Vandewalle et al., 2021; Wand et al., 2019; Wayland et al., 2021
	The toll of vigilance	Borisonik 2018; Giffin, 2008; Kjellin & Östman, 2005; McLaughlin et al., 2014; Nosek, 2008; Spillane et al., 2020; Sun & Long, 2008; Talseth et al., 2001; Wand et al., 2019; Wayland et al., 2021
3. Changing relationships		Asare-Doku et al., 2017; Borisonik 2018; Castelli Dransart & Guerry, 2017; Chessick et al., 2007; Chiang et al., 2015; Crasta et al., 2021; Dempsey et al., 2019; Fogarty et al., 2018; Giffin, 2008; Katz et al., 2015; Kjellin & Östman, 2005; Magne-Ingvar & Öjehagen, 1999a; McLaughlin et al., 2014; McLaughlin et al., 2016; Nosek, 2008; Nygaard et al., 2019; Sellin et al., 2017; Spillane et al., 2020; Sun & Long, 2008; Wand et al., 2019; Wayland et al., 2021
	Reframing relationships	Asare-Doku et al., 2017; Castelli Dransart & Guerry, 2017; Chessick et al., 2007; Dempsey et al., 2019; Fogarty et al., 2018; Giffin, 2008; Katz et al., 2015; Nosek, 2008; Nygaard et al., 2019; Sellin et al., 2017; Spillane et al., 2020; Wayland et al., 2021
	Tensions and conflicts	Asare-Doku et al., 2017; Chiang et al., 2015; Fogarty et al., 2018; Giffin, 2008; Kjellin & Östman, 2005; McLaughlin et al., 2016; Nosek, 2008; Wand et al., 2019; Wayland et al., 2021
	Familial effects	Asare-Doku et al., 2017; Borisonik 2018; Chiang et al., 2015; Crasta et al., 2021; Chessick et al., 2007; Dempsey et al., 2019; Giffin, 2008; Magne-Ingvar & Öjehagen, 1999a; McLaughlin et al., 2014; McLaughlin et al., 2016; Nygaard et al., 2019; Spillane et al., 2020; Sun & Long, 2008; Wand et al., 2019
4. Interface with healthcare professionals and services		Castelli Dransart & Guerry, 2017; Cerel et al., 2006; Dempsey et al., 2019; Fogarty et al., 2018; Giffin, 2008; Kjellin & Östman, 2005; Lawn & McMahon, 2015; Magne-Ingvar & Ojehagen, 1999; Magne-Ingvar & Öjehagen, 1999a; Maple et al., 2021; McLaughlin et al., 2016; McLaughlin et al., 2014; Rheinberger et al., 2021; Sellin et al., 2017; Spillane et al., 2020; Talseth et al., 2001; Vandewalle et al., 2021; Wand et al., 2019; Wayland et al., 2021
	Unseen, unheard, uninformed uninvolved	Castelli Dransart & Guerry, 2017; Cerel et al., 2006; Dempsey et al., 2019; Giffin, 2008; Lawn & McMahon, 2015; Magne-Ingvar & Öjehagen, 1999a; McLaughlin et al., 2016; Nosek, 2008;

		Rheinberger et al., 2021; Spillane et al., 2020; Talseth et al., 2001; Vandewalle et al., 2021; Wand et al., 2019; Wayland et al., 2021
	Discharge tension	Castelli Dransart & Guerry, 2017; Cerel et al., 2006; Dempsey et al., 2019; Giffin, 2008; Lawn & McMahon, 2015; Nosek, 2008; Rheinberger et al., 2021; Spillane et al., 2020; Talseth et al., 2001; Vandewalle et al., 2021; Wand et al., 2019; Wayland et al., 2021
	Flawed systems	Castelli Dransart & Guerry, 2017; Cerel et al., 2006; Dempsey et al., 2019; Giffin, 2008; Lawn & McMahon, 2015; McLaughlin et al., 2016; Rheinberger et al., 2021; Talseth et al., 2001; Vandewalle et al., 2021; Wayland et al., 2021
5. What carers want and need		Asare-Doku et al., 2017; Borisonik 2018; Castelli Dransart & Guerry, 2017; Cerel et al., 2006; Chessick et al., 2009; Chessick et al., 2007; Chiang et al., 2015; Crasta et al., 2021; Dempsey et al., 2019; Fogarty et al., 2018; Giffin, 2008; Katz et al., 2015; Kjellin & Östman, 2005; Lawn & McMahon, 2015; Magne-Ingvar & Ojehagen, 1999; Magne-Ingvar & Öjehagen, 1999a; McDonell et al., 2003; McLaughlin et al., 2016; McLaughlin et al., 2014; Nosek, 2008; Nygaard et al., 2019; Rheinberger et al., 2021; Sellin et al., 2017; Spillane et al., 2020; Sun & Long, 2008; Talseth et al., 2001; Vandewalle et al., 2021; Wand et al., 2019; Wayland et al., 2021
	Information and education	Asare-Doku et al., 2017; Castelli Dransart & Guerry, 2017; Crasta et al., 2021; Dempsey et al., 2019; Fogarty et al., 2018; Giffin, 2008; Katz et al., 2015; McDonell et al., 2003; McLaughlin et al., 2016; Nosek, 2008; Rheinberger et al., 2021; Sun & Long, 2008; Vandewalle et al., 2021; Wand et al., 2019; Wayland et al., 2021
	Recognition and appreciation	(Castelli Dransart & Guerry, 2017; Cerel et al., 2006; Giffin, 2008; McLaughlin et al., 2016; McLaughlin et al., 2014; Vandewalle et al., 2021; Wand et al., 2019; Wayland et al., 2021
	Communication and partnership	Castelli Dransart & Guerry, 2017; Cerel et al., 2006; Giffin, 2008; McLaughlin et al., 2016; McLaughlin et al., 2014; Rheinberger et al., 2021; Sellin et al., 2017; Spillane et al., 2020; Talseth et al., 2001; Vandewalle et al., 2021; Wand et al., 2019; Wayland et al., 2021
	Emotional, psychological and practical support	Asare-Doku et al., 2017; Borisonik 2018; Castelli Dransart & Guerry, 2017; Chiang et al., 2015; Chessick et al., 2007; Chessick et al., 2009; Dempsey et al., 2019; Giffin, 2008; Katz et al., 2015; Kjellin & Östman, 2005; Magne-Ingvar & Ojehagen, 1999; Magne-Ingvar & Öjehagen, 1999a; McLaughlin et al., 2014; McLaughlin et al., 2016; Nygaard et al., 2019; Sun and Long (2008); Vandewalle et al., 2021; Wand et al., 2019; Wayland et al., 2021

Chapter 3: Methodology & methods (appendices 9 – 21)

Appendix 9: Qualtrics survey

Introduction

Q1 **Experiences and support needs of adults in England who care for adults they consider to be at risk of suicide: A research study**

We are carrying out a survey to help us understand more about what life is like for adults who care for an adult family member or friend they think may be at risk of suicide.

We hope that the information we obtain from this survey will give professionals a better understanding of carers' needs and contribute to the development of resources for carers.

To find out more about the study please click on **NEXT** for the participant information.

Q2

Experiences and support needs of adults in England who care for adults they consider to be at risk of suicide: Participant Information

You are invited to take part in a research study by completing a survey about your experiences as a carer. Before you decide whether or not to take part, it is important for you to understand why the research is being done and what taking part will involve for you. Please take time to read the following information and think it over for a couple of days before you decide whether or not you want to take part.

The survey link will be available until 1st November 2021. After this time it will not be possible to complete the survey.

What is the purpose of the survey?

We want to find out about the experiences and support needs of adults in England who currently care for an adult family member or friend they consider to be, or who has previously been, at risk of suicide.

Why have I been invited to participate?

You have been invited to take part in the survey because:

You are 18 years or over;

You consider yourself to have current caring responsibility for an adult family member or friend (over the age of 18 years) who you think may be at risk, or has previously been at risk, of suicide;

You live in England.

Do I have to take part?

No, taking part is entirely voluntary. It is up to you to decide whether or not to take part. If you do decide to participate, you are still free to withdraw without giving a reason up until you have completed and submitted the survey. Once you have submitted the survey your data will be retained. Participation, non participation or withdrawal will not impact on any care you or the person you care for may be in receipt of.

What will happen to me if I take part?
If you would like to consider taking part in the survey you should first read this participant information. If you decide to take part, you will be asked to complete a consent section at the beginning of the survey to confirm that you have read and understand the participant information. You will then be asked to go on to complete the main survey. This is made up of some multiple-choice questions and some questions that involve writing short answers based on your experiences. In addition, you will be asked some general questions about yourself, and the person you care for.
To help us evaluate the experience of participating in the research, you will be asked to rate your mood before and after the survey and asked to complete a few questions about how you found taking part in the survey. You do not have to complete the evaluation if you do not want to.
Completing the survey should take between fifteen and twenty-five minutes depending on how much you write for the questions asking about your experiences.

What are the possible disadvantages and risks of taking part?
The research is investigating a sensitive area and it is possible you might find some of the questions upsetting if they bring difficult memories and experiences to mind. There are organisations that can provide support if you do feel distressed and these are listed at the end of this information section and at the end of the survey.

How will my participation make a difference?
We cannot promise that taking part in this research will benefit you or the person you care for. We don't know enough about the experiences and support needs of adults who care for other adults who may be at risk of suicide. The results of this study may help us to learn more about how we can improve the support that is offered to carers in the future. You will have the opportunity to let us know your views and reflections. Previous research suggests that many people find this an interesting and worthwhile experience, even when focusing on very sensitive and personal issues.

Will my responses be kept confidential and anonymous?
Yes, all of the information you provide for this study will be kept strictly confidential. You will not be asked for any information that may identify you. The results of the survey will always be presented in a manner that preserves the anonymity of those taking part. Direct quotes from some of the survey responses will be used in research reports and these will be anonymised.

Where will my information be kept and who will have access to it?In this research study we will use information obtained from you. Oxford Brookes University will act as the data controller for the study. This means that the University is responsible for looking after your information and using it properly. We will only use information that we need for the research study. Everyone involved in this study will keep your data safe and secure. We will follow all privacy rules. Research data will be stored in encrypted files in Google Drive, for which the university has a security agreement. Access to the data will be by the researcher. Following the research, the data generated will be kept securely for a period of ten years in line with university policy and anonymised data may be stored in a specialist data centre/repository relevant to this subject area for future research. We will make sure no-one can work out who you are from the reports we write. There is a question in the survey asking if you would like to take part in an interview to talk in more depth about your caring experiences. If you are interested in being interviewed you will be asked to share your email address. Your email address will be stored separately from your survey data so it will not be possible to identify which survey responses are yours. Only the researcher will have access to your email address. As soon as the research is complete your email address will be deleted.

What will happen to the results of the research study?

The results will be included in the doctoral thesis of the researcher and it is anticipated they will be published in academic journals and presented at conferences. In addition, findings will be used to provide recommendations for improving carer support and to develop resources for carers. If you would like to receive a summary research report you can email the researcher on the email provided below.

Where can I find out more about how my information is used?

You can contact Oxford Brookes University Information Management Team on 01865 485420 or email info.sec@brookes.ac.uk

Who is organising and funding the research?

This research is being carried out by Karen Lascelles as part of a professional doctorate at Oxford Brookes University Faculty of Life Sciences and is funded by Oxford Health NHS Foundation Trust.

Who has reviewed the study?

The research has been designed under the supervision of the research team: Professor Jane Appleton, Professor Debra Jackson and Dr Zoe Davey.

The research has been reviewed by the University Faculty Ethics Committee at Oxford Brookes University and the Thames Valley and South Midlands NHS Research Ethics Committee.

Contact for further information

You can contact the researcher Karen Lascelles on 17002640@brookes.ac.uk if you have any questions or require any further information.

If you have any concerns about the way in which this research study is carried out you can contact the Chair of the Oxford Brookes University Faculty of Health and Life Sciences Research Ethics Committee on frec@brookes.ac.uk

Support for Carers

There is support available for carers; listed below are oganisations you can contact if you require support.

Rethink (www.rethink.org) provides support to carers of people with mental health problems. Visit the website for more information.

CarersTrust (www.carers.org) is a national organisation, which provides information for carers, including about support networks. For more information email info@carers.org or visit the website to find your nearest service.

For younger people in your network who may need carer support **Carers Trust** and **Young Minds** (www.youngminds.org.uk) can help.

The **National Suicide Prevention Alliance** website www.nspa.org.uk provides information about suicide prevention and can signpost you to support agencies in your area.

If you need immediate support you can call **Samaritans** for free at any time on 116 123 to talk about how you are feeling.

Alternatively, you can arrange to see your GP for support and to discuss other services that might be helpful for you such as psychological therapy.

It you wish to raise concerns or make a complaint about healthcare you or your loved one has received you can seek advice from the **Patient Advisory Liaison Service (PALS)**. You can find your nearest PALS office on the NHS website (www.nhs.uk) or you can ask your GP surgery, hospital or NHS 111 for details of your nearest PALS.

Q3 **Before you proceed with the survey please confirm the consent statements below - your data cannot be used without your consent**

	Tick to confirm (1)
I Confirm that I have read and understand the participant information for this study (1)	○
I understand that my participation is voluntary and that I am free to withdraw at any time up until I submit the completed survey (2)	○
I agree to the use of anonymised quotes in reports and publications (3)	○
I understand that anonymised data gathered for this study may be stored in a specialist data centre/repository relevant to this subject area for future research (4)	○
I agree to take part in this survey (5)	○

Q4 This survey is for adult carers. Are you age 18 years or over?

○ Yes (1)

○ No (2)

Q5 Do you currently care for an adult family member or friend who is 18 years or over?

○ Yes (1)

○ No (2)

Q6 Have you ever considered the person for whom you currently care to be at risk of suicide?

○ Yes (1)

○ No (2)

Q7 Do you live in England?

○ Yes (1)

○ No (2)

Q8 Is this the first time you have completed this survey?

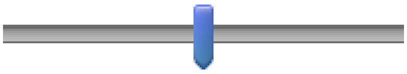
○ Yes (1)

○ No (3)

Q10 **How is your mood?**
Before you start the survey please rate your mood on the slider below between 0 and 100 if 0 is the worst mood imaginable and 100 is the best mood imaginable.
This question is optional.

0 10 20 30 40 50 60 70 80 90 100

0 = worst mood imaginable 100 = best mood imaginable ()



Q11
Please think about your experiences as a carer in the last few weeks and click on the circle that applies next to each statement. There are no right or wrong answers, we are just interested in what life is like for you as a carer.
© *Elwick et al 2010*

Support for caring

	Never (1)	Some of the time (2)	A lot of the time (3)	Always (4)
I have a good level of emotional support (1)	○	○	○	○
My needs as a carer are considered by professionals (2)	○	○	○	○
I am happy with the professional support that is provided for me (3)	○	○	○	○
I feel able to get the help and information I need (4)	○	○	○	○
I have all the practical support I need (5)	○	○	○	○

Q12 **Caring choice**

	Never (1)	Some of the time (2)	A lot of the time (3)	Always (4)
I feel that my life is on hold because of caring (1)	○	○	○	○
My social life has suffered because of caring (2)	○	○	○	○
I feel I have less choice about my future due to caring (3)	○	○	○	○
I feel I have no control over my own life (4)	○	○	○	○
Caring stops me doing what I want to do (5)	○	○	○	○

Q13 **Caring Stress**

	Never (1)	Some of the time (2)	A lot of the time (3)	Always (4)
I feel depressed due to caring (1)	○	○	○	○
I feel worn out as a result of caring (2)	○	○	○	○
I am mentally exhausted by caring (3)	○	○	○	○
I am physically exhausted by caring (4)	○	○	○	○
I feel stressed as a result of caring (5)	○	○	○	○

Q14 **Ability to care**

	Never (1)	Some of the time (2)	A lot of the time (3)	Always (4)
I am satisfied with my performance as a carer (1)	○	○	○	○
I can take care of the needs of the person I am caring for (2)	○	○	○	○
I feel I am able to make the life of the person I am looking after better (3)	○	○	○	○
I can manage most situations with the person I care for (4)	○	○	○	○
I am able to deal with a difficult situation (5)	○	○	○	○

Q15 **Carer satisfaction**

	Never (1)	Some of the time (2)	A lot of the time (3)	Always (4)
Caring is important to me (1)	○	○	○	○
I resent having to be a carer (2)	○	○	○	○
I feel frustrated with the person I am caring for (3)	○	○	○	○
I enjoy being a carer (4)	○	○	○	○
I am satisfied with my life as a carer (5)	○	○	○	○

Q16

In this part of the survey we are interested in your views about other people's feelings. The thirteen statements that you are going to read below refer to attitudes towards attempted suicide. These statements may not reflect how you feel about people who have attempted suicide, but how you believe others feel. You will probably disagree with some items and agree with others. We are interested in your views about other people's feelings. First impressions are usually the best so after you read each statement let us know if you strongly agree, agree, disagree or strongly disagree. There are no right or wrong answers.

	Strongly agree (1)	Agree (2)	Disagree (3)	Strongly disagree (4)
Most people would willingly accept a person who had attempted suicide as a close friend (1)	○	○	○	○
Most people believe that a person who attempted suicide is just as intelligent as the average person (2)	○	○	○	○
Most people believe that a person who attempted suicide is just as trustworthy as the average person (3)	○	○	○	○
Most people would accept a person who attempted suicide, and is healthy at the time, as a teacher of young children in a school (4)	○	○	○	○
Most people feel that attempted suicide is a sign of personal failure (5)	○	○	○	○

Most people would not hire a person who attempted suicide to take care of their children, even if he or she had been well for some time (6)	○	○	○	○
Most people think less of a person who attempted suicide (7)	○	○	○	○
Most employers will hire a person who attempted suicide if he or she is qualified for the job (8)	○	○	○	○
Most employers will pass over the application of a person who attempted suicide in favour of another applicant (9)	○	○	○	○
Most people in my community would treat a person who attempted suicide just as they would treat anyone (10)	○	○	○	○
Most people would be reluctant to date a person who attempted suicide (11)	○	○	○	○

Once they know a person has attempted suicide, most people will take their opinion less seriously (12)	○	○	○	○
Most people think that a person who attempted suicide has a mental disorder (13)	○	○	○	○

Q17 In the box below please briefly tell us what life is like for you as a carer.

Q18 If you have received support in your caring role please tick the relevant boxes to indicate where you have received support from and rate the helpfulness.

	Very helpful (1)	Helpful (2)	Neither helpful nor unhelpful (3)	Unhelpful (4)	Very unhelpful (5)
Mental Health Trust (1)	○	○	○	○	○
Carer Support Agency (2)	○	○	○	○	○
General Practitioner (3)	○	○	○	○	○
Family members (4)	○	○	○	○	○
Friends (5)	○	○	○	○	○
Other (please specify) (6)	○	○	○	○	○

Q19 Please briefly tell us more about the support you received and how you found it.

Q20 Do you think the Covid-19 pandemic and the associated restrictions, such as lockdown and social distancing, has influenced your experiences as a carer?

○ Yes (1)

○ No (2)

○ Unsure (3)

Q21 Please give reasons for your answer to the previous question.

Q22 Based on your experiences please briefly share your views on what support you think would help adults who care for adult family members or friends they think may be at risk of suicide.

Q23 We are interested in how you see your future as a carer. In the box below please briefly tell us about your thoughts on your future caring role.

Q24 How old are you?

- ○ 18- 25years (1)
- ○ 26-39 years (2)
- ○ 40-64 years (3)
- ○ 65+ years (4)

Q25 What is your gender identify? I identify as:

- ○ A man (1)
- ○ A woman (2)
- ○ Other (please specify) (3) ____
- ○ I prefer not to say (4)

Q26 Please indicate your ethnicity

- ○ White - British (1)
- ○ White - Irish (2)
- ○ White - any other (3)
- ○ Mixed - White and Black Caribbean (4)
- ○ Mixed - White and Black African (5)
- ○ Mixed - Any other mixed background (6)
- ○ Asian/Asian British - Indian (7)
- ○ Asian/Asian British - Pakistani (8)
- ○ Asian/Asian British - Bangladeshi (9)
- ○ Asian/Asian British - Any other Asian (10)
- ○ Black/Black British - Caribbean (11)
- ○ Black/Black British - African (12)
- ○ Black/Black British - Any other (13)
- ○ Chinese (14)
- ○ Any other ethnic background (15)
- ○ Prefer not to say (16)

Q27 Please supply the first part of your postcode e.g., OX4

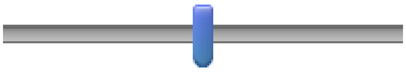
Q28 How many hours do you spend caring a week?

○ 0-10 hours (1)
○ 11-20 hours (9)
○ 21-30 hours (10)
○ 31-40 hours (11)
○ 41-50 hours (12)
○ 51-60 hours (13)
○ 61-70 hours (14)
○ Greater than 70 hours (15)

Q29 How long have you been a carer for? (please answer to the nearest year)

0 2 4 6 8 10 12 14 16 18 20

Less than one year - 20 years or more ()



Q30 Does the person for whom you care live with you?

○ Yes (1)

○ No (2)

Q31 What is your relationship to the person for whom you care?

Q32 Is the person for whom you care in touch with NHS mental health services?

○ Yes (1)

○ No they have never received input from NHS mental health services (2)

○ They have had input from NHS mental health services in the past but not currently (3)

Q33 Does the person for whom you care have a history of self-harm or suicide attempts?

○ Yes (1)

○ No (2)

Q34 What best describes the gender of the person you care for?

○ A man (1)

○ A woman (2)

○ Other (3)

○ Prefer not to say (4)

Q35 How old is the person you care for?

○ 18-25 years (1)

○ 26-39 years (2)

○ 40-64 years (3)

○ 65 + years (4)

Q36 We would like to carry out individual interviews with some of the respondents of this survey to obtain more detailed information about the caring experience. If you would like to find out more information about the interviews, please tick the box below.

Please note, once we have collected enough data, the interview part of the research study will end. This means we are unable to guarantee that everyone who expresses an interest will be interviewed.

○ I am interested in taking part in an interview about my experiences of caring for an adult I consider to be at risk of suicide (1)

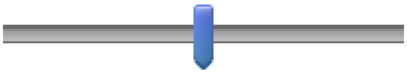
○ I am NOT interested in taking part in an interview (2)

Q37 If you are Interested in being interviewed please give your email address in the box below.

Q38 To help us evaluate the experience of completing the survey we would like to ask you to rate your mood as you did at the beginning of the survey (this is optional). Please rate your mood using the slider below if 1 is the worst mood imaginable and 100 is the best mood imaginable.

0 10 20 30 40 50 60 70 80 90 100

0 = worst mood imaginable 100 = best mood imaginable ()



Q39 How did you find taking part in this survey?

Q40 What was the best thing about taking part?

Q41 What was the worst thing about taking part?

Q42 Taking part in this study was:

	Strongly Agree (1)	Agree (2)	Neither agree nor disagree (3)	Disagree (4)	Strongly disagree (5)
Easy (1)	○	○	○	○	○
Upsetting (2)	○	○	○	○	○
Acceptable (3)	○	○	○	○	○
Beneficial (4)	○	○	○	○	○

Q43 You have answered all of the questions. Thank you for taking part.

○ Click here to end survey (4)

The below question is the skip logic when participants gave information that indicated they were not eligible for the study.

Q44 Due to the answers you have given to eligibility questions you are not eligible to complete this survey.

If you are under 18 and care for someone you think may be at risk of suicide there is support for you. Contact Carers Trust (www.carers.org) or Young Minds (www.youngminds.org.uk).

Appendix 10: AC-QoL validation discussion

The AC-QoL scale was developed in 2010 by researchers in the UK who have extensive experience of working with carers (Elwick *et al.,* 2010). The process of development involved review of the literature and initial identification of 100 items which were scrutinised and refined by expert panels and focus groups with carers.

For validation purposes the 100-item scale was piloted with 385 carers from 12 carers organisation in the UK (Joseph *et al.,* 2012). Initial analysis resulted in ten items with limited range of endorsement and a weak item-total correlation. These items were excluded from further analysis. Item reduction of the remaining 90 items was achieved by principal components analysis with varimax rotation to examine the structure of the questionnaire with eigenvalues > 1.00. Principal components analysis is a technique used to reduce the size of a dataset whilst preserving variation within it (Ringner, 2008). The varimax rotation helps to identify interpretable clusters of factors (latent variables) (Field, 2018). Eigenvalues represent the amount of variation explained by a factor and where these are >1.00 it means that common variance is accounted for and factors are reliable (Field, 2018). In the validation of the AC-QoL questionnaire, factor loadings (correlations between the item and the component) of > 0.40 were retained which is in keeping with best practice (Boateng *et al.*, 2018). This process resulted in a reduction from 90 to 40 items, which were grouped into eight domains and a further forced eight component principal components analysis was conducted. A reduction of this size is supported in the literature; Boateng *et al.* (2018) advise that the initial pool of items should be twice as large as the final number of items of the scale.

Convergent validity was tested by implementing AC-QoL pre and post a carer support intervention with carers from seven voluntary sector providers (Joseph *et al*. 2012). AC-QoL change scores were compared with carers perceptions of their increase in functioning based on a 16-item checklist also administered pre and post interventions. Higher AC-QoL change scores post intervention were moderately associated with higher change scores on participants' own perceptions of increased psychosocial functioning (r 1⁄4 0.33, p, 0.05).

The AC-QoL has been translated and validated with populations in China (Mei *et al.*, 2017), Italy (Negri *et al.*, 2019) and Portugal (Teixeira (Teixeira, Moura and Alves, 2021).

AC-QoL reliability

Internal consistency was achieved with a Chronbach's alpha value of a = 0.94 for the 40-item scale (Joseph *et al.,* 2012). There are different reports about the satisfactory values of Chronbahc's alpha (Tavakol and Dennick, 2011), with acceptable values ranging from 0.7 - 0.95. Values of the AC-QoL fall within these ranges suggesting acceptable internal reliability. Tavakol and Dennick (2011) argue that in a scale which comprises individual constructs accuracy will be improved by calculating alpha values for each construct rather than the scale as a whole to confirm unidimensionality of the subsets of items. The eight domains of the AC-QoL measure individual constructs of quality of life and Chronbach alpha values for these ranged from a = 0.78 - 0.89, which again suggest internal reliability.

In the pre and post intervention test, internal consistency reliability of the total AC-QoL was achieved (a = 0.94 and 0.95 for times 1 and 2, respectively). At both times, internal consistency of each of the subscales was satisfactory (time 1 a = 0.79 and at time 2 a = 0.83).

The processes undertaken by Joseph *et al.* (2012) to determine validity and reliability of AC-QoL are fair. Boateng *et al.* (2018) identify three phases (item generation, scale construction and scale evaluation) and nine steps of scale development and validation (dentification of domain and item generation, content validity, pre-testing of questions, sampling and survey administration, item reduction, extraction of factors, tests of dimensionality, tests of reliability and tests of validity). Most of these phases and steps have been met (see table below). Weaknesses associated with using the AC-QoL are that it has not been widely used and there are no comparable studies using it with carers of adults at risk of suicide. However, strengths include the involvement of carers, including carers of people with mental health problems, in its development, its relative recency compared to the caregiver burden scales identified in the literature review, the fact that it was developed in the UK where participants for this study were recruited, and the emphasis on general quality of life rather than solely negative attributes of caring.

Strengths and weaknesses of development of AC-QoL based on Boateng et al (2018) criteria

Phases and steps	Strengths	Weaknesses
Item generation		
Identification of domain and item generation	- Author expertise - Review of existing scales and identification of the need for the scale - Literature review identified three common themes - Pool of 100 items (over 2 x larger than final scale)	No inductive item generation involving carers
Content validity	- Judgement by expert panel - Focus groups with carers with an iterative approach involving adapting wording following groups and returning to the groups for further feedback.	No formalisation of expert panel judgement using statistical procedures Limited focus groups – two groups with a total of 14 carers
Scale development		
Pre-testing of questions	- Wording of questions was discussed within focus groups	No cognitive interviewing with target population
Sampling and survey administration	- Sample size for pilot of 100 item scale was 385 - Sample for pilot was from target population	
Item reduction	- Items with a restricted range of endorsement and a weak item-total correlation were flagged up for discussion by the authors with ten items excluded at this stage from further analysis - Principal component analysis with varimax rotation completed reducing items from 90 to 40	
Extraction of factors	- Principal component analysis completed	
Scale evaluation		
Tests of dimensionality	- Factor loading scores of > 0.4 were removed. - Second study to validate final 40 item survey involved pre and post administration - Unweighted scoring	No confirmatory factor analysis
Tests of reliability	- Chronbac's alpha value 0.94 for the 40-item scale, a = 0.78 - 0.89 for individual domains - Pre and post intervention a = 0.94 and 0.95 for times 1 and 2, respectively	
Tests of validity	- Convergent reliability from second study to validate final 40 item survey involved pre and post administration and comparison with participant perception measured via a checklist	No measures of discriminant validity

Appendix 11: STOSA validation discussion

STOSA reliability was measured by Guttman's lambada2 (glb) (Guttman, 1945) based on (Sijtsma, 2009) guidance on the limited utility of Chronbach's alpha and view that the glb provides a better estimation of reliability. Reliability values of glb 0.70 are considered acceptable (Bland and Altman, 1997). STOSA Glb scores were 0.762 for the general population, 0.767 for patients with mental disorders and 0.802 for suicide attempt survivors.

STOSA was repeated after four weeks with a sub-sample of 20 participants with the intraclass correlation coefficient (ICC). ICC is a correlation coefficient that assesses consistency between measures of the same class (Field, 2018), with scores > 0.60 indicating acceptability for clinical use (Brennan and Silman, 1992). It was reported that al ICC scores were acceptable.

Item-total correlation ranged from 0.253 – 0.509 with two items (items 5 and 6) having item-total correlation below 0.300.

Factor analysis involved Principle component analysis carried out with Pearson correlations and Promax rotation. Promax rotation is used over varimax rotation where there are large datasets (Field, 2018). A two-factor solution resulted; one grouping items to measure supportive, caring and respectful attitudes and one grouping items to measure stigmatising attitudes and beliefs. Reliability estimates were all >0.7 and the two extracted factors were highly correlated ($r = 0.444$, $p < 0.0001$), indicating that the two sets of items in the same scale achieves reliability.

During validation of STOSA there was no clustering around the central point (Scocco *et al.,* 2012). Strengths and weakness of STOSA against the Boateng *et al.* (2018) criteria are shown in the table below.

Strengths and weaknesses of development of the STOSA scale based on Boateng et al (2018) criteria

Phases and steps	Strengths	Weaknesses
Item generation		
Identification of domain and item generation	- STOSA was developed from a previous scale (PDD, Link 1989) with high psychometric properties	No inductive item generation involving carers or review by carers to assess suitability of PDD
Content validity		No expert panel judgement or lived experience review of appropriateness of PDD to suicide attempt population
Scale development		
Pre-testing of questions	- PDD structure was preserved with placement of suicide attempt instead of mental illness	No cognitive interviewing with target population
Sampling and survey administration	- Snowballing approach to sampling to optimise sample size - Total sample size good at 452	
Item reduction	N/A	
Extraction of factors	N/A	
Scale evaluation		
Tests of dimensionality	- Factor loading scores of > 0.4 were removed. - Second study to validate final 40 item survey involved pre and post administration - Unweighted scoring	No confirmatory factor analysis
Tests of reliability	- Guttlam's lambda2 vales all > 7.00 (0.762 general population, 0.767 patient population, 0.802 suicide attempter population)	Although test-retest stability was evidently carried out it was not reported for STOSA beyond ICC values were acceptable
Tests of validity	- Factor analysis	No measures of discriminant validity

Appendix 12: email correspondence with authors of AC-QoL regarding amending temporality of recall

---------- Forwarded message ---------
From: **Stephen Joseph** <Stephen.Joseph@nottingham.ac.uk>
Date: Mon, 12 Oct 2020 at 21:03
Subject: Re: adult carers quality of life questionnaire
To: Saul Becker <Saul.Becker@sussex.ac.uk>, Karen Lascelles <17002640@brookes.ac.uk>

Dear Karen,

You are welcome to use the change in wording.

But do keep in mind that if you do then it will not make sense to compare your scores with those of previous studies if you needed to do so.

I wish you success in your interesting work, it sounds like an important focus for investigation, and please do keep us informed of your results.

Best wishes,
Stephen

Professor Stephen Joseph
School of Education
University of Nottingham
Nottingham NG8 1BB, UK

NEW BOOK: *Authentic. How to be yourself and why it matters*
www.authenticityformula.com

From: Saul Becker <Saul.Becker@sussex.ac.uk>
Sent: 12 October 2020 10:40
To: Karen Lascelles <17002640@brookes.ac.uk>; Stephen Joseph <lqzsj@exmail.nottingham.ac.uk>
Subject: Re: adult carers quality of life questionnaire

Dear Karen, thanks for your email. I have copied in Stephen Joseph who will be able to advise you better about the change of words you are proposing, from the 'last two weeks' to the 'last few weeks'.

Best wishes for your doctorate.

Kind regards,

Saul

Professor Saul Becker

Provost

University of Sussex

Sussex House

Falmer

Brighton BN1 9RH

From: Karen Lascelles <17002640@brookes.ac.uk>
Date: Monday, 12 October 2020 at 10:35
To: Saul Becker <Saul.Becker@sussex.ac.uk>
Subject: adult carers quality of life questionnaire

Dear Professor Becker,

I am a professional doctorate student at Oxford Brookes University looking at the experiences and support needs of adult carers of adults at risk of suicide. I will be carrying out a survey and interviews. As part of my survey, I will be using some of the AC-QoL questions. I have a query regarding the introduction; in the preamble it says to think about life as a carer in the last two weeks. I would prefer to say the last *few* weeks in my survey. This is because the suicidality of the care recipients of my population is likely to ebb and flow and may not have been an issue in the previous fortnight but could have been within the last month or so.

I think I can defend this decision in my thesis but I wanted to seek approval from the original authors hence this email.

If you could share your thoughts on this and/or direct me to the other authors I would be very grateful.

With thanks in advance,

Karen Lascelles

Appendix 13: Recruitment invitation to participate in the survey

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Are you an adult who lives in England and currently cares for an adult family member or friend you think may be, or has previously been, at risk of suicide?

Are you interested in taking part in a research project looking at the experiences and support needs of carers like you?

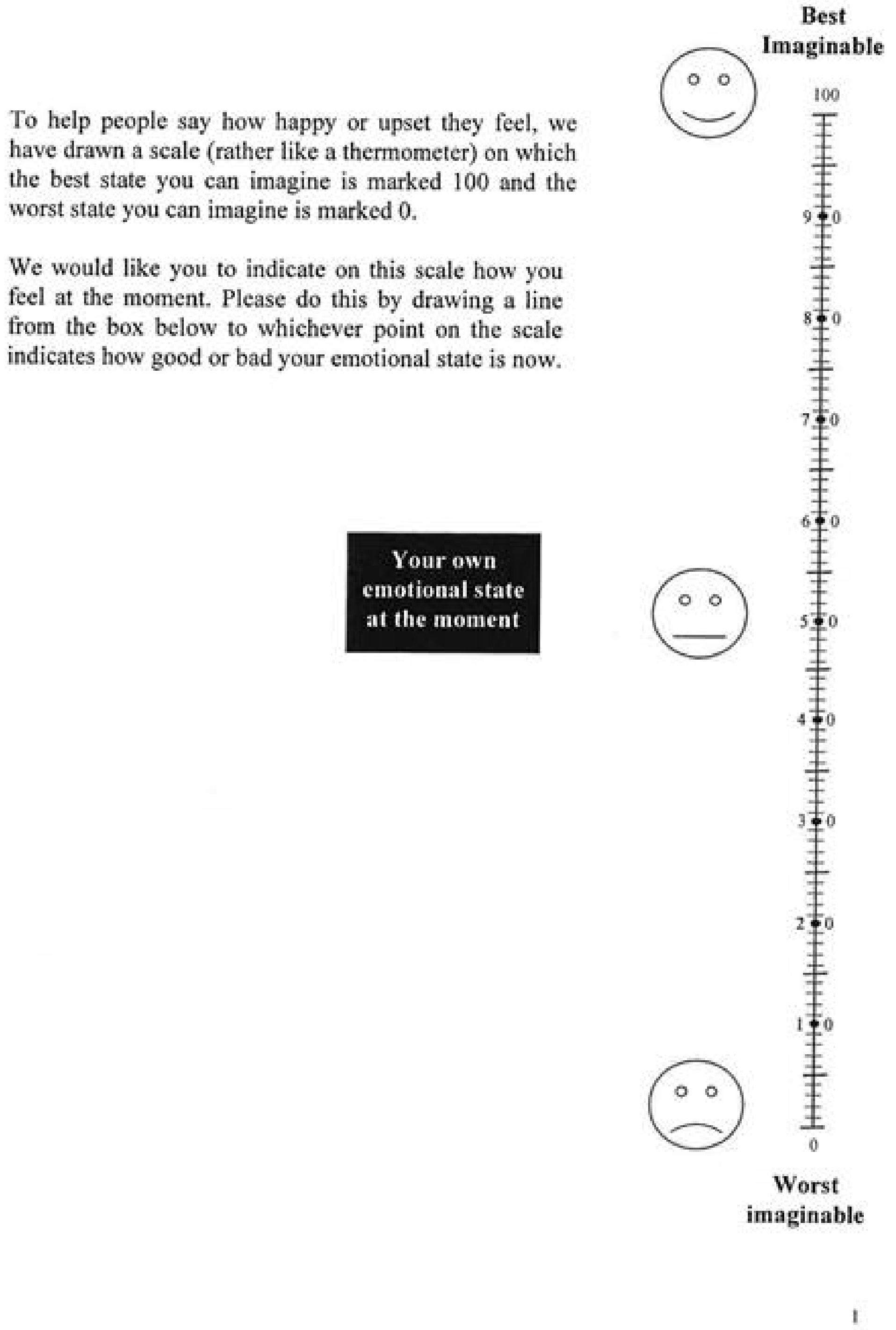
Find out more here [link to PIS & survey]

Appendix 14: Qualitative interview schedule

Interview 1 (main interview)

1. Visual analogue scale
2. Demographic questions
3. Interview questions
4. Debrief questions
5. Visual analogue scale evaluation questions
6. Discuss options for second telephone interview/questions for second interview
7. Further information and support sheet

1. **Visual Analogue Scale**



To help people say how happy or upset they feel, we have drawn a scale (rather like a thermometer) on which the best state you can imagine is marked 100 and the worst state you can imagine is marked 0.

We would like you to indicate on this scale how you feel at the moment. Please do this by drawing a line from the box below to whichever point on the scale indicates how good or bad your emotional state is now.

Your own emotional state at the moment

2. **Demographic Questions** (let the participant know that they will have completed these questions on the survey but we do not know which survey response is theirs, so we need to ask them again for the interview part of the research)

1. Age …………………….

2. How do you describe your gender

Man	
Woman	
Other (please specify if you would like to)	
Prefer not to say	

3. Ethnicity (ask the participant to indicate which box should be ticked)

White - British	
White - Irish	
White – any other	
Mixed – White and Black Caribbean	
Mixed – White and Black African	
Mixed – Any other mixed background	
Asian/Asian British - Indian	
Asian/Asian British - Pakistani	
Asian/Asian British - Bangladeshi	
Asian/Asian British – Any other Asian	
Black/Black British - Caribbean	
Black/Black British - African	
Black/Black British – Any other	
Chinese	
Any other ethnic background	
Prefer not to say	

4. What county in England do you live in? ……………………………

5. How many hours do you spend caring a week? (ask the participant to indicate which box should be ticked)

0 - 10 hours	
11 – 20 hours	
21 – 30 hours	
31 – 40 hours	
41 – 50 hours	

51 – 60 hours	
61 – 70 hours	
More than 71 hours	

6. How long have you been a carer for? …………………………….

7. Does the person for whom you care live with you?

Yes	
No	

8. Is the person you care for under the care of mental health services? (please tick one box)

Yes	
No	
Has been in the past but not currently	

9. Does the person you care for have a history of self-harm or suicide attempts?

Yes	
No	

10. How does the person you care for describe their gender?

Man	
Woman	
Other	

11. How old is the person you care for?

18-24 years	
25-39 years	
40-54 years	
55 years upwards	

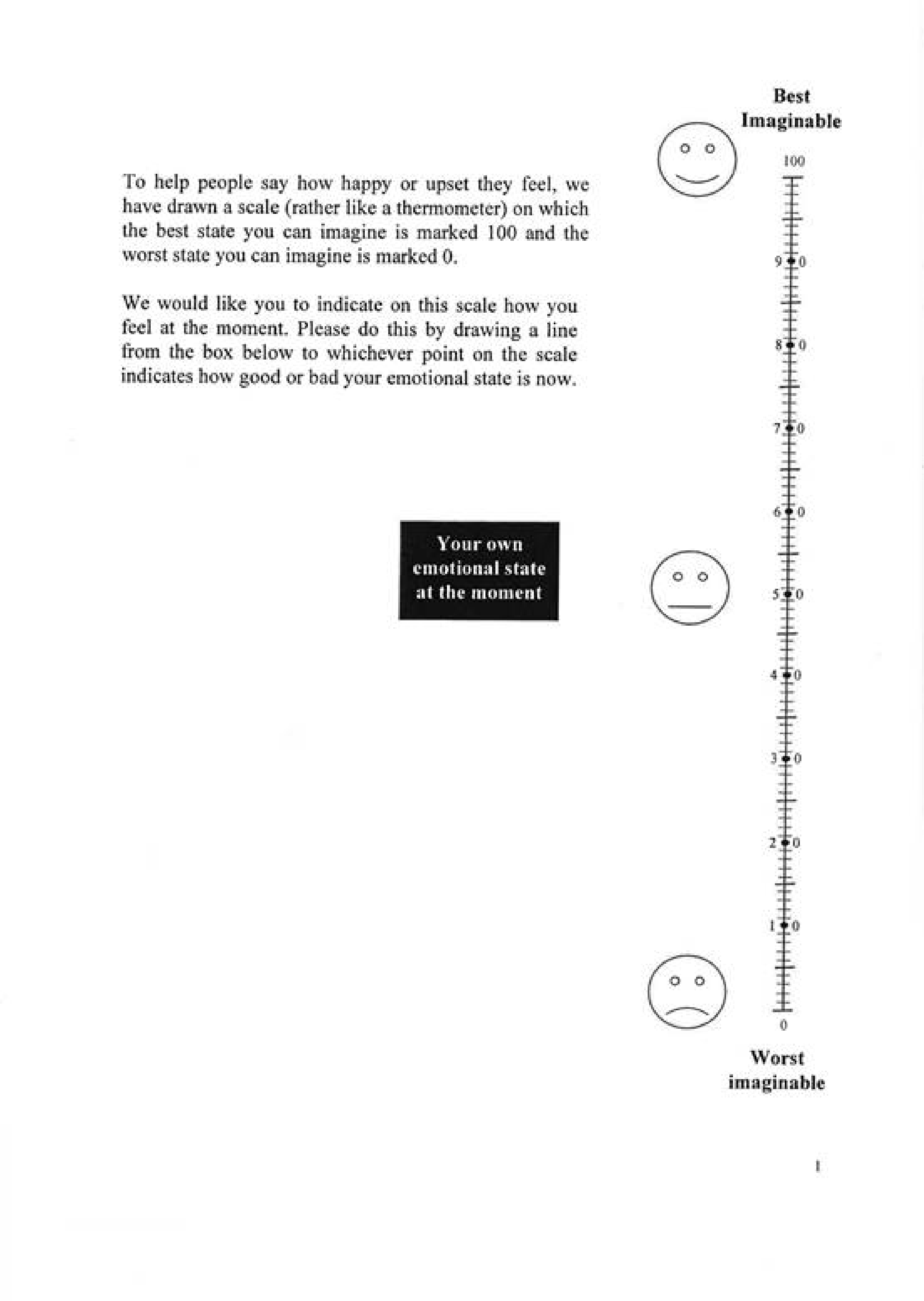
3. **Semi structured Interview**

Topic area	Questions/ probes
Introduction Relationship with the person they care for	Can I start by asking you how you became a carer? What is your relationship with the person you care for? In what way do you consider the person with whom you care to be at risk of suicide? Include probes - *In what way?* - *What happened then?* - *Can you tell me a bit more about that?* Include unscheduled probes as appropriate
The caring role	Can you tell me about your caring role? - *What is it like being a carer?* What impact has your caring role had on your life? What impact has your caring role had on your relationship with the person you care for? In your experience what is the most difficult aspect of being a carer? Probes (as appropriate if not volunteered in answers to above) - *How does your caring role affect you emotionally?* - *Do you find the caring role stressful? In what way?* - *Do you get any satisfaction from the caring role?*

	- *What are the positive aspects of caring?* Include unscheduled probes as appropriate
Stigma	Have you experienced any negative attitudes from others because of your role as a carer or the person you care for? Do you avoid talking about your situation for fear of negative responses from others? - *Can you tell me about that?* - *How did/does that make you feel?* Include unscheduled probes as appropriate
Support received	What support have you received in your role as a carer? - *Who have you received support from?* - *Elicit whether formal or informal support* Has the support you have received been helpful? In what way? - *Can you tell me more about that?* Has any of the support you have received been unhelpful? In what way? - *Can you tell me more about that?* Include unscheduled probes as appropriate
Support that would be helpful	Based on your experience as a carer, what support do you think should be available for carers? - *In what way/can you tell me more?* - *What might carers find helpful?* - *Is there anything else that might be of benefit?* Include unscheduled probes as appropriate

COVID-19	Do you think the COVID-19 pandemic and the associated restrictions, such as lockdown and social distancing, has influenced your experience as a carer? - *How/in what way/can you tell me more?* - *Were you/have you been able to access the same level of support?* - *If support changed how did it change?*
Future	How do you see you caring role in the future? - *What fears or anxieties do you have about the future for you and the person you care for?* - *What are your hopes for the future for you and the person you care for?* - *In what way/tell me more* Include unscheduled probes as appropriate
Anything else	Is there anything else, based on your experience as a carer, that you think it would be helpful for us to know for our research?

4. **Visual Analogue Scale**



To help people say how happy or upset they feel, we have drawn a scale (rather like a thermometer) on which the best state you can imagine is marked 100 and the worst state you can imagine is marked 0.

We would like you to indicate on this scale how you feel at the moment. Please do this by drawing a line from the box below to whichever point on the scale indicates how good or bad your emotional state is now.

Your own emotional state at the moment

4. Evaluation questions and debrief

I would like to ask you just a few final questions about how it felt to be interviewed and to take part in this research. You do not have to answer these questions if you do not want to (check whether or not they want to)

1. How did you find taking part in this research study? (*how do you feel talking about things like this? Ask about both the survey and the interview*)
2. What was the best thing about taking part?
3. What was the worst thing about taking part?
4. Ask the participant to complete the box below

Taking part in this study was:

Very Easy	1	2	3	4	5	Very Difficult
Very Upsetting	1	2	3	4	5	Not at all upsetting
Very Acceptable	1	2	3	4	5	Not at all acceptable
Very Beneficial	1	2	3	4	5	Not all beneficial

Debrief

Talk with the participant about attending to self care and if appropriate make suggestions. Talk them through the agencies on the debrief sheet, how to refer etc and give them a copy to keep.

5. Further information and support sheet (provide on headed paper)

Thank you for participating in the research study.

Please be assured that all of the information you have provided will be treated with the strictest confidentiality and any identifiable information shared in the interviews will be removed from transcripts. It will not be possible for you to be identified from quotes used in research reports or publications.

If you have any further questions about the research, please don't hesitate to contact me:

Karen Lascelles 17002640@brookes.ac.uk

Please find below a list of useful contacts of organisations that can offer support and advice should you require it.

Rethink www.rethink.org provides support to carers of people with mental health problems. Visit the website for more information.

Carers Trust https://carers.org is a national organisation which provides advice and information about support networks. For more information email info@carers.org or visit the website to find your nearest service.

For younger people in your network who may need carer support, Carers Trust and Young Minds www.youngminds.org.uk can help.

The National Suicide Prevention Alliance https://www.nspa.org.uk/ provides information and resources relating to suicide prevention and can signpost people to support in their local area.

If you need immediate support, you can call Samaritans for free at any time on 116123 to talk about how you are feeling.

Alternatively, you can arrange to see your GP for support and to discuss other services that might be helpful to you, such as psychological therapy.

If you wish to make a complaint about healthcare you or your loved one has received you can seek advice from the Patient Advisory and Liaison Service (PALS). You can find your nearest PALS office on the NHS website www.nhs.uk or you can ask your GP surgery, hospital or phone NHS 111 for details of your nearest PALS.

Appendix 15: Interview participant information sheet

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Experiences and Support Needs of Adults in England who Care for Adults they consider to be at Risk of Suicide: A Research Study

Invitation to participate in an interview research study

You are invited to take part in a research study by participating in interviews about your experiences as a carer of an adult family member or friend you consider to be, or has previously been, at risk of suicide. Before you decide whether or not to take part, it is important for you to understand why the research is being done and what taking part will involve for you. Please take time to read the following information carefully and think it over for a couple of days before making a decision.

What is the purpose of the research study?

We are studying the experiences and support needs of adults in England who currently care for an adult family member or friend they consider to be, or who has previously been, at risk of suicide.

A carer in this instance is any adult (18 years and over) who, on an unpaid basis, looks after a family member, partner or friend (over the age of 18 years).

Experiences and support needs might include personal experience of caring, views on support received from support services such as the NHS or other professional or voluntary services, or experiences of support from family and friends.

Once we have collected enough data, the interview part of the study will end. This means we are unable to guarantee that everyone who expresses an interest in taking part in this research will be interviewed.

Why have I been invited to participate?

You have been invited to take part because:

- You completed the survey part of this research, where you indicated interest in taking part in the interviews;
- You are 18 years old or over;
- You consider yourself to have current unpaid caring responsibilities for an adult (over the age of 18 years) who you think may be at risk, or has previously been at risk, of suicide;
- You live in England.

Do I have to take part?

No, it is entirely up to you whether to take part or not. If you do decide to take part, you will be given this information sheet along with a privacy notice which will explain how your data will be collected and used. You will also be asked to complete a consent form. You can withdraw from the research at any time without giving a reason. You may also withdraw your information up until data analysis begins (a month after your interview has taken place) by contacting the researcher via the email address provided below. Once data analysis has commenced it will not be possible to extract your information. If you are in receipt of healthcare, participation, non-participation or withdrawal will not impact on your care or the care of the person you care for.

What will happen to me if I take part?

If you decide to take part you will be invited for an Interview, which will take place by telephone, Google Meet or Zoom (video) or Google Chat (online messaging), depending on what is most practical for you. If you are unfamiliar with Google Meet, Zoom or Google Chat the researcher will explain how you can set them up.

To help us evaluate the experience of participating in this research, you will be asked to rate your mood before and after the interview and you will be asked a few questions about how you found the interview. You do not have to complete the evaluation if you do not want to.

After the interview, you will be invited to take part in an optional short second telephone interview one week later to ask if you have anything you would like to add. This is because research interviews offer an opportunity for reflection and often participants continue to reflect afterwards and have additional thoughts they might want to be included in the research. You do not have to take part in this second interview if you do not want to.

The first interview will last for around one hour and the optional second interview will be much shorter (between 10 and 20 minutes). All interviews will be audio recorded so that the researcher can later type up transcripts to use in the data analysis.

Interviews will be carried out by the researcher, Karen Lascelles, who is a doctoral student at Oxford Brookes University. Karen has several years' experience working with individuals who are suicidal and their carers as a mental health nurse.

What are the possible disadvantages and risks of taking part?

The research is looking at a sensitive area and it is possible that you may feel uncomfortable or distressed discussing aspects of your caring experiences. Before deciding if you want to take part in this study, please consider how this might impact on you.

Should you feel uncomfortable at any time during an interview, please be assured that you do not have to answer any questions if you do not wish to, and you can take a break or terminate the interview at any time. At the end of each interview the researcher will check you are still happy for us to use the information you have provided. We will also provide you with links to supportive contacts and organisations that may be helpful if you go on to experience distress after the interview. These are also listed at the end of this participant information sheet. If you agree to be interviewed, we will spend some time talking about what happens if you become distressed during or after the interview.

How will my participation make a difference?

We cannot promise that taking part in this research will benefit you or the person for whom you care. We don't know enough about the experiences and support needs of adults who care for other adults at risk of suicide. By participating in this research, you will be helping us to learn more about how we can improve the support that is offered to carers in the future. An additional benefit is that you may find the opportunity to discuss your experiences and share your views helpful. Previous research suggests that many people find interviews an interesting and worthwhile experience, even when focusing on very sensitive and personal issues.

What if something goes wrong?

If you have any concerns or complaints about the way in which this research study is carried out you can contact the researcher or her supervisor (see below for contact details) or the Chair of the Oxford Brookes University Faculty of Health and Life Sciences Research Ethics Committee on frec@brookes.ac.uk

Will my responses be kept confidential?

Information collected about you during this study will remain strictly confidential subject to legal limitations. If the researcher is concerned about your safety or that of the person for whom you care she will discuss this with you, and she may inform other services to ensure you receive the relevant support and advice.

As noted above, your interview will be audio recorded so that the researcher can listen to it and transcribe it later, but no-one except the researcher will be able to identify you. Once the transcript has been double-checked against the audio recording, all audio recordings will be deleted. All direct quotations used in research reports or publications will be pseudonymised (i.e., it will not be possible for readers to identify you or the person you care for from reading quotes). Nobody else outside the research team will have access to your interview recording or transcript.

Where will the information be kept and who will have access to it?

In this research study we will use information obtained from you. We will only use information that we need for the research study. Only the researcher will know your name and contact details. Everyone involved in this study will keep your data safe and secure. We will also follow all privacy rules. We will make sure no-one can work out who you are from the reports we write.

You can stop being part of the study at any time, without giving a reason, but once data analysis has commenced, we will keep information about you that we already have. We need to manage your records in specific ways for the research to be reliable. This means that we won’t be able to let you see or change the data we hold about you.

Oxford Brookes University will act as the data controller for this study. This means that the university is responsible for looking after your information and using it properly. Research data will be kept securely at all times. The laptop computer used for the research will be password protected and all data files encrypted. Data will be stored in Google Drive, for which the university has a security agreement. Data may be shared with the research supervisory team, but they will not be able to see your name or contact details. Your data will have a code number instead. Following the research, the data generated will be kept securely for a period of ten years in line with university policy in case it needs to be checked, and it may be stored in a specialist data centre/repository relevant to this subject area for future research. Any personal information such as email addresses or telephone numbers will be deleted as soon as the research is complete. Please read the privacy notice that will be given to you carefully.

Where can I find out more about how my information is used?

You can find out more about how we use your information at www.hra.nhs.uk/information-about-patients/ and info.sec@brookes.ac.uk

What will happen to the results of the research study?

The results will be included in the doctoral thesis of the researcher and it is anticipated they will be published in academic journals and presented at conferences. In addition, findings will be used to provide recommendations for improving carer support and to develop resources for carers.

Should you wish to receive a summary research report and links to any academic publications please email the researcher.

Who is organising and funding the research?

This research is being carried out by Karen Lascelles out as part of a professional doctorate at Oxford Brookes University Faculty of Health and Life Sciences, funded by Oxford Health NHS Foundation Trust.

Who has reviewed the study?

The research has been designed under the supervision of the research team: Professor Jane Appleton, Professor Debra Jackson and Dr Zoe Davy

The research has been reviewed by Oxford Brookes University Faculty of Health and Life Sciences Research Ethics Committee and the Thames Valley and South Midlands NHS Research Ethics Committee.

Contact for further information

You can contact the researcher Karen Lascelles on 17002640@brookes.ac.uk if you have any questions or require any further information.

Alternatively, you can contact Karen's supervisor and Director of Studies, Professor Jane Appleton on p0072764@brookes.ac.uk

Any concerns can be directed to or the Chair of the Oxford Brookes University Faculty of Health and Life Sciences Research Ethics Committee on frec@brookes.ac.uk

Support for Carers

Rethink www.rethink.org provides support to carers of people with mental health problems. Visit the website for more information.

Carers Trust https://carers.org is a national organisation which provides advice and information about support networks (including for young carers). For more information email info@carers.org or visit the website to find your nearest service.

The National Suicide Prevention Alliance website https://www.nspa.org.uk/ provides information about suicide prevention and can signpost you to support agencies in your area.

If you need immediate support, you can call Samaritans for free at any time on 116123 to talk about how you are feeling.

Alternatively, you can arrange to see your GP for support and to discuss other services that might be helpful to you, such as psychological therapy.

If you wish to make a complaint about healthcare you or your loved one has received you can seek advice from the Patient Advisory and Liaison Service (PALS). You can find your nearest PALS office on the NHS website www.nhs.uk or you can ask your GP surgery, hospital or phone NHS 111 for details of your nearest PALS.

Appendix 16: Overview of participants and initial post interview reflections/field notes

1. Alison

Alison is a 64 year old married woman with five adult children including her 24 year old autistic son who had a suicide attempt a few years ago and has been living at home since. Alison works in a school supporting students, some of whom have autism or experience suicidal thoughts so she describes her carer role as a bit of a busman's holiday. Her brother ended his life by suicide in the context of terminal cancer shortly before her son developed depression and suicidality, although this exposure did not seem to have a significant influence on her sensemaking of her son's presentation. She describes her family as close and they share the load and spend a lot of time together engaged in activities that her son will join. Alison has a strong faith which has helped her to make sense of things and cope and she is also aware of her personality and idiosyncrasies which help or hinder, for example she is aware that her mental health may be negatively affected by her situation if she doesn't take care of her wellbeing. She has confidantes and spends time with them, supported by her husband. Having her son at home has meant that Alison and her husband's retirement plans have been put on hold and she is keen to support her son to move forward so that he, and they, can have a better future. Alongside this she describes an ongoing concern about his wellbeing although this is not so much about suicide nowadays, but his mental health more generally. However, she had periods of constant worry which she can recall with clarity. She described sadness and anger that he hasn't had the life she wanted him to have. Alison's son doesn't really engage with services and she hasn't had any organised carer support but does feel that peer support would be helpful as only those who have experienced similar experiences can understand how it feels. Throughout the interview, despite Alison's experience with her brother's suicide and son's suicidality, suicide was not her major concern with her son, she had reached the conclusion that he had not meant to die, and this is not on his mind now. Her main worry was the implications of his autism, specifically his lack of social integration. So, from a caring for someone at risk of suicide perspective she was able to demonstrate that there is for some people a point at which the fear and uncertainty instilled by experiencing a suicide attempt can be transcended when there is some certainty reinstated by, I guess, the care recipient's shift away from suicidal thinking. Although she did nonetheless talk about constant worry which suggests that the fear never completely goes. Objectively, Alison's situation differed from most other people's in that the suicide attempt was somewhat of a one off. Similarly, Dot, whose husband is also autistic, voiced that her husband had had periods of suicidal ideation and behaviour but no actual attempt, and the main thrust of her caring at the time of interview was autism rather than suicidality per se. Obviously suicide is a behaviour and not a diagnosis so all participants were also dealing with other aspects of the care recipients mental health or mental illness (captured through additional caring demands code although this is unlikely to be a key component of any theme), although for most suicidality was the prominent feature. It is interesting that the two people caring for someone with autism expressed lower intent suicidality than others.

2. Betty

Betty is a 59-year-old mother of four who has two daughters with significant (different) mental health problems both of whom have engaged in suicidal behaviour. She focused the interview on the daughter who has had the most suicide attempts. Betty's husband is in fact the named carer as he doesn't work, Betty works full time but outside of that is also involved in the caring role. She was able to work at home pre-pandemic and also flexibly according to her daughters' needs and the pandemic made this even easier as she was working at home all of the time.

Betty very much had a whole family approach; her husband was involved and she talked about her sister, and her eldest daughter who doesn't have mental health problems supporting her daughters in the future (interestingly though not her son – is that a gendered thing?). In my nurse and my researcher role it made me feel quite hopeless in ways, hearing her perspectives on mental health care and what essentially it hasn't done for her daughter and the unhelpfulness of services. She found some of the specialised care they have had and the odd clinician helpful but generally she doesn't feel that MH services have responded to her daughter's needs sensitively or effectively. She has different beliefs about her daughter's needs to MH services. The only thing she feels she can do is complain and she does complain; she says MH services hate her because she complains. Hearing that as a researcher is important. Inside me there was the provider a bit of me sort of thinking gosh, I wonder what else we can do. It all does seem quite hopeless. What is it that we can do? So, a bit of an uncomfortable position to be in, kind of feeling guilty as a provider because there are so many people out there in this situation that we're just not helping and subsequently the families are suffering, but how do we help them? I think Betty is very angry at her situation and this is all projected onto mental health services. Betty was also I think holding on to her anger because she felt comfortable there and it meant that she could avoid thinking about the pain associated with potentially losing her daughters to suicide. When she talked about an attempt or near miss, or the fact that she thinks if her daughter was left alone she would be dead within a week, she was impassive in her narrative. She came across as emotionless throughout to some degree, the only emotion she was able to name was anger and this projected onto nobody cares, there is no support, nobody wants to know, nobody is interested, there's nothing there, mental health services are rubbish. In ways I think that she wanted to find someone to blame; she was angry understandably that she had elicited blame from others as a parent, and maybe she blames herself, and she wanted to find someone else to hold responsible. But inside I got the sense she knows nobody else is responsible, including her, but as a mother and carer she feels that she is the only one responsible for doing anything about it and actually she feels quite hopeless, but again it's easier for her to turn it into anger because perhaps anger is quite productive for her. She is very angry that services rarely hospitalise suicidal individuals and thinks it is grossly unfair that carers are expected to make someone safe 24/7, expressing that it isn’t possible for carers to prevent suicide because it can happen in moments.

I suppose if I was thinking about her in a clinical way I would be thinking that she is, no doubt unwittingly, hiding myriad emotions beneath her anger and detachment as it feels safer, but I am here in a research capacity. Nonetheless I do think her narrative is directly linked to how she manages her emotions and her interview was monopolised by her anger and sense that nobody cares, nobody can fix it, she can’t fix it, but it should be fixable. I felt that she considers herself to be in a different world – this is the main code I came up with in this interview, a bit like a parallel universe; she works and probably functions very well in that capacity, but her home life is different to that of anybody else that she knows. She doesn't talk about it to anybody and she finds it easier to exist in a different world because her perception is that no one else wants to know about it. And she protects herself by being angry at everyone and everything that she considers to perpetuate her own, and her daughters’ different world existence.

3. Carol

Carol is a 29 year old single woman who lives in the South East and works in policy development. She has a caring role for her mother who lives in another part of the country and who developed depression and anxiety following a stroke in 2017, and who has made several serious attempts on her life. The ambiguous nature of caring came up in that Carol lives and works in one city but is nonetheless doing a lot for her mother back at home, particularly when she is in and out of hospital; sorting all of the admin, being the next of kin, liaising with professionals. No support has been offered to Carol by professionals who she thinks see her as a competent and forthright young woman who is probably ok. Related, being calm in a crisis was evident because of everything that needed to be done and the need to prioritise her mum's safety. She talked about not stopping to process emotions, in part so that she could continue in crisis mode, in part because there is just no time. She has made use of therapy to help her process her experiences and emotional responses. She talked a lot about fear and expectancy touching on living with the possibility of death but not to the degree of acceptance. Carol talked at length of the changing relationship between her and her mother due to the caring role, particularly the 'very adult' conversations they have had to have about suicidality and keeping her mum safe, however also shared that they did have more 'normal' mother/daughter moments as well. Caring rewards were identified by Carol; her relationship with her mother has become much closer and she feels a sense of satisfaction for being instrumental in her mother still being alive, although of course she would rather this was not the situation. Her narrative again highlighted the 'different world' existence experienced by those caring for someone who struggles with suicidal thoughts and behaviours. For example, the assumptions made by others that as a child free 29 year old she is responsibility free when in fact she shoulders a lot of responsibility but can't really talk about it because people find the changeability and enduring cyclical nature of her mum's illness incomprehensible – they assume that depression is something people get over quite quickly and are always amazed to hear about prolonged hospital admissions. Alternatively, peers are perplexed when Carole texts her mum when on a night out, not appreciating that she is checking in for safety reasons. The different world concept was articulated through Carol's experiences of carer support in the workplace – they lump it in with parental leave, support available for people bereaved but not those still living with the aftermath of suicide attempts, she said ‘where are they’? Are they all existing within their unrecognised different world and just getting on with it alone? Carol talked of feeling lonely and at times isolated because of this different world she lives in. Perhaps related to the different world experience was the experience of stigma, linked to a lack of knowledge of people in the normal world, the lack of support for carers in the context of suicidality rather than suicide bereavement, and self-stigma in that Carol often didn’t talk because of her own sense of people not understanding, people judging etc, rather than finite evidence that this was the case. This reminded me of the stigma loop people can become such in whereby they perceive or fear stigma based on their own assumptions so they avoid contact or talking about it, then if they do they interpret stigma, perhaps because they already perceive it, which reinforces their perceptions and increases isolation.

Carol has two older brothers and the gendered nature of caring came up, there seems to be a tacit expectation that Carol will do it – the brothers have their own families. Some of this is from Carol, she says she has a high bar and others won’t necessarily meet it so she just gets on with it, therefore her brothers may view this as capability and wanting to take the lead role.

Carol’s perspective on the future involved a certain amount of uncertainty about whether her mum would recover, the possibility of death, and the want to do the things she had planned to do like travel with her international policy career. There was some tension between her want for her own life, which she has managed not to put on hold hitherto, despite feeling in a different world much of the time, and her sense of responsibility for her mum.

Carol has established a blog/collective for people in her position as she feels so strongly that people caring for depressed people who repeatedly make attempt on their lives are not adequately recognised or supported. Thus, using her lived experience to effect change, although not professionalising it to the degree that some of the other participants have done.

Carol is a millennial and her narrative and language is representative of the millennial mindset, for example articulations about her choices and rights in life differed from the other, more passively accepting narratives. This won’t be something I examine in any depth in this study, but it did lead me to think about the generational differences and perceptions of caring that might occur when millennials become the main carer population. It may be that the carer profile will be raised and recognised more in the future. Who knows. I suppose for this research it links to the category around one's own personality influencing care ability and responses, which is representative of the social ecology model i.e., the micro system of the individual interacting with the macro, meso and exo systems of the world around them.

4. Dot

Dot is a 52 year old woman who has been married to her 54 year old husband for 25 years. He has had periods of mental ill health during this time, the most recent episode lasted 3 years, was the most profound and included thoughts and near acts of suicide although no actual acts of self-harm or attempted suicide. He has fairly recently been diagnosed with autism which has been helpful in terms of understanding why he sees the world the way he does, what his triggers are and identifying potentially helpful strategies. Dot talked about the challenges of being a full-time carer alongside a full-time job, but also about how work has been her saving grace. She works in the mental health field as an administrator and this gave her insight into the workings of the system, which made it easier to navigate, and access to colleagues who are specialists in mental health. Furthermore, her managers and colleagues were thoughtful and accommodating with regard to her caring demands and she always had someone to talk to if she needed to, although often she preferred not to as work was her sanctuary. During lockdown working at home was helpful with regard to caring alongside work and she has worked at home since due to her being vulnerable because of diabetes. Because she was so familiar with the system she felt able to assert herself when she did not feel heard, but not having a voice, not being listened to was the biggest problem she encountered. She explained that clinicians only wanted to talk to her husband, because he was an adult, but she knew that he would not/could not talk easily to them. She also talked about the disjointed services and the need to repeat things to all new clinicians. She expressed concern for other carers who may not understand the system as she does or feel able to assert themselves.

Dot describes herself as a natural carer and presented as a very resilient individual who got a lot out of caring. She talked about not having children and I felt that the underlying inference here was that her caring role compensated for this in some way. She finds it rewarding to help her husband find ways of understanding and help himself. She acknowledged that it had an impact on the ‘normal’ husband/wife relationship and had experienced shifts from wife to carer, however she was hopeful that this was starting to shift back towards a wife-husband relationship. She talked about times when he was very unwell when he wasn’t really present, he had shut down so much. This resonated with the concept of ambiguous loss – being physically present but emotionally absent. Her practical logical and problem solving nature, along with work and family and friends helped her cope. When asked about stress, Dot indicated that she didn’t really experience stress but conceded that this perhaps manifested in her physical health e.g., her blood sugar at times. Dot had previously cared for her brother who had a severe mental illness and had ended his life by suicide in 2017, not that long before her husband became unwell, so she has been a serial carer. She described expectancy with regard to her brother; the family was not really surprised when he ended his life. This perhaps helped her make sense of her husband’s suicidal assertions – she did not believe her husband has ever wanted to die, she thinks the suicidal thoughts are a red flag and a call for help when he cannot articulate his needs in other ways. She doesn’t not feel any expectancy with him and is confident that he won’t act on thoughts. Her experiences with her brother, along with her knowledge of the system, have helped her feel able to speak up with healthcare providers. Regarding her serial caring role, her mother died a year or so ago and she will now be taking on an arm’s length caring role with her father. She is positive about this and looks forward to it because it will involve a lot of time in Spain, her husband will be able to go to as he is now retiring from work.

Dot talked about the inadequacies of MH care – delays, poor attitudes, but also described some very helpful interventions. In relation to carer support, because she is so high functioning she was told she wasn’t entitled to anything. She would have benefitted from some respite care to give her a bit of time to catch up and take time for herself. When he was taken out by a support worker however the activities her husband were offered were not helpful for him and he didn’t enjoy them. One of the themes from Dots interview has having to flex to fit the system rather than the system being flexible enough to meet individual needs. She was told about a carers group but it was during working hours – she thinks these should accommodate working carers and be more flexible. She thinks she would have benefitted from a peer support group. One has been established at her workplace but seems to have fizzled out a bit.

Dot is another participant who is in some way immersed in the mental health system and another example of how limited my research is.

I also reflected on the irony of mental health services as workplaces being very supportive of carers of people with mental health problems and suicidality but the very same mental health services as providers are not anywhere near as supportive of carers.

5. **Ewan**

Ewan is a 60 year old man who cares for his 54 year old wife who has a longstanding diagnosis of EUPD which has involved hospital admissions, various degrees of mental health care and self-harm and suicide attempts. They have been married for around 30 years and have two adult children who are both currently living at home.

Ewan is a 'matter of fact' possibly stereotypical northern man with an attitude of 'just get on with it', 'this is my lot' and a reluctance to consider his emotional self. I was curious as to his motivation for participating in the interview given his stoic acceptance of his situation. This was my only telephone interview and his affect seemed quite flat, although I suspect that this was less to do with depression and more to do with his personality. His situation must have had an impact on him though, and maybe he is depressed, perhaps he isn't conscious of the impact it has had. His whole essence seemed a bit 'battered' really, although he didn't identify this as being the case. The interview was quite difficult in ways as it felt that all of his responses came back to 'it is what it is'. There were some themes in terms of the vigilance, restrictions on life and wanting better treatment for his wife. He held a perspective that everything will be alright when my wife gets the treatment she needs, and as an outsider looking in and knowing the complexity of presentations such as his wife's, there isn't really a treatment that is going to change much in the short term. How realistic is that perspective? Do we over promise? Is there something about the fact that if you've got contact with services then services need to cure you? Is there something about that belief in the medical model that we need to address? Because if carers are in the position of 'when they get it right' 'when they give the right treatment' 'when they do it properly', it gives them hope and shifts the locus of control, or maybe helps them believe there is some control somewhere, when maybe there isn't. Do we allow them to have unrealistic expectations?

Ewan has had to reduce his working hours to part time and much of this is working from home, which is helpful because he can check on his wife regularly and she is less likely to harm herself when he is in the house. He has had numerous periods of suicide watch. The medication that eases the suicidality has the side effects of tipping her into a dementia type presentation so at the time of interview he as managing that (wandering, unsteadiness, confusion) rather than suicidality. They were waiting for mental health review. Ewan reported that he had been well involved in his wife's care and informed, he had been listened to. He said they had had some poor interventions and HCPs bit also some good. In terms of what would help him as a carer he could only suggest improved mental health care and some effective treatment for his wife. He did not want any conventional carer support; it wasn't for him. He had been offered carer support groups. He would have liked some respite for his wife so that he could go out and see friends occasionally, but this wasn't something he had been able to secure. Ewan does most things around the house – cooking, cleaning and seems to have done most of the child rearing. His says his own life is on hold at the moment. He says he doesn't feel bitter or angry about this, it is what it is. He would like to be able to go away for weekends or see his friends more, but he can't so he just gets on with it.

Regarding his relationship with his wife being affected by becoming her carer he says it depends on her mood, said it can be challenging but noted they're still together.

When asked about the future, Ewan just sees more of the same. The only positive of his caring role is that 'she's not dead' although he lives with an understanding that she may end her life – 'if it happens it happens'. Ewan didn't talk much about the impact on his children, he said they get frustrated with it and acknowledged that it can't have been easy growing up with his wife's mental illness.

Ewan works as a chiropractor and has a day with a GP surgery, he says they are relatively supportive. When he works outside the home, he sometimes crosses his fingers that his wife will still be there when he gets back. However, he doesn't describe caring as being stressful, he says his health is good, BP good, mood ok. It is what it is and this is his lot.

6. Fiona

Fiona is a 74 year old retired fruit farmer who lives with her husband. She is caring for her 19 year old granddaughter who attempted suicide by jumping from a bridge a few months before our interview. Her granddaughter sustained significant injuries (she is improving but will likely have ongoing mobility issues) and Fiona has needed to provide considerable physical care as well as emotional support.

Fiona's son (her granddaughter's father), ended his life by suicide some years ago, when his daughter was very young. Following his death Fiona became involved in suicide bereavement charities, initially to seek and latterly to provide support. She is now very immersed in suicide bereavement support work. This has meant that she has been able to seek support from her colleagues further to this recent situation with her granddaughter. She is a chaplain with a strong faith which has helped her through the very difficult times in her life.

Fiona talked about fearing another attempt by her granddaughter, specifically a railway death as her granddaughter has alluded to thoughts of doing this, and she described an example of not being able to sleep when her granddaughter goes to see friends on the train, at least not until she was assured that she was on the train or had arrived at her destination and left the station. She could not go further than expressing her fear, i.e., expectancy was not something she could tolerate talking about and this is understandable given her experience of losing her son. I got the sense that she has somewhat detached herself from her emotional self and in this interview, it was difficult at times to shift Fiona from talking about her campaigning and charitable work to her thoughts and feelings specifically related to her own caring role. I wondered if she found it easier to frame her experience in the context of her quasi-professional work, maybe it is this which protects her somewhat from her inner thoughts, emotions and fears.

Fiona's relationship with her granddaughter she says has become closer, but she talks about oscillating between grandmother, who fusses and cooks and does washing for her, and approaching her granddaughter as a kind of client, drawing on the knowledge and training she has developed over the years since her son died. This reinforced my sense that she was staying somewhat emotionally detached in order not to have to sit with the possibility of death (notwithstanding the worry regarding stations). At one point she shared how she advises chaplaincy colleagues that they can only keep their clients "*safe for now*"…."*if they do decide in the end that they've had enough, that is not your responsibility*". I reflected that I wish I had asked how she resonated with this statement in relation to her granddaughter. I think the reason I didn't is that I had asked in a number of ways about her thoughts and feelings regarding her granddaughter's future and I would have perhaps been overdoing it if I'd asked again. I wonder if she does intellectually or quasi-professionally know this in relation to her daughter but can't say it/accept it so, as aforementioned, frames it within her safe professionalised context.

Fiona talked about her experience with her granddaughter helping her sensemaking regarding her son, i.e., understanding how lonely and desperate he must have felt, and this felt as though it was somewhat healing for her.

Fiona does not feel she has been supported by mental health services and doesn't consider the care her granddaughter has received as being adequate. She thinks there should be more emotional support for carers and much more timely support for patients. She commits herself to campaigning for better resources and delivering support through her various charitable endeavours.

After this interview I reflected that a number of my participants have been very immersed in mental health or suicide work as a result of their experiences. This immersion would have meant that my research would have appealed to them, and indeed that they would have been more likely to access websites advertising the study or have had the link sent to them. it raised the question for me about reaching those who are not immersed in the suicide field, who use different strategies to cope and who do not access these rather 'professionalised' forms of distribution.

7. Grace

Grace is a 57 year old single mother of a 21 year old young woman who experienced some years of significant mental health issues and who struggles with self-harm and suicidality, although who is now in a much better place than she has been. Grace's daughter now lives away from home and Grace talked about the transition from living with to living apart and the worries that continue to sit alongside her understanding that she needs to prioritise her daughter's autonomy. Grace has greatly professionalised her lived experience and works within a mental health trust and with other agencies linked to mental health. She described her experience as changing her, including changing her passions and she could not go back to her previous career because her passions have changed, and she is now committed to improving mental health care for patients and carers. She expressed dissatisfaction with the carer label and alluded the to the ambiguous caring category – caring being less tangible in the context of mental health. She said she is a mother not a carer but also said she was quick to adopt the carer role early on because it was something to hold on to, perhaps validating the experience and naming the issue for her. Grace described her difficult experiences with mental health services and her perceptions that services were stigmatising and generally fairly useless. She described battling the system to get her daughter the care she needed. She had a lot of conflict with services, describing her fear being projected onto unhelpful professionals in the form of anger and that this was not understood by professionals, so conflict and hostility grew. Grace also experienced a certain amount of stigma from friends who struggled to understand the different world she lived in and often gave either unhelpful advice and platitudes or inferred that they didn't want to hear about it anymore. Grace's life changed when she found an educational and support programme for carers, which educated and empowered her to communicate more effectively with her daughter. She had little else in terms of carer support, she wanted peer support but wasn't signposted to any. She has since engaged with peer support but is of the view that this needs to be facilitated to avoid it becoming a 'negative fest' – she finds hearing other carers' stories tiring and if negativity is too pronounced in groups they become ineffective. Grace talked about feeling very positive about her daughter's future yet still uncertain and she has, with the help of the family connections course, reached a point of acceptance about the possibility of loss. The 'can't fix it' category resonated in Grace's story and the importance of realising and accepting this. Grace had not been exposed to self-harm or suicidality within her family or social network before her daughter's experiences and transitioned from unknowing to living experience, with further transitions throughout her daughter's recovery journey, culminating with the aforementioned acceptance and respect for her daughter's autonomy.

8. Hatty

Hatty is a 55 year old single mother of a 28 year old daughter who had a period of a number of years of significant mental health issues including a 3 year specialist hospital placement. Hatty's daughter has had numerous suicide attempts including some very serious ones – Hatty talked about witnessing her daughter dying and being brought back to live by CPR in resus on 4 separate occasions. She talked of the need for support for carers after witnessing this level of trauma. Hatty balances a successful full-time job with her caring responsibilities and has no life in between. She describes her daughter as her life and she has been a tireless advocate for her, referring, as others have done to battling the system in order to get her daughter the care she needs. Hatty uses but struggles with the term carer, sharing that she does what she does as a mother not a carer. She was a carer for her parents before they died and talked about how it is different with her daughter partly because as a mum you care anyway and partly because of the intangible nature of caring for someone with mental health problems. She described her role as an advocate, someone who gives practical and emotional support. She talked of being very close with her daughter and if there is any reward that is it but actually it isn't rewarding, it is something you just do. The 'can't fix it' category was pronounced and the helplessness she experienced because she watched her daughter in pain but couldn't do anything to take it away. At one point she was of the mindset that death by suicide was an inevitability, perhaps experiencing anticipatory loss, however she now has more hope for the future although the constant worry due to fear and uncertainty is still there, just to a lesser degree. Hatty has not professionalised her caring role in the way that others have done although her daughter has done and is very vocal about mental health issues. This has led Hatty to feel a sense of responsibility to be open also and she says she has not allowed any stigma, suggesting she has transcended any self-stigma and surrounded herself with people who either do not convey or who she somehow disallows to display stigmatised attitudes. In term of support, Hatty did not receive any support from her local mental health services, which she describes as appalling, but she did receive specialist counselling with her daughter which helped their communication and enabled her to show her feelings such as fear and anxiety, which she had previously kept hidden. Linked, Hatty has had to come to terms with the possibility of losing her daughter to suicide and knows she cannot be responsible for her daughter's safety. This statement seems a little at odds with her behaviour which is to devote her all to her daughter outside of work. It is as though this level of devotion is to compensate for the future uncertainty – as though she is proving to herself that she is doing absolutely everything she can to preserve her daughter's life, thus allowing herself to accept that she cannot be any more responsible for the daughter's choices about suicide. Hatty had a carers assessment and was told there was nothing for her. She said that had she been depressed she would have been entitled to more support, however although she was emotionally hugely affected, she was not depressed. She tried carers groups, but the local group was not specific to mental health and she did not feel aligned with the other carers (different world). She is clear that guidance is needed right at the beginning to help people navigate the system. She had no experience of self-harm or mental health issues before her daughter and entered the system with complete trust in services and professionals, which was thwarted because of experiences with negative professionals (particularly one psychiatrist) with stigmatising and harmful attitudes.

9. Irene

Irene is a 54 year old single mum of two who is a carer for her 28 year old daughter who has a long history or mental health problems and extreme suicidal behaviour and although has had some periods of relative wellness has also had long (up to 3.5 year) placements in hospital over the years. Irene has an issue with the term carer and talked about the difficulty defining this in the context of mental health. Her daughter was 15 when her mental health problems started and Irene expressed that as a mum she did what she had to do and incorporated caring into motherhood, raising the difficulty in pulling apart the mum and carer roles even now. She talked about the usual perceptions of carers e.g., of people with dementia or with physical health problems not fitting with the fluctuating nature of caring for someone with mental health issues. The caring role is different, for her it might involve driving to see her daughter in a placement 200 miles away, or providing emotional support, but always being available at the drop of a hat. She also described the trauma associated with witnessing severe self-harm and near death and talked about the impact on her mental health, notably PTSD for which fortunately she has counselling but only because there happens to be a free trauma counselling service linked to her GP, she would not be able to afford it otherwise.

Irene entered the different world of caring with no previous understanding or experience of mental illness, self-harm or suicide and has learnt along the way. She explained the relational changes associated with caring and her sadness about not being able to just be a ‘normal’ mum but said that it’s been so long caring she doesn’t really know how to do that anymore. At the time of interview her daughter was living independently, and she described a recent experience whereby her daughter drove over to see her and they had a cup of tea together. She said it was so normal most people wouldn’t even think about it, but for her it was monumental and that her daughter could do something so simple and normal was very emotional for her.

Irene has lost friends due to her need to be constantly on call and having nothing else to talk about other than her daughter. She said people don’t want to hear it and this has resulted in her withdrawing significantly, although her family has been very supportive, including financially as she had to give up work for a time and was not entitled to carers benefits because she was told she wasn't doing conventional caring. She has had carers assessments in the past with limited benefit

Irene described the constant worry she carries regarding her daughter's wellbeing, always fearing the 'what next' and whilst she wants to be hopeful regarding the future, her experiences make her very aware that things can change and thus actually the future is uncertain to the degree that she fully expects suicidal crises to reoccur, she just doesn't know when. Her biggest fear is that next time her daughter will succeed. This happened to her daughter's friend. Accordingly, she doesn't make plans for the future, but lives week to week, with her life being very much on hold to accommodate her daughter's needs. With regard to her own emotional and mental health this has been grossly affected with PTSD and depression, she described constant anxiety and her bucket being constantly full so she has no capacity to deal with anything else.

Irene talked about some difficult and traumatic experiences with mental health services, including an exclusion culture and the unhelpfulness of the medical model, and described battling services on her daughter's behalf, seeing advocacy as a large part of her carer role. She talked about the barriers of confidentiality and her frustration about how this was interpreted and used by clinicians who she says can listen to carers regardless, but they don't. She described hostility – it seems that if carers are assertive towards services they are met with hostility, she is not the first person to raise this.

Irene has now professionalised her lived experience and works extensively with mental health services to improve services for young people and carers. This mental health context is where she feels most comfortable as it has been part of her life for so long. She gets satisfaction from helping other carers and describes key support needs as being education and tailored support, including peer support and counselling. She was offered a generic carers group which just reinforced her different world, she did not feel she could bring up her experiences with self-harm and suicide, it felt inappropriate. Irene wants carers to be recognised as integral to care and valued as a collaborator as well as being seen as individuals in their own right who need their own support.

There are parallels with mental health nursing in this and others' narratives around ambiguous caring – the difficulties described with defining a carer of people with mental health problems echo the longstanding debate about what mental health nursing is. Even mental health nurses struggle to define it. There is a mountain of literature around this and we still haven't arrived at a conclusion.

10. Jane

Jane is a 42 year old single woman who cares for and currently lives with her mother who has had mental health problems throughout Jane's life. Jane has been in a caring role since she was 13/14. She has three older brothers who have been far less involved with her mother which raises the gendered caring role once again; even from that young age the bulk of the caring responsibility was placed on Jane. The different world category resonated strongly with Jane, she grew up not talking about her mum or home situation with her friends because she wanted to enjoy herself with them, away from her caring responsibility. She didn't think other people had the same experiences, so her world was different and has affected her whole life, all the major decisions. She also thinks it is why she isn't in a relationship. She is a pharmacist and 10/15 years ago was drawn to working in mental health, and this was when she realised that others do have similar experiences to her own. However, she has learnt to compartmentalise things over the years, so she hasn't engaged in any peer support and has a quiet existence balancing work and her caring role. Her relationship with her mother is somewhat reversed and she finds herself in the parenting role, however she identifies caring rewards and talks of having a very close relationship wither her mother. The constant worry expressed by many other interviewees was also referred to by Jane, not so much in an acute way but as being constantly on her mind; what might she find when she comes home. She herself suffers from depression and thinks it is 50/50 with regard to being genetic and situational. Ambiguous caring was also pronounced with Jane, because it can be difficult to specify exactly what the caring is it can be difficult to self-identify as a carer and therefore you don't know what support is available. She talked of the need to target carers at the outset. Had she been recognised as a young carer all those years ago it is possible her life could have been different.

11. Kay

Kay is a 49 year old single mum who completed the survey and expressed interest in the interview in relation to her 18 year old son who had experienced mental health problems and suicidality since the age of 15. Tragically, her son ended his life by suicide between her completing the survey and being contacted for interview, however she expressed a keen desire to proceed with the interview. We discussed in supervision and agreed to seek approval from ethics to go ahead with the interview despite Kay no longer meeting the criteria of being a carer based on the fact that she had been at the time of completing the survey. We agreed that excluding her from the interview at a time when she very much wanted to share her story was likely to be of more detriment than her experiencing distress when talking about her son. The distress was already there, the worst thing had happened, she had lost her son.

Kay is a senior mental health nurse and expressed that she believed her son was only taken on by adult services (having been discharged by CAMHS due to his age) because of that fact. Her son deteriorated significantly during COVID-19 and Kay talked about her frustration that clinicians rarely saw her son, instead relying on phone calls or zoom calls in which her son turned the camera off. Her son was difficult to engage and services were limited in their involvement due to this, stating that he had capacity. Kay thought otherwise and a major criticism of the lack of face to face contact was that clinicians could not see his dishevelled state, smell him, see his red raw hands from excessive handwashing. They did not accept her communication that his mental health had grossly deteriorated and repeated their assessment that he had capacity. He was seen briefly 6 weeks before he died but otherwise had minimal face to face contact.

Kay talked about her constant worry and her sense of expectancy and how she felt she had lost her son before he died, due to his withdrawal from life, the fact that he existed in his room and was not engaging in life like his friends were. She described walking on egg shells, never knowing what he was going to ask or how he would react, how his mood and state would affect her and her daughter's day. She cried herself to sleep at night thinking about what it would be like if he died. She also talked of the sense of loss she experienced for herself, from not seeing her son grow up as she had hoped, to the restrictions caring for her son had placed on her own life and that of her daughter. She thought she would never have a relationship again because no one would tolerate her son, she couldn't go away with her daughter for longer than a very occasional night, her life was on hold and apart from working and caring she felt she had no life. The different world category was evident in her narrative and the loss was associated with having entered that different world and feeling stuck and isolated there. Family support was limited, it was there in theory but what she wanted was a bit of respite and no one was able to take her son for any time, likely due to fear and stigma. Services told her that she had the right to kick him out of home but as a mother she didn't not feel she could do that, which exacerbated her feeling of stuckness. Kay's insights into the resource constraints fuelled her hopelessness but also her frustration with campaigns such as zero suicide because she feels that such promises will never be realised whilst services are so under resourced. The other reoccurring theme was to do with the relational changes; whilst her son was reaching adulthood Kay was having to do everything for him which felt incongruent with the transition he should have been experiencing. Kay felt that she was the only person who challenged her son, she felt that professionals were frightened of doing so due to his propensity of disengagement. She felt very alone with managing her son's unpredictable behaviour. There was no professional support for her, a carers assessment came to nothing. In a crisis services were present for her son but outside of crises there was nothing. However, she said support had been provided for her daughter.

12. Lucy

Lucy is a 49 year old woman who cares for her partner of three years who has a diagnosis of EUPD and substance misuse. Lucy was friends with her partner for some time before embarking on a relationship with him. Lucy is a nurse who works for the mental health trust as an addiction specialist. The main thing that struck me from this interview is the way Lucy defines herself as a carer. When I asked how long she had been in a caring role for, in the context of the interview she responded that she had been in a caring role since she had her children, so 25-30 years. I suspect her entry into nursing was very much a vocational move. Lucy identifies that at times the partner/carer/nurse roles become blurred and this seemed apparent from her narrative. If I hadn't known she was a nurse I would have guessed it. She said that some of her friends have questioned whether she is with her partner as a project. She vehemently denies this, but my sense was in fact that he is a project. At one point, when defending against this statement, she talked about him being someone she liked (as opposed to loved). I wondered if he is in fact a project and one that enables her to avoid other things in her life. She is so busy with working and checking in with her partner, keeping him on the straight and narrow, she has little time for anything else. The category 'personality influencing care ability and responses' has been identified within the analysis and this was very pronounced with Lucy. Of course, it is inevitable that our personality effects the way we do things, respond to things and interpret things, but we don't generally think about that when we refer to ‘carers’, we just lump them all together, apart from young carers who are identified as a unique group. This lumping together means that we probably do not recognise individualised needs adequately. The interviews clearly highlight that there is no one size fits all support mechanism for carers. We first need to understand the carer as a person. For example there are natural worriers, such as Mae, who might benefit from a CBT informed approach, people who channel emotions into anger such as Betty, who may benefit from validation and curiosity around inner emotional responses, and project managers such as Lucy who would benefit from a partnership approach from the outset. Much as we aim for person centred care with our patients (often not achieving it based on the interviews in this study), we need to do the same for carers. This comes into the recognition and appreciation category, which was identified in the literature review, but adds depth – recognise me as a carer but also as a person with my own characteristics, strengths and needs.

13. Mae

Mae is a 68 year old married woman who cares for her 42 year son who developed depression following the breakup of his marriage 6 years ago and subsequently carried out 2 suicide attempts, once resulting in ICU admission. At the time of interview, he was doing better and was living independently but he had lived with Mae for some time after the marriage break up. Mae also cares for her husband due to physical health reasons. Although Mae was aware that her son was struggling after the marriage, his first suicide attempt was a complete surprise to her, she had thought he was absolutely fine. Also, with the second more serious attempt, she had eased off being vigilant as she had through his risk had diminished, so again she was taken by surprise.

The main message or the most frequent code that I came up with in this interview is constant worry and constant worry seems to be kind of a little bit of an overarching code if that's a possibility, because it results in certain behaviours such as hyper vigilance, it results in certain consequences such as low mood, and it results in concerns about being over vigilant as opposed to facilitating independence. Constant worry was also described as an experience underpinned by evidence i.e., he had made serious attempts on his life before, when it was not expected and therefore there is a potential for it happening again. Now, the constant worry *could in theory (or due to my bias)* be linked to expectancy and anticipatory loss however it wasn't really described in that way. Mae is constantly worried that another suicide attempt might occur, however she's not anticipating his death. She's frightened about that but she's not expecting it and she's not anticipating it. This can be seen by her response to thinking about the future, when she was able to talk about staying hopeful that he'll improve, clearly he has improved already, and she talked about her want and aspiration to ‘move on’, wanting herself to move on and be able to step away from the caring role and for her son to move on and integrate back into general society as opposed to the mental health peer groups.

14. Nancy

Nancy is a 38 year old post doc researcher who is married to and lives with her wife who has a history of mental health problems and suicide attempts that pre-date their relationship and for which Nancy took over the caring role from her wife’s family around 7 years ago. Nancy didn’t consider herself to be in a carer role until her wife indicated that she was and that she should access support on that basis. She talked about it being what you do for a partner. Like others Nancy highlighted the fluctuating and ambiguous nature of caring, feeling ambivalent about the label of carer but recognising its functionality. Also, because at times of crisis Nancy has to put her life on hold, cancel everything and take time of work, it helps to be able to say to work that she has a caring role for her wife who has health issues – she hasn’t said what these issues are, due to privacy but also potentially perceived stigma. Nancy’s work is autonomous and flexible which has been immensely helpful, and she has had support with carers leave, with no questions being asked. Nancy has been faced with the possibility of death and doesn’t allow herself to dwell on this, ensuring she understands the cyclical nature of her wife’s suicidal crises because this means she is able to see an end when they occur and take everything over. It helps her to visualise a hopeful future although she does carry underlying worry and uncertainty, which I suspect she isn’t able to fully address. She has talked a bit to her wife’s trauma therapist, but I got the sense that she is someone who actually needs her own therapy to help her voice her inner fears that it seems she buries so that she can be wholly present for her wife. Although Nancy has previous experience of supporting and talking to people about suicide and depression and has lived with her wife’s suicidality for some years she said the experience and expectancy does not prepare you for the reality of finding your partner after a suicide attempt. Nancy talked about how she and her wife work in partnership to plan and manage suicidal crises and she takes care to try and maintain the equal partnership and balance care and autonomy, although at times has had to reduce access to means to take on more responsibility with liaising with services and she feels rather uncomfortable about this. They work in partnership with regard to who they tell about their situation as well. Nancy talked about the crisis aftermath whereby she will feel exhausted after having been on autopilot throughout the crisis in order to manage it and ensure her wife's safety. She talked about the impact this has had on her health and wellbeing, particularly physical health i.e., susceptibility to illness after crises. She talked about her dissatisfaction with services, particularly the crisis team model of different people, the need to repeat stories and the fact that she has been excluded despite her wife's willingness for her to be included. She expressed frustration with the ack of resources and shared her belief that if there was some form of sanctuary model – spa type thing- she and her wife could get through crises more quickly and without the interference of the medical model.

The different world category came up in relation to carer support and her going to a generic carer group where she felt she couldn't talk about her experiences which were so very different to anyone else's in the group. She is of the view that peer support needs to be tailored to the relevant experiences and expressed that a same sex peer support option would be valuable. Nancy did not talk about overt stigma but alluded to self-stigma, particularly her wife's and the need to respect this thus not talk to people unless her wife is comfortable with it. This has included her family, so she finds not talking about this significant aspect of her life to her family draining at times.

15. Noah

Noah is a 51 year old non binary person who lives with their husband for whom they are a carer due to his longstanding mental health problems which include suicidality. Noah was aware of their husband's mental health issues when they met 7 years ago and although the couple had talked about experiences of suicidal behaviour Noah was not aware of the extent of their husband's behaviour until they first witnessed it around 4 years ago. So, despite prior knowledge the behaviour was unexpected.

Noah has a history of domestic violence in a previous relationship and related PTSD including past suicidal thoughts but no acts. Their husband's suicidal behaviour, which they interpret as violence towards the self, has been triggering for Noah due to their experiences of violence from another person. In addition, Noah has in the last year been diagnosed with autism which has been a helpful diagnosis as it explains a lot of aspects about their behaviour. Noah has identified that their autism has influenced their caring role in terms of interpretation of behaviours and contribution to dysregulated responses.

Noah's husband is also a carer for Noah due to periodic physical health issues and to some degree autism, so there is an element of reciprocity. Strengths within this are their ability to communicate.

There had been some exposure to suicide in recent years as Noah's husband's sister ended her life a few years ago.

Noah works in a lived experience role, professionalising their caring and own mental health lived experience. Linked, Noah has found out about and made use of any support available and their insights into what is around from working in the field has been helpful.

The main thrust of this interview was around the relationship; shifting from partner to a parental role and the difficulties that this can bring up for both partners; it is dissatisfying for Noah and their husband can feel frustrated when his autonomy is compromised. Noah is unsure whether or not they want to continue in the marriage because of the detrimental impact their husband's mental health and suicidality can have on their own wellbeing and mental health. They shared the dilemma of knowing that leaving the relationship may result in a suicide attempt or completed suicide. There seemed to be a bit of a battle between a need for self-preservation and a want for their husband to get better. Noah described an 'end to end existence', which I took to mean that everything they tried did not alter the potential of suicide. As they said 'I can't fix it'.

Appendix 17: Example of reflexivity - reflection on use of paraphrasing during interviews

I noticed that I paraphrased a few times during the interview, which I don't think particularly affected Noah's responses, but I felt a sense of discomfort and a need to reflect on this. Does it help cocreation or does it overrule the participants narrative?
De Gialdino (2009) talks about the 'knowing subject' (researcher) and the 'known subject' (participant) and claims that scientific knowledge actually can't be developed without both participant and researcher subjectivity within the interview context. She discusses philosophical standpoints and talks about epistemological reflection, defined as a 'persistent creative activity that is reviewed time and time again' and she says that epistemological reflection is what helps us elucidate the different paradigms which give up different answers to the questions raised by epistemology. She espouses paradigm coexistence, claiming that all of the paradigms are relevant in some way to the quest for scientific knowledge and that this coexistence informs the epistemology of the 'knowing subject', the researcher although noting that generally someone who wants to engage in qualitative research will have an epistemology closer to the interpretive paradigm because it's closer to the 'known subject', that's what that's the motivation. But then she talks about the fact that many people are still rooted in the need for distance between researcher and participant, to recognise oneself as an impartial observer and therefore the participant is an 'object to be gazed at'.
I wonder if that's me then, my claim that I am not interested in coproducing within the research context, rather I am interested in only the participants experience and perspective. Maybe this claim is perhaps really me articulating my need, or my belief, that I have to have that impartial distance and actually how possible, or desirable, is this?
So, when I was paraphrasing, what is it am I doing? I'm certainly not maintaining an impartial distance, because surely if I were, I would not engage this way in the dialogue. So, if I am engaging within a dialogue what am I doing by paraphrasing? Am I translating the subjective knowns knowledge into the subjective knower's words, and if so, am I actually then doing what De Gialdino warns against; hiding the subjective known's identity behind the subjective knower's, or, am I using it to reflect with the subjective known to co-create knowledge? Take this example:

Yeah I’m sure, yeah. You’ve identified some of those feelings of frustration and guilt and then frustration again and it sounds as though it can be quite cyclical…?

Yeah

The monosyllabic answer might mean I had it in a nutshell but might mean I was way off track – I didn’t use Noah’s words; I shared my interpretation of them. So, maybe I stymied Noah, it wasn’t cocreation as it was my words.

On the subject of cocreation, (McGrath, Palmgren and Liljedahl, 2019) in their twelve top tips for qualitative researcher states very clearly ‘remember you are a cocreator of knowledge’. I need to reflect more on this an enable/allow myself to realise this role. Currently there is a bit of a dissonance between my intellectual acceptance of the researcher influence on the research process and my emotional acceptance of this. Underpinned I think by my commitment to the voice of the subjective known. But am I threatening this commitment by paraphrasing?

When I paraphrase within a therapeutic relationship my purposes are threefold really; firstly, to convey that I am actively listening because by paraphrasing back you’re conveying to the person that they are important enough to be heard; second is checking with the person that my understanding is the right understanding; but third is to inform my diagnostic thinking. I don't want to be forming my diagnostic thinking as a researcher, however I do come into the research context with some pre-formed, a priori ideas, that's why I'm even here doing what I am doing.

De Gialdino (2009) talks about ontological characteristics in relation to human identity, the essential and existential components. Essential aspects are common to all and existential components distinguish humans from each other, making each individual unique. She says both of these components need to be known, you cannot know one through the other. Perhaps essentials can be known through quantitative methods but existential aspects can only be explored through qualitative methods. Interestingly she goes on to question whether ontologically different data can be compared, and challenges triangulation (and therefore arguably mixed methods) but surely if we need to know both the essential and the existential, mixed methods is a helpful approach? Also does this not contradict paradigm coexistence? I need to read this paper again to fully understand it.

When Vasilachis de Gialdino note that the known subject's voice can disappear behind the voice of the knowing subject she refers to translation of data into codes; 'the violence of interpretive codes'.

This is something I will need to consider when I get to analysis, but the questioning I am considering now is can paraphrasing in the interview context result in the known subject's voice disappearing behind the knowing subjects? I think the answer is a pretty resounding yes. Louw, Todd and Jimarkon (2011) examine active listening skills, in the context of linguistic research and espouse paraphrasing as key to active listening for very much the reasons I've noted above. They consider paraphrasing to be "the essence of the interviewer's message to provide the speaker with a 'mirror' in which to examine the message, expand on it, correct it and reflect its implication". They highlight the importance of non -interpretation in paraphrasing. I think my discomfort with my paraphrasing with Noah is that I allowed an element of interpretation to creep in. Evans *et al.* (2010) discussing investigative interviews with maltreated children highlight the risk of paraphrasing distorting details of the person's narrative and note that if this distortion is not corrected by the interviewee it can continue, resulting in inaccurate data. Interpretive paraphrasing could be seen as distorting the participants narrative. I summarised/interpreted my paraphrases rather than repeating Noah's words, this may have distorted Noah's narrative.

Louw, Todd and Jimarkon (2011), despite their enthusiasm for paraphrasing in principle found it to be problematic in research due to the way the researcher signalled their intervention to paraphrase. Where paraphrasing opened with words such as 'so', 'ok' or 'right', the implicit (if unrecognised by the researcher) message is that the transaction is ending, therefore the participant is much less likely to correct or expand.

I've noticed I use 'so' as an opener a lot, I will need to work on that. When I used it to open a paraphrase in this interview, I got one of the shortest answer of the entire interview:

So it sounds as though there are questions really. You've got some hopes, you've got some fears and you, perhaps you've got to face either one of those at some point but you're not certain at the moment how that might pan out.

Yeah, yeah. We're working on it but I'm aware that at some point I may just have to make a decision and I don't know which way it will go. I'm still engaged in the process of trying to manage it.

I still got a valuable and affirming response (uncertainty about the future), however if I had used a more expansive paraphrasing style (e.g., you've said you have some hopes, some fears and you've perhaps got to face either one of these at some point but you've some uncertainty. I wonder if you could share a bit more about that uncertainty?), I may have obtained additional information. Certainly, Louw Todd and Jimarkon (2011) suggest openers to paraphrasing such as "if I've understood you properly……", "let me see if understand you", "just let me check that I'm with you".
Evans *et al.,* (2010) concur that expansive paraphrasing is the approach most likely to elicit additional detail and caution against yes/no paraphrasing i.e., that which incites a monosyllabic affirmative or otherwise (you are more likely to get the affirmative even to distorted paraphrasing) and also cured invitations i.e., tell me more about ……*whatever they've told you*, not just tell me more. They seem to be opposed to summarising paraphrasing which is what I have a tendency to use, so I need to be very reflexive about my use of paraphrasing hereafter. However, Evans *et al* (2010) were concerned with children and there may be some differences with adults.

Appendix 18: Example of reflexivity – reflection on use of radical presence

Early in the interview it became apparent that Alison’s* son had autism and I couldn’t help but identify a little bit with some of what she said throughout the interview based on my own daughter’s diagnosis of autism, particularly some of the difficulties she expressed around him not being able to take to conventional therapies, his lack of social integration, and her own sadness that perhaps his future isn't the future that she anticipated he may have, and also some sadness around what is the future going to be. I could relate to that, but I didn't find that it interfered in my presence in the interview. I could also relate to some of the more endearing aspects such as him having so much money because he never goes out, and his funny autistic ways.

But I don’t feel I over-identified, I didn’t feel tearful when she was tearful and whilst I related with her feelings I didn’t think about my daughter as such; I didn’t drift from her and her son. I believe I practised radical presence, a concept originating from, but not dependent on, religion and spirituality (Harrison, 2017), which is gaining increasing respect in healthcare and a concept and which, I believe, has relevance to the research context. (McNamee, 2020) argues that radical presence beholds a relational ethic, which demands that we attend to what is going on in the situation and interactions in which we are present, recognising context and valuing the individual, environmental and social components of both self and other. She discusses the holding of ‘one’s own ground while being open to the others orientation’. In this interview I did not feel I lost touch with my own ground (as a researcher), even when I was immersed in Alison’s ground and noticing the parallels in our experiences. Harrison (2017, p. 197) describes presence as ‘a way of compassionate relating that involves the whole person, physical, emotional, spiritual and social’. Compassionate relating sits comfortably with me and I feel this occurred within our interview. Perhaps it was compassionate relating that underpinned a couple of questions I asked as the interview drew to a close that I reflected might have been influenced by my identification with the participant. The first question in italics below was a reflection on autism and I asked myself if my own knowledge and experience of a mother of an autistic young adult influenced the question. I think it did but being present in the participants story made me consider it in the context of Alison’s situation. It is an example of how we cannot separate ourselves from our own life but actually we can use our experiences to enable better presence and empathy when we are immersed in the stories of others. I got the sense it was experienced as a helpful question, although arguably it could be considered to be a leading question.

Do you find, or in your experience have you picked up that some of the therapies offered aren't necessarily framed in such a way that is helpful for people with autism?
Yes, definitely. I think it was my daughter that flagged that up to me because our grandson is also high functioning autism, and she was the one who said why don't you have a diagnosis because I think [son] is in that place and I didn't see any signs of anything and she said the trouble is if he goes to normal counselling they won't necessarily understand his communication difficulties and how he sees thing and how he sees the world and you really need to find someone…..And so now I have found a list of local people that he could try out, you know. But yeah, [organisation] is a local, I think they give you 6 sessions after the diagnosis and between going to uni or something, I can't remember when, and he went along and didn't find it helpful at all, yeah, nothing changed with those sessions.

I went on to extend a hopeful message:
I hope he reaches a time that he's able to consider something with someone who can work effectively with his style of communication. It's about being patient I guess as a carer isn't it and waiting for when that time might come, even though I imagine you wish it might be sooner.
Oh absolutely, I mean that's when things will get to me when I think it's not right that this is happening, and I get a sense of injustice about it and think why can he not enjoy his life and do all the things that a person his age ought to be doing…..

Arguable researchers should not express their own views in the interview. It may be that my views were expressed in the above question, in honesty they were, as my greatest learning with my daughter is patience, deep, person centred patience. This was reflected in the question above, although Alison had alluded to patience throughout the interview when she talked about [son] not doing things until he was ready. Probably this deep patience is something we have both learnt. To me complete bracketing of ones own experiences does not allow full recognition of the extent of the interpersonal dynamic and the role of the 'researcher as instrument' (Hammersley and P, 1995). I think the questions wherein I deviated from the schedule and asked autistic related questions could be an example of how I used myself as an instrument, given that Alison's responses to both of the questions I asked suggested resonance.

Perspectives on the role of the researcher range from them being detached information extractors who extend little (conscious) self into the researcher milieu, through to them being connected, empathetic and involved facilitators who value the inherent subjectivity of human interaction (Jack, 2008; Pezalla, Pettigrew and Miller-Day, 2012). Pezalla and colleagues (2012) carried out an interesting study into researcher styles and I found it interesting to consider my own approach alongside their descriptions of the three researchers they studied. They noted affirmation, energetic, interpretive, neutral, naïve and self-disclosure styles. Those most appealing to me were affirming (although not in the way the transcripts in the paper described, which involved lots of effervescent adjectives), neutral, and naïve. The examples of the interpretive style presented in the paper came across as leading questions, although this may have been the inexperience of the researcher. I was repelled by the self-disclosure style, finding it invasive in the excerpts I read. The neutral and naïve approaches involved space and curiosity which was clear in the text and which I was attracted to. My aim is not desire to 'coproduce' in this research, it is the participants experiences I am interested in. However, the human experience is such that we will encounter unexpected parallels with people we come across in all walks of life. My key learning here is the importance of presence, knowing where you are on the continuum of interview styles and why, and in keeping with my guiding philosophy of pragmatism, it is important to keep thinking about what the research is for, who is it for and how I, as the researcher am influencing it (Feilzer, 2010).

Appendix 19: Interview distress protocol for semi structured interviews

Indications of Distress During Interview	**Responses**
Participant indicates distress verbally or behaviourally (e.g., excessive crying/sobbing; inability to concentrate due to distress)	- Offer to suspend interview or make the decision to suspend or terminate if it becomes apparent that the participant is unable to make a decision - Remind the participant of their right to withdraw and check for understanding - Offer time and space, including refreshments if possible - Offer to recommence the interview when the participant feels able and emphasise that this can be on another day - Check who the participant has at home/in their social network for support - Revisit informed consent prior to recommencing interview - Use reflexive journal and seek supervision to reflect on situation, explore own responses and consider future actions
Participant indicates risk to self to the degree that the researcher is concerned about safety	- Suspend the interview and address the issue e.g., “it seems, from what you are saying, that you are having some difficult thoughts about hurting yourself/ending your own life/suicide”. I’m just going to pause the interview and give you some information about where you can get support. We can complete the interview afterwards or another time if you feel up to it. - Ascertain ideation and intent - Provide signposting information and check for understanding - Check who the participant has at home for support - If appropriate and with consent alert relevant practitioners - Revisit informed consent process before recommencing interview - Use reflexive journal and seek supervision to reflect on situation,

	explore own responses and consider future actions
Participant indicates harm to others to the degree that the researcher is concerned about safety	- Suspend the interview and address the issue e.g., "It seems, from what you are saying, that you are experiencing strong emotions and thoughts about causing harm to X". I'm just going to pause the interview so we can talk about that a bit more. - Ascertain thoughts and intent - Provide signposting information and check for understanding - Check who the participant has at home for support - If appropriate and ideally with consent alert relevant practitioners - Revisit informed consent process before recommencing interview - Use reflexive journal and seek supervision to reflect on situation, explore own responses and consider future actions

Appendix 20: Ethical approvals from Oxford Brookes Faculty Research Ethics Committee the NHS Health Research Authority

Karen Lascelles
Oxford Brookes University
Marston Road Campus
Jack Straws Lane
OX3 0FL

5 November 2020

Dear Karen,

Re. Experiences and Support Needs of Adults in England who Care for Adults they consider to be at Risk of Suicide: A Research Study

Thank you for submitting your response to FREC on the 13/10/20. I am pleased to approve the research by Chair's Action subject to the following conditions:

1. You amend your PIS to include HRA transparency phrasing.

You may submit to NRES and HRA via the central booking system on completion and return of the attached clinical governance checklist. Please prepare your site agreement documents.

Yours sincerely

Kellie Tune
Chair, Faculty of Health and Life Sciences Research Ethics Committee

Cc –Ruzena Zemanova

Oxford Brookes University

Faculty of Health and Life Sciences

Decision on application for ethics approval

The Departmental Research Ethics Officer (DREO) / Faculty Research Ethics Committee (FREC) has considered the application for ethics approval for the following project:

Project Title: Experiences and Support Needs of Adults in England who Care for Adults they consider to be at Risk of Suicide: A Research Study

FREC Study Number: F.02.2019.15

Name of Applicant: Karen Lascelles

Please tick one box

1. The Faculty Research Ethics Committee gives ethical approval for the research project. ☐

Please note that the research protocol as laid down in the application and hereby approved must not be changed without the approval of the DREO / FREC

2. The Departmental Research Ethics Officer / Faculty Research Ethics Committee gives ethical approval for the research project, subject to the following: √ ☒
   2. You insert HRA transperncy phrasing in to your PIS.

3. The Departmental Research Officer / Faculty Research Ethics Committee cannot give ethical approval for the research project. The reasons for this and the action required are as follows: ☐

Signed: …Kellie Tune … ……………………… Approval Date:.5 November 2020...……

Designation: Departmental Research Ethics Officer

(Signed on behalf of the Faculty Research Ethics Committee)

Date when application reviewed (*office use only*): 5 February 2020
………………………………

Ymchwil Iechyd
a Gofal Cymru
Health and Care
Research Wales

NHS
Health Research
Authority

Email: approvals@hra.nhs.uk

HCRW.approvals@wales.nhs.uk

Mrs Karen Lascelles

64 Wantage Road

Wallingford
Oxon

OX10 0LY 21 April 2021

Dear Mrs Lascelles

HRA and Health and Care Research Wales (HCRW) Approval Letter

Study title: Experiences and Support Needs of Adult Carers of Adults at Risk of Suicide: A Mixed Methods Doctoral Research Study

IRAS project ID: **279698**

Protocol number: **f.02.2019.15**

REC reference: **21/LO/0183**

Sponsor: **Oxford Brookes University**

I am pleased to confirm that **HRA and Health and Care Research Wales (HCRW) Approval** has been given for the above referenced study, on the basis described in the application form, protocol, supporting documentation and any clarifications received. You should not expect to receive anything further relating to this application.

Please now work with participating NHS organisations to confirm capacity and capability, in line with the instructions provided in the “Information to support study set up” section towards the end of this letter.

How should I work with participating NHS/HSC organisations in Northern Ireland and Scotland?

HRA and HCRW Approval does not apply to NHS/HSC organisations within Northern Ireland and Scotland.

If you indicated in your IRAS form that you do have participating organisations in either of these devolved administrations, the final document set and the study wide governance report (including this letter) have been sent to the coordinating centre of each participating nation. The relevant national coordinating function/s will contact you as appropriate.

Please see IRAS Help for information on working with NHS/HSC organisations in Northern Ireland and Scotland.

How should I work with participating non-NHS organisations?

HRA and HCRW Approval does not apply to non-NHS organisations. You should work with your non-NHS organisations to obtain local agreement in accordance with their procedures.

What are my notification responsibilities during the study?

The standard conditions document “*After Ethical Review – guidance for sponsors and investigators*”, issued with your REC favourable opinion, gives detailed guidance on reporting expectations for studies, including:

- Registration of research
- Notifying amendments
- Notifying the end of the study

The HRA website also provides guidance on these topics, and is updated in the light of changes in reporting expectations or procedures.

Who should I contact for further information?

Please do not hesitate to contact me for assistance with this application. My contact details are below.

Your IRAS project ID is **279698**. Please quote this on all correspondence.
Yours sincerely,

Kathryn Davies
Approvals Specialist
Email: approvals@hra.nhs.uk

Copy to:

Ms Kellie Tune

NHS
Health Research
Authority

London - Brent Research Ethics Committee

80 London Road Skipton House London SE1 6LH

Please note: This is the favourable opinion of the REC only and does not allow you to start your study at NHS sites in England until you receive HRA Approval

19 April 2021

Mrs Karen Lascelles

64 Wantage Road

Wallingford
Oxon OX10 0LY

Dear Mrs Lascelles

Study title: Experiences and Support Needs of Adult Carers of Adults at Risk of Suicide: A Mixed Methods Doctoral Research Study

REC reference: **21/LO/0183**

Protocol number: **F.02.2019.15**

IRAS project ID: 279698

Thank you for your letter of 06 April 2021, responding to the Research Ethics Committee's (REC) request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chair.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

Good practice principles and responsibilities

The UK Policy Framework for Health and Social Care Research sets out principles of good practice in the management and conduct of health and social care research. It also outlines the responsibilities of individuals and organisations, including those related to the four elements of research transparency:

1. registering research studies
2. reporting results
3. informing participants
4. sharing study data and tissue

Conditions of the favourable opinion

The REC favourable opinion is subject to the following conditions being met prior to the start of the study.

Confirmation of Capacity and Capability (in England, Northern Ireland and Wales) or NHS management permission (in Scotland) should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements. Each NHS organisation must confirm through the signing of agreements and/or other documents that it has given permission for the research to proceed (except where explicitly specified otherwise).

Guidance on applying for HRA and HCRW Approval (England and Wales)/ NHS permission for research is available in the Integrated Research Application System.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of management permissions from host organisations

Registration of Clinical Trials

All research should be registered in a publicly accessible database and we expect all researchers, research sponsors and others to meet this fundamental best practice standard.

It is a condition of the REC favourable opinion that **all clinical trials are registered** on a publicly accessible database within six weeks of recruiting the first research participant. For this purpose, 'clinical trials' are defined as the first four project categories in IRAS project filter question 2. Failure to register a clinical trial is a breach of these approval conditions, unless a deferral has been agreed by or on behalf of the Research Ethics Committee (see here for more information on requesting a deferral: https://www.hra.nhs.uk/planning-and-improving-research/research-planning/research-registratio n-research-project-identifiers/

If you have not already included registration details in your IRAS application form, you should notify the REC of the registration details as soon as possible.

Further guidance on registration is available at:

https://www.hra.nhs.uk/planning-and-improving-research/research-planning/transparency-respo nsibilities/

Publication of Your Research Summary

We will publish your research summary for the above study on the research summaries section of our website, together with your contact details, no earlier than three months from the date of this favourable opinion letter.

Should you wish to provide a substitute contact point, make a request to defer, or require further information, please visit: https://www.hra.nhs.uk/planning-and-improving-research/application-summaries/research-sum maries/

N.B. If your study is related to COVID-19 we will aim to publish your research summary within 3 days rather than three months.

During this public health emergency, it is vital that everyone can promptly identify all relevant research related to COVID-19 that is taking place globally. If you haven't already done so, please register your study on a public registry as soon as possible and provide the REC with the registration detail, which will be posted alongside other information relating to your project. We are also asking sponsors not to request deferral of publication of research summary for any projects relating to COVID-19. In addition, to facilitate finding and extracting studies related to COVID-19 from public databases, please enter the WHO official acronym for the coronavirus disease (COVID-19) in the full title of your study. Approved COVID-19 studies can be found at: https://www.hra.nhs.uk/covid-19-research/approved-covid-19-research/

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

After ethical review: Reporting requirements

The attached document "After ethical review – guidance for researchers" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol

- Progress and safety reports
- Notifying the end of the study, including early termination of the study
- Final report
- Reporting results

The latest guidance on these topics can be found at https://www.hra.nhs.uk/approvals-amendments/managing-your-approval/.

Ethical review of research sites

NHS/HSC sites
The favourable opinion applies to all NHS/HSC sites taking part in the study, subject to confirmation of Capacity and Capability (in England, Northern Ireland and Wales) or management permission (in Scotland) being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Non-NHS/HSC sites
I am pleased to confirm that the favourable opinion applies to any non-NHS/HSC sites listed in the application, subject to site management permission being obtained prior to the start of the study at the site.

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

Document	*Version*	*Date*
Confirmation of any other Regulatory Approvals (e.g. CAG) and all correspondence [F.02.2019.15 IRAS ID 279698 Research Governance Checklist]	1	06 November 2020
Copies of materials calling attention of potential participants to the research [F.02.2019.15 IRAS ID 26798 Appendix 8 Poster, flier and social media texts.docx v4 09.10.2020]	4	09 October 2020
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [F.02.2019.15 IRAS ID 279698 Confirmation of indemnity]	1	21 August 2020
Interview schedules or topic guides for participants [Interview schedule]	5	30 March 2021
IRAS Application Form [IRAS_Form_04022021]		04 February 2021
Letter from sponsor [F.02.2019.15 IRAS ID 279698 Letter from sponsor]	1	12 November 2020
Non-validated questionnaire [Qualtrics survey Experiences and support needs of adult carers of adults at risk of suicide]	5	30 March 2021
Other [Privacy Notice]	4	09 October 2020
Other [Brent Rec provisional opinion responses]	1	30 March 2021
Participant consent form [Interview consent form]	4	27 November 2020
Participant information sheet (PIS) [Participant information sheet interviews]	7	30 March 2021
Research protocol or project proposal [Research protocol Experiences and support needs of adult carers of adults at risk of suicide]	4	09 October 2020

Summary CV for Chief Investigator (CI) [Summary CV for CI]	1	17 December 2020
Summary CV for student [F.02.2019.15 IRAS ID 279698]	1	17 December 2020
Summary CV for supervisor (student research) [F.02.2019.15 IRAS ID 279698]	1	17 December 2020

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

User Feedback

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please use the feedback form

available on the HRA website:

http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance/

HRA Learning

We are pleased to welcome researchers and research staff to our HRA Learning Events and online learning opportunities– see details at: https://www.hra.nhs.uk/planning-and-improving-research/learning/

With the Committee's best wishes for the success of this project. Yours sincerely

Dr Manish Saxena
Chair Email:brent.rec@hra.nhs.uk

Enclosures: "After ethical review – guidance for researchers" *[SL-AR2]*

Copy to: Ms Kellie Tune

Lead Nation

England: approvals@hra.nhs.uk

Appendix 21: Interview informed consent form

OXFORD BROOKES UNIVERSITY

INFORMED CONSENT FORM Experiences and Support Needs of Adult Carers of Adults at Risk of Suicide: A Mixed Methods Study (Interview component)

Name, position and contact address of Researcher:
Karen Lascelles, Professional Doctorate (DNurse) student Oxford Brookes University Faculty of Health and Life Sciences and Nurse Consultant, Oxford Health NHS Foundation Trust
Email 17002640@brookes.ac.uk

Please initial box

1. I confirm that I have read and understand the information sheet for the above study and have had the opportunity to ask questions. ☐

2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving reason. ☐

3. I agree to take part in the above study. ☐

4. I agree to the interview being audio recorded ☐

Please initial box

	Yes	No
5. I agree to the use of pseudonymised quotes in publications	☐	☐
6. I have received a privacy notice and agree that a pseudonymised data set, gathered for this study may be stored in a specialist data centre/repository relevant to this subject area for future research	☐	☐

Name of Participant ______________________ Date ______________ Signature ______________________

Name of Researcher ______________________ ______________ ______________________

Appendix 22: Reflection on use of pseudonyms

When selecting pseudonyms for the research participants I attempted to reduce any personal bias around names by selecting pseudonyms alphabetically and quickly i.e., the first name beginning with that letter that came to mind (which was different from any of the participants real names). My deliberation about the pseudonym of the non-binary participant was longer as I wanted to ensure an acceptable non-gendered name.

I was surprised at how quickly I adapted to the pseudonyms, to the degree that after a while, I could no longer easily remember participants real names although I could recall their physical features and still felt a relational researcher/participant attachment to them. Initially I considered this positively; if I was identifying participants by their pseudonyms so easily perhaps I had chosen them well. However, Lahman et al (2015) caution that readers will assign certain characteristics to participants based on their interpretation of the pseudonym. This led me to reflect again on my choices. Were names such as Betty or Hatty, which came easily to me in my alphabetical approach to selection going to be interpreted differently by readers? I suddenly thought of Hatty Jakes from the Carry on films and Betty from the Frank Spencer sitcom. I hadn't contemplated these potential links previously but now wondered if they might be considered by others. Given I did not particularly enjoy either of these past programmes I didn't think I had been influenced by them in my section. My mother-in-law was called Betty, which probably explains why that name had come to me so quickly and Hatty is just a name I quite like. But what is clear here is that identification with the pseudonyms will differ from readers and indeed from participants perspectives on them.

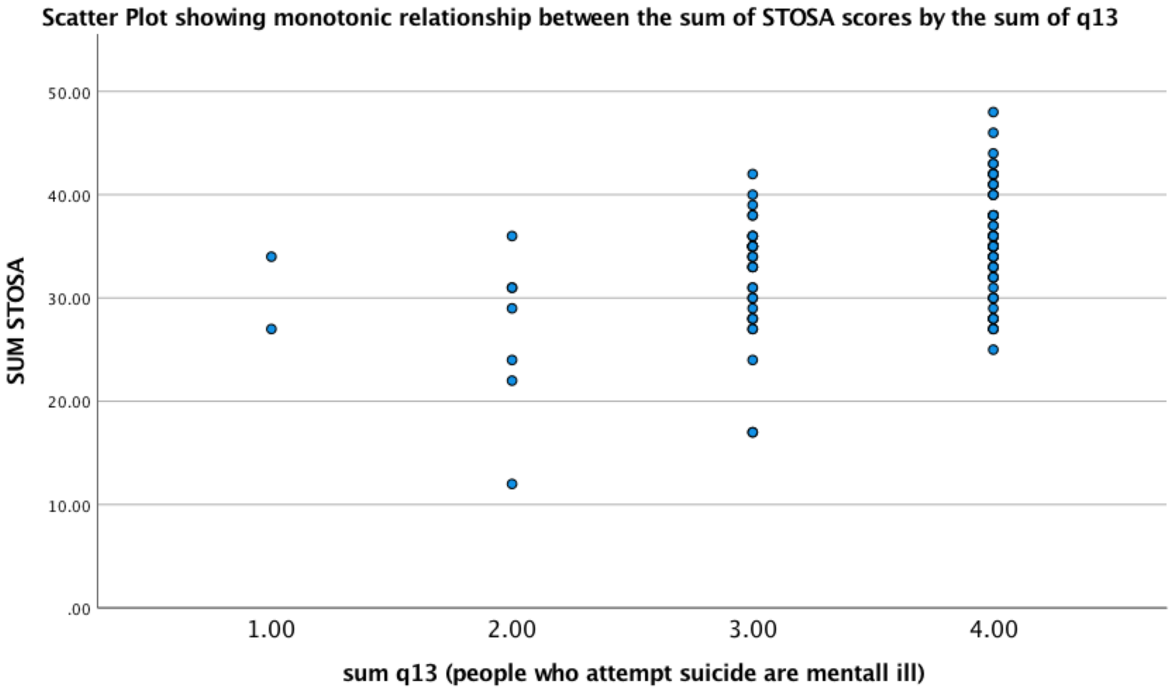
I felt discomfort about not having extended choice of pseudonym to participants and I became conscious of the power I had exerted; as a white, middle class, middle aged, cisgender, heterosexual female, inevitably the pseudonyms I gave to the participants were influenced by my way of being (Lahman, Thomas and Teman 2022). In their discussion about respectful naming, Allen and Wiles (2016) highlighted that selection of pseudonyms may have psychological meaning for participants. I had attended only to the psychological meaning for myself. For example, whilst I had tried to make sure my understanding of cultural and generational connotations of the pseudonyms I chose were aligned with those of participants own names, this alignment was still based on my perceptions. Furthermore, the non-binary research participant did not have a non-gendered name and yet I had applied a non-gendered pseudonym, which again indicates that as the researcher I held the power around how this individual was portrayed. Allen and Wiles (2016) suggest that a pseudonym is an opportunity for participants to transcend cultural associations by choosing a name with entirely different connotations than their own. By not extending choice to the research participants I had withheld this opportunity from them.

Notwithstanding my regrets, affording choice is not without its dilemmas. For example, participants may prefer their real name to be used in research reports (Brear 2018). Such choice involves permanency due to presence of names published research reports, and further choices to withdraw names cannot be made. Accordingly, consent procedures must be adapted to reflect participant choice and their understanding of the permanence of their decision (Lahman et al 2015). Real names also run the risk of others associated with participants being identified (Lahman et al 2015). In this research, participants were talking about their experiences caring for family members or friends they considered to be at risk of suicide. Whilst I took care to ensure quotes I used did not convey information about care recipients that might be identifiable and all mentions of care recipients names and locations were excluded from accounts at the point of transcribing, if participants used their real names care recipients would potentially be able to identify that participants were referring to them. Thus, I do not feel participants real names would have been an acceptable measure. However, my reflections led me to feel wistful about the approach I had taken, wishing I had extended choice of pseudonym.

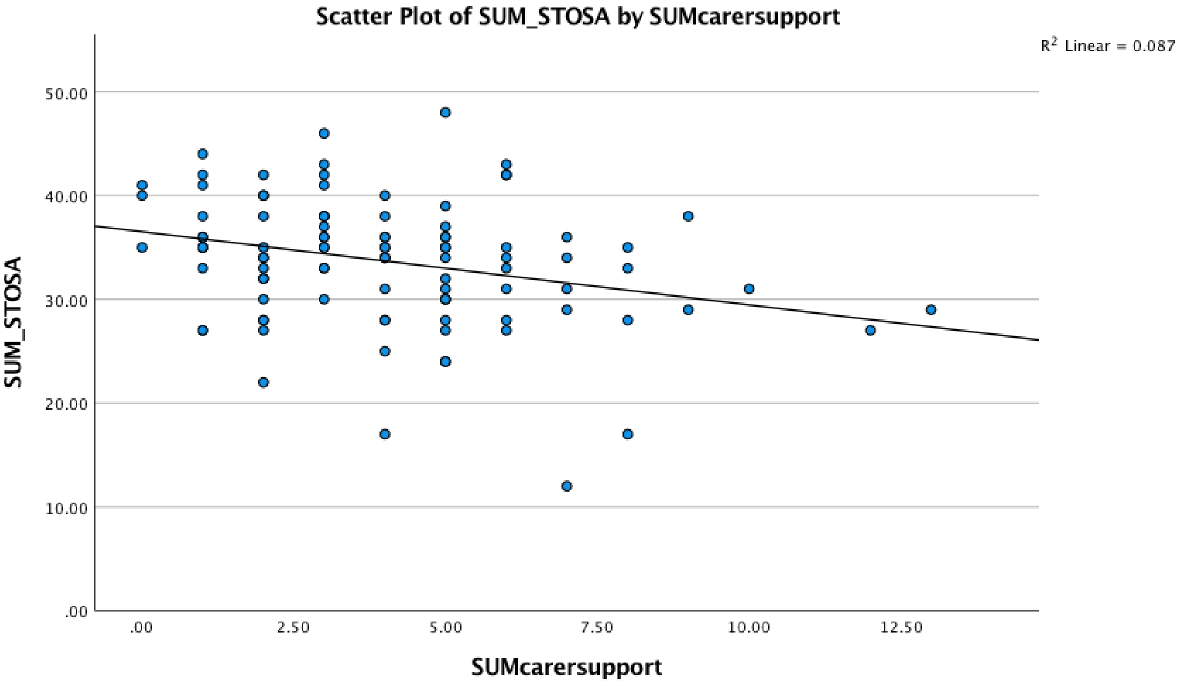
Lahman, Thomas and Teman (2023) advise reflexivity when considering pseudonyms and urge researchers to discuss pseudonyms with participants and document processes regarding them in research accounts. At the point of writing my thesis I did not consider that contacting participants to ask their views about pseudonyms was the right step to take to rectify the lack of choice they had been given about pseudonym. However, all interview participants have expressed interest in receiving a lay research report on completion of my doctorate. This provides me with an opportunity to discuss pseudonyms with them with a view to enabling choice around pseudonyms used in research reports that are submitted for publication.

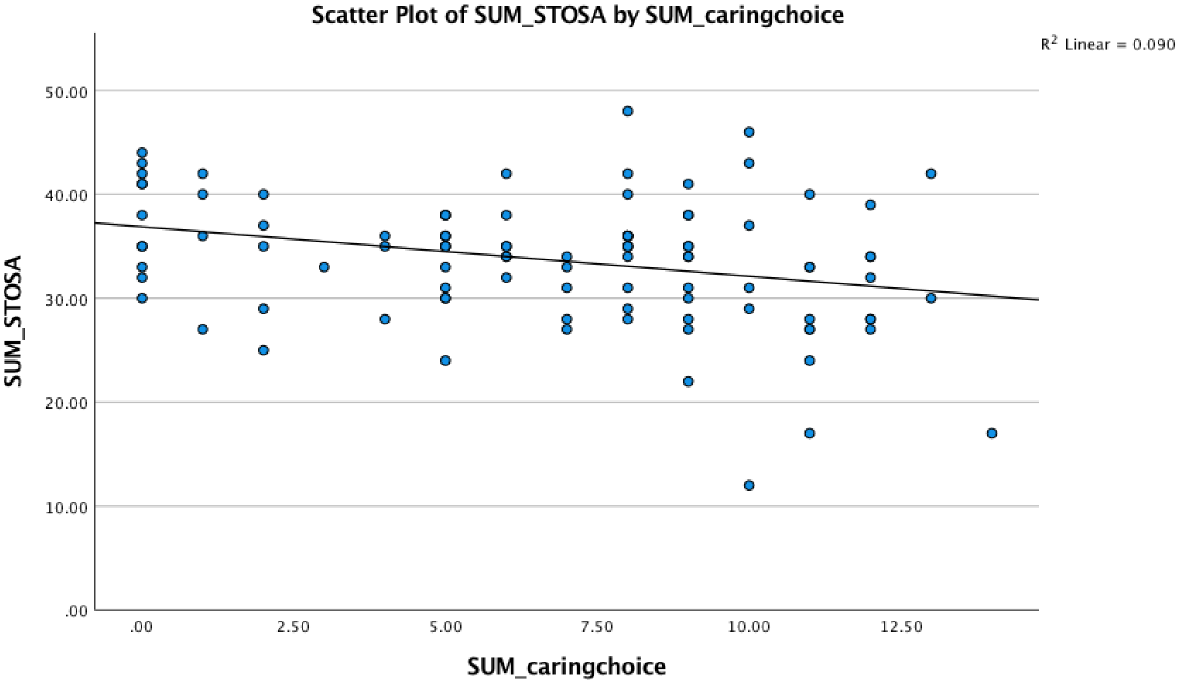
Chapter 4: Results (appendices 22 – 25)

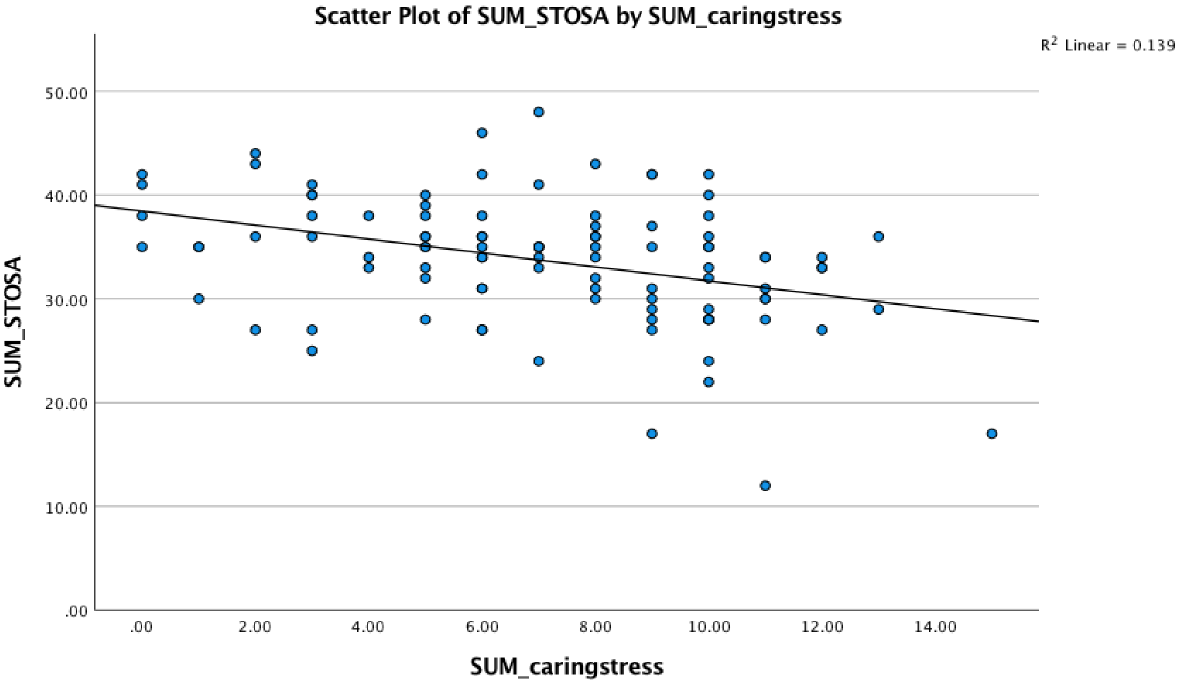
Appendix 23: Scatter plot demonstrating relationship between perceived stigma and perceptions that suicide attempt is associated with mental illness

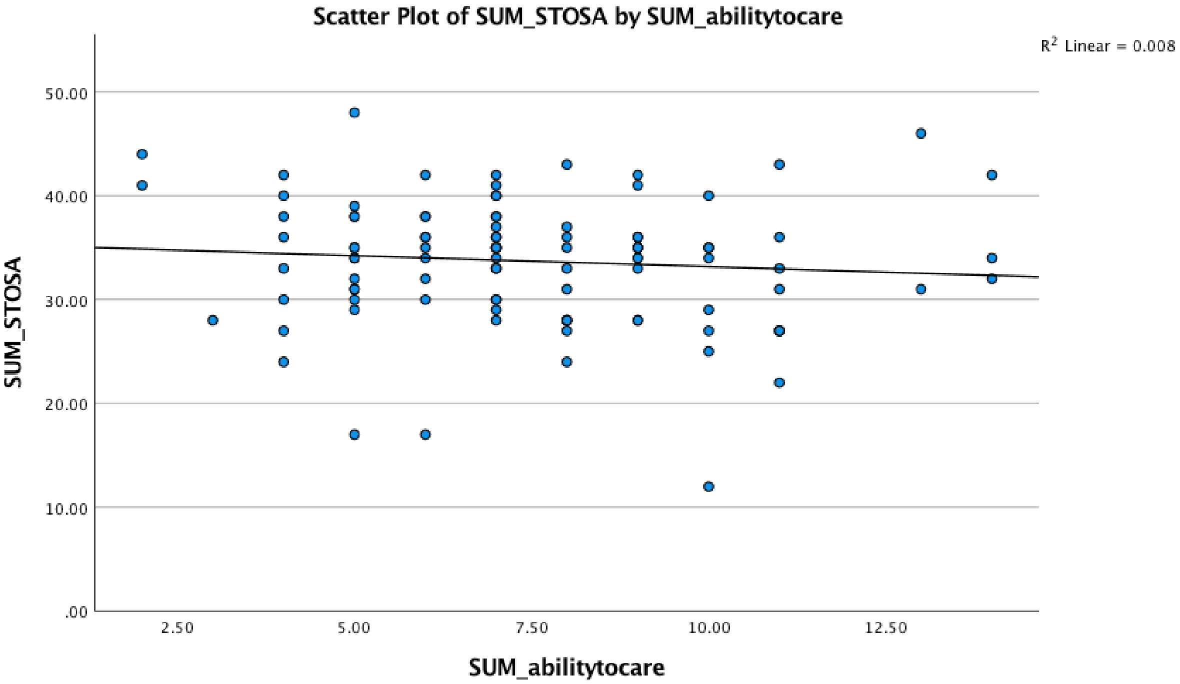


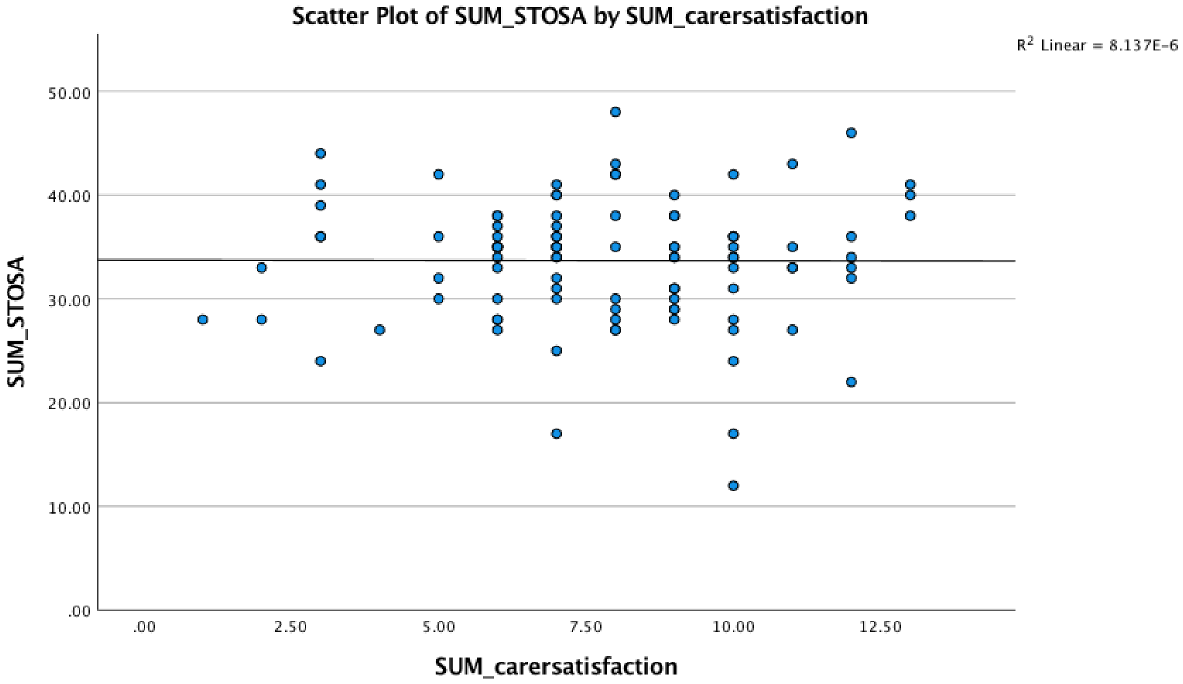
Appendix 24: Scatter plots, QQ plots, and histograms for relationship between STOSA and AC-QoL



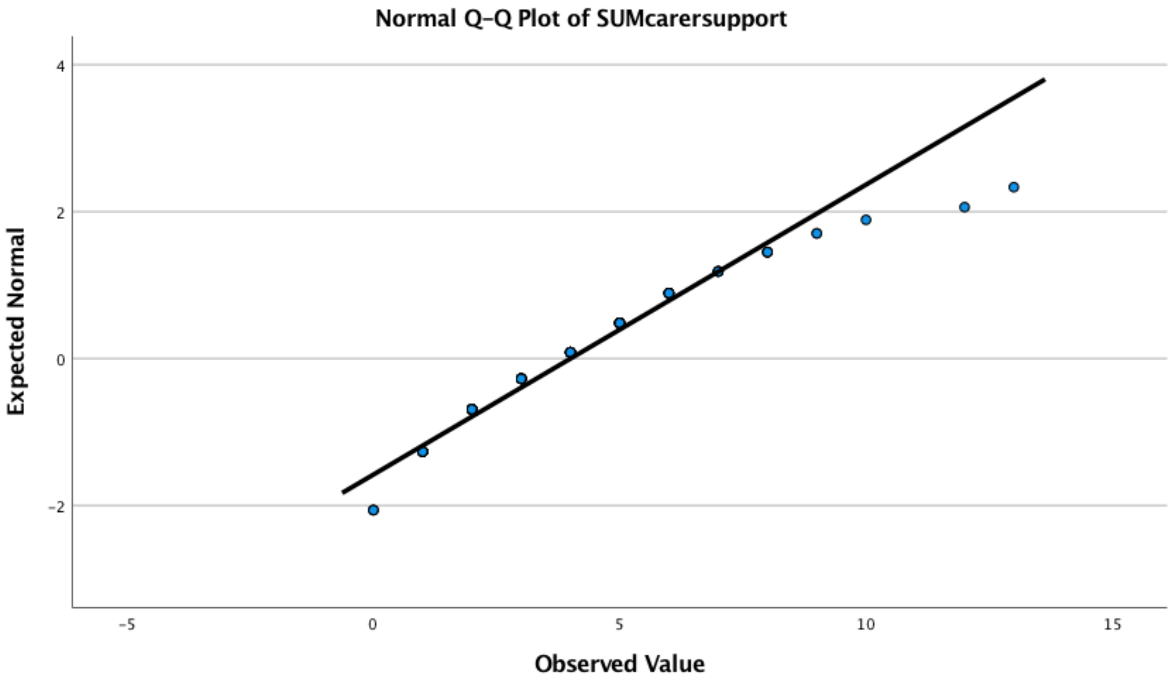


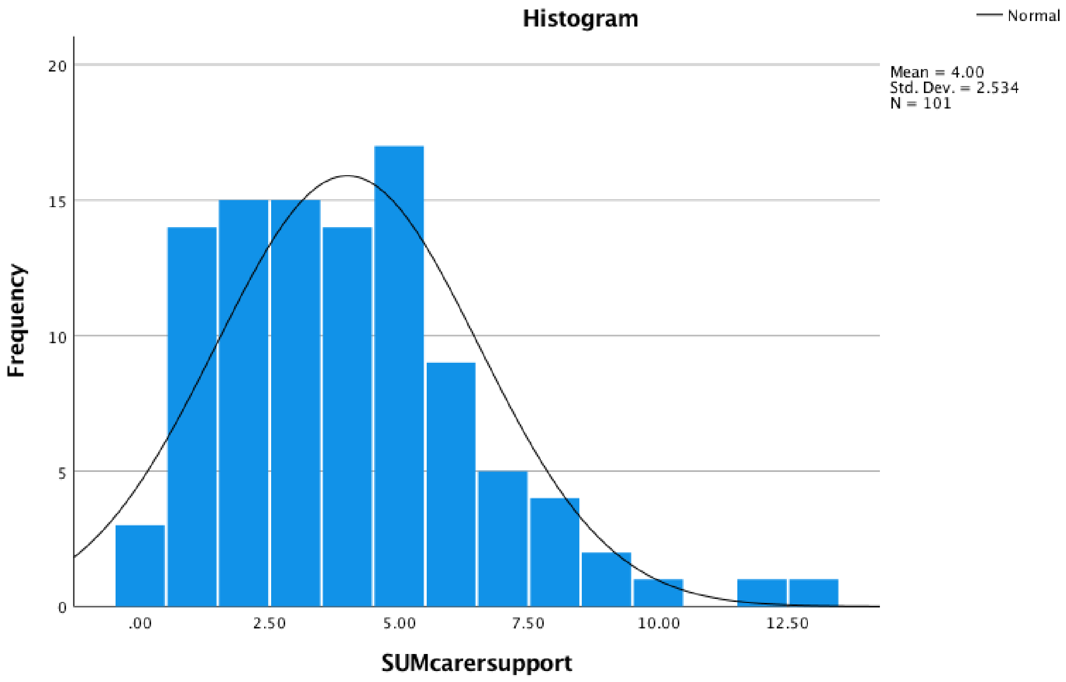

Scatter Plot of SUM_STOSA by SUM_caringstress
R² Linear = 0.139
SUM_STOSA
50.00
40.00
30.00
20.00
10.00
.00
.00
2.00
4.00
6.00
8.00
10.00
12.00
14.00
SUM_caringstress


Scatter Plot of SUM_STOSA by SUM_abilitytocare
R² Linear = 0.008
SUM_STOSA
50.00
40.00
30.00
20.00
10.00
.00
2.50
5.00
7.50
10.00
12.50
SUM_abilitytocare

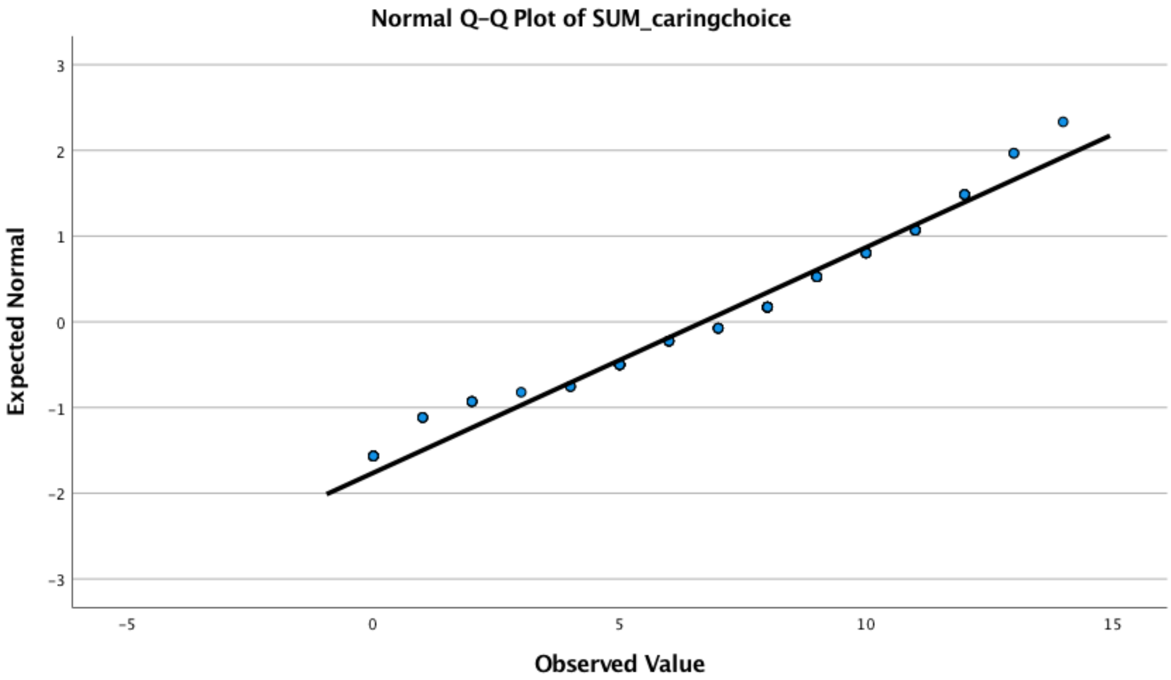


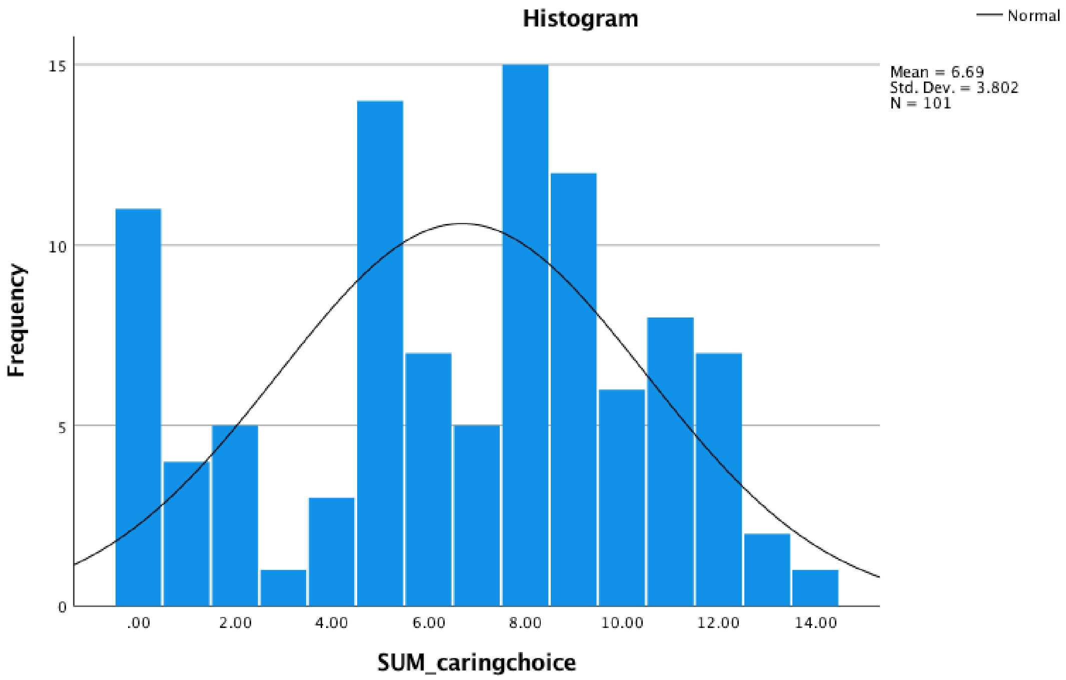
Normal Distribution QQ plot and histogram: support for caring



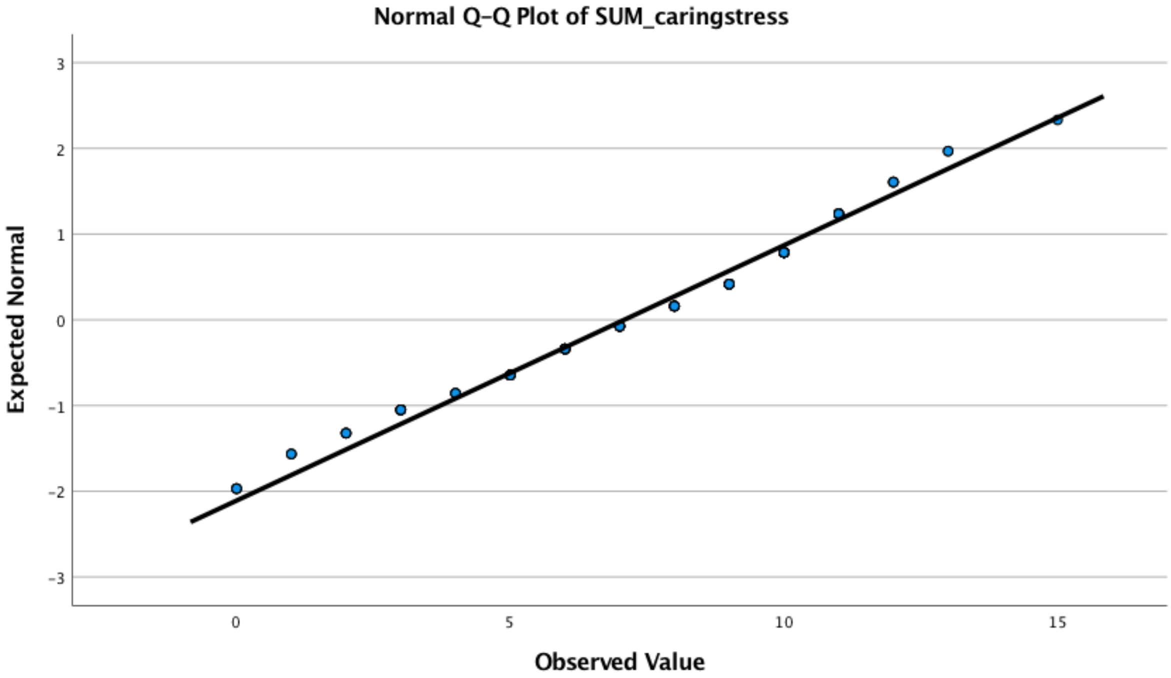


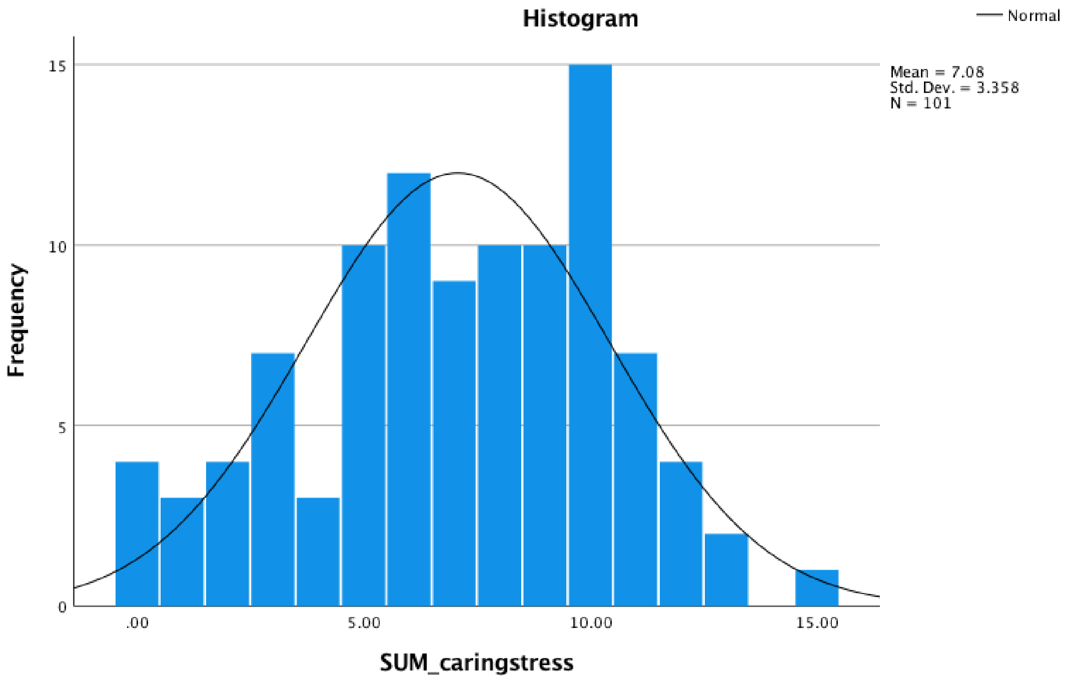
Normal Distribution QQ plot and histogram: Caring choice



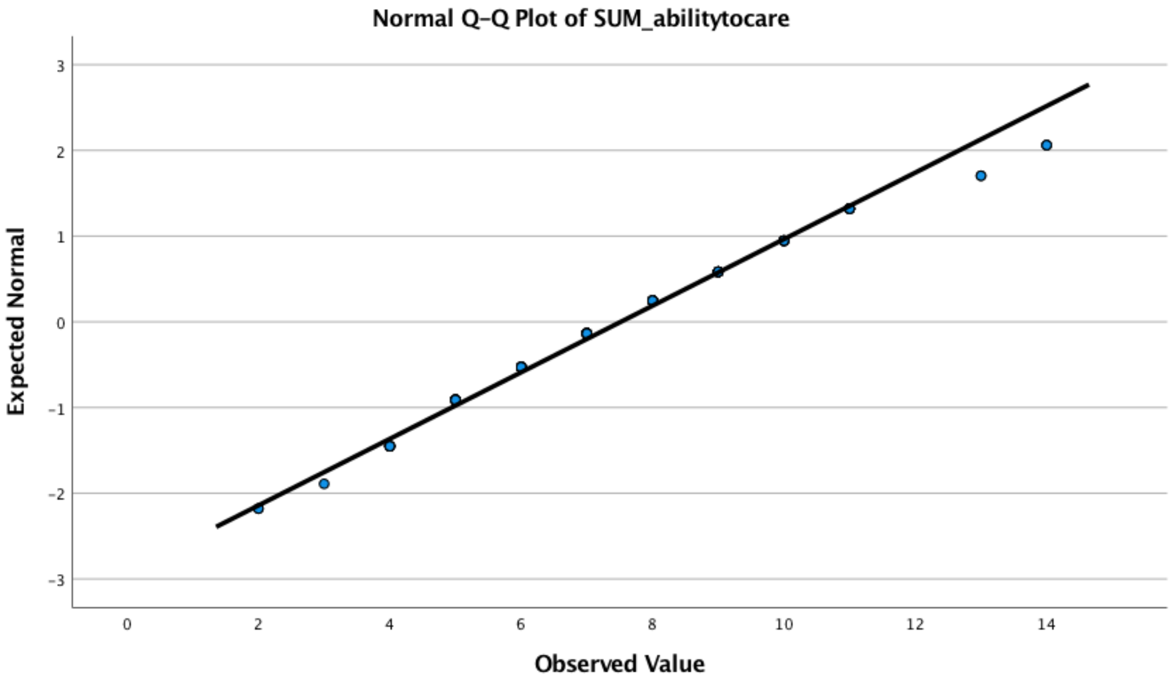


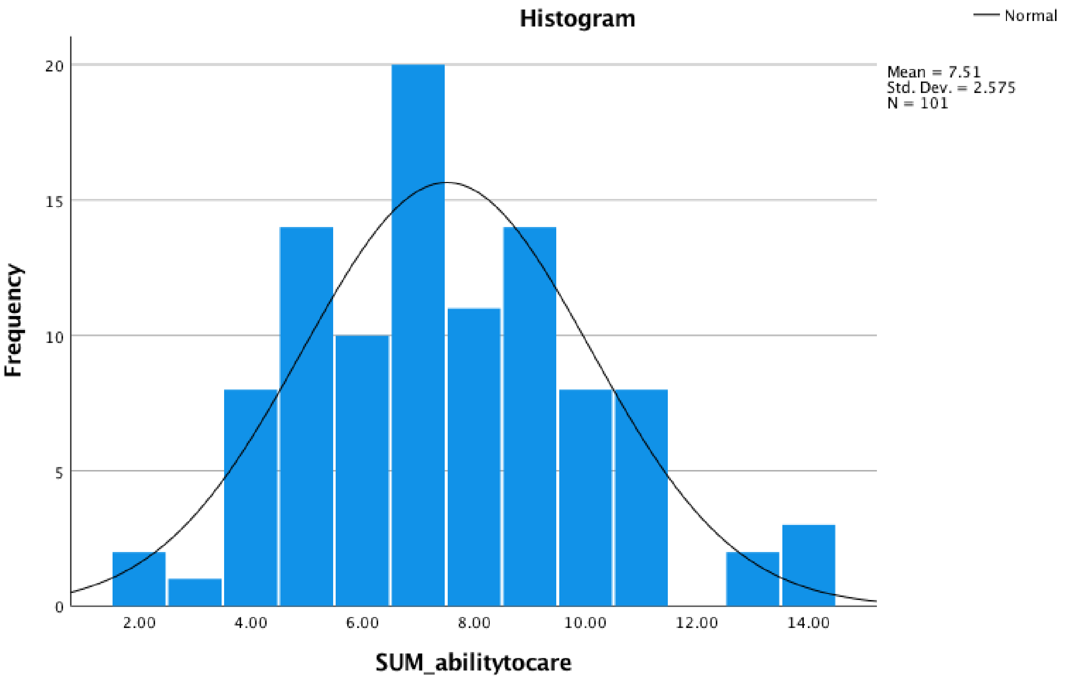
Normal Distribution QQ plot and histogram: Caring stress



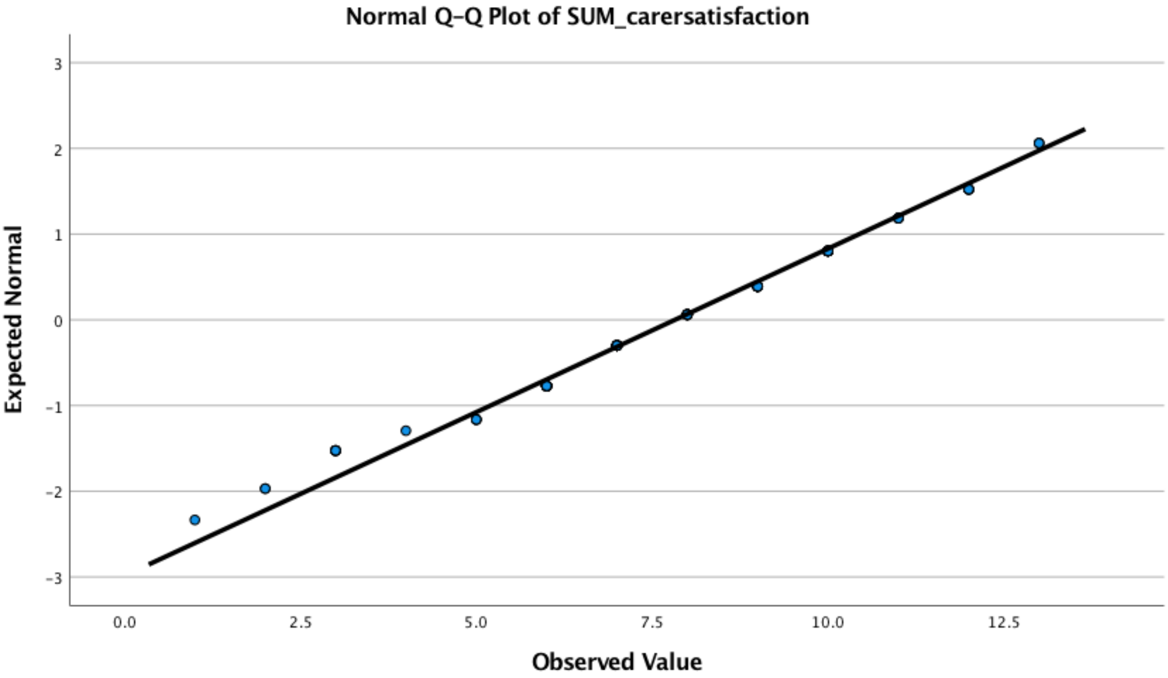


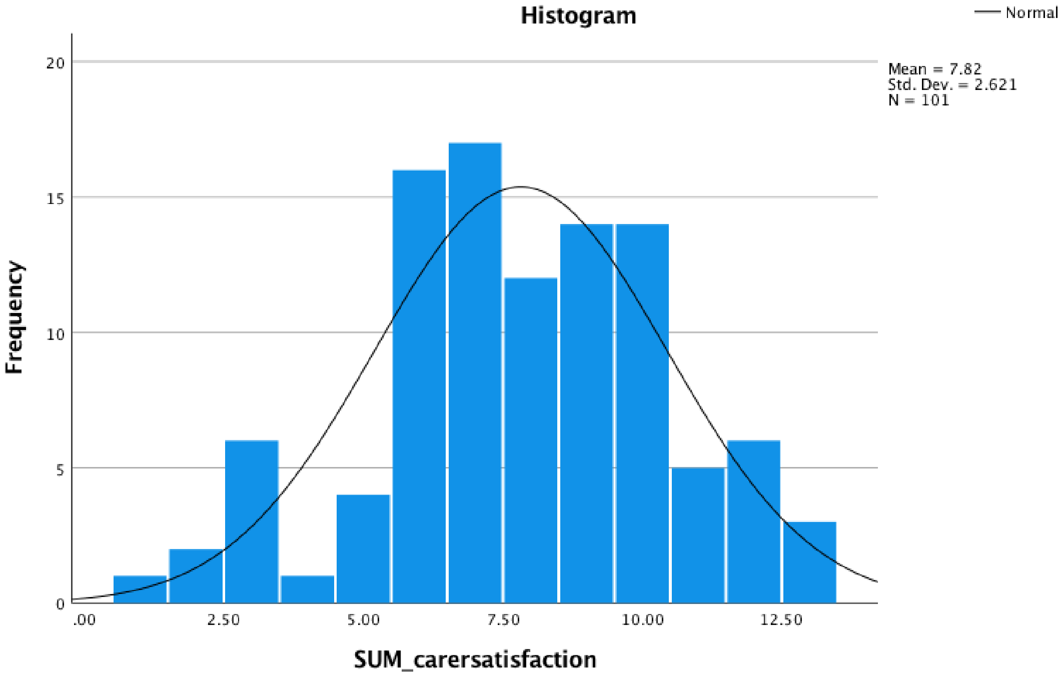
Normal Distribution QQ plot and histogram: Ability to care





Normal Distribution QQ plot and histogram: Carer satisfaction





Histogram
Normal
Mean = 7.82
Std. Dev. = 2.621
N = 101
Frequency
20
15
10
5
0
.00
2.50
5.00
7.50
10.00
12.50
SUM_carersatisfaction

Appendix 25 Unstandardised regression coefficients for ability to care and carer satisfaction domains

Ability to care

Variable	B (S.E)	p	95% CI for B
Sex of care recipient	0.508 (0.592)	0.394	-0.670 – 1.685
Relationship = partner*	0.187 (0.791)	0.814	-1.387 – 1.760
Relationship = other*	-0.050 (0.816)	0.951	-1.673 – 1.573
Living with care recipient	-0.221 (0.791)	0.780	-1.794 – 1.352
Years spent caring	-0.002 (0.003)	0.517	-0.007 – 0.004
Hours caring per week	0.047 (0.129)	0.720	-0.211 – 0.304
Participant age	-0.198 (0.650)	0.761	-1.491 – 1.094
Perceived stigma	-0.414 (0.606)	0.497	-1.619 – 0.791

Carer Satisfaction

Variable	**B (S.E)**	**p**	**95% CI for B**
Sex of care recipient	-0.390 (0.571)	0.496	-1.525 – 0.745
Relationship = partner*	-0.678 (0.763)	0.376	-2.195 – 0.839
Relationship = other*	0.155 (0.787)	0.845	-1.410 – 1.719
Living with care recipient	-0.226 (0.762)	0.767	-1.743 – 1.290
Years spent caring	0.002 (0.003)	0.446	-0.003 – 0.007
Hours caring per week	0.139 (0.125)	0.268	-0.109 – 0.387
Participant age	0.509 (0.627)	0.419	-0.738 – 1.755
Perceived stigma	0.136 (0.584)	0.816	-1.026 – 1.298

Appendix 26: Sentiment analysis disagreements further to researcher manual review of Qualtrics Text IQ

N	Participant response	Qualtrics classification	Researcher review and re-classification (in bold)
1	At times challenging	Negative	The 'at times' indicates challenging times are not continuous therefore the category of **mixed** is more appropriate
2	Full time watching, adapting how I live to reduce risk of them committing suicide. At times thinking it is inevitable one day the attempts will succeed and maybe then they will be at peace and life can move on. Keeping suicide attempts hidden so as not to distress other relatives	Positive	This might have been classified as positive because of the phrase '*one day the attempts will succeed and maybe then they will be at peace and life can move on*'. Given the context of suicide and the remainder of the response indicating negative emotional tone, this statement should be re-categorised as **negative**.
3	It means that you are always considering their needs above and beyond your own.	Positive	Whilst in some contexts this statement might denote a positive tone, in response to the survey question it was conveying a **negative** tone.
4	It was hell, but I found support in a Carer programme called "Family Connections" and this saved my life! The person I care for has improved greatly and my life is back on track too.	Positive	The phrase '*this saved my life!*' likely influenced the categorisation of positive, however reference to the situation having been *'hell'* suggests the situation has not always been positive and therefore a **mixed** classification is considered appropriate.
5	My life was placed on hold whilst I was trying to keep my son safe and prevent him from harming himself and to keep him alive. I could not sleep in fear that he would not be there he following day. My health deteriorated and I had to be admitted to hospital due to shock which caused a hypertensive crisis. I am now on medication for this. I love my son and wanted to make everything better for him but trying to get support from appropriate services was difficult.	Mixed	The phrase '*I love my son and wanted to make everything better for him'* might have resulted in the mixed category, however, in the context of the overall response the emotional tone is **negative**.
6	My life as a carer is hugely variable depending on the level of suicidality and self-harming behaviours my daughter is exhibiting. Right now things are relatively calm, but there have periods of many months (sometimes years) when I have lived with the daily threat of her taking her life. This has resulted in my daughter having extended periods of psychiatric hospitalisation. I now experience symptoms of PTSD as a result	Mixed	The phrase *'right now things are relatively calm'* may have influenced a mixed response but in the context of the overall response the emotional tone is **negative**.

	of what I have lived alongside for so long. It has affected every aspect of my life - work, relationships, friendships and my own outlook on life.		
7	I care for my elderly mum and my elderly uncle and it is hard. My uncle has significant mental health issues and he has spoken of taking his own life, and how he will do this, on many occasions. I manage to listen to him in a crisis and help him get through any 'unclear thinking' moments but the pressure on me to protect him is immense. His GP and other health professionals, including his Mental Health Nurse are all aware of his issues but they don't seem to take my uncle seriously. I provide practical, physical and emotional support to both my mum and uncle, and work part-time, and at times it can be draining.	Mixed	The phrase '*I manage to listen to him in a crisis and help him get through any 'unclear thinking' moments'* might have resulted in a mixed classification, however, in the context of the overall response the emotional tone is **negative**.
8	Continual walking on eggshells	Neutral	In response to the question this response has a **negative** emotional tone.
9	I live on tenterhooks all the time	Neutral	In response to the question this response has a **negative** emotional tone.
10	Never ending	Neutral	In response to the question this response has a **negative** emotional tone.
11	Challenging	Neutral	In response to the question this response has a **negative** emotional tone.
12	A roller coaster of highs and lows	Neutral	In response to the question this response has a **mixed** emotional tone.
13	Tiring	Neutral	In response to the question this response has a **negative** emotional tone.

Chapter 5: Integration (Appendix 26)

Appendix 27: Integration of quantitative and qualitative survey and interview data

Summative content analysis	AC-QoL and STOSA	Qualitative thematic analysis (sub themes and illustrative quotes)	Convergence or divergence	Mixed methods interpretation
Experiences of Caring for an adult at risk of suicide				
Overall emotional tone negative in 68/86 responses to what is life like for you as a carer question. **Reactive affect** Difficult emotions mentioned in 63/86 responses Worry, fear and frustration = most frequently named negative emotions	Caring stress mean score 7.08 indicating mid-range QoL. Caring stress significantly negatively correlated with perceived stigma (r (99) = 0.372, $p < 0.001$) STOSA mean score 2.81 (SD 0.5) indicating presence of perceived stigma Caring stress significantly associated with hours caring ($p = .004$) and perceived stigma ($p = .013$). Association with years	**Constant and fluctuating worry** *“I never know what I‘m going to find when I get home from work”* **Changing relationships** *“That was a shock for me, I hadn't ever experienced that in my life”* *“I’d get frustrated because I felt very stuck, very hopeless, very sad, very angry”* **Influence of health care services on carer identity** *“I could see the treatment that was going on and knew it was wrong, that sixth sense, because I knew nothing about mental health at the time, I let it go on because I believed they*	**Convergence:** qualitative categories and themes highlight that caring is a stressful experience and the AC-QoL caring stress domain indicates a mid-range QoL. Association between caring stress and stigma suggest that perceived stigma adds to stress and qualitative data found stigmatised attitudes from mental health staff stressful aspects of caring.	Worry, fear, uncertainty and strong reactive emotions to the threat of suicide contribute to caring stress and therefore impact quality of life. Lack of professional support and perceived and experienced stigma from healthcare services perpetuates uncertainty and stress. Uncertainty and lack of professional understanding of caring in the context of

	spent caring nearing significance (p = .065)	*were the experts and it took six months for me to then stand up and say no this stops now"* **Ambiguity of the term 'carer'** *"I really think there needs to be a huge distinction between mental health, caring and old age care, dementia caring, physical, because it's, it is different"* **Emotional and health consequences of worry and vigilance** *"There were times when I literally felt like I was coming apart, the strain of what I was trying to hold was unbearable"*		suicidality adds to stress.
Caring characteristics Hypervigilance and walking on eggshells named in 24/86 responses **Carer wellbeing** Exhaustion related to caring or negative impact on health mentioned by 33/86 participants **Fears**	Caring stress mean score 7.08 indicating mid-range QoL. Caring ability mean score 7.51 indicating mid-range quality of life. Multiple regression found hours caring (p =	**Becoming hypervigilant** *"Sometimes I need to be with him 24 hours a day"* *"I religiously locked doors so he was never alone"* **Emotional and health consequences of worry and vigilance**	**Convergence:** Hypervigilance was highlighted as a key caring characteristic in the survey and interviews and was experienced as stressful, with health consequences for some. Fear of poor health	Hypervigilance is a key characteristic of caring underpinned by uncertainty, fear and worry, and is a major source of caring stress. Ongoing hypervigilance increases stress.

Deterioration of health named in 11/95 responses	.004) and perceived stigma (p= .013) contributory to caring stress. Association with years spent caring nearing significance (p = .065)	*"I find it very draining…I don't think I've ever probably had a decent night's sleep"* **"***If I'm not careful my own mental health can be affected, if I get to close to how blighted his life has been then that would really take me down so I have to stand back from it a bit"*	reducing ability to care was a stress factor for some participants. Caring stress and caring ability AC-QoL domains indicate mid-range QoL which supports the stressful experiences and the fact that despite this carers continue with hypervigilance.	Carer stress can lead to detrimental health consequences
Care Intensity 46/86 responses referred to the constancy of caring and associated reactions **COVID-19** 22/93 respondents reported increased care intensity in COVID-19 **Expectations** 62/95 responses mentioned expectations of continuation of caring role, 6/95 responses named anticipation of suicide	Caring choice mean score 6.69 indicating mid-range quality of life. Caring choice significantly correlated with perceived stigma (r(99) = 0.299, p = 0.002) Caring ability mean score 7.51 indicating mid-range quality of life. No significant correlation with perceived stigma. Multiple regression found hours caring	**Putting own life on hold** *I became that sole carer, the restriction of not having time to myself, not having a life to myself* **Accepting you can't fix it** *"…you settle into there's nothing I can do, you get into a place of well it is what it is…..accepting of something that's not acceptable really"* **Balancing hopes and fears for the future** *I don't really have any hope that things will improve* **Changing relationships** *"I have to learn to accept that my daughter may pass away at any point by her own hand*	**Convergence:** Qualitative data highlighted experiences of participants lives being put on hold due to caring, which was supported by the AC-QoL caring choice domain score showing a lower end of mid-range quality of life. The AC-QoL caring ability domain indicates mid-range quality of life which reflects the ongoing nature of caring. Supporting this are the qualitative subthemes and categories relating	Carers take on the role because of their pre-existing relationship and not due to independent choice. Caring is perceived as continuous despite fluctuations of care intensity. Higher demand on carers associated with lower caring choice quality of life Carers have to accept their limitations with regard to changing

	(p<.001) contributory to lower QoL in caring choice domain. Near significant associations with perceived stigma (p = .080) and years caring (.065)	*and, that is her choice. And if that is, if that's something she wishes to do, it, it's nothing to do with me”.* **“Learning ways to adjust** *I will give him space….I’ve got to let him know that I trust him….it gives me a bit of breathing space as well*	to acceptance, adjustment and continuation	care recipients mind about suicide to enable them to continue with their caring role
Unconnected carers 33 mentions of lack of support and/or loneliness and isolation in 86 responses **COVID-19** Loss or reduction of mental health supports in mentioned in 46/93 responses Isolation reported in 25/93 responses Reduced contact with social network in 12/93 responses	Support for caring mean score 4.00 indicating low quality of life. Support for caring significantly negatively correlated with perceived stigma r(99) = 0.295, p = 0.003 Multiple regression found perceived stigmas as contributory to low quality of life in support for caring domain (p = .017)	**Ambiguity of the term carer** *“I was deemed not to be doing enough caring”* **Influence of early healthcare service contact on carer identify and engagement** *“I was desperate to trust but the staff I met did not make me trust”* *“It was a battle to get that help”* **Changing relationships** *“I couldn’t talk to him about how I was feeling”* **Disconnected and reconnected** *“I found myself quite isolated very quickly”* *“I just didn’t talk about what’s going on ……. I was probably*	**Convergence:** Isolation and loneliness were key findings from qualitative survey and interview data analysis. Isolation increased during COVID-19 but was a strong factor before the pandemic. Lack of support from mental healthcare services was identified as a major contributor to isolation and loneliness. This was supported by the AC-QoL support for caring score which showed low QoL. Support for caring was inversely correlated with perceived stigma and	Isolation of carers is associated with low quality of life and perceived stigma. It is influenced by external assumptions about caring, exclusion and stigmatised responses from healthcare providers, reduced social contact and the changed relationship with the care recipient. Work can be protective and help to reduce isolation, but workplace support can be limited.

embarrassed……I had such a stigma around it” *“…my saving grace was work because I had a different focus”* **Influence of healthcare services on isolation** *“We had one person that came and she stood in the hall and said there’s nothing wrong with him you know, he’s just playing you”* **Professional support in for the long haul** *“On the one hand people expect carers will know what to do and on the other hand they dismiss us as nobody”* *“Basically, the criteria for admissions seemed to be have you miraculously survived death”* **Impact of COVID-19** *“That was the longest I'd ever not seen my mom when she was in hospital and she couldn't have visitors. It's the longest I've ever not seen her and it was awful”*	this was confirmed by stigmatising experiences with healthcare services resulting in participants feeling unsupported.	Lived experience activity increases connection.

Positive emotional responses emotional reward and hope mentioned in 9/86 responses **COVID-19** 7/93 responses to COVID-19 question reported a positive impact in part due to relational proximity **Hopes** 25/95 responses focused on hope that the caring role would diminish as care recipient improved	Carer satisfaction mean score 7.82 indicating mid-range quality of life. No significant correlation with perceived stigma. Caring ability mean score 7.51 indicating mid-range quality of life. No significant correlation with perceived stigma.	**Changing relationships** *"Me and mum have a better relationship ow than ever….I find it easier to be happier with less"* **Balancing hope and fear for the future** *"We are hopefully going to move …. I hope by moving….. things will be a bit better …..I'm feeling cautiously optimistic"* *"I don't feel the risk will ever go away …… I'm hoping things will get better"*	**Part convergence:** Carer satisfaction and caring ability domains of the AC-QoL showed mid-range of QoL and no association with perceived stigma. These findings are relatable to the more positive experiences identified from the qualitative data, which were closeness with care recipients.	Carers find satisfaction through the closeness of their relationships. Maintaining hope helps carers deal with their ongoing caring role and fears for the care recipient.
Stigma and mental illness				
98/101 survey respondents reported that their care recipients were either in current contact with mental health services or had been under the care of services previously.	Mean score of control question (most people think people who attempt suicide have a mental disorder) 3.48 (SD 0.72). Significant moderate positive correlation between the control question and the overall STOSA score r_s (99) = 0.353, p < 0.001.	**Disconnected and reconnected** *"His sister said are you with him because it's a project…..he's got mental health issues, they're never going to go away, why would you want to be with someone like that?"*	**Convergence:** Nearly all participants care recipients had mental health problems of a nature that required contact with mental health services and perception that most people who attempt suicide have a mental disorder was high.	Perceptions of suicidality being associated with mental illness are reinforced by contact with mental health services.

What support do carers of adults at risk of suicide need?				
Individual level Information and education, emotional and/or peer support mentioned in 45/96 responses	Support for caring significantly negatively correlated with perceived stigma r(99) = 0.295, p = 0.003 Caring stress mean score 7.08 indicating mid-range QoL. Caring choice significantly correlated with perceived stigma (r(99) = 0.299, p = 0.002) Caring ability mean score 7.51 indicating mid-range quality of life. Carer satisfaction mean score 7.82 indicating mid-range quality of life. STOSA mean score = 2.81 (SD 0.5)	**Disconnected and reconnected** *“Its just being able to talk to someone who knows”* **Learning ways to adjust** *“I’ve put myself through training”* **Professional support in the long haul** *“I think the first thing people need is ….an understanding of what the heck is happening so some level of psychoeducation.”* *“Where you’ve got professional carers coming to the house to help, that they’re there not just for the person but to check up on the carer”* *“Having a group that you could sit around and talk to about how other people are dealing with things, that would be really good”* *“Access to proper therapy”* *“The last thing I want to do is to sit in a room with a load of*	Needs identified from qualitative data reflect the lack of support and presence of caring stress	Education and suicide specific peer support should be available to all. Support should be tailored to context and individual need and include offers of emotional, psychological and practical support.

	others moaning about how life's any good"	
Healthcare services level Recognition and appreciation by HCPs, better care for patients and/or carer involvement in care mentioned in 49/96 responses	**Professional support in the long haul** *We know best, we are with this, we are with these people…..every day* *"I just don't even know where to start with how that feels and why services can ever say that that's ok to behave like that and work like that and not to pick up the phone and go are you ok, this has happened and we know that you know about it so is there anything you need?"*	Carers want to be recognised, understood and involved. HCPs and services should be non-stigmatising.
Societal level Improved community awareness, financial needs and/or better employer support mentioned in 15/96 responses	**Ambiguity of the term carer** *"I find that the term carer, particularly in mental health, a little bit patronising and, and I only use it because that's the terminology used in the NHS….. I really think there needs to be a huge distinction between mental health, caring*	Awareness and understanding of the

and old age care, dementia caring, physical, because it's, it is different.” **Professional support in the long haul** *“I think carers organisations could work a bit harder to make sure that employers are more aware of how to support cares in their employment”*	carer role should be wider than organisational level