The psychological needs of informal caregivers for people living with dementia: Exploring experiences of grief and self-compassion.

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Word Count

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Thesis overview

Self-compassion is a relatively new construct that is part of a burgeoning research area connected with positive psychology, mindfulness and health. Improved psychological well-being and resilience has been shown to be connected to self-compassion (MacBeth & Gumley, 2012). Much of the existing research focuses on providing compassionate care or receiving compassion from others (Sinclair, 2016). Whilst there is emerging interest in self-compassion in the field of dementia caregivers (Martin, Gilbert, McEwan & Irons, 2006; Lloyd, Muers, Patterson & Marczak, 2018), this research is not yet extensive.

This thesis comprises two papers: a systematic literature review and an original research paper, briefly described below. The systematic literature review was prepared for submission to Dementia: The International Journal of Social Research and Practice (Appendix 1). Systematic searches were applied, and a thematic synthesis was conducted to construct and synthesise the existing qualitative literature on the experiences of grief in caregivers for individuals diagnosed with dementia. Nine papers were eligible for inclusion in the review and appraised for methodological quality. Six analytical themes were constructed: Differing aspects of loss; Changing nature of grief; Feeling psychologically threatened; Care for the carer, Accepting loss and Rebuilding life.

The empirical paper was also prepared for submission to Dementia. It utilised a Grounded Theory approach with ten dementia caregivers. This paper explored dementia caregiver's experiences of self-compassion, including the factors that facilitated and inhibited their capacity for self-compassion. A comprehensive theoretical model of the findings was created, visually representing the unique processes that influenced self-compassion, for example, the quality of participant's surrounding support systems.

Cultivating self-compassion is important for helping to relieve psychological distress, especially during times of adversity and suffering (Neff, 2003b). In dementia caregivers, research has reported key components of psychological distress including high rates of grief and loss stemming from caregiving roles (Chan, Livingston, Jones & Sampson, 2013). The findings of the review are discussed in terms of caregiver's psychological needs, whilst the empirical paper highlights factors involved in fostering an enhanced capacity for self-compassion, which could offer ways to psychologically support grief reactions such as feelings of guilt in caregivers; a time of possible suffering.

Informal dementia caregiver's experiences of grief: A systematic review and thematic synthesis

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Marsha Mawson is a Trainee Clinical Psychologist at the University of Liverpool. This work formed the major research component of her Doctorate in Clinical Psychology, supervised by Dr Sarah Butchard and Dr Katy Lobley.

Prepared for submission to Dementia.

Abstract

Purpose: Understanding informal dementia caregiver's experiences of grief is essential in delivering effective psychological support, given the central nature of loss present within dementia. A previous systematic review exploring grief in dementia caregivers reviewed the research prior to 2009. The current review provides an updated synthesis of more recent qualitative literature since 2009, exploring the lived experiences of grief within dementia caregivers, covering a period of global austerity in social care and health systems.

Design / methodology: Four electronic databases (PsychINFO, Medline, CINAHL and Academic Search Complete) were searched in November 2019 for peer-reviewed, qualitative English language studies exploring the grief experience in dementia caregivers. Nine studies were included, appraised for methodological quality and a thematic synthesis was conducted.

Findings: Participant's narratives contained six analytical themes: Differing aspects of loss, changing nature of grief, feeling psychologically threatened, care for the carer, accepting the loss and rebuilding life.

Clinical implications: It is important for professionals to understand the complex and varied emotional reactions to caregiving, support the emotional processing of grief and guilt, and encourage collaborative decision-making about terminal care. Caregiver's experiences of professionals and social support have an impact upon the grief experience; therefore, professionals should be supported to enhance their understanding in ways to appropriately meet caregiver's and the person with dementia's emotional needs.

Keywords

Grief, dementia, informal caregivers, systematic review, qualitative, thematic synthesis

Introduction

Globally, it is estimated that 24 million people are currently living with dementia, with rates predicted to rise to 81 million by 2040 as life expectancy increases (Ferri et al., 2005). Due to the progressive loss of cognitive abilities and activities of daily living skills, it has been suggested that the experience of dementia can be likened to a ‘gradual death’ (Small, Froggatt & Downs, 2007). However, this end of life position is not universally accepted and there has been a move towards a model of ‘living well’ with dementia (Department of Health, 2009).

Payne et al. (2010) defined family members who care for a relative at home or within the community without pay as informal caregivers. Whilst considerable literature has highlighted psychological difficulties such as depression and anxiety in informal dementia caregivers (Grant et al., 2002), there has been less of an emphasis on caregiver’s grief experiences. Walker and Pomeroy (1996) suggested that caregiver grief is often pathologised as depression. Mace and Rabins (1981) referenced grief early on in ‘*The 36-Hour Day’*, suggesting that caregiver grief is continuous throughout caregiving.

Grief

Rando (2000) claimed that grief is a normal, complex and psychological reaction to the perception of loss with struggles of yearning, sadness, anger, guilt, regret, anxiety, loneliness, fatigue, shock, numbness, physical symptoms and positive feelings unique to the individual. Complicated grief has been defined as experiencing emotional, cognitive and behavioural difficulties or separation distress causing a significant impairment in social or occupational functioning for more than six months post bereavement (Ponder & Pomeroy, 1996). Rando further suggested that anticipatory grief illustrates grief that is experienced when anticipating losses. This concept has been commonly used to describe the grief experience in dementia caregivers (Ponder & Pomeroy, 1996) and grief in caregivers of long-term medical and neurological conditions (Covinsky, 2003). To accommodate for idiosyncratic journeys experienced by dementia caregivers, the current review employed the term grief to capture different aspects of experiences including anticipatory grief, complicated grief, positive growth and learning.

Obtaining dementia caregiver's experiences

In England, a target of the National Dementia Strategy is to provide more effective services for dementia caregivers (Department of Health, 2009). Chan, Livingston, Jones, and Sampson (2013) conducted a systematic review investigating grief reactions in dementia caregivers covering the literature from 1992 to 2009. Reviewed studies included quantitative, qualitative and mixed methods primary research. They found that grief and loss comprised of ambiguous loss, loss of intimacy, companionship and feelings of sadness, anger, and guilt. A key finding was that presentations of clinical depression in dementia caregivers are possibly 'normal' grief reactions, supporting the idea that grief reactions in caregivers can be pathologised as depression (Walker & Pomeroy, 1996). Spousal caregivers were open to discussions about the future and focused on maintaining their relationship with their loved one throughout their caregiving journey. The review also highlighted that for many caregivers, grief occurred from the point of diagnosis and increased during the severe stages of dementia. When investigating institutionalisation, caregivers reported a loss of their caring role, deep feelings of guilt and failure as a caregiver.

Chan et al. (2013) also found that caregivers who were less satisfied with formal care for their loved one experienced higher levels of grief. When researching the characteristics of post-death grief, dementia caregivers reported feelings of guilt and regret in relation to care home placements. When caregivers expected and were present for the death of their loved one, they coped better with grief, and for some caregivers, the death signalled an end of suffering for the person with dementia and therefore a sense of relief for the caregiver. Furthermore, the results emphasised the importance of social, religious, practical and emotional support from family and friends.

Given that the above review only covered the literature up until 2009, it was felt important to update this review of the experiences of dementia caregivers, particularly given the increased interest and study of dementia in the past decade; alongside initiatives of living well with dementia (Department of Health, 2009). Additionally, given the changing social context of austerity measures which have impacted upon the NHS and social care, subsequently affecting people diagnosed with dementia and their caregivers (Carers UK, 2015); this area of research felt important to update. The current review built upon previous literature by aiming to gain an understanding of caregiver’s felt experiences of grief. The review also aimed to suggest recommendations to inform future policy about how services can psychologically support caregivers, and thus improve the quality of life for the person diagnosed with dementia; as research suggests that the well-being of caregivers directly influences the well-being of the person living with dementia (Grant et al., 2002).

Approach to synthesis

Thematic synthesis (Thomas & Harden, 2008) provides a high level of analytic abstraction from the primary studies, allowing new formations of participants’ narratives. Thematic synthesis was applied to analyse data for the current review. The research question asked was: ‘What are the experiences of grief for current and former dementia caregivers?’

Method

A protocol for the current review was registered with the PROSPERO database for systematic reviews (CRD42019124171). PRISMA guidelines for completing and reporting systematic reviews were utilised (Moher, Alessandra, Tetzlaff & Douglas, 2009).

Search Strategy

Search terms were formulated using the PICo tool (Methley, Campbell, Chew-Graham, McNally & Cheraghi-Sohi, 2014) (Table 1). Thesaurus tools were employed to identify relevant terms within each database (Table 2; Appendix 2). Following consultation with a Trust Librarian, literature searches were conducted in November 2019 on the following databases: PsychoINFO, Medline, CINAHL and Academic Search Complete. Literature searches were updated during April 2020 to search for any recent eligible studies. No new studies were discovered. PROSPERO and The Cochrane Library were searched to identify existing or anticipated reviews in the same research area. Google Scholar, key journals including Dementia, The International Journal of Social Research and Practice, Age and Aging, and The International Journal of The British Geriatrics Society, cited references in eligible articles and key review articles were reviewed. Experts within the field were also contacted to advise on any missed or future research studies in the topic area (Appendix 3). Endnote reference management software was utilised to store the articles and to aid the screening procedure.

Table 1. PICo tool

Domain		Criteria
P	Population	Dementia caregivers
I	Phenomenon of interest	Grief
Co	Context	Community (informal)

Table 2. Search terms

Dementia	Dement* OR Alzheimer* OR Degenerat* OR Cogniti* OR "cognitive impairment" OR Memory
Carers	Caring OR Carer* OR Caregiver* OR Informal OR Family OR Relative* OR Spouse*
Grief	Grie* OR Loss OR Mourn* OR Sorrow OR Bereave* OR Death
Experiences	"Life experiences" OR Experiences OR Expectations OR Opinions OR Attitudes OR Beliefs OR Stories OR Narratives

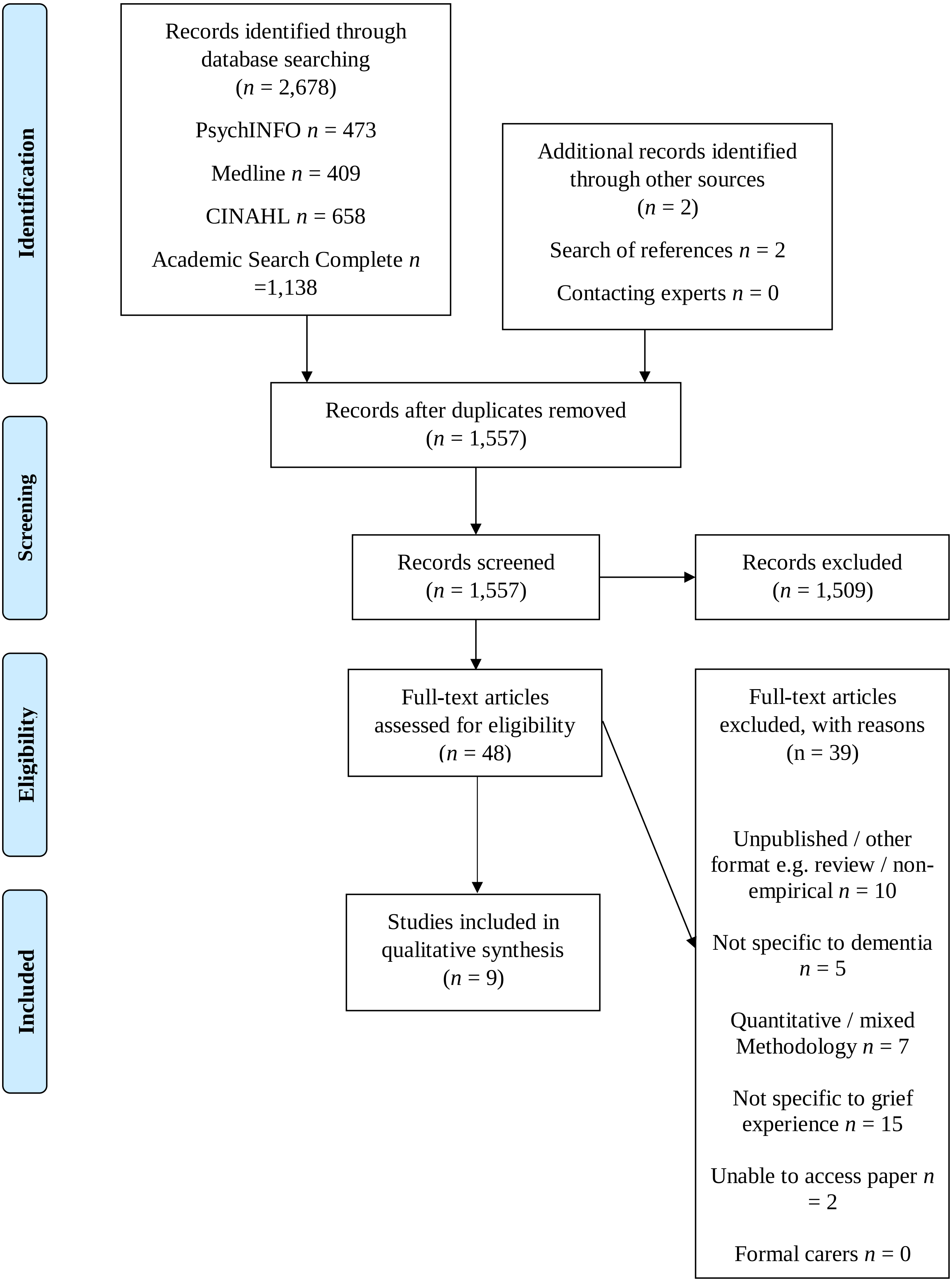
Inclusion and exclusion criteria

The inclusion criteria included papers that contained: (a) peer-reviewed, primary research; (b) any type of dementia; (c) constructions of grief; (d) qualitative methodology; (e) informal caregivers (f) dated from 2009 onwards (g) papers available in English (Appendix 4). Papers were excluded if they were unpublished dissertations, books, conference presentations, letters to journal editors or studies not subject to peer-review. Additionally, papers with no focus on dementia or constructions of grief were excluded. Papers of quantitative or mixed methodology were excluded due to the lack of depth in qualitative analysis. Furthermore, papers were excluded if they focused on formal caregivers, were dated prior to 2009 and only available in languages other than English.

Study selection

The initial search yielded 2678 articles (PsychINFO, 473; Medline, 409; CINAHL, 658); Academic Search Complete, 1138). During the screening process, the removal of duplicates resulted in 1557 papers and a further 1509 papers were excluded due to being unrelated to the topic area. Subsequently, the author applied the inclusion/exclusion criteria to the 48 remaining papers, resulting in 9 studies eligible for synthesis (Figure 1). A second researcher supported both the screening of the title/abstract and full text stages to support the eligibility of identified papers. No disagreements arose during the decision-making process regarding the included studies.

Figure 1. Flow diagram showing identification of papers



Quality assessment

The CASP assessment tool (Critical Appraisal Skills Programme, 2018) was employed to critically appraise the quality of papers using a ten-question protocol to evaluate areas such as methodological issues and researcher bias (Appendix 5). The CASP was chosen as it is commonly recognised in research literature and aims to assess internal and external validity. Given that the CASP does not include a formal scoring system, a scoring system (Butler, Hall & Copnell, 2016) was implemented and adapted for the current review: No (item not met=0), unsure (item partially met/unsure=1) and yes (item fully met=2) to enable scrutiny. The author and a colleague independently assessed the studies. Discrepancies between reviewers arose regarding the rigour of data analysis of the studies and were resolved through discussion.

All studies were included in the synthesis and quality assessment scores ranged from 13 to 17 (Table 3), with lower scores reflecting lower methodological quality and 20 being the maximum score. Studies rated as poorer quality, for example, no information reported about researcher bias are reflected upon in the results section. Findings are interpreted in the context of quality.

Table 3. Included articles assessed for rigour using the CASP (2018): a ten-question protocol to evaluate the quality of findings

Authors	**Aims**	**Methodology**	**Design**	**Recruitment**	**Data Collection**	**Researcher Bias**	**Ethical Issues**	**Data Analysis**	**Findings**	**Valuable**	**Score /20**
Hovland-Scafe and Kramer (2016)	Yes	Yes	Yes	Yes	Yes	No	Yes	Unsure	Yes	Yes	17
Vlachogianni et al. (2016)	Yes	Yes	Yes	Yes	Yes	No	Yes	Unsure	Yes	Yes	17
Corey et al. (2017)	Yes	Yes	Yes	Yes	Yes	No	Yes	Unsure	Yes	Yes	17
Peacock et al. (2018)	Yes	Yes	Yes	Yes	Unsure	No	Yes	Unsure	Yes	Yes	16
Dempsey et al. (2018)	Yes	Yes	Yes	Yes	Yes	No	Unsure	Unsure	Yes	Yes	16
Hovland (2018)	Yes	Yes	Unsure	Yes	Yes	No	Unsure	Unsure	Yes	Yes	15
Wladkowski (2016)	Yes	Yes	Unsure	Yes	Unsure	No	Unsure	Unsure	Yes	Yes	14
Ford et al. (2012)	Yes	Yes	Yes	Yes	Unsure	No	No	Unsure	Yes	Yes	14
Shanley et al. (2011)	Yes	Yes	Unsure	Yes	Unsure	No	Unsure	Unsure	Unsure	Yes	13

Note: questions in full (CASP, 2018) Aims = Was there a clear statement of the aims of the research? Methodology = Is a qualitative methodology appropriate? Design = Was the research design appropriate to address the aims of the research? Recruitment = Was the recruitment strategy appropriate to the aims of the research? Data collection = Was the data collected in a way that addressed the research issue? Research bias = Has the relationship between researcher and participants been adequately considered? Ethical issues = Have ethical issues been taken into consideration? Data analysis = Was the data analysis sufficiently rigorous? Findings = Is there a clear statement of findings? Valuable = How valuable is the research?

Data extraction and synthesis

Information was extracted from the included studies (Table 4) using a data extraction tool designed by the author (Appendix 6). The following data were extracted: author, year of publication, title of paper, research aims, participant characteristics, sampling approach, setting / location, methodology, analysis and summary of outcomes in relation to grief.

A thematic approach was used to synthesise research findings (Thomas & Harden, 2008). This approach applies techniques from Grounded Theory to create descriptive and interpretative analytical themes that go beyond the primary studies and construct new understandings. This method deems all text labelled ‘results’ or ‘findings’ as raw data including original participant quotes (first order constructs) and author interpretations (second order constructs). Capturing both types of data enables the review to be grounded in participants’ experiences (Toye et al., 2014).

All full-text articles were exported into QSR’s NVivo 12 for qualitative data analysis. Initially, all data was coded using line-by-line analysis to capture the meaning embedded in each sentence. Most sentences had several codes applied to them. Next, data was compared between studies by applying existing codes or creating new codes. A second researcher supported the analysis by looking at the similarities and differences between codes. Codes were then grouped to form a hierarchical structure (Appendix 7), leading to the development of descriptive themes. Lastly, these themes were grouped and discussed, leading to the development of analytical themes.

Reflexivity

It is acknowledged that researcher bias may be instinctive with the subjective perceptions of researchers impacting upon findings. As a Trainee Clinical Psychologist, it is possible that psychological aspects of grief were noticed, selected, extracted and synthesised.

This could have possibly minimised other aspects of the grief experience such as physical health changes in caregivers. From clinical experience of working with dementia caregivers, the author expected anticipatory grief and difficult aspects of grief experiences to be constructed as common themes. However, some of the papers highlighted helpful aspects of grief experiences such as, positive understandings of the death, positive self-narratives, extending care to others, reconnecting with others, focusing on the self and re-engaging with meaningful activities. This was a unique finding that challenged the author's pre-conceptions and supported the development of a more balanced view about the impact of grief within the context of dementia caregiving. Attempts were made to enhance objectivity including utilising a second/independent reviewer throughout quality assessment and data synthesis as well as utilising research supervision.

Table 4. The study characteristics and outcomes related to grief of the included articles

Paper Identification Number	Author, year of publication & title of paper	Research Aims	Participant Characteristics	Sampling Approach	Location / Setting	Methodology	Analysis	Summary of outcomes related to grief
1.	Hovalnd-Scafe and Kramer (2016). *Preparedness for Death: How Caregivers of Elders With Dementia Define and Perceive its Value*	To ascertain how bereaved caregivers of a family member who died from a dementia related diagnosis defined preparedness and perceived its value.	N = 30 caregivers (24 females & 6 males) Caring for spouse = 18, parent = 12 Mean age for females = 65 Mean age for males = 75 Former carers Ethnicity, white = 28, black = 2 Mean time bereaved = 9 months	Purposive Criterion Sampling	United States Setting not stated	In-depth interviews using open-ended questions (24 – face to face, 6 - telephone)	Content Analysis	Preparedness for death of a loved one was defined as: • Accepting reality • Knowing that death is near • Saying what you needed to say • Getting your house in order • Planning for legal, medical and insurance considerations Preparation may improve caregivers' experience of: • The dying process • Easing transitions to bereavement • Supporting making post-death decisions and death-related responsibilities
2.	Vlachogianni, Efthymiou, Potamianou, Sakka and Orgeta	To explore the key psychological changes associated	N = 31 caregivers for spouse or parent (all females)	Purposive Sampling	Greece Community	Face to face semi-structured and telephone interviews	Thematic Analysis	Key factors in adapting to loss: • A lack of physical tiredness • Relief from stress • Support from family

	(2016). *Life after care: psychological adjustment to bereavement in family carers of people with dementia*	with carers' adjustment to bereavement and "life after care." To explore strategies carers used to cope with and adapt to their new role.	Mean age = 59.84 Former caregivers Ethnicity not stated Mean time spent caring not stated					and friends • Engaging in pleasant activities Caregivers described processes of: • Making sense of and accepting the loss • Managing feelings and maintaining emotional stability • Rebuilding friendships as part of the grief experience following their relative's deaths
3.	Corey and McCurry (2017). *When Caregiving Ends: The Experiences of Former Family Caregivers of People with Dementia*	To examine the health of former family caregivers and describe their experiences following the death of a care recipient with dementia.	N = 8 caregivers (7 females, 1 male) Caring for spouse = 5, partner = 1, parent = 2 Ages = 50 – 90 Former caregivers Ethnicity = Caucasian Length of time spent caring = 4 – 13 years	Purposive and snowball sampling	United States Community - setting not stated.	Face to face semi-structured interviews	Content Analysis	Following the death of their loved one, caregivers described experiencing: • Sleep disturbances • Changes in health status • Learning to live again • Physical and psychological health did not always relent following the care recipient's death • Feelings of guilt and regret for their care decisions up to 7 years post-caregiving, specifically decisions in relation to nursing homes • Daily intermittent triggers which

			Post-caring period = 4 months – 10 years					provoked difficult emotions and memories • Personal growth development from caregiving
4.	Peacock et al. (2018). *The bereavement experience of spousal caregivers to persons with dementia: Reclaiming self*	To describe the bereavement experience of spousal caregivers. To explore facilitators of bereavement.	N = 10 caregivers (8 females & 2 males) Caring for spouses Aged 65+ Mean age = 81.6 Former caregivers Ethnicity = Caucasian Mean time bereaved = 41 months	Volunteer sampling	Canada Community – place of residence	Face to face interviews - Interpretive description	Thematic Analysis	Key aspects of bereavement included: • Grief beginning prior to death • A focus on the self after death • Changes to the intensity of the bereavement over time Factors which facilitated the bereavement journey included: • Positive understandings of the death • Positive self-narratives • Keeping connection • Social support • Staying active and involved
5.	Dempsey, Dowling, Larkin and Murphy (2018). *Providing care for a person with late-stage*	To explore the experiences of carers who provide end-of-life care for a person with late-stage	N = 23 caregivers (16 females, 7 males) Caring for parent = 18, parent-in-law = 2, spouse = 3	Volunteer sampling	Ireland Community – place of residence	Face to face semi-structured interviews (19 one to one and 2 couple interviews)	Interpretative Phenomenological Analysis	Caregivers recounted: • Emotionally withdrawing from their caring role to cope with loss • Receiving effective social and emotional support pre-bereavement facilitated

	dementia at home: What are carers' experiences?	dementia at home.	Mean age = 50 – 59 Current caregivers = 17, former caregivers = 6 Ethnicity not stated Mean time spent caring = 5 – 9 years					better adjustment post bereavement Caregivers expressed: • Regret for not discussing end of life and death preferences with their loved ones • Shock and a post-death void following the death of their loved one
6.	Hovland (2018). *Welcoming Death: Exploring Pre-Death Grief Experiences of Caregivers of Older Adults with Dementia*	To explore the end-of-life experiences for bereaved family caregivers of older adults with dementia; focusing on understanding their experiences with pre-death grief.	N = 36 caregivers (29 females, 7 males) Caring for spouse = 20, parent = 15, sibling = 1 Mean age for females = 64 Mean age for males = 74 Former caregivers Ethnicity,	Purposive sampling	United states Community – place of residence	In-depth interviews using open-ended questions (30 face to face and 6 telephone interviews)	Content Analysis	Caregivers stated their primary reasons for welcoming death were to avoid unwelcome alternatives including: • Suffering of the older adult • Nursing home admission • Fear of the caregiver dying first Caregivers wished to: • Send their loved one to a better place • Regard death as a relief

			Caucasian = 28, African American = 8 Range of time spent caring 2-12 years Mean time bereaved not stated					
7.	Wladkowski (2016). *Live Discharge from Hospice and the Grief Experience of Dementia Caregivers*	To explore the experience of caregivers of adults with dementia, who experienced a live discharge from hospice; specifically, the experience of grief.	N = 24 caregivers (20 females & 4 males) Caring for a parent = 19, partner or spouse = 3, non-family = 2 Mean age = 63 Ethnicity not stated Mean time spent caring not stated	Volunteer Sampling	United States Community – private residences and public venues	Semi-structured interviews (18 - face to face, 6 – telephone interviews)	Thematic Analysis	Caregivers struggled to understand how the model of “end-of-life-care” fitted: • The dementia disease process • Their own experience of grief A change in a terminal prognosis resulted in: • A disruption of anticipating death • Feelings of being unsettled • Feelings of uncertainty about the future Findings suggested that caregivers reside on a continuum of grief
8.	Ford, Linde, Gigliotti and Kim (2012). *Grief experiences*	To explore the meanings caregivers attribute to their caregiving	N = 3 caregivers (all females) Caring for spouses	Phenomenological case-study approach Purposive sampling	United States Community – Veterans Affairs Medical	Face to face, in-depth interviews using open-ended questions	Not stated, reported themes	Key aspects of grief emphasised: • The irreplaceable value of the long-standing partnership • Yearnings for how

	of 3 caregiving wives of veterans with dementia	experience. To explore the ways caregivers define, process and grieve their losses.	Aged 51, 71 and 84 Ethnicity not stated Mean time spent caring not stated		Centre			things used to be • Intergenerational losses Time in the military service impacted the caring experience including: • The value of care provided by Veterans Affairs • Continuing relational interaction • Ongoing emotional support from family and friends
9.	Shanley, Russell, Middleton & Simpson-Young (2011). *Living through end-stage dementia: The experiences and expressed needs of family carers*	To better understand the end-of-life experiences and needs of persons with dementia and their family carers.	N = 15 caregivers (8 females & 7 males) Caring for a spouse = 10, parent = 5 Mean age for spouses = 64 Mean age for children = 48 Ethnicity not stated Mean time caring = 8 years	Purposive sampling	Australia Setting not stated	Face to face semi-structured interviews	Thematic Analysis	Dementia caregivers have a need for: • Empathy • Understanding • Connection Caregivers can feel very alone when experiencing: • The loss of their loved one • A reduction in social support • Health professionals who are task-focused in their work practices It is important to caregivers for professional staff to: • Respect their role as a caregiver • Involve caregivers in all decisions about the care for their loved one

- Encourage caregivers to take certain actions such as: joining a carer support group, if they believe it is in the best interests of the caregiver

Results

Six over-arching themes in relation to current and former caregiver's experiences of grief were identified: 1) Differing aspects of loss (double loss, changes to identity, loss of caring role, loss of companionship and bearing witness to decline). 2) Changing nature of grief (anticipatory grief, disconnecting over time and uncertainty for the future). 3) Feeling psychologically threatened (difficult emotions including guilt, loneliness, regret and feeling conflicted and negative experiences of services). 4) Care for the carer (gratitude for support and receiving support from others). 5) Accepting loss (cherishing those moments, preparations for death, sense of relief and the right time to go). 6) Rebuilding life (extending care and maintaining a connection). Although the themes are structured linearly, it is recognised that the process of grief in dementia caregivers involves different trajectories outlined within the analysis.

Evaluation of quality

When interpreting study findings, it is essential to consider the quality of the papers contributing to the evidence base. No studies were excluded from the review based on quality, however some of the studies lacked rigour (Wladkowski, 2016; Ford et al., 2012; Shanley et al., 2011). These three studies failed to meet most of the criteria, scoring below 15/20. They did not provide sufficient information regarding ethical issues, therefore failing to meet professional standards in relation to ethical principles. Additionally, they failed to provide enough information about data collection and analysis, making it difficult to interpret research findings, possibly reducing the reliability of their results about grief experiences for dementia caregivers. Furthermore, Wladkowski and Shanley et al. did not provide sufficient information about the design of their study, thus having further implications for the reliability of findings.

As lower quality papers contributed to some of the themes, their results must be considered with caution. Wladkowski (2016) contributed to the following themes: differing aspects of loss, changing nature of grief, feeling psychologically threatened and accepting loss. Ford et al. (2012) contributed to differing aspects of loss, feeling psychologically threatened, care for the carer and rebuilding life. Lastly, Shanley et al. (2011) contributed to all themes apart from theme six (rebuilding life). However, contributions to the results from lower quality papers were also supported by contributions from higher quality studies where similar themes were constructed. The remaining six studies were deemed of a higher quality due to meeting most of the criteria (scoring 15/20 or above). Higher quality papers with larger amounts of data gave greater contributions to the thematic synthesis (Hovland-Scafe & Kramer, 2016; Vlachogianna et al., 2016; Peacock et al., 2018; Dempsey et al., 2018), therefore all reported themes are grounded more within the higher quality papers.

A common methodological problem across all studies was an absence of acknowledging the researcher's position and potential researcher bias on participants and study findings, consequently lacking rigour due to a lack of transparency of the analytical process and credibility of findings. It is possible that researcher bias, for example, assumptions and prejudices influenced the interpretation of data, possibly affecting the validity of research findings about grief. Lastly, most of the studies employed volunteer sampling which could have skewed results in being representative of dementia caregivers who seek help and not capturing caregivers who are not in services. This could have influenced population validity and minimised the generalisation and representation to the general population.

Sample quotes from different studies reflecting themes are displayed in Table 5.

Table 5. Table of quotes reflecting descriptive themes

Analytical and descriptive themes	Participant *quotes* and/or authors' interpretations	Research study	Quality of study
Differing aspects of loss			
- Double loss	*'I grieved as much while she was alive as after she passed away. With the whatchamacallit, the diagnosis and the actual death. I lost her twice'*.	Peacock et al. (2018)	High
	'*I've lost my father a long time ago, what I'm about to lose is my son'*	Dempsey et al. (2018)	High
	The 3 wives described painful experiences of the psychological and eventual physical loss of their spouse.	Ford et al. (2012)	Low
- Changes to identity	*'I had been a caregiver for so long and it was what identified me'*	Corey and McCurry (2017)	High
	Part of the grief period involved letting go of the caring role as a central aspect of their identity.	Shanley et al. (2011)	Low
	Many participants considered caregiving to be part of their identity.	Corey and McCurry (2017)	High
- Loss of caring role	*'I miss taking care of him'.*	Vlachogianni et al. (2016)	High
	You keep thinking that this time I used to care for him, talk to him, feed him'.	Vlachogianna et al. (2016)	High
	'It's freedom I don't want… I would give anything to be providing that care'	Corey and McCurry (2017)	High
	Former caregivers grieved the loss of caregiving.	Dempsey et al. (2018)	High
- Loss of companionship	'*The companionship just dwindled'*.	Shanley et l. (2011)	Low
	Arthur described the diagnosis as '*a sledgehammer hitting you*,' which signalled the end of his life with his wife.	Peacock et al. (2018)	High
	Zeke described moving his wife from their residence to long-term care as '*an ending of their life together'*.	Peacock et al. (2018)	High

- Bearing witness to decline	Participants spent a great deal of their time witness to their spouse's functional decline.	Hovland (2018)	High
	'His thighs were just like sticks. The hips, you know, it was just incredible, and to think that the heart inside was still keeping him alive'	Shanley et al. (2011)	Low
	The experience of watching their spouse or parent go through the end-stage of dementia was very harrowing for many of the carers.	Wladkowski (2016)	Low
Changing nature of grief			
- Anticipatory Grief	*'I think unconsciously I anticipated we will have a time to mourn, we will have a time to grieve, it's coming soon'.*	Wladkowski (2016)	Low
	'*The thing with chronic grief, is ... makes it sort of difficult, makes it easier to deal with a death, because you anticipate it*'.	Hovland-Scafe and Kramer (2016)	High
	Most reported that grief began with their spouse's diagnosis of dementia.	Peacock et al. (2018)	High
- Disconnecting over time	*'You are already disconnecting for what – three, four, five years? You're gradually disconnecting from the loved one'.*	Peacock et al. (2018)	High
	'They're just disappearing so you really have been saying goodbye to that person for quite some time'.	Hovland (2018)	High
	'Well it starts when the dementia starts getting bad. So that process of disconnection is – already has been in the works'.	Shanley et al. (2011)	Low
- Uncertainty for the future	Fiona (daughter) said, *'you just go from day to day and you don't know what is going to happen'.*	Dempsey et al. (2018)	High
	Carers described the uncertainty of not knowing what to expect from one day to the next, exacerbating their	Dempsey et al (2018)	High

	struggle to provide care. Caregivers identified a prominent void in their day immediately following the death of the care recipient, resulting in feelings of uncertainty and ambiguity. Caregivers frequently asked themselves: '*What do I do now*?'.	Corey and McCurry (2017)	High
Feeling psychologically threatened			
- Difficult emotions (including guilt, loneliness, regret and feeling conflicted.	Ellie (wife) said '*Guilt, guilt, guilt. Guilty he was like that, guilty that I was getting frustrated that I was repeating everything, guilty that I wasn't doing enough. When I was putting him into respite, I felt dreadful for leaving'.*	Dempsey et al. (2018)	High
	Jack (son) said '*You have no one. The heavy tick of the clock that you never heard when your mother was here with you, that's when you know you're on a lonely journey*'.	Vlachogianna et al. (2016)	High
	Carers spoke of having regrets including not discussing death and dying early in the disease trajectory.	Dempsey et al. (2018)	High
	Most caregivers believed the individual would die while in hospice care. This change in terminal prognosis left caregivers feeling emotionally unprepared for the termination, which conflicted with their understanding of a terminal diagnosis.	Wladkowski (2016)	Low
- Negative experiences of services	*'They don't have time to feed him . . . they are very busy. They don't hydrate him'.*	Ford et al. (2012)	Low
	'We kept thinking how can you think we don't need help? How come you don't think she's for hospice? … she's just a body lying there'.	Wladkowski (2016)	Low
	'Many times you need a team effort, but there is not the connection between the social worker, the Home Care, the doctor, the whatever'.	Shanley et al. (2011)	Low
	Some carers were constantly at the nursing home providing direct care themselves or making complaints to	Hovland-Scafe and Kramer (2016).	High

	the management about the standard of care.		
Care for the carer			
- Gratitude for support	All 3 caregiving wives acknowledged being fortunate that their veteran spouses had access to veteran's affairs residential care.	Ford et al. (2012)	Low
	Carers valued psychosocial support for acknowledgement of their role, help with difficult decisions or just having an empathetic person to talk to.	Shanley et al. (2011)	Low
	'Without the carers group I never would have survived, they were my lifeline'.	Shanley et al. (2011)	Low
- Receiving support from others	Mrs Benson stressed the importance of her family (siblings and children) and good friends (known them since school days) in terms of both instrumental and emotional support.	Vlachogianna et al. (2016)	High
	'We always had many people around us; everyone calls me even now that he is gone'.	Peacock et al. (2018)	High
	'It helped talking to my friends about all I have been through, I felt so much better'.	Dempsey et al. (2018)	High
Accepting loss			
- Cherishing those moments	*'I gave him a kiss goodbye the other day. He looked at me clearly and said, 'Thank you' . . . that has given me strength for the past several weeks . . . life's simple pleasures'.*	Hovland-Scafe and Kramer (2016)	High
	Occasionally, there would be this wonderful spark, and you see the sense of humour return or a little comment, and it's nice to see, and it kind of makes you smile'.	Vlachogianna et al. (2016)	High
	Most of the carers tried to preserve what level of connection and intimacy they could e.g. quietly holding hands or giving a cuddle to their partner.	Peacock et al. (2018)	High
- Preparations for	*'Being prepared…for legal, estate, religion, family and*	Hovland-Scafe and Kramer (2016)	High

death	*funeral arrangements…there should be a plan in place and an agreement with the family'*.		
	'I think when you're prepared, it's easier to accept, it eliminates the surprise'.	Hovland (2018)	High
	Caregivers had ample time to engage in both practical and psychological preparations for their death.	Hovland-Scafe and Kramer (2016)	High
- Sense of relief	*'I was so relieved when he passed away not only for the sake of me, it was for the sake of him'.*	Hovland (2018)	High
	'I have accepted my father's death; I thought about it so long, I was not sad but relieved'.	Peacock et al. (2018)	High
	When hospice services were introduced, most caregivers reported feeling a sense of relief as a terminal prognosis could bring closure.	Wladkowski (2016)	Low
- The right time to go	*'You know, it was time for him to go. That's the way I felt, it was time to let go'.*	Hovland (2018)	High
	Caregivers highlighted the need to give '*permission'* for their family member to die. They discussed '*letting them go*' and granting permission as '*lifting the weight of the world off* [their] *shoulders'*.	Hovland-Scafe and Kramer (2016)	High
	Many caregivers felt that it was the '*right time'* for their spouse to die, understood their death as peaceful or as embodying a release from suffering.	Vlachogianni et al. (2016)	High
Rebuilding life			
- Extending care	*'It's just that since he died, I'm here and I just do everything I can for my kids… like if I'm washing my clothes, then I'll tell my daughter that I'm washing coloured clothes... 'Do you have anything?'*	Peacock et al. (2018)	High
	'It is my way to honour Gloria. I couldn't do anything for her in terms of saving her or changing the progression of her illness, but if I can do something that will help some other family not have to go through what I've gone	Corey and McCurry (2017)	High

	through, what she's gone through, then that's what I can do for her'.		
	All carers wanted to stay involved with the Veterinary Affairs and active in the lives of their loved ones. They expressed a strong need to help others and to extend this beyond their husbands and benefit other residents and their families as well.	Ford et al. (2012)	Low
- Maintaining a connection	*'I pretend that I talk to him that gives me great relief'.*	Vlachogianna et al. (2016)	High
	'I look after my husband's grave; to me that means I can still care for him'.	Peacock et al. (2018)	High
	Trudy described her appreciation for friends who would invoke her husband's name and discuss memories as this enabled her to keep a connection with him.	Peacock et al. (2018)	High

Theme 1: Differing aspects of loss

The first analytical theme highlighted the various aspects of loss that participants experienced, including within the person diagnosed with dementia and for the caregiver.

Double loss

Most participants considered the dementia diagnosis as symbolising the start of the psychological loss of their loved one. This included changes to the person's cognitive functioning affecting their personality and abilities to complete daily tasks. Most participants expressed that they no longer recognised the person with dementia as a family member. The psychological loss was added to by the eventual or actual physical death of the person, contributing to two distinct forms of loss within participant's experiences (Ford et al., 2012; Wladkowski, 2016; Hovland-Scafe & Kramer, 2016; Dempsey et al., 2018; Peacock et al., 2018).

Changes to identity

Some participants considered their caring role to be core to their sense of self. Spouses naturally became their loved one's caregiver and many children gave up their working life to care for a parent. Participants expressed that caring defined their identity and their time (Shanley et al., 2011; Peacock et al., 2018). Former caregivers experienced loss when they were no longer able to care and this loss further changed their identity, for example, becoming a widow (Corey & McCurry, 2017).

Loss of caring role

Some former caregivers spoke about missing taking care of their loved one, and consequently struggling to adjust to the loss of their caring role following their family member moving into nursing or hospice care or following bereavement. Participants reflected that as they cared for their loved one full-time, they struggled to know how to spend their time (Shanley et al., 2011; Vlachogianna et al., 2016; Wladkowski, 2016; Corey & McCurry, 2017; Dempsey et al., 2018). Whilst some former caregivers expressed a wish to continue caring for their family member, other caregivers reported a sense of relief following the loss of their caring role (Hovland, 2018; Peacock et al., 2018).

Loss of companionship

Most current spousal caregivers spoke about the diagnosis of dementia representing the end of a shared life together (Shanley et al., 2011; Dempsey et al., 2018; Peacock et al., 2018). Some participants also considered the decision to move their loved one into long-term care as marking the end of their life together (Ford et al., 2012). Both current and former caregivers reflected that as the dementia progressed, physical affection and intimacy diminished leading to a loss of companionship, leaving caregivers feeling intense loneliness (Vlachogianna et al., 2016).

Bearing witness to decline

All participants commented on witnessing the decline of their loved one as the dementia progressed over time. For some this involved observing a decline in daily functioning, and for others a deterioration of the person with dementia's physical health or both (Shanley et al., 2011; Wladkowski 2016; Dempsey et al., 2018; Hovland, 2018). Witnessing the changing appearance of their family member contributed to caregivers experiencing emotional distress and for some caregivers, the creation of traumatic memories. Some participants stated that the traumatic memories became triggers of distress (Vlachogianna et al., 2016; Corey & McCurry, 2017).

Theme 2: Changing nature of grief

Anticipatory grief

All studies reported that current and former caregiver's grief experience started following their loved one's diagnosis of dementia. Former caregivers described a felt sense of knowing that the death of their family member was near and therefore anticipated their death. Some participants expressed that anticipating the death helped them to deal with the actual death easier because it eliminated the '*shock factor'* (Hovland-Scafe & Kramer, 2016). For other participants, the death still came as a shock despite experiencing anticipatory grief (Shanley et al., 2011; Hovland-Scafe & Kramer, 2016; Dempsey et al., 2018)

Disconnecting over time

Most participants described a process of gradually disconnecting to their family member in parallel to the progression of the dementia over time (Peacock et al., 2018; Hovland, 2018). Some participants caring for their loved one with advanced dementia expressed a detachment from the person as they no longer related to them as, for example, '*my mummy*' (Shanley et al., 2011; Dempsey et al., 2018).

Uncertainty for the future

Both current and former caregivers reported feelings of uncertainty at some point in their caring journey. One of the main struggles of caring included not knowing what to expect day to day due to the unpredictable nature of dementia. Some former caregivers described feelings of uncertainty as they struggled to navigate their free time post bereavement (Corey & McCurry, 2017; Wladkowski, 2016). Other former caregivers used their free time to reconnect with family and friends, and to invest their time into personal interests to cope with feelings of uncertainty (Peacock et al., 2018).

Theme 3: Feeling psychologically threatened

Participants spoke about experiencing a range of difficult emotions within their psychological distress. This distress was often influenced by feeling let down by professional services.

Difficult emotions

Most studies reported that participants expressed intense guilt for various reasons such as feeling like they should have been a better caregiver or for utilising respite services (Corey & McCurry, 2017). The loss of companionship, particularly for spousal caregivers led to feelings of extreme loneliness (Vlachogianna et al., 2016). Many former caregivers spoke about feelings of regret, for example, for putting their loved one into long-term care or for not discussing death plans with them. Feelings of regret were intensified when caregivers felt that their loved one was not being adequately cared for by professionals (Shanley et al., 2011; Corey & McCurry, 2017; Hovland-Scafe & Kramer, 2016; Dempsey et al., 2018). Feelings of inner conflict arose for most participants as they struggled with dilemmas such as not wanting their loved one to die but wishing for their suffering to end (Wladkowski, 2016; Hovland, 2018).

Negative experiences with services

Many of the studies described times where current and former caregivers felt let down by professionals and struggled to navigate professional systems. Some described having to '*battle*' with services and making complaints which led to feelings of stress (Ford et al., 2012). One study found that caregivers loved ones being discharged from hospice affected the caregiver's grief process by complicating their understanding of end of life care, leading to a sense of injustice for the caregiver and person with dementia (Wladkowski, 2016).

Theme 4: Care for the carer

Gratitude for support

Most studies reported that participants appreciated support at different stages of their caregiving journey. One paper found that veteran spouses valued support provided by veteran's affairs for their husbands including access to residential care and receiving financial support (Ford et al., 2012). Most current caregivers who had attended carer groups spoke about their appreciation for psychosocial support that recognised their caring role and enabled them to relate their experiences to other caregivers (Shanley et al., 2011).

Receiving support from others

Most participants talked about the importance of obtaining support from the people around them, for example, family, friends and neighbours. Having access to emotional support from others helped to protect against feelings of isolation (Vlachogianna et al., 2016; Peacock et al., 2018). One paper talked about a male former caregiver who lived in a rural location and received support from his neighbours which acted as a buffer to intense loneliness (Dempsey et al., 2018).

Theme 5: Accepting loss

Cherishing those moments

Some current caregivers talked about moments where they experienced glimmers of their loved one's personality reminding them of the person they were before the dementia diagnosis. These moments tended to elicit a positive emotion in caregivers, helping them to feel connected to their loved one. Others talked about how these moments gave them the resilience they needed to carry on (Hovland-Scafe & Kramer, 2016; Vlachogianna et al., 2016; Peacock; 2018).

Preparations for death

Some of the studies found that former caregivers who felt psychologically and practically prepared for their loved one's death found it easier to accept the death. Caregivers spoke about '*getting your house in order'* and the importance of having a plan for decisions such as funeral arrangements (Hovland-Scafe & Kramer, 2016; Hovland, 2018). Other caregivers talked about feeling unprepared for their loved one's death and thus experiencing the death as a shock (Shanley et al., 2011; Dempsey et al., 2018).

Sense of relief

Some former caregivers reported that during their caregiving journey, they experienced a sense of relief for different processes including the end of suffering for their loved one, a terminal diagnosis, the end of anticipatory grief or of their caregiving duties. These processes allowed participants to have closure (Hovland, 2018; Peacock et al., 2018).

The right time to go

Some of the studies found that former caregivers got to a point in their journey where they felt it was '*time to let go'*. For some caregivers this involved acknowledging that it was '*the right time'* for their loved one to die in order to liberate them from suffering. For other caregivers, this involved granting their loved one '*the permission'* to die, as this felt like the moral thing to do (Hovland-Scafe & Kramer, 2016; Hovland, 2018; Peacock et al., 2018).

Theme 6: Rebuilding life

Extending care

Many of the studies found that some caregivers had a wish to extend their caregiving beyond their loved one, for example, former dementia caregivers talked about caring for their children and grandchildren whenever they could, some talked about caring for another ill family member and others spoke about helping other families through inputting into dementia services (Vlachogianna et al., 2016; Corey & McCurry, 2017; Peacock et al., 2018). One study found that current caregivers of veterans in residential facilities played an active role in their husband's care and voiced a strong need to support other residents and families (Ford et al., 2012).

Maintaining a connection

Most of the studies which included former caregivers found that participants valued continuing a connection with their loved one post bereavement. Participants preserved this connection through various ways such as talking to their loved one, keeping some of their belongings, visiting and looking after their grave and reminiscing on positive memories (Vlachogianna et al., 2016; Peacock et al., 2018).

Discussion

Six analytical themes were constructed and synthesised drawing from nine primary research studies (180 participants) regarding participant's lived experiences of grief. Participant's reported on different aspects of the grief process in the following themes: 1) Differing aspects of loss, 2) Changing nature of grief, 3) Feeling psychologically threatened, 4) Care for the carer, 5) Accepting loss, and 6) Rebuilding life.

In relation to psychological theory, Bowlby (1980) claimed that individuals are primed to develop attachments in early life in order for security and survival. When attachments are disrupted or lost, individuals can experience psychological distress including anxiety, sadness and anger. The current review's themes (differing aspects of loss and the changing nature of grief) support the idea that disruption or loss of an attachment can lead to psychological distress; further providing support for the theme of feeling psychologically threatened. Additionally, Silverman and Klass (1996) understand the grief process in relation to continuing bonds with the deceased. The person is remembered and not forgotten, and family members continue to have a connection with their loved one through memories. The current review's themes of accepting the loss and rebuilding life could provide support for the continuing bonds model.

When comparing the current review to the previous review on grief reactions in dementia caregivers (Chan et al., 2013), the synthesis built upon existing literature whilst offering new insights into the nature of grief during and after caregiving. Similarly, to Chan et al. (2013), the current review developed themes that contained anticipatory grief, loss of companionship and feelings of guilt and regret, providing support for the previous review. The previous review highlighted that spousal dementia caregivers focused on maintaining their relationship with their loved one whilst caring, which links to the current review’s theme of cherishing those moments. However, the current review extends this theme further by highlighting the need for some dementia caregivers to continue to maintain this connection post bereavement, for example, by caring for their loved one’s grave, reminiscing on positive memories or keeping some of their belongings. It is possible that the current review incorporated more research exploring the post-bereavement period.

Dementia caregiver’s detailed accounts indicate high levels of unmet physical and psychological needs and emphasise the argument for improving dementia services for caregivers, a target of the National Dementia Strategy (Department of Health, 2009). Family members find themselves in a threatening situation where they lack knowledge, choice and experience. Consequently, they are simultaneously caring and grieving (Hennings, Froggatt & Keady, 2010). When their loved one is approaching the end of life within care homes, caregivers are often disappointed with the standard of care, leading to feelings of inner conflict, regret and guilt, complicating the grief experience. Some participants reported battling with professionals, for example, in nursing homes or hospice care to strive to get appropriate care for their loved one or to make complaints (Shanley et al., 2011). This finding also supports the results of the previous systematic review which reported that caregivers who were less satisfied with formal care expressed greater grief (Chan et al., 2013). This indicates that practitioners working with dementia should work closely with nursing staff to support their understanding of dementia, the death experience and associated emotional needs of caregivers and people with dementia.

Building on this finding, one paper highlighted how live discharges from hospice care affected the grief process in caregivers by disrupting their understanding of end of life care and reinforcing feelings of guilt (Wladkowski, 2016). Guilt has been described as the most distressing emotion for caregivers (Oliver & Bock, 1985). The current synthesis supports the previous review which highlighted guilt and failure as key feelings that caregivers experience in relation to decisions about care home placements (Chan et al., 2013). This indicates that professionals should recognise and respond with psychological interventions to emotionally support caregiver's feelings of guilt.

Most of the studies reflected a loss in companionship and in parental cases, role reversals in relation to the parent-child dynamic. The changes to cognitive functioning including personality shifts and a reduction in communication skills led to the experience of anticipatory grief (Rando, 2000). Dempsey and Baago (1998) reported that anticipatory grief may allow caregivers and care receivers time to adjust to loss by having time to discuss dying, prepare for the death, and potentially resolve any difficulties within the caregiver-care receiver relationship. Such discussions and shared decisions can be difficult to achieve given the cognitive implications of dementia.

Whilst the previous review reported feelings of regret regarding care home placements, the current synthesis extends this finding to include feelings of regret for missing opportunities to discuss death with loved ones, whilst having the chance to and therefore experiencing post death shock. In other studies, participants reported having time to prepare for the death physically and psychologically, although discussions were more likely held with family members and/or professionals instead of with their loved one (Hovland-Scafe & Kramer, 2016). This indicates that professionals could support families in understanding the person with dementia as well as caregiver's beliefs and wishes about terminal care and ensuring wishes are respected during decision-making. Additionally, these findings have wider implications for society in regarding death as an important matter that should be openly talked about within the general population. Talking about dying can relieve anxiety for participants in the conversation and help final wishes to be honoured (Generous & Keeley, 2014).

During and after caregiving, intense loneliness was commonly reported by caregivers who experienced a loss of companionship, disconnection to the person with dementia, loss of their caring role, the transition into long-term care, the physical death of their loved one and giving up occupations or activities linked to social support. Isolation has been strongly associated with caregiver depression following the death of their loved one (George, Blazer, Hughes & Fowler, 1989). This indicates the significance of supporting social inclusion for the caregiver during and after caregiving to shield against depression. Most of the studies highlighted the use of social support throughout the caregiving journey through family, friends, neighbours and professionals, providing support for the previous review which highlighted the value of family and friends support for dementia caregivers (Chan et al., 2013). Social support aided shared discussions about death, difficult decisions regarding long-term care and facilitated respite for caregivers and social connection (Dempsey et al., 2018).

Former caregivers expressed granting the permission for their loved one to die as this was the right time to go. This supports literature that suggests acceptance as a key part of the grief process, allowing a sense of relief to be felt (Small, Froggatt & Downs, 2007). The synthesis offers new understandings on how participants adapted to and survived with grief through rebuilding their lives by reclaiming their identity as a caregiver through extending their care to others such as another ill family member, children, and grandchildren or by inputting into dementia services. Post bereavement, other participants used their free time to focus on their own needs by taking up previously given up activities and re-establishing social connections (Peacock, 2018).

Implications for practice

Current and former dementia caregiver’s narratives emphasised the unique experience of grief for each of them and reinforced the value of hearing these accounts as part of the intervention process. The review revealed key emotions that caregivers experienced during their caregiving journeys including guilt, regret, loneliness and feelings of conflict. To protect against pathologising grief, services ought to fully assess and understand each caregiver’s unique reaction to the emotional challenges of caregiving to contextualise distress. Practitioners with psychological training could offer support on grief first aid to frontline staff, to create more awareness of the complexity and varied reactions in dementia caregivers.

For caregivers who have a loved one in a care facility, it is important for positive interpersonal relationships to be facilitated between healthcare staff and informal caregivers. This could be achieved by healthcare staff being attuned to, asking about and aiming to meet the individual needs of families, for example, asking about cultural, religious and spiritual needs or providing specifically requested information from families. Additionally, positive interpersonal relationships could be attained by healthcare staff providing emotional support to family members using active listening skills, understanding, empathy, validation and time, therefore building up trust within the relationship. Possible ruptures in relationships should be attended to and dealt with therapeutically.

Services such as long-term care and hospice facilities ought to consider supporting frontline staff providing terminal care to people with dementia. This could be facilitated through Clinical Psychologists delivering training on end of life care, and offering clinical supervision to nursing staff to provide ongoing support in implementing psychological interventions. Additionally, Clinical Psychologists could offer reflective practice to frontline staff, to provide a safe space to emotionally digest possible distress derived from working with dementia and end of life care.

The review highlighted that often the person with dementia and sometimes caregivers were not included in decisions regarding terminal care. Services should support practitioners to sensitively initiate conversations about dying with the person with dementia early on, whilst recognising, respecting and involving caregivers in these conversations and decisions. It is important for practitioners to identify possible barriers to discussing death, for example, asking about fear of death or religious beliefs (Generous & Keeley, 2014). This may protect against feelings of regret and guilt following the death of a loved one. Additionally, caring facilities could consider implementing protocols which require staff to record that they have consulted caregivers about terminal care.

It was evident from the synthesis that caregivers had access to practical support in relation to the dying process for their loved one, for example, being advised on decisions regarding long-term care or hospice services. However, this practical focus often overlooked the impact of grief upon caregiver's psychological well-being. Practitioners with psychological training could offer caregivers space to emotionally process the multiple losses during caregiving. This may assist caregivers in adjusting to the physical death of their loved one, and therefore protect against complicated grief (Ponder & Pomeroy, 1996).

Furthermore, participants described appreciating instrumental and emotional support from others to shield against feelings of loneliness during and after caring. This suggests that dementia services should offer an assessment of caregiver's social needs and resources early on, to consider ways to help meet unmet social needs such as loneliness and a sense of belonging. The review pointed out the value of social connection, and that this may protect against later depression after caring. When caregiving roles diminish or come to an end, caregivers need to be acknowledged into bereavement and post bereavement support should be offered. For example, former caregivers could be invited to psychosocial interventions such as community groups ran by dementia services or charities, to share their experiences or to offer support to current caregivers (to extend their care).

Strengths and limitations

All studies were published within the last 10 years, showing the significance of qualitative research within this area. As well as supporting themes from the previous review on this topic, the current review provides an important update as it emphasises the feelings of regret some caregivers face regarding decisions about death. Additionally, it emphasises the importance of maintaining a connection with the person with dementia beyond bereavement and the value of extending caregiving roles in different and creative ways post bereavement. Furthermore, this update reinforces the unique emotional reactions included within caregiver's experiences of grief and therefore the need to comprehensively understand individual responses (guilt, regret, loneliness and conflict) in order to effectively support caregiver's psychological needs.

Different methodological factors evident in the review and from the included studies may have limited the findings. The review was limited to studies that were published in English which may have excluded key results from other languages, restricting the diversity of findings. Although the current review included studies from different geographical locations with different caregiver populations, due to insufficient data these factors were not reflected upon within the analysis. The current review is biased towards published work and the decision to exclude unpublished studies may have led to relevant articles being overlooked. However, due to the absence of the peer-reviewing process in unpublished work, this decision was made by considering the quality ratings of included studies. The review contained a limited amount of eligible studies, thus conclusions drawn from the synthesis need to be considered within this context. However, the themes revealed in the review were relatively consistent across all studies, allowing for applicability of the findings.

Future research

The above research was conducted in Western, individualistic cultures; therefore, future research should consider the concept of grief in other cultures. Research has highlighted differences in African Americans who were less likely to grieve before the physical death, accept death or experience death as a relief when compared to white caregivers (Owen, Goode & Haley, 2001). Seeking diversity in relation to ethnicity and religion would deepen our understanding of how other cultures experience the grief process and potentially enhance person-centred interventions. Most of the research in this field places great emphasis on the challenges and complexities of the grief experience. Future research ought to further explore understandings of the more positive processes that enable caregivers to survive the difficult parts of grief and to live well with dementia. This could also consider exploring post-traumatic growth (Tedeshi & Calhoun, 2004) in former caregivers when reflecting upon their grief experiences.

Conclusions

Grief is a common process present within the dementia caregiving journey and has significant implications for caregiver’s psychological well-being. Fully understanding the complexity and variation in emotional reactions, acknowledging and making space for caregivers to emotionally process grief during caregiving, encouraging a collaborative and shared approach to decisions regarding death, supporting nursing staff to understand the needs of people with dementia and caregivers, developing positive relationships between staff, caregivers and the person with dementia and encouraging social connection may protect against the psychological impact of perceived, anticipatory, actual and complicated loss.

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Self-compassion in informal caregivers for people living with dementia: A grounded theory study.

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Abstract

Purpose: There is debate over theoretical definitions of compassion and how compassion is measured. Gilbert (2005) defines compassion as a motivation utilising courage and wisdom in response to suffering to the self and others. Neff (2003b) defines self-compassion as encompassing self-kindness, common humanity and mindfulness. Emerging evidence suggests that higher levels of self-compassion can lead to a reduction in psychological distress for dementia caregivers (Lloyd, Muers, Patterson & Marczak, 2018). The purpose of this study was to explore dementia caregiver's experiences and how these related to their understanding of self-compassion.

Design / methodology: Ten semi-structured interviews with current and former caregivers were completed. Given the variety in conceptualisation and measurement of self-compassion, a social constructionist grounded theory approach was chosen to develop a theoretical model, with the aim of capturing the breadth of experiences and understanding related to self-compassion in dementia caregivers.

Findings: Participants described four key processes which facilitated and inhibited their capacity for self-compassion: uncertainty of dementia, difficult emotions, surrounding network and conceptualisation of self-compassion. Participant's responses to these processes influenced their capacity for self-compassion. A reduced capacity for self-compassion included self-criticism, emotional suppression and defending against emotional pain. An enhanced capacity for self-compassion included self-care, emotional expression and varied ways of coping, allowing the consideration of both caregiver's needs and those of the person diagnosed with dementia.

Clinical implications: Findings indicate a need for professionals to understand the unique nature of the uncertainty of dementia for caregivers, to support the acknowledgement of difficult emotions and recognition of caregiver's own needs. With the aim of developing self-compassion, assessment of motivations for engaging with distress and active coping strategies are considered important. Services should develop secure relationships, explicitly modelling compassion to caregivers. Caregivers who report difficult family dynamics should specifically be targeted and the nature of these relationships assessed. Supporting the understanding of the meaning of self-compassion through psychoeducation and extending psychoeducation to systems surrounding caregivers are considered vital to build compassionate networks.

Keywords

Self-compassion, dementia, informal caregivers, qualitative, grounded theory

Introduction

Payne et al. (2010) defined family members who care for a relative at home or within the community without pay as informal caregivers. Dementia caregivers have the responsibility of attending to a variety of needs for the person with dementia, for example, administrative, practical, emotional, and physical needs, alongside responding to changes to caregiving needs as dementia changes (Razani et al., 2014).

Dementia is a neurological progressive condition which can lead to changes in cognitive functioning, for example, memory loss, language abilities, visual perception skills, and behaviour and mood (Alzheimer’s Association, 2016). Schulz and Martire (2004) highlighted that most people diagnosed with dementia live in the community and are cared for by family members. There are estimated to be over 670,000 people in the United Kingdom acting as primary, unpaid caregivers for people with dementia, saving approximately £11 billion for services each year and supporting the economy (Alzheimer’s Society, 2014). Additionally, the Care Act (Department of Health, 2014) requires local authorities to assess caregiver’s support needs and to provide support if needs are considered eligible (Alzheimer’s Society, 2014).

Baumgarten et al. (1992) compared the needs of family members caring for a person with dementia to family members caring for an older adult not diagnosed with dementia. They found that dementia caregivers had significantly higher levels of depression and physical health difficulties, particularly because of the behavioural difficulties that can present and challenge caregivers in dementia. Caregiver stress has been found to predict poorer psychological health in dementia caregivers (Razani et al., 2014) and poorer outcomes for people with dementia (Afram et al., 2014). Emotion-focused coping strategies including self-compassion have been associated with lower levels of stress in dementia caregivers (Lloyd et al., 2018).

Research into dementia has highlighted primary stressors derived from the demands of caregiving such as behaviours that challenge caregivers like aggression and changes to cognitive functioning and daily dependencies (Pearlin, Mullan, Semple & Skaff, 1990). These are thought to lead to secondary stressors including family conflicts, restrictions on social and occupational life, financial strain and damaged self-concepts for caregivers. Secondary stressors have been shown to be correlated with depression in caregivers (Pearlin, et al., 1990). Whilst this research highlights possible dementia caregiver's needs, it emphasises practical aspects of caregiving, possibly overlooking psychological elements such as loss, adjustment, attachment, and grief.

More recent compassion literature has focused on the psychological aspects of caregiving. Martin, Gilbert, McEwan and Irons (2006) found that depression in dementia caregivers was linked to experiences of shame related to feelings of entrapment, other people's expectations, fear of criticism from others and self-criticism. Given the intense demands of caregiving, informal caregivers may ignore their own well-being to avoid feelings of guilt and inadequacy in their role as a caregiver (Martin et al., 2006). McCabe, You and Tatangelo (2016) claimed that unmet needs in dementia caregivers can lead to burnout and therefore poorer outcomes for the care recipient such as depression, poor quality of life, early admission to care facilities and mortality.

Given the high demands upon dementia caregivers, there is an economic drive to support caregivers and promote their well-being (Alzheimer's Association, 2016). Brodaty, Thomson, Thompson and Fine (2005) found that dementia caregivers were less likely to access support from services when experiencing high levels of burden, a lack of informal support, denial of need and expectations of an invasion of privacy. La Fontaine, Read, Brooker, Evans & Jutlla (2016) found that barriers to accessing caregiver support included protecting the person with dementia from seeing others diagnosed with dementia, indicating higher levels of shame and difficulties tolerating distress in this population.

Whilst the above research has focused on the stress of dementia caregiving, general caregiving literature has highlighted that positive feelings such as love and satisfaction can be associated with caring for others (Schwartz, Meisenhelder, Yusheng & Reed, 2003). However, when caregiving feels obligatory, or the needs of the care recipient exceed the resources caregivers wish to invest, this can have a negative impact upon caregiver's health and well-being (Vitaliano, Zhang & Scanlan, 2003), and increase the likelihood of caregivers placing loved ones into a care home (Aneshensel, Pearlin & Schuler 1993).

Within the literature, there is ongoing debate regarding theoretical conceptualisations of the construct compassion and how it is measured. Gilbert (2005) defines compassion as a motivation including sensitivity to the suffering of the self and others, complemented with a commitment to attempt to alleviate or prevent distress. Gilbert et al. (2017) recently developed a scale that measures engagement with distress and alleviation (action) of distress, complimenting Compassion-Focused Therapy (CFT) devised for clinical populations. However, Neff (2003a; 2003b) defined and developed a scale from the general population that measures self-compassion as comprising of self-kindness (being warm towards oneself), common humanity (recognising that suffering is a shared human experience) and mindfulness (a non-judgemental mind state, observing one's thoughts and feelings). Studies have reported that self-compassion is closely associated with compassion to others (Neff & Pommier, 2013; Welp & Brown, 2014). However, Gilbert et al. (2017) considered multiple flows of compassion (self-other, other-self and self-self) as operating independently, suggesting that self-compassion is not necessarily required for showing compassion to others.

Enhanced self-compassion has been connected to improved psychological well-being (MacBeth & Gumey, 2012; Danucalov, Kozasa, Afonso, Galduroz & Leite, 2015). Neff (2018) reported that self-compassion can protect the emotional energy required to serve others and relating to the self with a reflective capacity can help cope with the demands of caregiving (Mcpherson, Hiskey & Alderson, 2016). More specifically, Lloyd et al. (2018) found that high levels of psychological distress in dementia caregivers was reduced in caregivers with higher levels of self-compassion, suggesting that interventions aimed at increasing self-compassion could be beneficial for caregivers. A recent study evaluating a CFT group for spousal couples experiencing a dementia diagnosis, found that couples reported clinically significant improvements in depression and anxiety post intervention. 80% of spouses reported clinical improvement, indicating the impact of CFT in alleviating anxiety and depression in those with high distress (Collins, Gilligan & Poz, 2018).

The construct of compassion is also embedded into NHS culture and is considered an essential part of the care sector (Wollenburg, 2004). NHS England (2016) define compassion as comprising of empathy, respect and dignity through relationships. Sinclair et al. (2016) found that service users, family members and policy makers regarded compassion as a core dimension of quality of care. Despite this aspiration to create compassionate services, Gilbert (2013) highlighted that the NHS employ threat-based measures in attempt to increase compassion in healthcare staff, thus reducing the capacity for compassion through increased threat. Facilitating a scientifically informed supportive and encouraging climate influenced by compassion could cultivate cultural change in the NHS (Gilbert, 2013).

The current study

As stated above, evidence is emerging in relation to self-compassion in informal dementia caregivers (Danucalov et al., 2015; Lloyd et al., 2018; Collins et al., 2018) and therefore warrants further study. Given the quantitative nature of existing empirical studies and the variation in conceptualisation and measurement of self-compassion, a qualitative approach utilising grounded theory was chosen to construct a theoretical model. It aimed to capture the breadth of experiences and understanding relating to self-compassion in dementia caregivers, to inform services to better support caregivers' psychological needs in line with the Care Act (Department of Health, 2014).

Method

Recruitment

All participants were recruited from one NHS Older Adults Service, a specialist service for dementia located in England. Service leads were contacted to discuss research aims, confirm service involvement and to distribute the study advert (Appendix 9) and information sheet (Appendix 10). Service leads provided contact details to the researcher for dementia caregivers who had agreed to be contacted. Caregivers were contacted by telephone and email to confirm their consent after reading the participant information sheet. Following an expression of interest, the researcher screened each participant for eligibility using the inclusion and exclusion criteria. All participants approached to participate were considered eligible for the study and no caregivers were excluded. All caregivers who were contacted by the researcher consented to take part and were invited to confirm a convenient interview date and location, and for future contact to allow opportunity for theoretical sampling and feedback.

Participants and Sampling

Ten dementia caregivers (six females and four males) caring for 2 to 10 years participated. Participant demographic information is presented in Table 1. All participant names are pseudonyms. Interviews took place between May-December 2019. Inclusion criteria consisted of caregivers who were currently caring or had previously cared for a loved one diagnosed with dementia, and caregivers caring within the community (at home or supporting a loved one in a care facility). Current and former caregivers were chosen by the researcher in order to seek a heterogeneous sample in line with grounded theory (Charmaz, 2014). Participants were excluded if their loved one had received a dementia diagnosis within the last six months, to allow time for adjustment to the diagnosis. Professional healthcare staff (formal, paid caregivers) were also excluded from the study.

Convenience sampling was utilised for the first five participants. Subsequent participants were sampled theoretically to further explore emerging relationships between participant's narratives, living circumstances and caring role. Figure 1 represents the operationalisation of the theoretical sampling process.

Table 1. Demographic information for participants

Participant	Age (years)	Gender	Ethnicity	Relationship to person with dementia	Time spent caring (years)	Status (current or former)	Living circumstances
Megan	66	Female	White British	Spouse	4	Current	Living with
Sally	58	Female	White British	Daughter	4	Current	Living with
Andrew	72	Male	White British	Spouse	3	Current	Living with
George	69	Male	White British	Spouse	7	Current	Living with
Jenny	76	Female	White British	Spouse	2	Current	Living with
Martha	67	Female	White British	Sister	5	Current	Living separately - community
Rob	84	Male	White	Spouse	10	Former	Lived

			British				separately - community
Callum	73	Male	White British	Spouse	7	Current	Living separately – nursing home
Debra	76	Female	White American	Spouse	6	Current	Living separately – nursing home
Susan	77	Female	White British	Spouse	2	Former	Lived together

Note. Further demographic information is available upon request.

The interviews

All participants were interviewed once using a semi-structured interview topic guide (Appendix 12). Participants were not provided with an existing definition of self-compassion in order to prevent leading the direction of data, not capturing personal interpretations of self-compassion and potentially skewing participant’s responses. However, it is recognised that the concept may not be universally recognised, possibly leading to difficulty in responding to questions about participant’s understanding of self-compassion.

This interview included the following topic areas: demographics (e.g. ‘What is your relationship to the person diagnosed with dementia?’), experiences and responses (e.g. ‘If you make a mistake, what do you say to yourself?’, ‘Do you notice when you have distressing feelings?’), the emotional impact (e.g. ‘What sense do you make of your emotional responses to caregiving?’), thoughts about feelings (e.g. ‘Do you notice any thoughts about difficult feelings?’), managing difficult feelings (e.g. ‘When things are difficult, what do you do to help yourself?’), coping mechanisms (e.g. ‘Are there times where you share your experiences with other people?’) self-compassion (e.g. What is your understanding of self-compassion) and learning (e.g. ‘What have you learnt about yourself as a caregiver?’).

Interviews lasted between 49-86 minutes and were recorded using an electronic voice recorder. The researcher adopted a curious position to maintain a phenomenological stance to adapt to participant's responses and probe areas of interest (Smith, 1995). Following interview five, the topic guide evolved to explore relationships between emerging themes (Appendix 13).

Design

Grounded theory was chosen given the gap of qualitative understanding of self-compassion in dementia caregivers and in hope of providing a new perspective on participant's experiences of self-compassion (Schreiber, 2001). Acquiring this qualitative knowledge was considered helpful in addressing some of the challenges in meeting dementia caregiver's psychological needs, for example, services undervaluing the needs of caregivers and primarily focusing on the person with dementia (Carers UK, 2015). Grounded theory allows new knowledge to be constructed from real interactions with participants about their experiences and by interpreting how participant's make sense of their perceptions and actions (Charmaz, 2014).

Charmaz (2014) introduced a constructivist position to original grounded theory positivist approaches (Glaser, 1978; Straus & Corbin, 1990), where multiple perspectives of phenomena may exist in a complex social world. In contrast to earlier versions of grounded theory, Charmaz viewed research as a collective process involving participants and researchers, for example, researcher's personal and professional experiences and knowledge of existing literature as aiding understanding. Given that the researcher and supervisors had considerable knowledge and experience of dementia and compassion-focused work, it was deemed appropriate to choose Charmaz's version of grounded theory, to accommodate for the inevitable interaction between this prior experience and knowledge and the research data.

Charmaz (2014) also highlighted the importance of researchers being aware of the changing context of data as opposed to one reality of the phenomena of interest. Given the researcher's knowledge of the changing context of dementia, it was thought that this may feature within the data and therefore considered important to meet study aims. Furthermore, this methodological approach was chosen in order to give voice to a population that has possibly had less of a voice, whilst allowing the recruitment of a heterogeneous sample and the exploration of similarities and differences between participants.

Data Analysis

Iteratively, each transcript was analysed using line-by-line, focused and theoretical coding (Charmaz, 2014). During the coding process, a constant comparison approach was applied, complimented by memo writing, research diary writing and supervision to support analytical thinking. The researcher transcribed the first two interviews to become fully immersed in the data. Subsequent interviews were transcribed by an external, university approved transcriber. Interviews were transcribed and coded prior to upcoming interviews. Following each interview, a reflective summary was completed containing participant narratives, their experience of self-compassion, possible hypotheses, ideas and questions about the emerging theory, reflections on the interview process and a visual diagram of their story (Appendix 16).

Data storage and analysis was facilitated using QSR's NVivo 12 (Appendix 17). Each transcript was fully read and then re-read during line-by-line coding. Codes were considered in relation to their potential for abstraction to develop into focused or theoretical codes. Subsequent interviews were coded using existing codes and new codes were also constructed. After interview five, line-by-line codes were collapsed and synthesised into focused codes, for example, self-care, uncertainty of dementia, emotional suppression.

Findings derived from codes were used to adapt the interview topic guide to identify directions for theoretical sampling, for example, participants living separately from the person with dementia and bereaved participants. Figure 1 displays the theoretical sampling process. Five subsequent interviews were completed and transcribed. Wherever data did not fit existing codes, focused codes were modified. Following interview eight, the researcher actively sought differing accounts, however, no new codes were constructed and therefore it was decided that data was approaching theoretical saturation. The final two interviews were used to refine analytical thinking. The constant comparison approach allowed theoretical codes to be distinguished, supported using detailed memos and matrices of focused codes (Appendix 18). Utilising a top-down approach highlighted prominent focused codes, leading to a clear understanding of all data (Appendix 19). No further interviews were completed following the tenth interview due to reaching theoretical saturation.

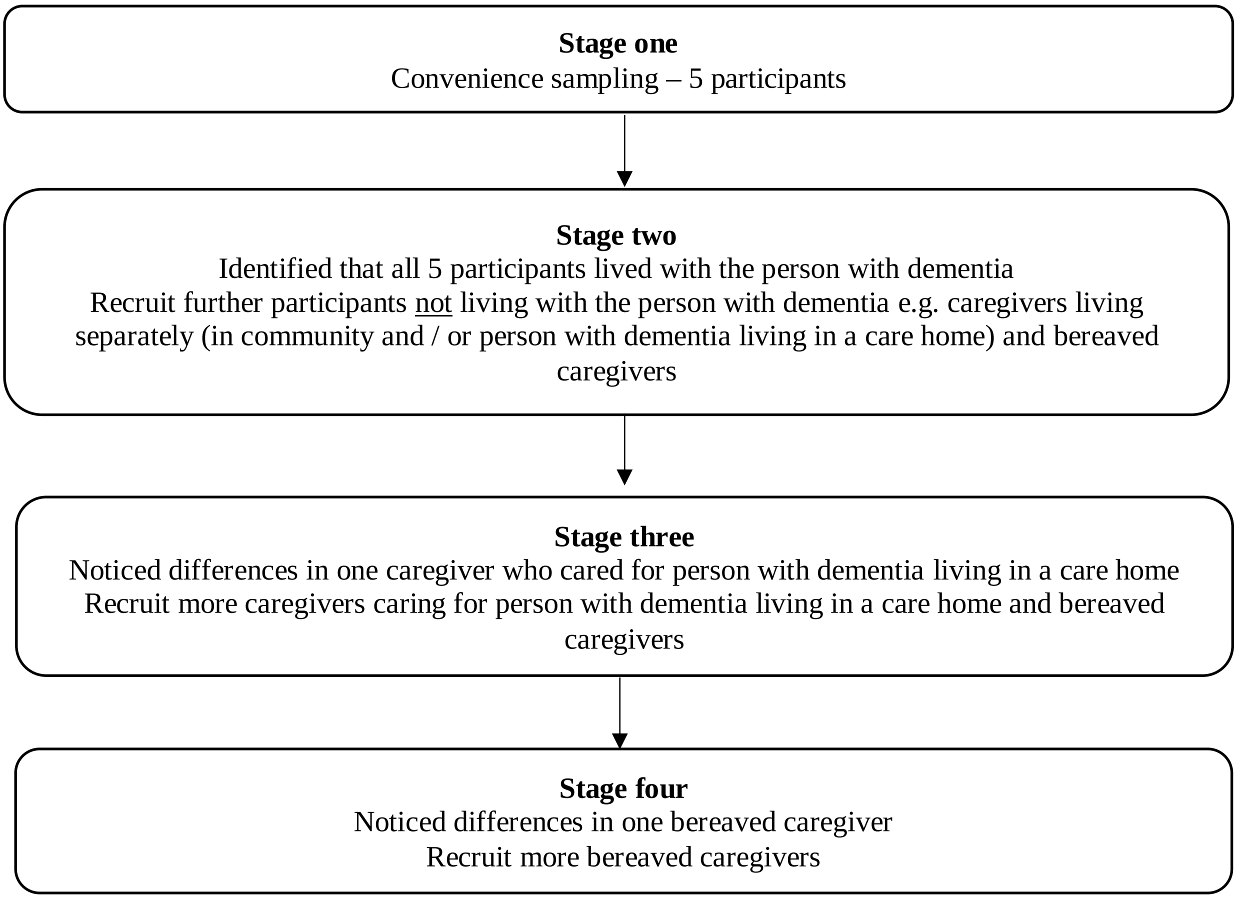

Figure 1. Process for theoretical sampling

Reflexivity

Walsh and Downe (2006) highlight the importance of reflexivity in qualitative research. As researchers actively engage in data interpretation (Charmaz, 2014), it was crucial to consider reflexivity to manage the researcher's influences upon emerging data and to ensure the theory was grounded in participant's accounts. This was conducted by writing a reflexive statement prior to data collection about the researcher's background, experience, thoughts and expectations of upcoming data (Appendix 14) and by keeping a research diary (Appendix 15) throughout the study. The researcher's clinical experience of working in dementia services, and training in CFT will have influenced the research process throughout, as did the clinical training and special interests of the supervisors. This will be reflected upon further in the discussion section.

Quality Assurance

Elliot, Fischer and Rennie (1999) highlighted key guidelines to ensure quality in qualitative research. These guidelines and how they were met are presented in Table 2.

Table 2. Quality guidelines for qualitative research

Guidelines	How guidelines were met
1. **Owning one's perspective:** Researchers specify their personal, theoretical and methodological orientations.	• The researcher was a 27-year-old, mixed White British and Afro-Caribbean, female Trainee Clinical psychologist with clinical experience working with individuals diagnosed with dementia and their caregivers. • Supervisors had clinical experience and knowledge of dementia and applying CFT. • Prior to recruitment a three-day CFT training programme designed from Gilberts' (2005) definition of compassion was completed. • The researcher took a social constructionist position (Charmaz, 2014).

2. **Situating the sample:** Researchers describe participants' and their life circumstances.	- Demographic information and living circumstances for each participant is provided in table 1. - Detailed narrative and visual summaries for each participant including reflections on the interview process were completed (Appendix 16).
3. **Grounding in examples:** Researchers provide multiple examples of themes.	- Line-by-line coding was used to stay close to the data. - Direct participant quotes were embedded throughout the results section. - In vivo participant quotes were included within the coding process and final theoretical model.
4. Providing credibility checks: Researchers check the credibility of data by checking understanding with original informants and / or using multiple qualitative analysts.	- Interviewing skills were refined through research supervision. - Validation checks were provided by reviewing transcripts in research supervision. - The researcher wrote a research diary to record interactions with the data and influences on decisions made throughout the study (Appendix 15). - Research supervision allowed for a second researcher to code some of the data. - The researcher and primary supervisor invited participants to feedback on the theoretical model to check understanding and support the development, validation and conceptualisation of the theory (Appendix 20).
5. Coherence: The understanding fits together to form a data-based narrative, map, framework or underlying structure of the phenomenon.	- Coding categories are provided (Appendix 19). - An integrative narrative and visual summary of research data is presented within the results section, displaying relationships between categories.

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Expert by Experience Consultation

Liverpool Expert by Experience group members were consulted early on when planning the research. One current and one former caregiver took part in a pilot interview.

The procedures, study documents and interview topic guide were adapted following their feedback, for example, caregivers advised on ways to enhance recruitment methods and language within study documents and interview questions were re-worded to support accessibility and understanding. Following the completion of interviews, all participants were invited to provide feedback on the theoretical model to support the development, validation and conceptualisation of the theory. Therefore, the final model not only reflected synthesis from the research team but also expert by experience input at the synthesis and data interpretation level.

During the participant feedback session, caregivers reflected that they recognised parts of themselves in both sides of the model and that their responses to the influencing processes (uncertainty of dementia, difficult emotions, surrounding network and conceptualisation of self-compassion) could change daily. Additionally, caregivers and the researchers discussed how both sides of the model were neither right nor wrong places to be, but more adaptive survival responses, and that the reduced capacity for self-compassion side was an understandable overwhelmed position. A narrative summary provided to participants is presented in (Appendix 20).

Ethics

The University of Liverpool Health and Life Sciences Research Ethics Committee, NHS Ethics, The Health Research Authority and Research and Development department at the NHS recruitment site approved the study (Appendix 8). Sponsorship was also granted by The University of Liverpool.

Prior to the interviews, participants were emailed a participant information sheet. Interviews were conducted by the researcher at participant's home address or at the NHS trust site. Before signing the consent form (Appendix 11), participants were offered another opportunity to read the information sheet and to ask any questions. Interview and participant confidentiality and the right to withdraw participation and data were discussed with participants.

Results

Figure 2 portrays an explanatory model of the research findings, describing the processes involved for an enhanced and reduced capacity for self-compassion within the context of caring for a person with dementia. Each category is based upon focused codes most salient to the model and is supported by participant quotes. The model is visually conveyed through two overlapping circles. At the top of the model sits the first category: transitioning into dementia world. This included the loss process, becoming the leader, becoming the visitor, re-evaluation of life goals and values and positive experiences.

The overlap of circles contains the influencing processes involved in shaping one's capacity for self-compassion. Transitioning into dementia world had a direct relationship to the uncertainty of dementia. Tolerating the uncertainty led to varied ways of coping such as mindfulness and externalising. Struggling to tolerate the uncertainty led to participants behaving in ways driven by a need to defend against overwhelming emotional pain, for example, keeping busy and striving. The uncertainty of dementia had a bi-directional relationship to difficult emotions. Acknowledging difficult emotions such as frustration, guilt or anxiety led to emotional expression, where participants would share their internal feelings and therefore have opportunities to be understood and supported by others. Overlooking difficult emotions led to emotional suppression, where participants were left feeling threatened and alone.

Participants surrounding network including family, friends and professionals had a direct influence on their relationship towards themselves. When caregivers perceived their surrounding networks as supportive, they tended to relate to themselves with self-care. However, if the people around caregivers were perceived as rejecting, this made it more likely that caregivers would relate to themselves with self-criticism. Participant's surrounding network had a bi-directional relationship to their conceptualisation of self-compassion. Those with supportive networks perceived self-compassion as something that they deserved for themselves and therefore had an enhanced capacity for self-compassion. On the other hand, those with rejecting networks perceived self-compassion as a sacrifice of one's own emotional needs. Two caregivers expressed that compassion was not connected to the self but was other directed.

In summary, an enhanced capacity for self-compassion was associated with self-care, emotional expression and varied ways of coping. This had a bi-directional relationship to caring is sharing (both the caregiver's and person with dementia's needs being attended to). A reduced capacity for self-compassion contained self-criticism, emotional suppression and defending against emotional pain.

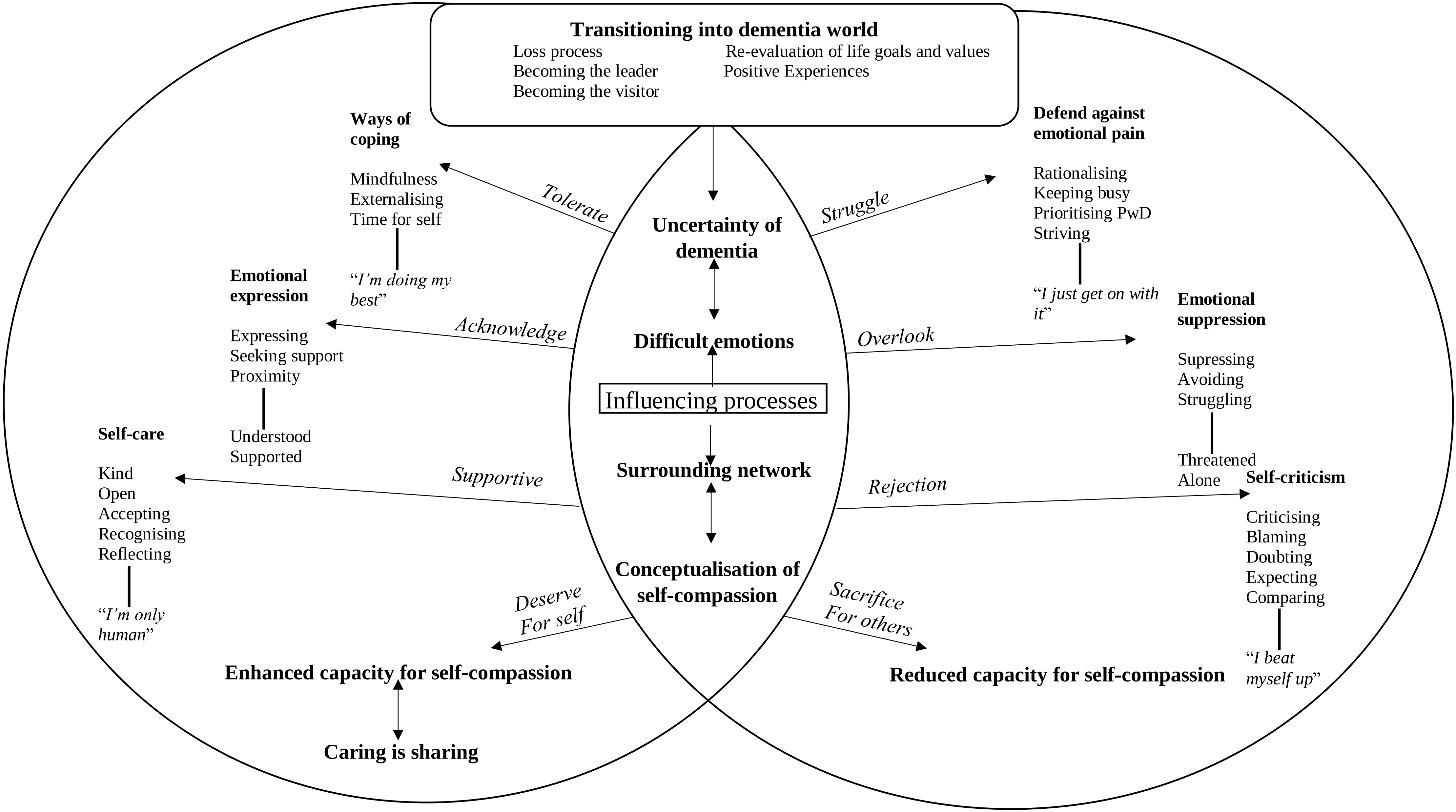

Figure 2. Grounded theory model based on dementia caregiver's experiences of self-compassion

Transitioning into dementia world

Part of compassion involves recognising the nature and causes of suffering in the self, others and human condition (Gilbert, 2005). Gilbert (2005) suggested that it is natural for humans to turn away from suffering including aging and dying. A diagnosis of dementia forces individuals to confront this reality, making denial and awareness harder to avoid but also providing the opportunity for self-compassion in relation to potential suffering.

All participants described transitioning into the world of dementia following the diagnosis of their loved one. There were five themes within participant's descriptions of their transition. All participants spoke about the loss process where they experienced loss, grief and a sense of injustice from the implications of the dementia which included a decline in their loved one's cognitive and daily living abilities. For example, Megan said '*it's like a sense of loss isn't it that you can feel when, if somebody's gone missing'.* Similarly, Andrew expressed *'I love my wife, I wish it wasn't the way it is because I have lost someone who I've been with all my life'*, and Martha described her sister in the past tense, *'she was my sister you know she looked after me a lot in childhood. I feel as if I've lost my sister she's just like, she's just a body now isn't she, she's you know her personality seems to have changed*". Furthermore, Susan described a sense of injustice, *'you think why has this happened to us? It's not fair and erm you know he doesn't deserve to be like this and then sometimes you say, and I don't deserve to have to be in this position either'.*

All participants spoke about becoming the 'leader', describing their caring role as taking the lead with daily tasks and making decisions. For example, George said '*I'm slowly learning to be able to take a more leading role in err our project to carry on doing what we can. That's probably been the biggest difference for me is having to lead from the front'.* When considering their leading role, many caregivers drew parallels to the parent-child dynamic. *'I mean I've never had children, but I know if I lost a child how I'd you know I think I know how parents feel because that's how I feel with him'* (Megan), and Debra voiced *'he's my kid, he's my little boy'.* Four participants extended their descriptions of their transition to include caring from a distance and long-term care facilities, and therefore becoming the 'visitor'. '*I go in and see her, I was at the home yesterday, I visit every couple of days'* (Callum). Essentially, participant's transition was strongly impacted by the loss of abilities in the person with dementia and therefore the amount of support they required.

Most participants spoke about the need to re-evaluate their lives. This included the dementia diagnosis representing a change in caregiver's life trajectories and a need to prepare for the future. For example, Andrew said, *'it's changed both of our lives, we never thought our life would be finished like this'* and Megan said, '*I need to explore my priorities because it's taken over my life'.* Callum talked about making health and financial decisions, '*I decided to get power of attorney for her and we both did new wills too'*. Only four participants described positive experiences within their caring role, for example, George talked about reconnecting with his family following the dementia diagnosis '*in some ways its' brought us all together*' and appreciating new opportunities including travelling and visiting new places.

Influencing processes

Uncertainty of dementia

Following participant's transition into dementia world, they described processes that influenced their own capacity for self-compassion. All participants spoke about the uncertainty of dementia including bereaved caregivers when recalling their experiences. For example, Rob talked about the unpredictable nature of dementia '*there were times she was really aggressive towards me and then 5 minutes later she was hugging me and squeezing the breath out of me'*. Similarly, Sally said, '*her moods are like you can have times when she's* *not joining in at all and she looks quite angry you know or she's sitting there looking confused*'. Sally also talked about having no control over the progression '*I can't stop it progressing. Activities can help her have a good day but it's not helping her to, it's not helping her Alzheimer's you know. We can't kind of bring it back can we?*'. Some participants made comparisons to death when reflecting upon the unpredictability of the future, '*in some ways it's like a little bereavement isn't it because you don't know what the outcome is going to be*' (Megan).

Five participants described tolerating this uncertainty by drawing upon **different ways of coping**. Martha talked about using knowledge to understand the condition, '*I have a background in social care, so erm I already know quite a bit about dementia and understand that it gets worse over time*'. Debra drew upon mindful activity, '*I like watching old movies, I'll do that, I read a lot, so I'll just get stuck into that*'. Similarly, George said '*I go and put some music on because erm that's my thing that's my little saviour, but it is something that is a mood enhancer. I love to draw sometimes I can get lost in that. I look up and I think God it's 3 o'clock in the morning, the hours can roll away and I don't realise*'. Andrew spoke about the importance of having time for himself, '*my brother and his wife will come down to give me some time away from her, which is nice because that relieves some of the pressure*' and externalising the dementia '*it's not their fault it's the dementia*'. Having varied ways of coping fostered a compassionate mindset in participants of '*I'm doing my best*'.

Three participants described struggling to tolerate the uncertainty of dementia and responding to this by keeping busy and functioning with a *'get on with it'* mindset. For example, '*well I keep busy and try to keep going, I've got lots to do here. I try not to analyse my emotions; I just get on with life*" (Robert). Similarly, Jenny said, '*I'm a practical person, I just get on with it, I'm a coper by nature*' and George said '*no point in me being negative about it, I've got to be positive, it's just it's happened, get on with it*'. This doing nature represented a protective function for caregivers allowing them to **defend against overwhelming emotional pain**, for example, '*It's a downward spiral the more you think about all the things that you miss and you can just go down and down, so you have to just pull yourself together*' (Susan). This had the unintended consequence of reducing caregiver's capacity for self-compassion.

Difficult emotions

The uncertain nature of dementia led participants to experience a range of strong, difficult emotions derived from their caring role, impacting upon their emotional well-being. These included feelings of anxiety and worry, for example, '*It's the constant worry, I'm on edge all the time trying to keep her mood good because that seems to work and sometimes it doesn't work you know*' (Martha) and '*I don't know if he's going to have a good day or a bad day, I get a physical it's kind of a knot in my stomach, like an anxiety attack*' (Debra). Many participants spoke about feelings of frustration, '*he went through a phase where his only conversation was something from 70 years ago, I found that infuriating*' (Jenny) and '*I do get frustrated inwardly*' (Andrew). Most participants expressed feelings of guilt, for example, '*the day I put him in that nursing home was the absolute worst feeling in the world, I felt like I'd abandoned him. It was guilt, I felt like I'd done something that I shouldn't had*' (Debra). Three participants also talked about caregiver stress, '*there's no sense of oh she's my sister, it's down to duty now, it's a bit of a burden'* (Martha).

Five participants described a process of acknowledging their difficult emotions by seeking emotional support from the people around them and **expressing their internal feelings**. For example, Andrew spoke about finding expressing his emotions helpful, '*you are discussing the situation, you are letting your feelings come out, I've sort of you know I've cried a lot these last few years. It is hard but I think emotionally it does you good. I express* *my feelings more than I have ever done, if I kept it all to myself, I think I'd go off my head*'. Many participants reflected on the importance of living in proximity to family, friends and healthcare professionals, as this provided an emotional comfort for them, '*it's a very comforting feeling that she's (*friend*) nearby, I know I've got someone I can rely on*' and '*there's something very comforting about being close to the hospital, when I come here it's a feeling of safety*' (Debra). Additionally, Rob spoke about the usefulness of '*letting it all out*' to a counsellor.

Five participants described a process of overlooking difficult emotions by trying to **supress their internal feelings**. This was driven by participant's perceiving their own emotional needs as unworthy of being listened to, a fear of burdening or being criticised by others, or not having anybody to talk to. For example, *'I'm very conscious of not, when I'm out with other people not spending too much time talking about what's going on with mum because I just don't want to be that friend who people go oh God you know'* (Sally) and '*I didn't have anybody to talk to, it was difficult and I don't want my family to criticise me'* (Jenny). Similarly, when asked about having people around to talk to, Callum said '*well not really no, there's nobody to talk to*'. Suppression of caregiver's emotional needs led to the unintended consequence of leaving caregiver's feeling alone, reducing their capacity for self-compassion. For example, when Susan reflected upon her caring role, she expressed '*when we had little episodes you tended to feel well you're on your own, you get that sort of feeling of isolation especially if something happens in the middle of the night, you don't want to be ringing family and friends'* and '*it's very difficult and it becomes very lonely'* (Callum).

Surrounding network

The provision of emotional support from different sources varied between participants. These included support from family, friends, other caregivers and professional services. George talked about receiving positive support from family, '*my daughter lives around the corner and I've got my son on the end of the phone, so I've never felt as if I'm like on my own or abandoned in anyway. There is always somebody I can get in touch with. I think all the difficult stuff you know, I have talked with my little Psychiatrist buddy, my son which is a tremendous help. He is my little bouncing board that I can talk to about my worries. He and I have gone on the same courses you know*'. Debra talked about the value of friendship when considering reducing the amount of time she spent visiting her husband at the care home, '*she said to me, show a little compassion to yourself, why stay there and upset yourself if it's not doing you or him any good. I haven't done it yet but it's certainly something I'm considering*'. Emotional support from the people surrounding caregivers provided a protective factor for caregivers to consider and attend to their own emotional needs, fostering an enhanced capacity for self-compassion.

Supportive voices from family members, friends and professionals were internalised by caregivers, leading caregivers to relate to themselves with **self-care** and a forgiving mindset of "*I am only human*". For example, when talking about support from her husband, Sally expressed '*I'm married to an amazing husband who is still there. He is with mum now, as well as being supportive, he just says you know, you're doing your best and don't be beating yourself up about erm things*'. This influenced Sally's self-talk, for example, '*I've learnt not to beat myself up, you know the situation were in it's not my fault*' and '*I think I've gotten better at being a bit kinder a bit more understanding a bit more err giving myself, not a pat on the back but just saying you're doing okay. My thoughts and feelings are just part and parcel of being human, it's as much about me being okay as it is about you being okay*'. Similarly, Andrew commented '*we are human, I'm human*'.

On the other hand, four participants described perceived rejecting or critical voices from the people surrounding them. For example, Martha described difficult family dynamics, '*my brother is not speaking to me at the moment because we've fallen out over a few things, but his wife was quite unpleasant she thinks I should be going to my sister's more and doing her personal care. You know I do feel guilty because I've got my sister-in-law calling me for you know not doing enough*'. Robert talked about experiencing power struggles with his wife's children, '*after I had a heart attack, they jumped in and took full charge of her. By the time I came out of hospital our marriage was broken, she was away living at her daughters, there was no way I could even try and look after her because I wasn't even allowed to see her*'.

Megan talked about how she felt professionals had forgotten her caregiver identity when she was volunteering for dementia services, '*I think people start to lose sight of the fact that you have a husband to support, volunteering should be recognised as an additional role'*. Furthermore, Jenny spoke about friends rejecting them following the dementia diagnosis of her husband, '*there has been one or two people that I have known for many years suddenly didn't bother contacting us, didn't ask us out. I had one person who was a very close friend and she actually wrote me a letter saying you know you've got problems, they're not my problems and erm you'll just have to get on with them by yourself and she actually said I no longer want to be your friend. The anger I felt from that was astronomical*'. Similarly, George commented '*we had quite a few friends that don't show up anymore*'.

Rejecting or critical voices internalised by caregivers made it more likely that caregivers would relate to themselves with **self-criticism** characterised by criticising and blaming themselves and comparing themselves to others. For example, Megan said '*I just feel devastated you know when something's gone wrong, I start thinking erm that shouldn't have happened, and I feel angry with myself*'' and '*I think I'm not as good as other people who are caring you know, other carers you know you think oh gosh I wish I could be more like them'*. Similarly, Debra talked about comparing herself to other caregivers, '*there are two other* *carers at the nursing home, two men funnily enough and they spend the entire day there and I think oh God why don't I do that'*. Self-criticism fostered a reduced capacity for self-compassion.

Conceptualisation of self-compassion

Supportive voices from others had an influence on caregiver's understanding of self-compassion as something caregivers deserved for themselves. For example, '*if people help you and say well I'll sit with them for the evening, you go and have a meal with your friends, you know that's what it's there for, if you don't look after yourself you can't look after another person and erm I think just try and take things easy, make some time for yourself and don't feel guilty about it*' (Susan). When reflecting on receiving compassion from staff at the hospital, Debra said '*it kind of teaches you that or shows you that you know compassion can be really, it can encompass a great part of your life*'. Also, when asked what self-compassion meant to her, Sally explained '*it's about being able to look after yourself and putting your own needs fairly high up'* and Susan said '*I think it's about being kind to yourself, having some time away so that you feel refreshed, giving yourself a little treat*' and '*some people may not have had anybody show compassion towards them but if you don't love yourself or take care of yourself it's a very sad do*'. A positive view of the concept fostered an enhanced capacity of self-compassion.

Negative voices from others influenced an understanding of self-compassion as sacrificing of one's own needs. For example, Megan said '*I've got to put my husband at the top of the list whatever I'm planning, if I plan as him as the primary focus things won't go wrong as often and so I've got less to feel guilty about*'. Also, George expressed '*this has become the ordinary, it's become you know like a reflex thing, everything we do has got to be about how it's going to impact my wife*'. When asked what was understood of the concept self-compassion, Callum described a detachment from the self, seeing self-compassion as other directed, '*I mean you've got to be compassionate to other people, I don't see how you can be compassionate to yourself, you can feel sorry for yourself erm and you'd probably be a bit miserable, moaning and complaining'*. Also, Debra expressed, '*funnily enough, it's not a word that I really associate with myself, err I have compassion for a few people, self-compassion I don't know what do I think about compassion, is it empathising with yourself? Is it treating yourself better*?'

Furthermore, Megan questioned the meaning of the concept, '*if you feel empathy for somebody that will affect how you deal with that person you know in a more positive way and so if I feel empathy for me, do I need to deal with myself more positively?*'. Similarly, Debra questioned what her own needs were, '*it's a difficult one because I don't know what my needs are necessarily*'. Martha described a view of self-compassion as, '*it's like feeling sorry for yourself*'.

Caring is sharing

An enhanced capacity for self-compassion influenced the likelihood of both the caregiver's and their loved one's needs being met. This category represented a shared life within the caring role which included shared decision making, shared mindfulness and doing activities together. Most participants reflected that if their loved one was okay, then they were okay. For example, when talking about her mother's mood, Sally expressed '*if I know she's okay, she feels good then it makes things easier and you feel better in yourself'*. Robert said, '*you can't care for somebody if you're not reasonably fit and able, so you have to keep that balance going, you have to compromise*'. Other participants reflected that if they were okay, then their loved one would be okay. For example, George reflected '*if I'm happy then she will be happy*' and Susan said, '*if I'm okay then he will be okay*'.

Three participants talked about self-compassion as a process for both themselves and the person with dementia. For example, '*I think it's a balance really like thinking of when I was doing my best to look after my wife, it was how can I look after myself well enough to be able to look after her in all respects, erm try and cater for the both of us as well as I could and not seeing it as being mainly for my benefit or mainly for hers because when we got married we did our best to come to live as one'* (Robert).

Discussion

This study explored dementia caregiver's experiences of self-compassion within the context of their caregiving role. This extended existing research by acknowledging the key processes involved in facilitating and inhibiting one's capacity for self-compassion, whilst highlighting the differing interpretations of the construct compassion.

Participant's narratives highlighted a transition process of adjusting to the dementia diagnosis accompanied by loss and therefore a re-evaluation of life goals and values. All participants described the uncertainty of the dementia, resulting in experiencing difficult emotions such as anxiety, frustration, guilt and stress. Perceived caring and supportive voices from family, friends, other caregivers and professionals facilitated self-care and therefore a self-forgiving mindset. Supportive voices led to an understanding of self-compassion as something caregivers deserved for themselves.

On the contrary, perceived rejecting and critical voices from others facilitated self-criticism leading to an inadequate mindset, and an understanding of self-compassion as sacrificing one's own emotional needs for others. These findings emphasise the importance of providing caring and supportive relationships through services, allowing caregivers the opportunity to internalise a compassionate style of relating, particularly, caregivers surrounded by critical systems or who have minimal informal support. Additionally, these findings support the idea that threat (feeling rejected or criticised) inhibits one's capacity for compassion (Gilbert, 2013). Furthermore, these findings highlight the need for systemic work with families to enhance their understanding about the impact of their responses upon the person with dementia and primary caregiver. This supports existing research that suggests family members can influence how dementia is experienced and managed for the person with dementia and caregiver (Allen, Oyebode & Allen, 2009; Garwick, Detzner & Boss, 1994; Piercy, 2007).

In the present study, some participants talked about becoming the '*leader'* due to the implications of the dementia, which involved a decline in cognitive abilities, for example, memory, attention and language and activities of daily living skills; supporting the primary stressors within dementia caregiving proposed by the Process Stress Model (Mullan et al., 1990). Becoming the leader may provide support for the alleviation (action) part of compassion, and the idea of flows of compassion, for example, self-other (Gilbert et al., 2017). Additionally, some participants described becoming the '*visitor*'. This finding indicates that as professionals get more involved in the person with dementia's care, the family caregiver can feel like an outsider, a potentially threatening position further diminishing compassion (Gilbert, 2013). Further supporting the Process Stress Model, participants talked about different secondary stressors such as difficult family dynamics, social and occupational restriction, social rejection, and inadequate self-concepts underpinned by self-criticism and comparing themselves to other caregivers (Mullan et al., 1990).

Consistent with findings from previous research (Martin et al., 2006), some participants expressed feelings of entrapment, many reflected on other people's expectations of them including family, friends and professionals and some described engaging in self-criticism. Martin et al. (2006) reported that these processes were related to feelings of shame.

In relation to evolutionary theory, Gilbert (1989) suggested that shame was connected to social rank and status judgements; of feeling inferior, powerless or bad in comparison with others. In the current study, most caregivers denied experiencing shame, however, many spoke about making social comparisons, making upwards comparisons and thinking about how others perceived them; possibly indicating feelings of shame.

Participants described different behavioural strategies including prioritising the person with dementia, blocking things out and keeping busy which was interpreted as defending against emotional pain. This supports existing research which highlighted that caregivers ignored their own well-being to avoid feelings of inadequacy and guilt (Martin et al., 2006). Gilbert (1989) suggested that guilt evolved as a self-monitoring system to motivate giving help to others and avoiding harming others. Gilbert suggested that guilt is related to having letting others down in some way. Supporting this definition, all caregivers spoke about working hard to care for and protect the person with dementia from psychological and physical harm. Some caregivers reported experiencing guilt when perceiving they had let their loved one down, for example, when utilising respite care, or considering long-term care.

Previous research (Brodaty et al., 2005) looked at the barriers to caregivers accessing support from services which included a lack of informal support and expectations of invasions of privacy. A key finding of the current study revealed that the voices of others surrounding caregivers had a direct influence on how they related to themselves, including their relationship to help, for example, being open to and accepting of help or putting high expectations upon the self to cope autonomously. This emphasises the importance of caregivers being adequately supported by the systems around them to promote their relationship to professional help, whilst considering and working with their expectations of privacy (Brodaty et al., 2005).

Crucially, this study found that participants who were surrounded by supportive relationships were more likely to understand self-compassion as something that they deserved for themselves. An enhanced capacity for self-compassion was connected to ‘caring is sharing’ which represented both the caregiver’s and the person with dementia’s needs being attended to. This supports research which indicates that self-compassion can protect the emotional energy needed to serve others (Neff, 2018), and that self-compassion is closely linked to compassion to others (Neff & Pommier, 2013; Welp & Brown, 2014). However, Gilbert et al. (2017) referred to different flows of compassion that operate independently and claimed that self-self-compassion is not required for other-self-compassion.

Participants who were surrounded by critical or rejecting relationships were more likely to understand self-compassion as sacrificing their own needs. Two participants expressed that compassion was not connected to the self but was other directed, possibly providing support for the model of multiple flows of compassion (Gilbert et al., 2017). These findings extend existing research defining the meaning of self-compassion in the general population (Neff, 2003a) and clinical populations (Gilbert, 2005), by demonstrating variations in understanding of the construct in dementia caregivers. Interestingly, some participants described the construct as recognising and prioritising their own needs, whilst others questioned the meaning of the concept and struggled to understand how one would convey compassion inwardly, viewing compassion as other directed. Furthermore, some participants understood self-compassion as both needs as one. These findings emphasise the importance of supporting caregivers to understand the true meaning of self-compassion and recognise their own needs, in order to enhance their courage to turn towards suffering and utilise wisdom in attempt to relieve distress (Gilbert, 2005).

It is acknowledged that the researchers and supervisors knowledge of the different theoretical conceptualisations of self-compassion were drawn upon to create questions for the semi-structured interviews, potentially influencing the type of data constructed. For example, questions such as ‘Do you notice distress within yourself?’ and ‘What do you do to help yourself?’ reflected Gilberts’ (2005) model. Whereas questions such as ‘How easy is it to be kind to yourself?’ and ‘Do you relate your experiences to others?’ reflected Neffs’ (2003a) model. Therefore, it is acknowledged that codes derived from participant accounts are likely to reflect a broader definition of compassion than either single model.

Prior to data collection, the researcher completed a three-day CFT introductory training programme delivered by The Compassionate Mind Foundation founded by Gilbert. Additionally, the empirical research was supervised by clinical practitioners who also work within this model of compassion. Consequently, it is likely that interpreted participant data and analytical thinking occurred though the lens of Gilbert’s (2005) conceptualisation, shaping proposed clinical implications influenced by recent developments in the construct compassion (Gilbert et al., 2017).

Clinical implications

Whilst the theoretical model incorporates an interpretation of participant’s accounts, it is essential to recognise that interpretations remain grounded in the perceived experiences of caregivers. Participants within the study highlighted times where they struggled to tolerate the uncertainty of dementia, which incorporated a variety of experiences such as thinking about their own future health, the unpredictable nature of dementia, having no control over the progression and feeling uncertain about the future. All experiences were valid, serving different purposes at different times for caregivers. Current psychosocial interventions offered by dementia services such as, caregiver groups, could be enhanced by initiating conversations about the unique nature of uncertainty for dementia caregivers. Practitioners could directly ask about experiences, beliefs and feelings about uncertainty, with the aim of supporting the toleration of unknowns.

Participants also described experiencing difficult emotions in relation to caring. These varied amongst participants from feeling frustrated, unappreciated, resentment, guilt and many more. It is important for clinicians with psychological training to offer a safe space for caregivers to reflect upon their internal world, using validation principles to support the acknowledgement of distress, with the aim of building caregiver's capacity to practice emotional expression and therefore self-compassion. Whilst current models of service provision view caregivers in adjunct to the person with dementia, in line with the Care Act (Department of Health, 2014), dementia services should provide a needs assessment to promote caregiver's needs to be recognised within their own right. It may be beneficial for practitioners to target caregivers who feel unable to acknowledge their own needs or perceive themselves as failing if they do.

As shown in the findings of this study, it is fundamentally important that services provide secure, caring and compassionate interactions through professional relationships, for caregivers to access supportive voices that can be internalised into self-compassion. Professional voices, for example, Clinical Psychologists could encourage reflective thinking, assessing motivations for engaging in and alleviating distress, promoting self-compassion towards emotions, thoughts and situations that distress caregivers (Gilbert et al., 2017). Gilbert's (2017) compassion scale could be employed to achieve this.

The current findings about the influence of surrounding networks on caregiver's conceptualisation of self-compassion, extends existing research which highlights the effectiveness of applying compassion-focused therapy with spousal couples experiencing a dementia diagnosis (Collins et al., 2018). Dementia services should consider specifically targeting caregiver's who report difficult dynamics within their social systems, for example, criticism or high expectations from family members, loss of friendships and limited or no support. It would be beneficial for practitioners such as Clinical Psychologists to understand who is defined as family by the person with dementia and their caregiver, whilst assessing the nature of these relationships, how relationships are negotiated and how challenges are managed when considering appropriate interventions to support families to live well with dementia.

The current study highlights the significance of supporting caregivers to fully understand the true meaning of self-compassion. This could be facilitated through psychoeducational resources derived from Compassion-Focused Therapy (Gilbert, 2005) delivered by practitioners with therapy training. Given that some participants rejected the notion of self-compassion, part of the therapeutic work could involve assessing for possible blocks, fears, or resistances to self-compassion, using Gilbert's fears of compassion scale (Gilbert et al., 2012). Additionally, practitioners should consider extending this psychoeducation on compassion to people surrounding caregivers, for example, by delivering teaching to frontline staff in nursing homes. These actions would promote the development of a compassionate systemic network where compassion is explicitly modelled to caregivers, with the aim of promoting self-compassion in caregivers.

Strengths and limitations

This study addressed a gap in the research literature by exploring dementia caregiver's experiences of self-compassion. To ensure high research quality, guidelines for conducting and reporting qualitative research were adhered to throughout the research (Elliot, Fischer & Rennie, 1999). Using a qualitative design with a curious and flexible semi-structured interview allowed the collection of rich in detail narratives. A social constructionist grounded theory framework permitted the understanding of the processes that facilitate and inhibit one's capacity for self-compassion within the context of dementia caregiving. This led to a detailed theoretical explanatory model.

Theoretical sampling of participants enabled the exploration of narratives from a range of participants, for example, caregivers living with the person with dementia, caring for the person with dementia who lived in a care home and bereaved caregivers, and allowed the exploration of similarities and differences in experiences. However, despite recruiting from a varied population, most participants were spousal caregivers. Alzheimer's Association and National Alliance for Caregiving (2004) reported that the largest proportion of caregivers were spouses, followed by children, children-in-law and were mostly female. It may be beneficial for future research to actively seek informal caregivers who do not identify as the person with dementia's spouse. Additionally, all participants identified as White British, highlighting a potential limitation in ethnic diversity and a possible avenue for future research. Incorporating participants from varied backgrounds may enrich findings by shedding light on different cultural, religious, or spiritual beliefs which could influence the caring relationship and highlight different constructs of self-compassion. Although, grounded theory does not aim to generalise findings to all dementia caregivers, rather it aims to recognise important theoretical categories and the relationships between them to support clinicians in thinking about the needs of this population.

To ensure research credibility, all participants were invited to attend a group feedback session in relation to the study findings. Six caregivers attended the session, whilst the remaining four were consulted via email. Seeking participant's feedback allowed study findings to obtain respondent validation enhancing the validity of findings. All participants agreed with the explanatory model, reporting that the diagrammatic and narrative summary accurately reflected their experiences. Participants expressed that they recognised themselves in both parts of the model (reduced and enhanced capacity for self-compassion), as opposed to being positioned on one side, which enhanced the final conceptualisation of the model.

Caregivers talked about how both sides of the model were necessary to survive, which the researcher and caregivers named as understandable, adaptive survival responses.

Suggestions for future research

Future research could further develop and strengthen the presented theoretical model by exploring a more thorough understanding and possible misconceptions of self-compassion. Additionally, this exploration could include possible fears, blocks, or resistances (Gilbert et al., 2012) to self-compassion, particularly for those caregivers who do not connect compassion to the self. The fears of compassion questionnaire (Gilbert et al., 2012) could be administered to decipher specific fears in this client group.

Most caregivers who participated in the research described a good relationship with their loved one and a wish to care for their relative. Therefore, it may be beneficial to investigate experiences of caring and self-compassion in informal caregivers who report a complicated relationship to the person with dementia, and ambivalence about their caring role. This could reveal further external and internal blocks to self-compassion, highlighting factors that are associated with lower levels of self-compassion.

Conclusion

Informal caregivers revealed different ways of self-relating, of responding to emotions and behavioural strategies that facilitated and inhibited their capacities for self-compassion within the context of dementia caregiving. This study emphasised the need to provide dementia caregivers with compassionate relationships through services and building up compassionate networks around caregivers through psychoeducation to support their psychological needs. Supporting the development of self-care, emotional expression and varied ways of coping will help caregivers to engage in self-compassion, whilst caring for their loved one.

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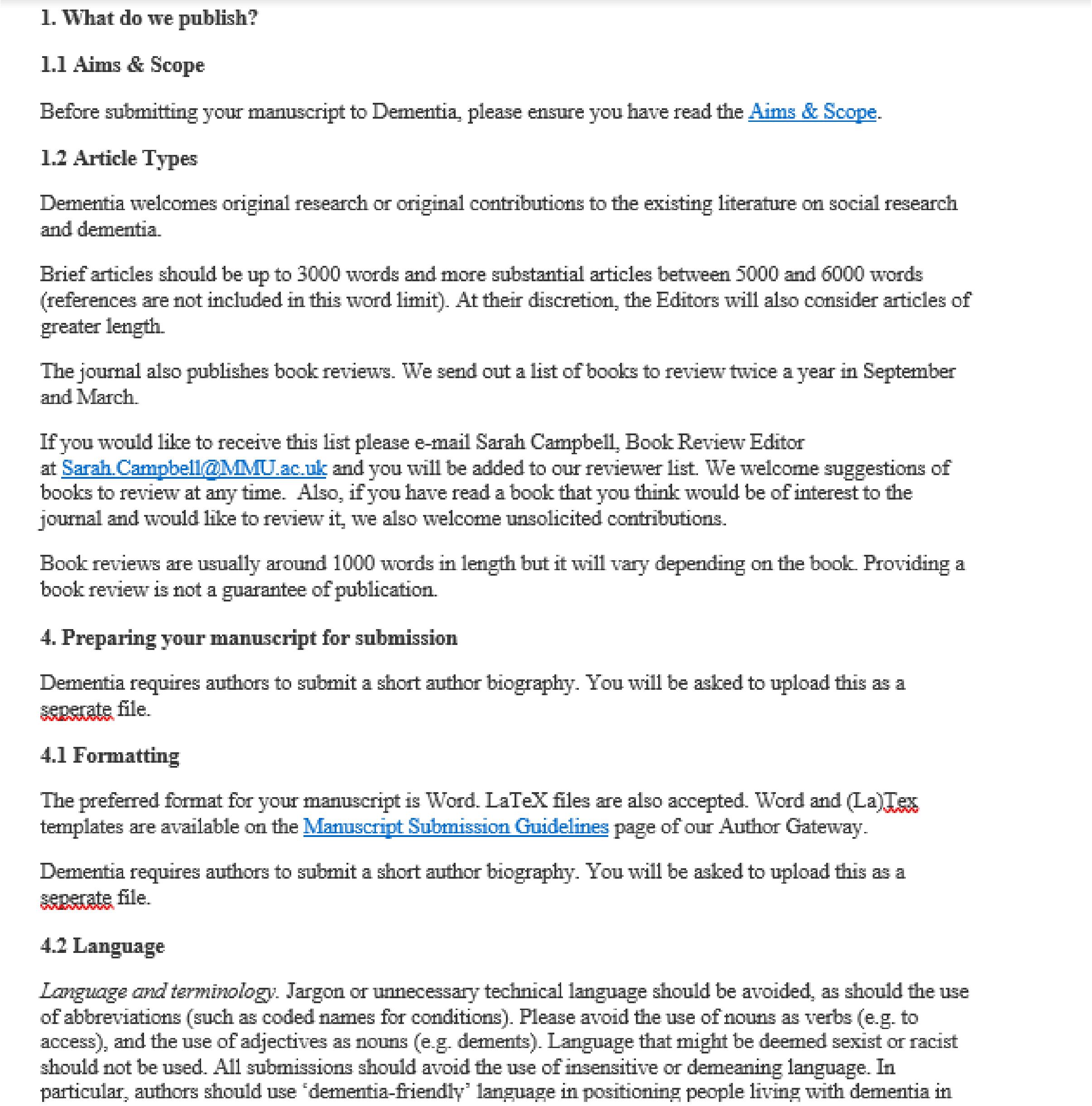
Appendix 1

Author guidelines for Dementia



1. What do we publish?

1.1 Aims & Scope

Before submitting your manuscript to Dementia, please ensure you have read the Aims & Scope.

1.2 Article Types

Dementia welcomes original research or original contributions to the existing literature on social research and dementia.

Brief articles should be up to 3000 words and more substantial articles between 5000 and 6000 words (references are not included in this word limit). At their discretion, the Editors will also consider articles of greater length.

The journal also publishes book reviews. We send out a list of books to review twice a year in September and March.

If you would like to receive this list please e-mail Sarah Campbell, Book Review Editor at Sarah.Campbell@MMU.ac.uk and you will be added to our reviewer list. We welcome suggestions of books to review at any time. Also, if you have read a book that you think would be of interest to the journal and would like to review it, we also welcome unsolicited contributions.

Book reviews are usually around 1000 words in length but it will vary depending on the book. Providing a book review is not a guarantee of publication.

4. Preparing your manuscript for submission

Dementia requires authors to submit a short author biography. You will be asked to upload this as a seperate file.

4.1 Formatting

The preferred format for your manuscript is Word. LaTeX files are also accepted. Word and (La)Tex templates are available on the Manuscript Submission Guidelines page of our Author Gateway.

Dementia requires authors to submit a short author biography. You will be asked to upload this as a seperate file.

4.2 Language

Language and terminology. Jargon or unnecessary technical language should be avoided, as should the use of abbreviations (such as coded names for conditions). Please avoid the use of nouns as verbs (e.g. to access), and the use of adjectives as nouns (e.g. dements). Language that might be deemed sexist or racist should not be used. All submissions should avoid the use of insensitive or demeaning language. In particular, authors should use 'dementia-friendly' language in positioning people living with dementia in

Please also consider how you are using abbreviations in your submission. Whilst QoL (for quality of life) and MMSE (for Mini-mental State Examination) may have common usage, please try to avoid unnecessary abbreviations in the submission of your manuscript, such as PWD (for people with dementia) and abbreviations that detract from the overall flow of the manuscript.

Abbreviations. As far as possible, please avoid the use of initials, except for terms in common use. Please provide a list, in alphabetical order, of abbreviations used, and spell them out (with the abbreviations in brackets) the first time they are mentioned in the text.

Useful websites to refer to for guidance

We recommend that authors refer to the Dementia Engagement and Empowerment Project (DEEP) guidance which was developed by people living with dementia and offers a range of advice and support, including writing dementia-friendly information.

Alternatively, Alzheimer's Australia sets out guidelines for dementia-friendly language, as do the Alzheimer Society of Canada, both of which are useful for guidance.

4.3 Artwork, figures and other graphics

For guidance on the preparation of illustrations, pictures and graphs in electronic format, please visit SAGE's Manuscript Submission Guidelines.

Figures supplied in colour will appear in colour online regardless of whether or not these illustrations are reproduced in colour in the printed version. For specifically requested colour reproduction in print, you will receive information regarding the costs from SAGE after receipt of your accepted article.

4.4 Supplemental material

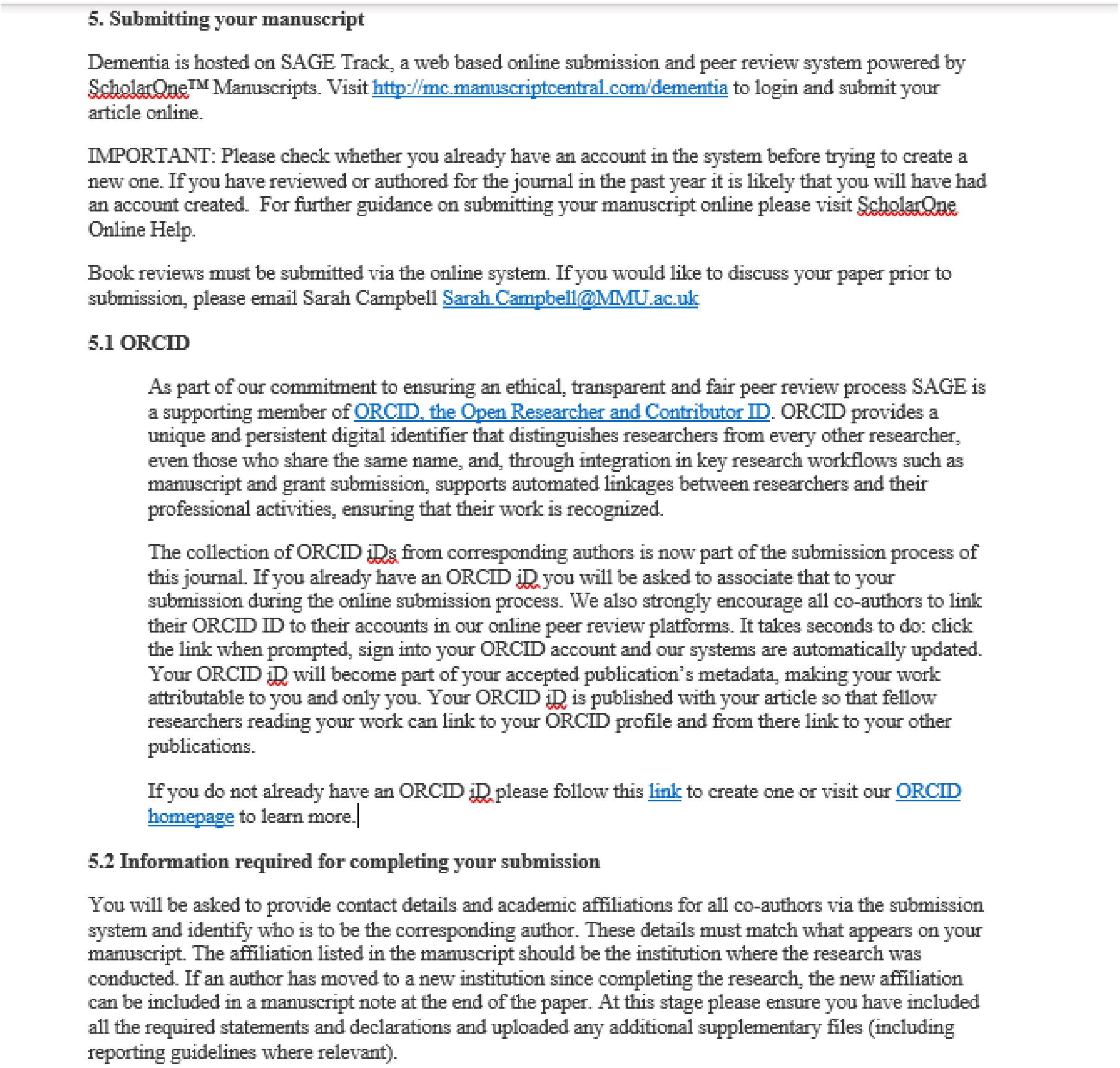
This journal is able to host additional materials online (e.g. datasets, podcasts, videos, images etc) alongside the full-text of the article. For more information please refer to our guidelines on submitting supplementary files.

4.5 Reference style

Dementia adheres to the APA reference style. View the APA guidelines to ensure your manuscript conforms to this reference style.

4.6 English language editing services

Authors seeking assistance with English language editing, translation, or figure and manuscript formatting to fit the journal's specifications should consider using SAGE Language Services. Visit SAGE Language Services on our Journal Author Gateway for further information.



5. Submitting your manuscript

Dementia is hosted on SAGE Track, a web based online submission and peer review system powered by ScholarOne™ Manuscripts. Visit http://mc.manuscriptcentral.com/dementia to login and submit your article online.

IMPORTANT: Please check whether you already have an account in the system before trying to create a new one. If you have reviewed or authored for the journal in the past year it is likely that you will have had an account created. For further guidance on submitting your manuscript online please visit ScholarOne Online Help.

Book reviews must be submitted via the online system. If you would like to discuss your paper prior to submission, please email Sarah Campbell Sarah.Campbell@MMU.ac.uk

5.1 ORCID

As part of our commitment to ensuring an ethical, transparent and fair peer review process SAGE is a supporting member of ORCID, the Open Researcher and Contributor ID. ORCID provides a unique and persistent digital identifier that distinguishes researchers from every other researcher, even those who share the same name, and, through integration in key research workflows such as manuscript and grant submission, supports automated linkages between researchers and their professional activities, ensuring that their work is recognized.

The collection of ORCID iDs from corresponding authors is now part of the submission process of this journal. If you already have an ORCID iD you will be asked to associate that to your submission during the online submission process. We also strongly encourage all co-authors to link their ORCID ID to their accounts in our online peer review platforms. It takes seconds to do: click the link when prompted, sign into your ORCID account and our systems are automatically updated. Your ORCID iD will become part of your accepted publication's metadata, making your work attributable to you and only you. Your ORCID iD is published with your article so that fellow researchers reading your work can link to your ORCID profile and from there link to your other publications.

If you do not already have an ORCID iD please follow this link to create one or visit our ORCID homepage to learn more.

5.2 Information required for completing your submission

You will be asked to provide contact details and academic affiliations for all co-authors via the submission system and identify who is to be the corresponding author. These details must match what appears on your manuscript. The affiliation listed in the manuscript should be the institution where the research was conducted. If an author has moved to a new institution since completing the research, the new affiliation can be included in a manuscript note at the end of the paper. At this stage please ensure you have included all the required statements and declarations and uploaded any additional supplementary files (including reporting guidelines where relevant).

5.3 Permissions

Please also ensure that you have obtained any necessary permission from copyright holders for reproducing any illustrations, tables, figures or lengthy quotations previously published elsewhere. For further information including guidance on fair dealing for criticism and review, please see the Copyright and Permissions page on the SAGE Author Gateway.

6. On acceptance and publication

6.1 SAGE Production

Your SAGE Production Editor will keep you informed as to your article's progress throughout the production process. Proofs will be made available to the corresponding author via our editing portal SAGE Edit or by email, and corrections should be made directly or notified to us promptly. Authors are reminded to check their proofs carefully to confirm that all author information, including names, affiliations, sequence and contact details are correct, and that Funding and Conflict of Interest statements, if any, are accurate. Please note that if there are any changes to the author list at this stage all authors will be required to complete and sign a form authorising the change.

6.2 Online First publication

Online First allows final articles (completed and approved articles awaiting assignment to a future issue) to be published online prior to their inclusion in a journal issue, which significantly reduces the lead time between submission and publication. Visit the SAGE Journals help page for more details, including how to cite Online First articles.

6.3 Access to your published article

SAGE provides authors with online access to their final article.

6.4 Promoting your article

Publication is not the end of the process! You can help disseminate your paper and ensure it is as widely read and cited as possible. The SAGE Author Gateway has numerous resources to help you promote your work. Visit the Promote Your Article page on the Gateway for tips and advice. In addition, SAGE is partnered with Kudos, a free service that allows authors to explain, enrich, share, and measure the impact of their article. Find out how to maximise your article's impact with Kudos.

7. Further information

Any correspondence, queries or additional requests for information on the manuscript submission process should be sent to the Dementia editorial office as follows:

dem.pra@sagepub.com

Appendix 2

Example search strategy

1. Dement*
2. Alzheimer*
3. Degenerat*
4. Cogniti*
5. “Cognitive impairment”
6. Memory
7. Caring
8. Carer*
9. Caregiver*
10. Informal
11. Family
12. Relative*
13. Spouse*
14. Grie*
15. Loss
16. Mourn*
17. Sorrow
18. Bereave*
19. Death
20. “Life experiences”
21. Experiences
22. Expectations
23. Opinions
24. Attitudes
25. Beliefs
26. Stories
27. Narratives

1 OR 2 OR 3 OR 4 OR 5 OR 6 AND 7 OR 8 OR 9 OR 10 OR 11 OR 12 OR 13 AND 14 OR 15 OR 16 OR 17 OR 18 OR 19 AND 20 OR 21 OR 22 OR 23 OR 24 OR 25 OR 26 OR 27

Appendix 3

Experts email

Dear X,

I am currently conducting a systematic review as part of my Doctoral Thesis at The University of Liverpool. I have attached my protocol to this email, which contains more information about the aims of the review and the planned methodology. After completing my searching and applying my inclusion and exclusion criteria, I have identified nine studies for inclusion in my review (please see attached).

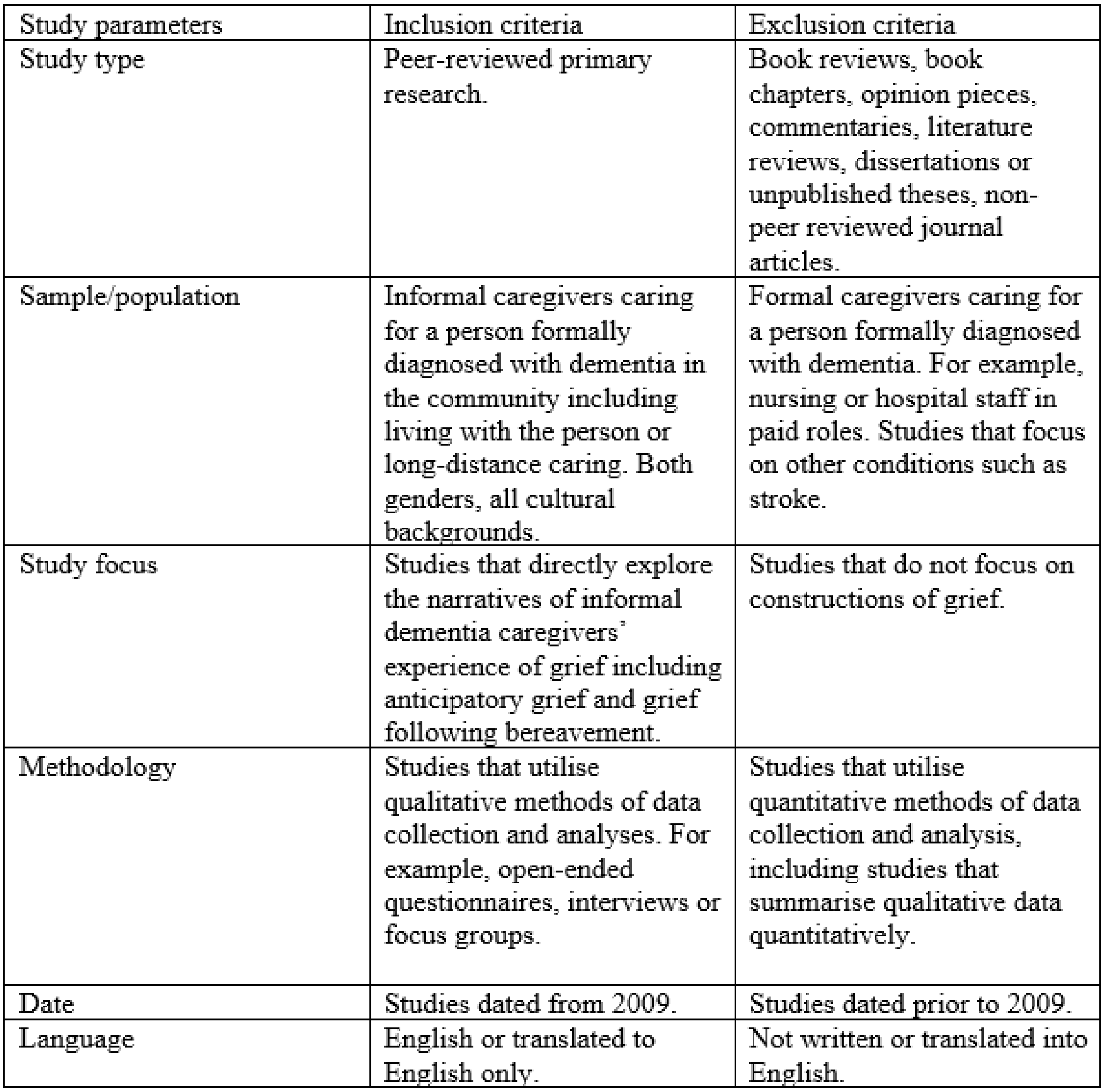
As a published expert in this clinical area, I would be very grateful if you could have a quick read through this list and let me know if you are aware of any other relevant studies that I have missed and/or of any ongoing studies that are due be published in the next 3 months?

Many thanks for your time and help.

Kind regards,
XXX
Trainee Clinical Psychologist

Appendix 4

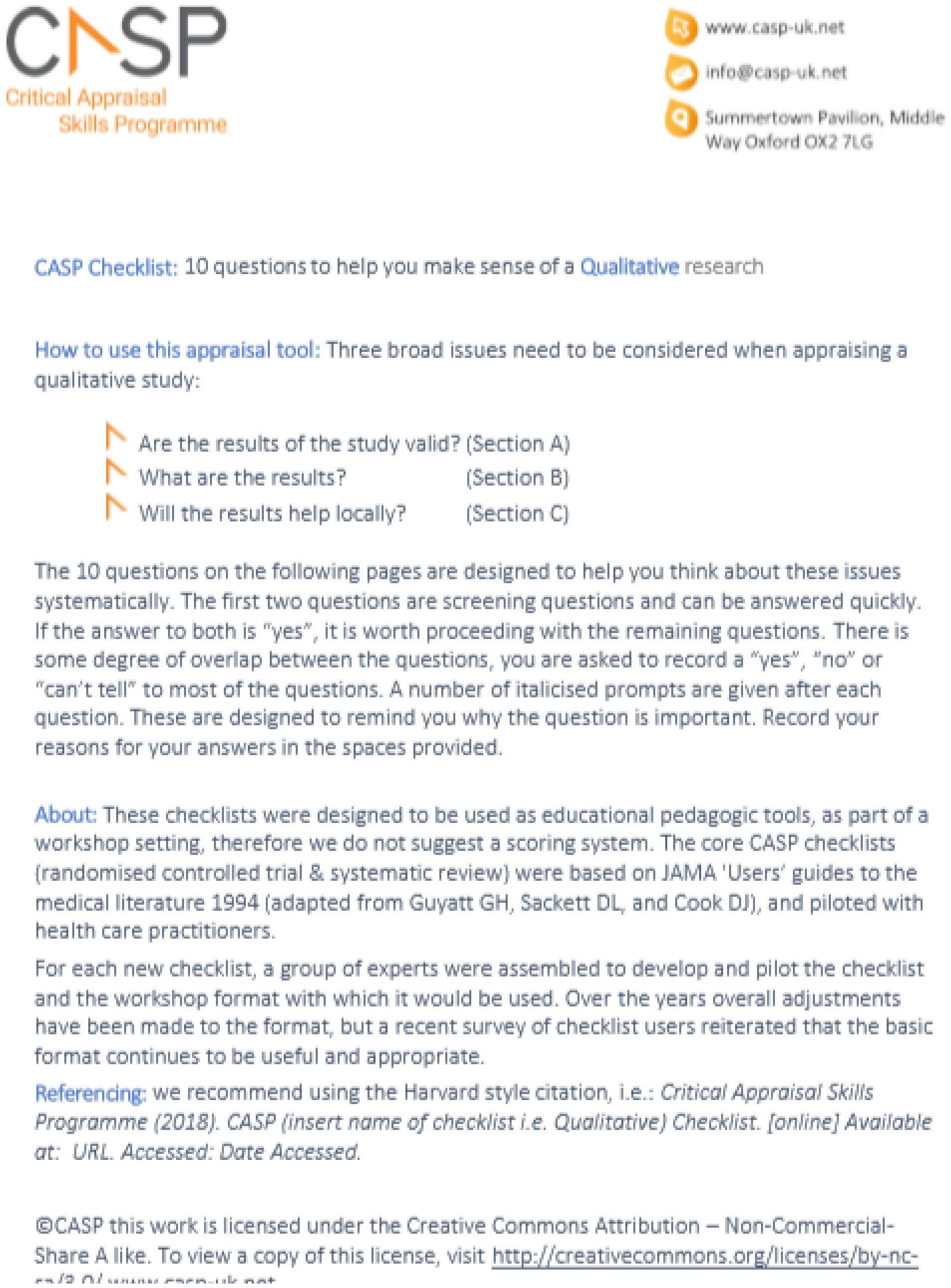
Inclusion and exclusion criteria



Study parameters	Inclusion criteria	Exclusion criteria
Study type	Peer-reviewed primary research.	Book reviews, book chapters, opinion pieces, commentaries, literature reviews, dissertations or unpublished theses, non-peer reviewed journal articles.
Sample/population	Informal caregivers caring for a person formally diagnosed with dementia in the community including living with the person or long-distance caring. Both genders, all cultural backgrounds.	Formal caregivers caring for a person formally diagnosed with dementia. For example, nursing or hospital staff in paid roles. Studies that focus on other conditions such as stroke.
Study focus	Studies that directly explore the narratives of informal dementia caregivers' experience of grief including anticipatory grief and grief following bereavement.	Studies that do not focus on constructions of grief.
Methodology	Studies that utilise qualitative methods of data collection and analyses. For example, open-ended questionnaires, interviews or focus groups.	Studies that utilise quantitative methods of data collection and analysis, including studies that summarise qualitative data quantitatively.
Date	Studies dated from 2009.	Studies dated prior to 2009.
Language	English or translated to English only.	Not written or translated into English.

Appendix 5

Critical Appraisal Skills Programme (2018)



CASP
Critical Appraisal
Skills Programme

www.casp-uk.net
info@casp-uk.net
Summertown Pavilion, Middle
Way Oxford OX2 7LG

CASP Checklist: 10 questions to help you make sense of a Qualitative research

How to use this appraisal tool: Three broad issues need to be considered when appraising a qualitative study:

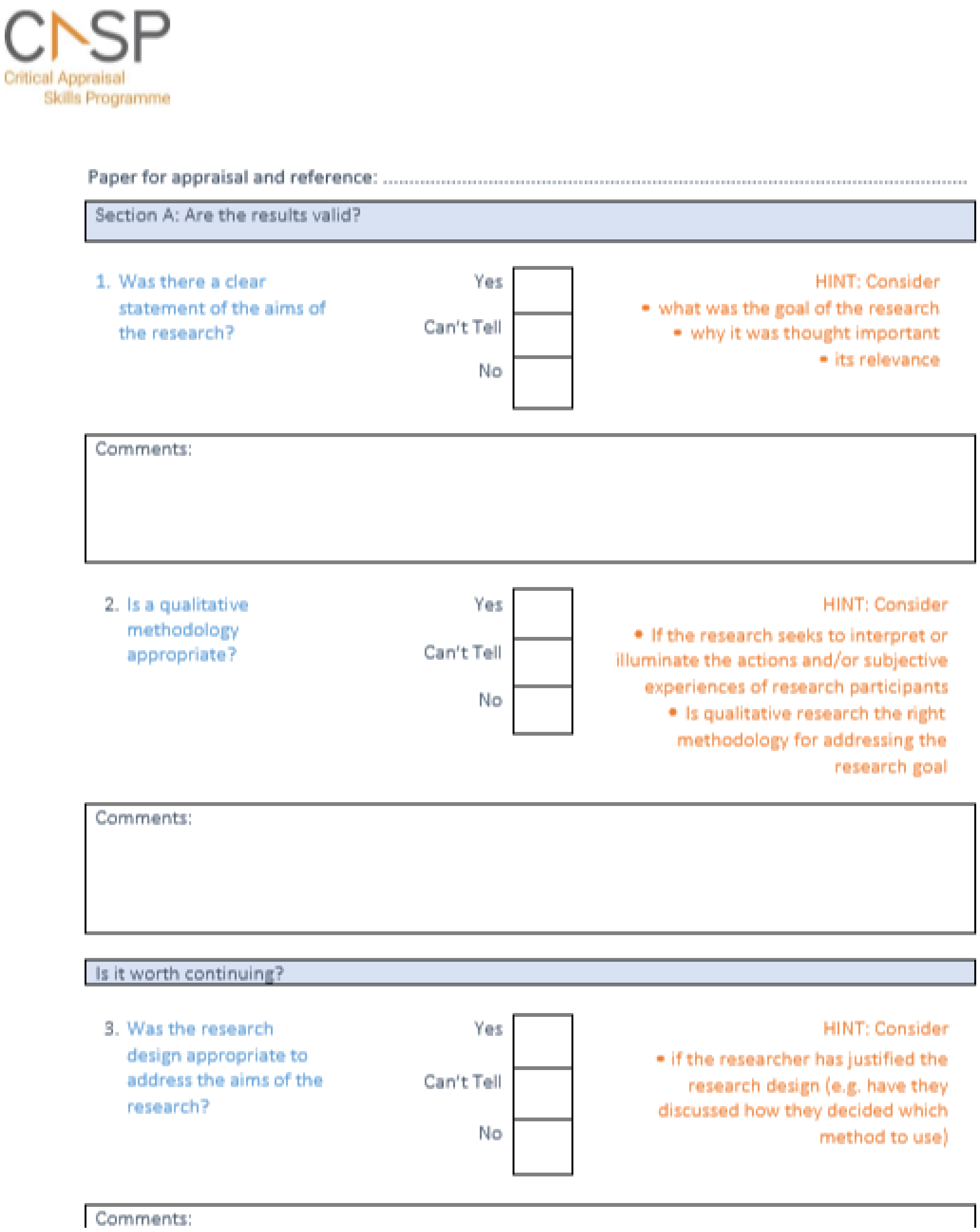
- Are the results of the study valid? (Section A)
- What are the results? (Section B)
- Will the results help locally? (Section C)

The 10 questions on the following pages are designed to help you think about these issues systematically. The first two questions are screening questions and can be answered quickly. If the answer to both is "yes", it is worth proceeding with the remaining questions. There is some degree of overlap between the questions, you are asked to record a "yes", "no" or "can't tell" to most of the questions. A number of italicised prompts are given after each question. These are designed to remind you why the question is important. Record your reasons for your answers in the spaces provided.

About: These checklists were designed to be used as educational pedagogic tools, as part of a workshop setting, therefore we do not suggest a scoring system. The core CASP checklists (randomised controlled trial & systematic review) were based on JAMA 'Users' guides to the medical literature 1994 (adapted from Guyatt GH, Sackett DL, and Cook DJ), and piloted with health care practitioners.

For each new checklist, a group of experts were assembled to develop and pilot the checklist and the workshop format with which it would be used. Over the years overall adjustments have been made to the format, but a recent survey of checklist users reiterated that the basic format continues to be useful and appropriate.

Referencing: we recommend using the Harvard style citation, i.e.: *Critical Appraisal Skills Programme (2018). CASP (insert name of checklist i.e. Qualitative) Checklist. [online] Available at: URL. Accessed: Date Accessed.*



CASP
Critical Appraisal
Skills Programme

Paper for appraisal and reference: ....

Section A: Are the results valid?

1. Was there a clear statement of the aims of the research?	Yes ☐ Can't Tell ☐ No ☐	HINT: Consider • what was the goal of the research • why it was thought important • its relevance

Comments:

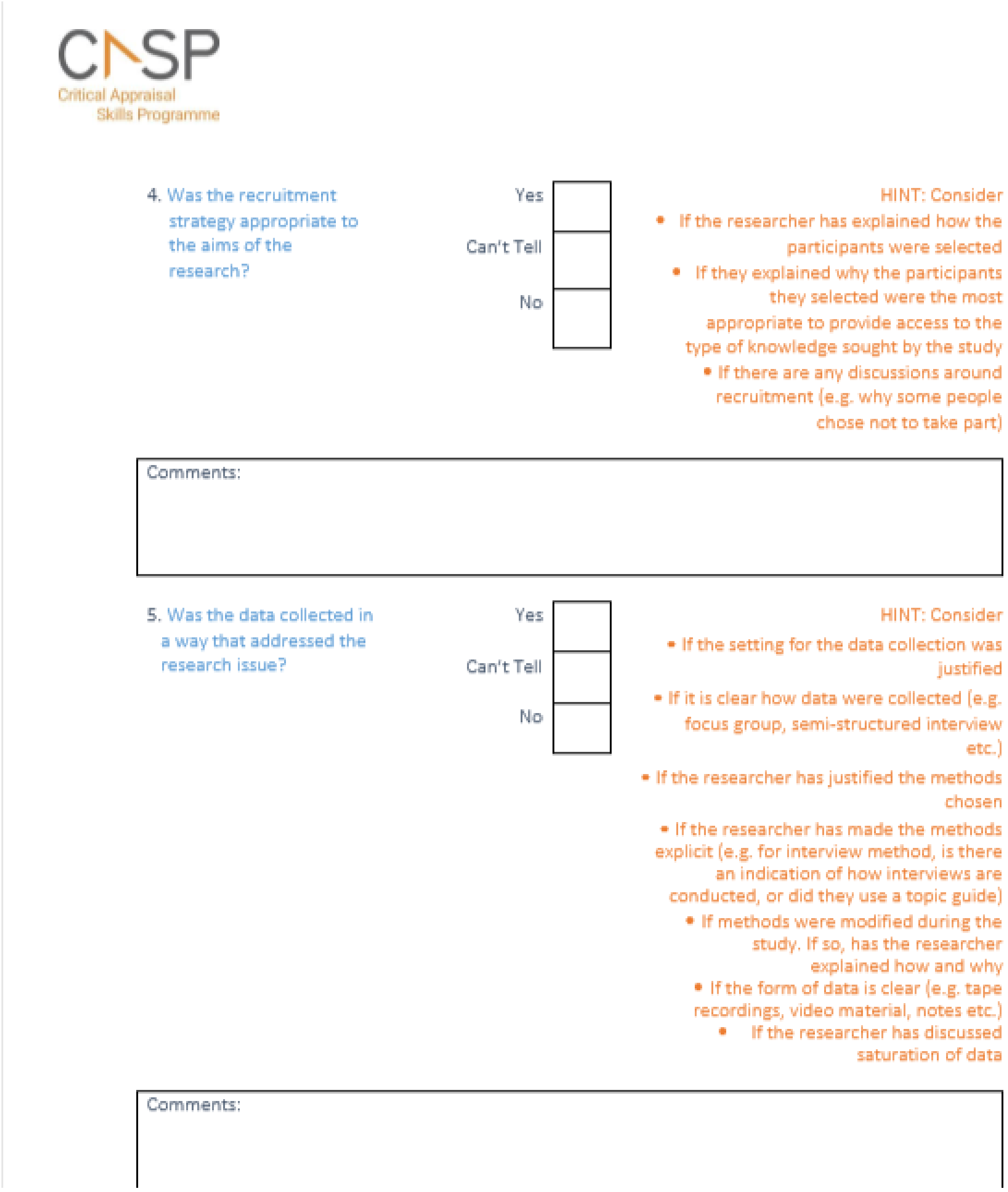
2. Is a qualitative methodology appropriate?	Yes ☐ Can't Tell ☐ No ☐	HINT: Consider • If the research seeks to interpret or illuminate the actions and/or subjective experiences of research participants • Is qualitative research the right methodology for addressing the research goal

Comments:

Is it worth continuing?

3. Was the research design appropriate to address the aims of the research?	Yes ☐ Can't Tell ☐ No ☐	HINT: Consider • if the researcher has justified the research design (e.g. have they discussed how they decided which method to use)

Comments:



CASP
Critical Appraisal
Skills Programme

4. Was the recruitment strategy appropriate to the aims of the research?

Yes ☐
Can't Tell ☐
No ☐

HINT: Consider
- If the researcher has explained how the participants were selected
- If they explained why the participants they selected were the most appropriate to provide access to the type of knowledge sought by the study
- If there are any discussions around recruitment (e.g. why some people chose not to take part)

Comments:

5. Was the data collected in a way that addressed the research issue?

Yes ☐
Can't Tell ☐
No ☐

HINT: Consider
- If the setting for the data collection was justified
- If it is clear how data were collected (e.g. focus group, semi-structured interview etc.)
- If the researcher has justified the methods chosen
- If the researcher has made the methods explicit (e.g. for interview method, is there an indication of how interviews are conducted, or did they use a topic guide)
- If methods were modified during the study. If so, has the researcher explained how and why
- If the form of data is clear (e.g. tape recordings, video material, notes etc.)
- If the researcher has discussed saturation of data

Comments:

6. Has the relationship between researcher and participants been adequately considered?

Yes ☐
Can't Tell ☐
No ☐

HINT: Consider
- If the researcher critically examined their own role, potential bias and influence during (a) formulation of the research questions (b) data collection, including sample recruitment and choice of location
- How the researcher responded to events during the study and whether they considered the implications of any changes in the research design

Comments:

Section B: What are the results?

7. Have ethical issues been taken into consideration?

Yes ☐
Can't Tell ☐
No ☐

HINT: Consider
- If there are sufficient details of how the research was explained to participants for the reader to assess whether ethical standards were maintained
- If the researcher has discussed issues raised by the study (e.g. issues around informed consent or confidentiality or how they have handled the effects of the study on the participants during and after the study)
- If approval has been sought from the ethics committee

8. Was the data analysis sufficiently rigorous?

Yes ☐
Can't Tell ☐
No ☐

HINT: Consider
- If there is an in-depth description of the analysis process
- If thematic analysis is used. If so, is it clear how the categories/themes were derived from the data
- Whether the researcher explains how the data presented were selected from the original sample to demonstrate the analysis process
- If sufficient data are presented to support the findings
- To what extent contradictory data are taken into account
- Whether the researcher critically examined their own role, potential bias and influence during analysis and selection of data for presentation

Comments:

9. Is there a clear statement of findings?

Yes ☐
Can't Tell ☐
No ☐

HINT: Consider whether
- If the findings are explicit
- If there is adequate discussion of the evidence both for and against the researcher's arguments
- If the researcher has discussed the credibility of their findings (e.g. triangulation, respondent validation, more than one analyst)
- If the findings are discussed in relation to the original research question

Comments:

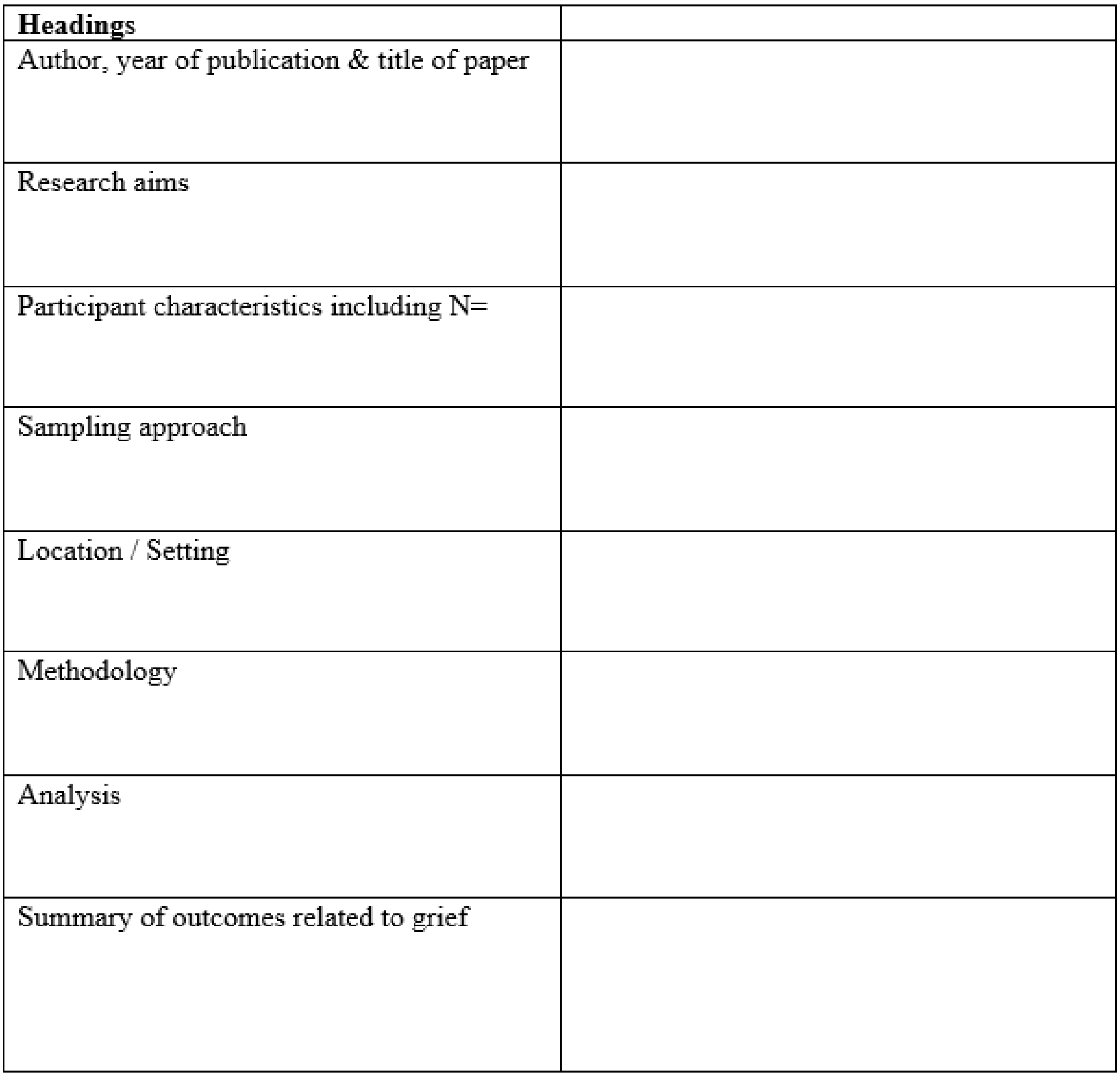
Section C: Will the results help locally?

10. How valuable is the research?	HINT: Consider • If the researcher discusses the contribution the study makes to existing knowledge or understanding (e.g. do they consider the findings in relation to current practice or policy, or relevant research-based literature • If they identify new areas where research is necessary • If the researchers have discussed whether or how the findings can be transferred to other populations or considered other ways the research may be used

Comments:

Appendix 6

Data extraction tool



Headings	
Author, year of publication & title of paper	
Research aims	
Participant characteristics including N=	
Sampling approach	
Location / Setting	
Methodology	
Analysis	
Summary of outcomes related to grief	

Appendix 7

Coding for thematic synthesis

Themes relevant to each paper:

- Anticipatory grief
- Cherishing those moments
- Difficult emotions (conflicted, guilt, loneliness, regret)
- Disconnecting over time
- Double loss
- Extending care
- Gratitude for support
- Identity
- Loss of caring role
- Loss of companionship / The end of a shared life
- Maintaining a connection
- Negative experiences of services
- Preparations for death
- Receiving support from others
- Sense of relief
- The right time to go
- Uncertainty
- Witnessing decline

These were then grouped numerous ways before the final coding grouping of descriptive themes. For example:

- Sense of loss
- Mourning before physical death
- Distress
- Psychosocial support
- Acknowledgement
- Continuation

Descriptive themes were then translated into the following analytical themes:

Sense of loss > Differing aspects of loss

Mourning before physical death > Changing nature of grief

Distress > Feeling psychologically threatened

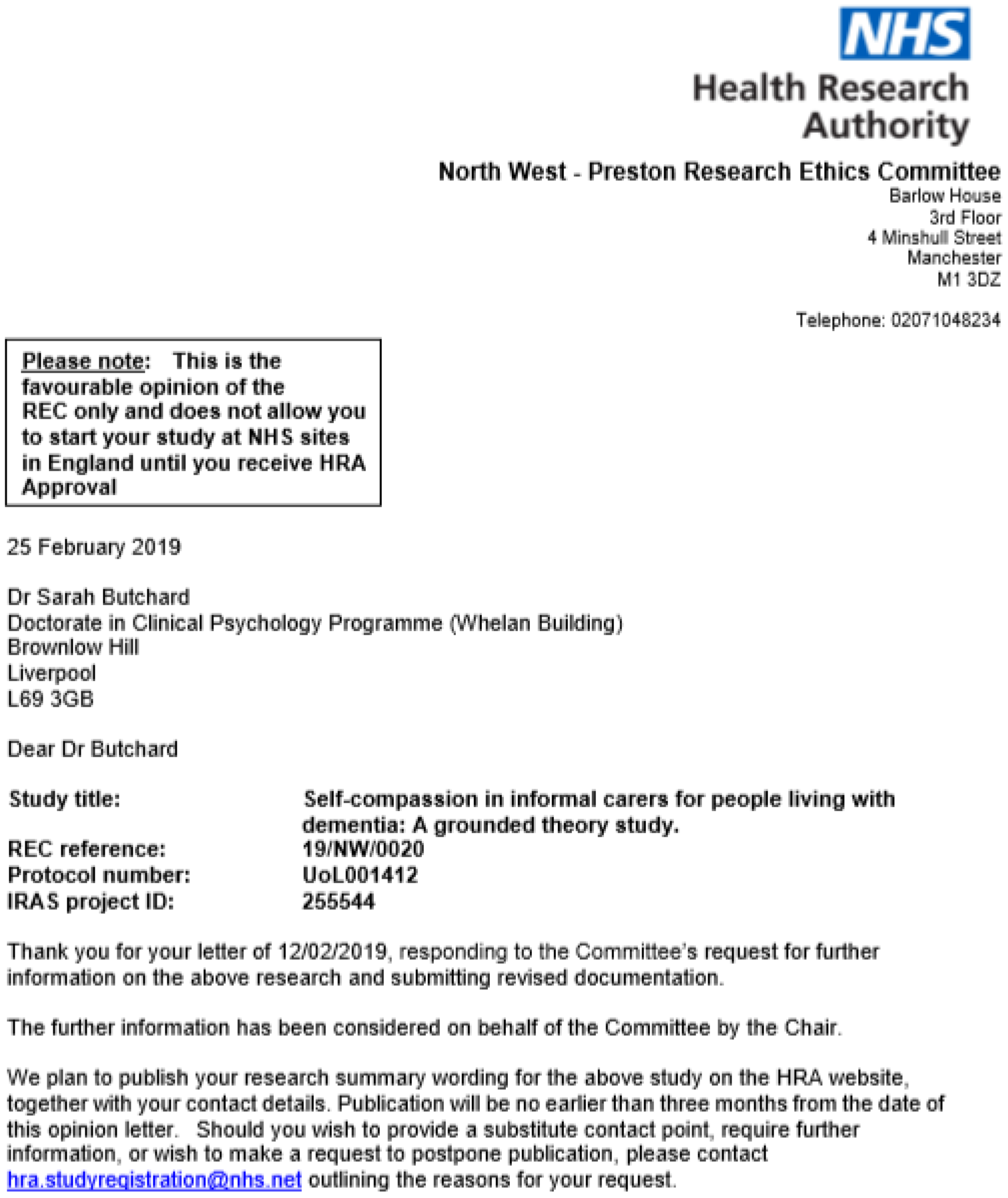
Psychosocial support > Care for the carer

Acknowledgment > Accepting loss

Continuation > Rebuilding life

Appendix 8

Ethical approval



NHS
Health Research
Authority

North West - Preston Research Ethics Committee
Barlow House
3rd Floor
4 Minshull Street
Manchester
M1 3DZ

Telephone: 02071048234

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

25 February 2019

Dr Sarah Butchard
Doctorate in Clinical Psychology Programme (Whelan Building)
Brownlow Hill
Liverpool
L69 3GB

Dear Dr Butchard

Study title:	**Self-compassion in informal carers for people living with dementia: A grounded theory study.**
REC reference:	**19/NW/0020**
Protocol number:	**UoL001412**
IRAS project ID:	**255544**

Thank you for your letter of 12/02/2019, responding to the Committee's 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.

We plan to publish your research summary wording for the above study on the HRA website, together with your contact details. Publication will be no earlier than three months from the date of this opinion letter. Should you wish to provide a substitute contact point, require further information, or wish to make a request to postpone publication, please contact hra.studyregistration@nhs.net outlining the reasons for your request.

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.

Conditions of the favourable opinion

The REC favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission 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, at www.hra.nhs.uk or at http://www.rdforum.nhs.uk.

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

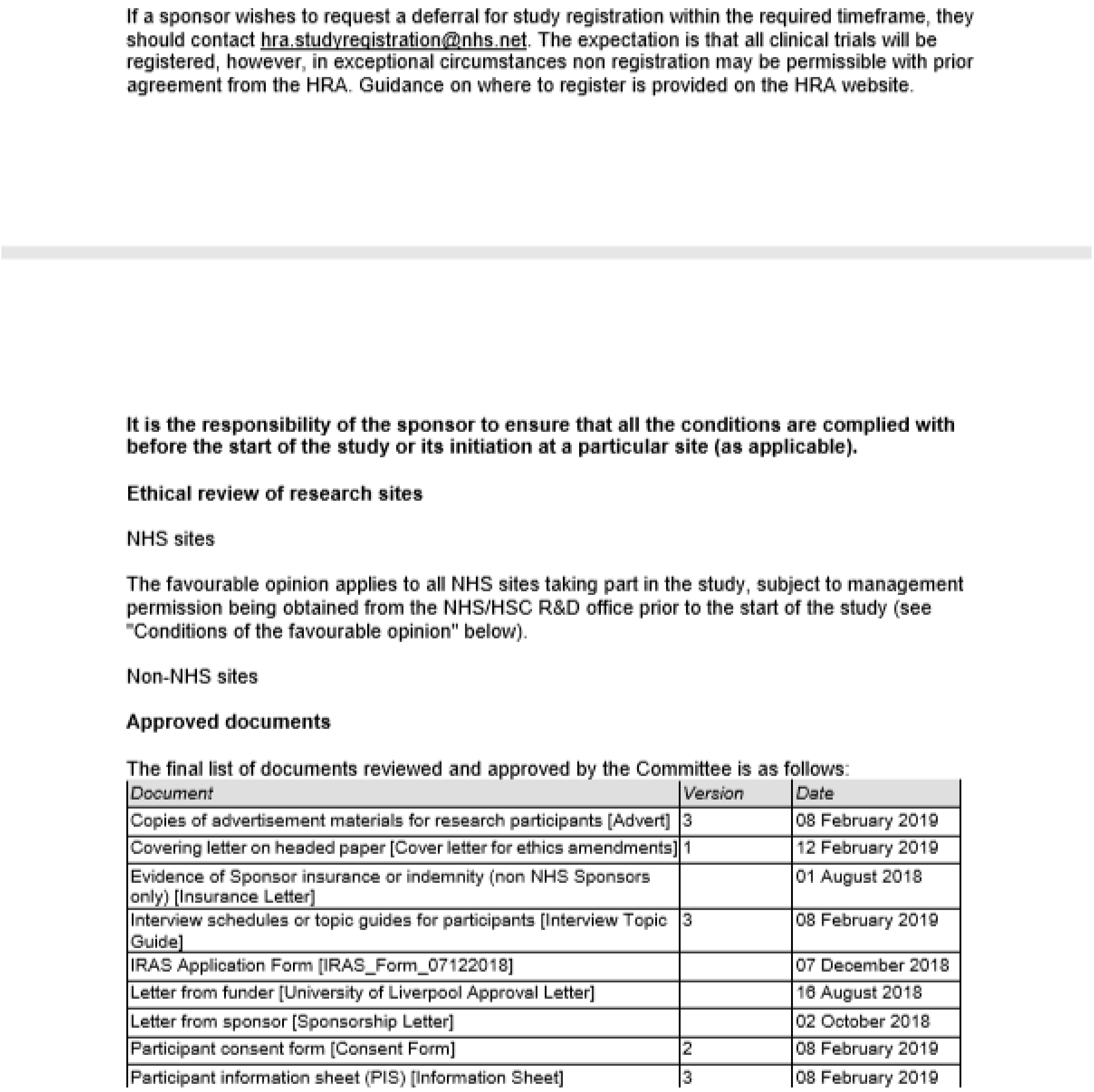
Sponsors are not required to notify the Committee of management permissions from host organisations

Registration of Clinical Trials

All clinical trials (defined as the first four categories on the IRAS filter page) must be registered on a publically accessible database within 6 weeks of recruitment of the first participant (for medical device studies, within the timeline determined by the current registration and publication trees).

There is no requirement to separately notify the REC but you should do so at the earliest opportunity e.g. when submitting an amendment. We will audit the registration details as part of the annual progress reporting process.

To ensure transparency in research, we strongly recommend that all research is registered but for non-clinical trials this is not currently mandatory.



If a sponsor wishes to request a deferral for study registration within the required timeframe, they should contact hra.studyregistration@nhs.net. The expectation is that all clinical trials will be registered, however, in exceptional circumstances non registration may be permissible with prior agreement from the HRA. Guidance on where to register is provided on the HRA website.

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).

Ethical review of research sites

NHS sites

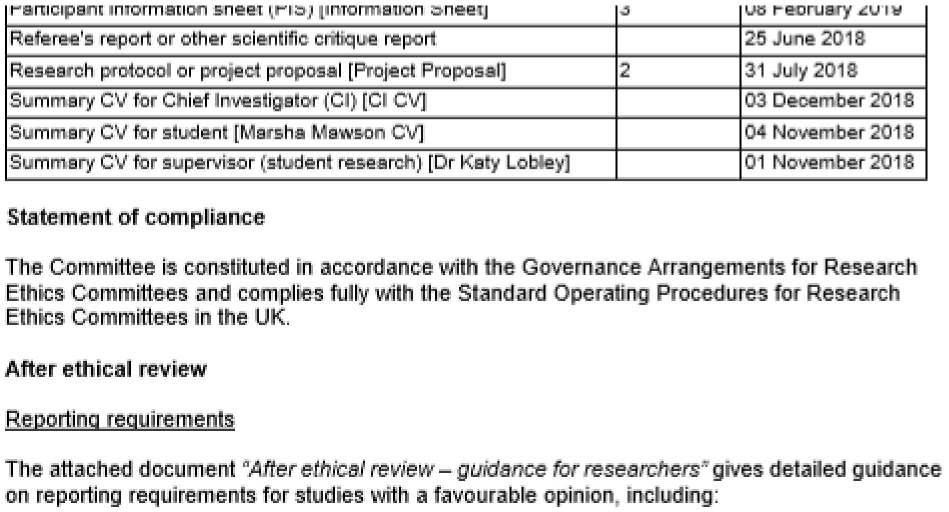
The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Non-NHS sites

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

Document	*Version*	*Date*
Copies of advertisement materials for research participants [Advert]	3	08 February 2019
Covering letter on headed paper [Cover letter for ethics amendments]	1	12 February 2019
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [Insurance Letter]		01 August 2018
Interview schedules or topic guides for participants [Interview Topic Guide]	3	08 February 2019
IRAS Application Form [IRAS_Form_07122018]		07 December 2018
Letter from funder [University of Liverpool Approval Letter]		16 August 2018
Letter from sponsor [Sponsorship Letter]		02 October 2018
Participant consent form [Consent Form]	2	08 February 2019
Participant information sheet (PIS) [Information Sheet]	3	08 February 2019



Participant information sheet (PIS) [Information Sheet]	3	08 February 2019
Referee's report or other scientific critique report		25 June 2018
Research protocol or project proposal [Project Proposal]	2	31 July 2018
Summary CV for Chief Investigator (CI) [CI CV]		03 December 2018
Summary CV for student [Marsha Mawson CV]		04 November 2018
Summary CV for supervisor (student research) [Dr Katy Lobley]		01 November 2018

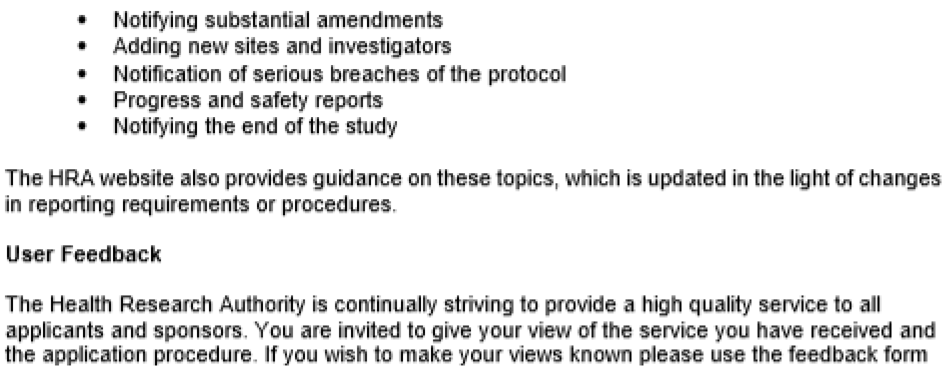
Statement of compliance

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.

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:

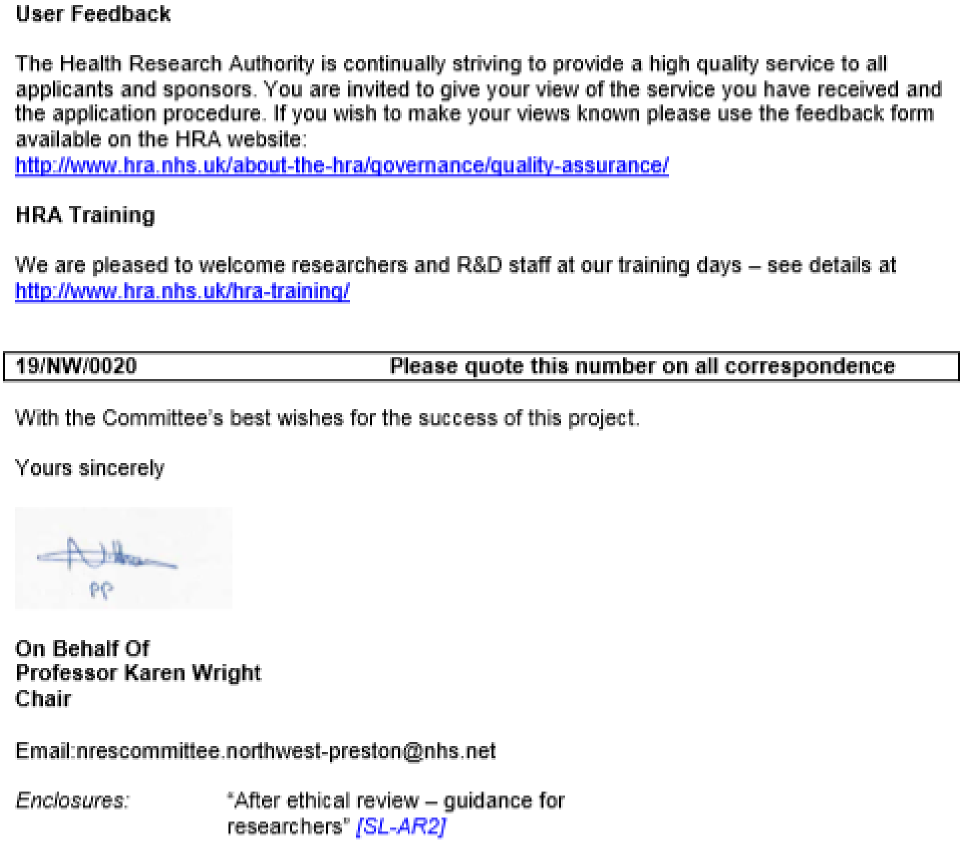


- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The HRA website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

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



User Feedback

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http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance/

HRA Training

We are pleased to welcome researchers and R&D staff at our training days – see details at
http://www.hra.nhs.uk/hra-training/

19/NW/0020	**Please quote this number on all correspondence**

With the Committee's best wishes for the success of this project.

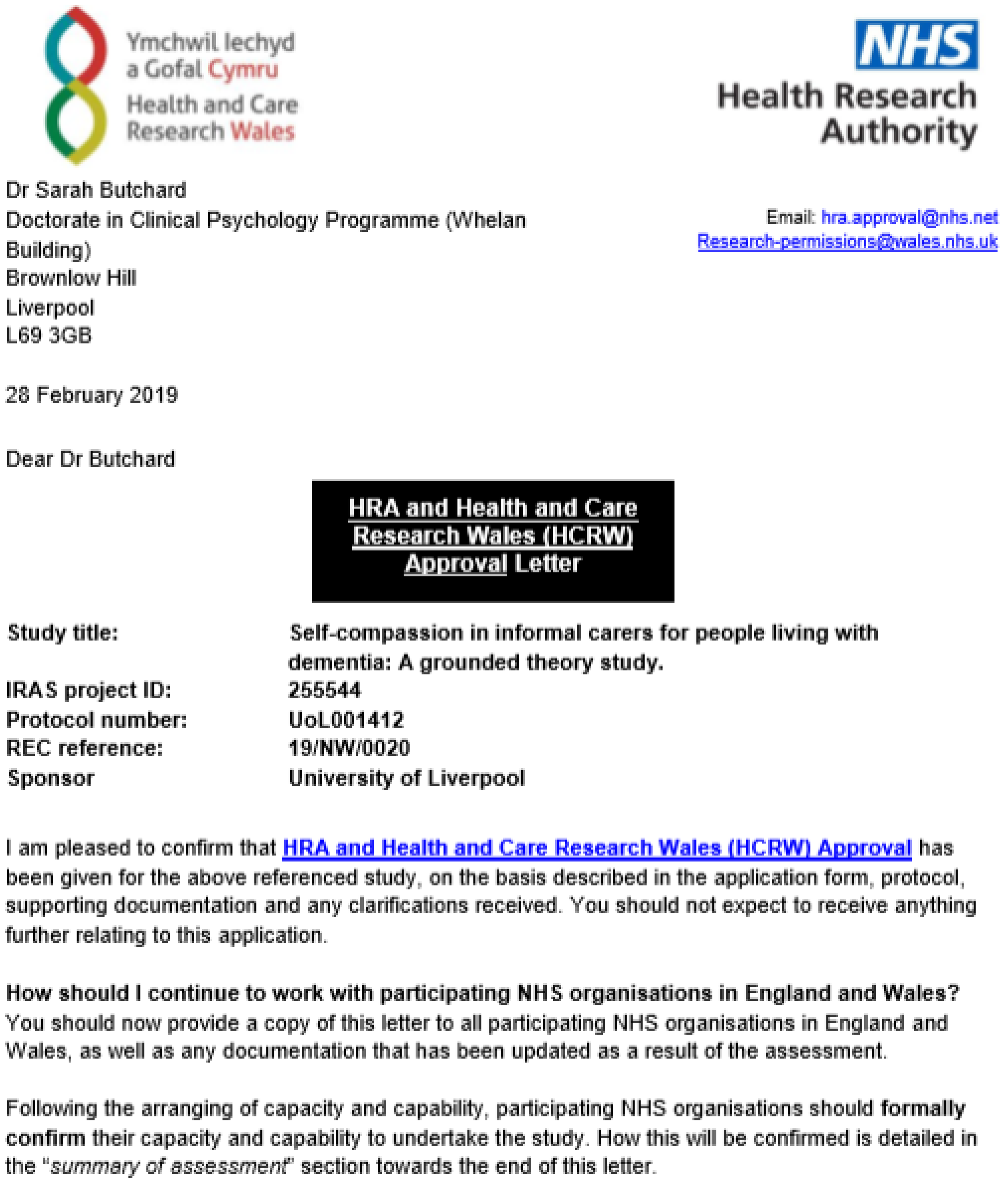
Yours sincerely

pp

On Behalf Of
Professor Karen Wright
Chair

Email:nrescommittee.northwest-preston@nhs.net

Enclosures:	"After ethical review – guidance for researchers" *[SL-AR2]*



Ymchwil Iechyd
a Gofal Cymru
Health and Care
Research Wales

NHS
Health Research
Authority

Dr Sarah Butchard
Doctorate in Clinical Psychology Programme (Whelan
Building)
Brownlow Hill
Liverpool
L69 3GB

Email: hra.approval@nhs.net
Research-permissions@wales.nhs.uk

28 February 2019

Dear Dr Butchard

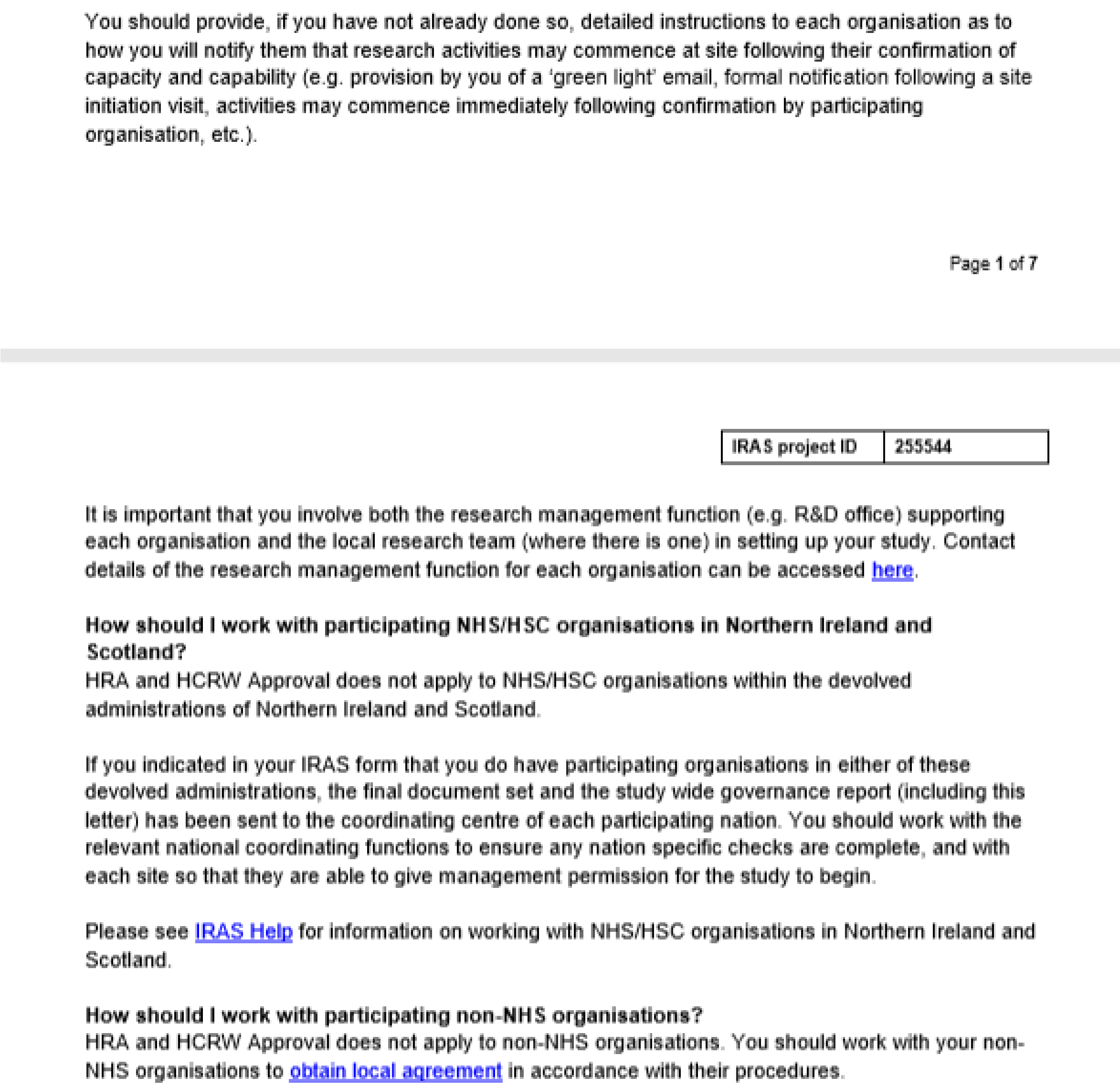
HRA and Health and Care Research Wales (HCRW) Approval Letter

Study title:	**Self-compassion in informal carers for people living with dementia: A grounded theory study.**
IRAS project ID:	**255544**
Protocol number:	**UoL001412**
REC reference:	**19/NW/0020**
Sponsor	**University of Liverpool**

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.

How should I continue to work with participating NHS organisations in England and Wales?
You should now provide a copy of this letter to all participating NHS organisations in England and Wales, as well as any documentation that has been updated as a result of the assessment.

Following the arranging of capacity and capability, participating NHS organisations should **formally confirm** their capacity and capability to undertake the study. How this will be confirmed is detailed in the "*summary of assessment*" section towards the end of this letter.



You should provide, if you have not already done so, detailed instructions to each organisation as to how you will notify them that research activities may commence at site following their confirmation of capacity and capability (e.g. provision by you of a 'green light' email, formal notification following a site initiation visit, activities may commence immediately following confirmation by participating organisation, etc.).

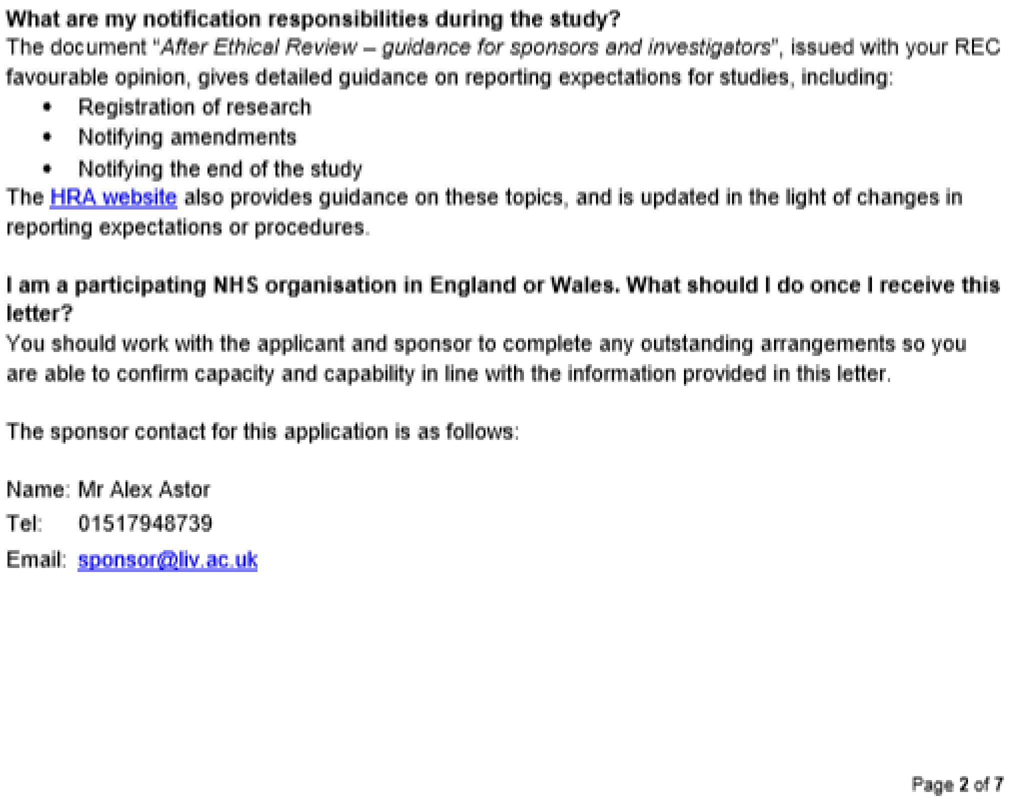
It is important that you involve both the research management function (e.g. R&D office) supporting each organisation and the local research team (where there is one) in setting up your study. Contact details of the research management function for each organisation can be accessed here.

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 the devolved administrations of 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) has been sent to the coordinating centre of each participating nation. You should work with the relevant national coordinating functions to ensure any nation specific checks are complete, and with each site so that they are able to give management permission for the study to begin.

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 document "*After Ethical Review – guidance for sponsors and investigators*", issued with your REC favourable opinion, gives detailed guidance on reporting expectations for studies, including:

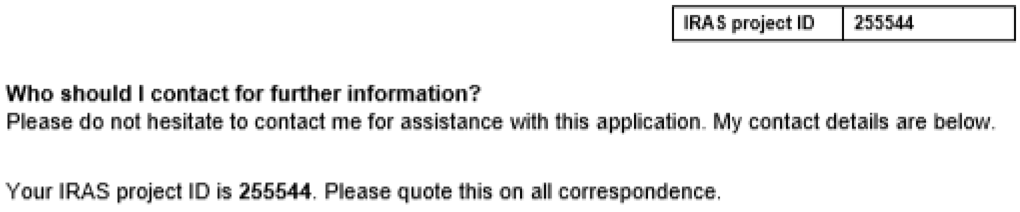
- Registration of research
- Notifying amendments
- Notifying the end of the study

The HRA website also provides guidance on these topics, and is updated in the light of changes in reporting expectations or procedures.

I am a participating NHS organisation in England or Wales. What should I do once I receive this letter?
You should work with the applicant and sponsor to complete any outstanding arrangements so you are able to confirm capacity and capability in line with the information provided in this letter.

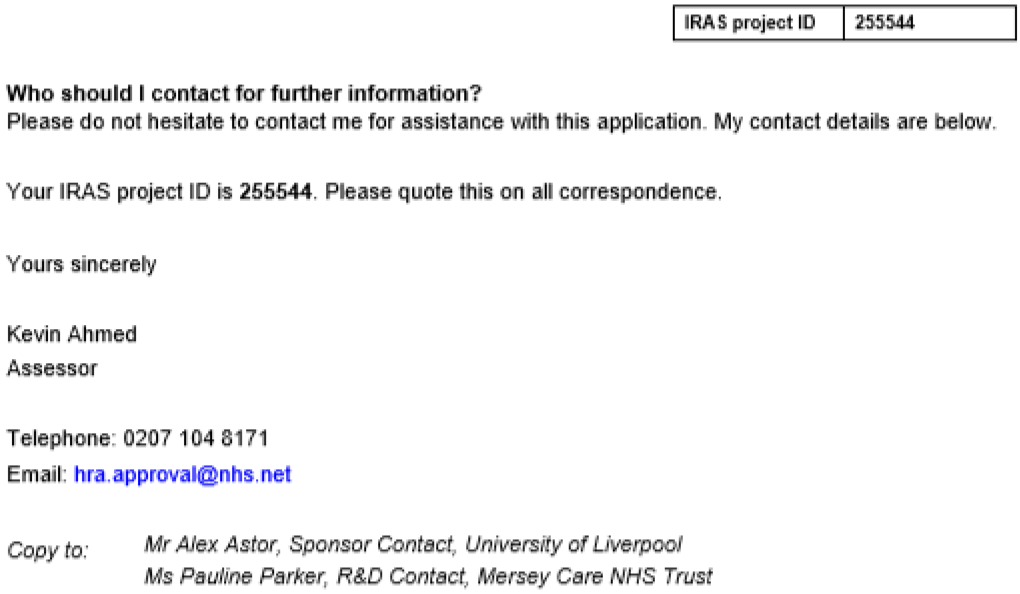
The sponsor contact for this application is as follows:

Name: Mr Alex Astor
Tel: 01517948739
Email: sponsor@liv.ac.uk



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 **255544**. Please quote this on all correspondence.



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 **255544**. Please quote this on all correspondence.

Yours sincerely

Kevin Ahmed
Assessor

Telephone: 0207 104 8171
Email: hra.approval@nhs.net

Copy to: *Mr Alex Astor, Sponsor Contact, University of Liverpool*
Ms Pauline Parker, R&D Contact, Mersey Care NHS Trust

Appendix 9

Study advert

- **Are you an informal, non-paid family carer for a loved one with dementia?**
- **Do you currently care for or have you previously cared for a loved one at home or in the community?**
- **Has your loved one been diagnosed for more than 6 months?**

Yes

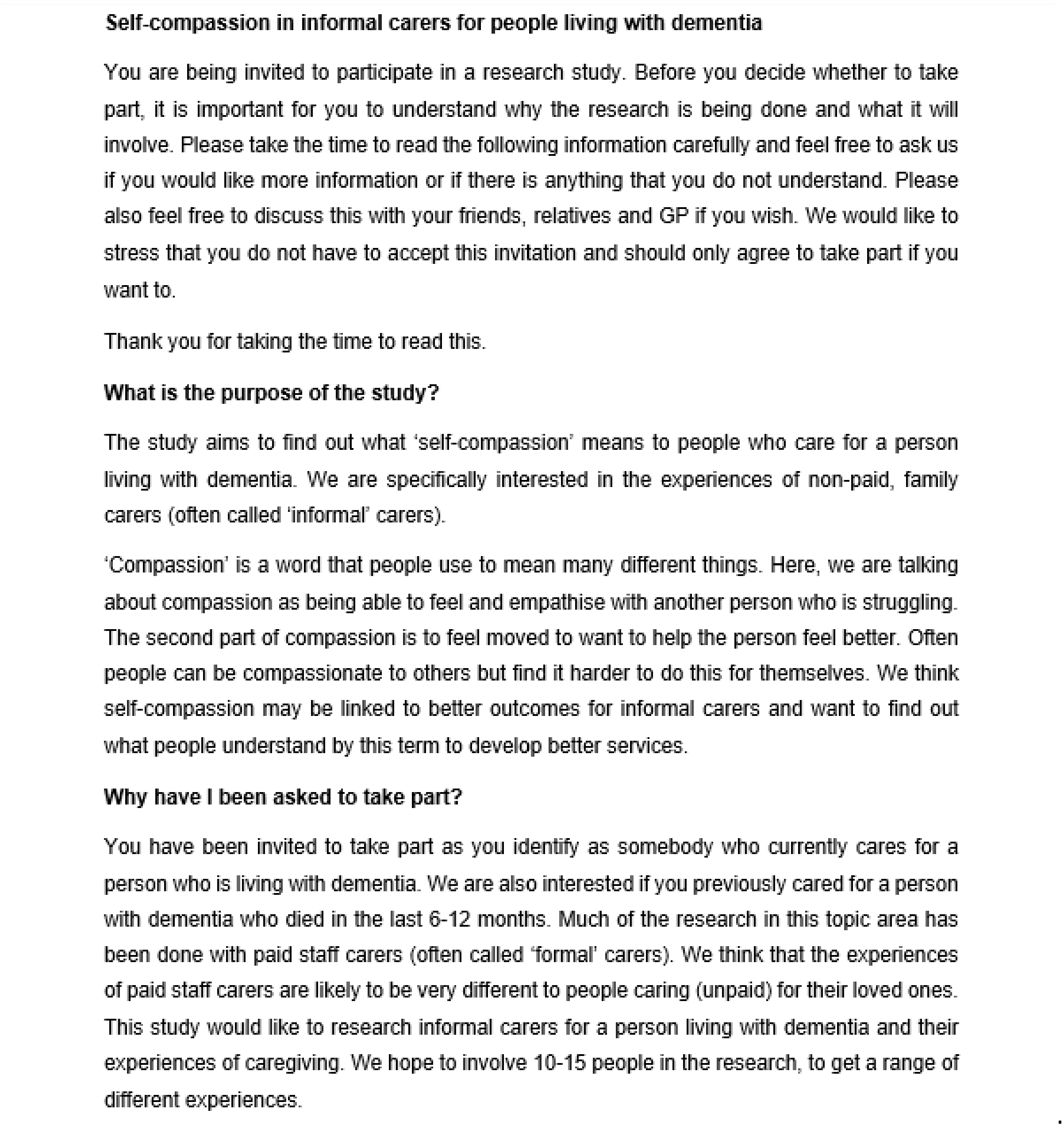
We would like to find out the experiences of self-compassion in people who care for a person living with dementia. We are particularly interested in your experiences if you are a non-paid, family carer (often called 'informal' carers).

'Compassion' is a word that lots of people use to mean different things. Here, we are talking about compassion as being able to empathise with another person who is struggling. The second part of compassion is to want to provide for others who are struggling. It can be often easier to give care and understanding to others than to ourselves! Finding out more about the what it's like to be an informal carer, will help services understand more about what support carers need.

If you are interested in finding out more about this research, please contact Marsha Mawson (Trainee Clinical Psychologist) by email (Marsha.Mawson@liverpool.ac.uk) or telephone (01517945102). Thank you for taking the time to read this poster. We look forward to hearing from you.

Appendix 10

Information sheet



Self-compassion in informal carers for people living with dementia

You are being invited to participate in a research study. Before you decide whether to take part, it is important for you to understand why the research is being done and what it will involve. Please take the time to read the following information carefully and feel free to ask us if you would like more information or if there is anything that you do not understand. Please also feel free to discuss this with your friends, relatives and GP if you wish. We would like to stress that you do not have to accept this invitation and should only agree to take part if you want to.

Thank you for taking the time to read this.

What is the purpose of the study?

The study aims to find out what 'self-compassion' means to people who care for a person living with dementia. We are specifically interested in the experiences of non-paid, family carers (often called 'informal' carers).

'Compassion' is a word that people use to mean many different things. Here, we are talking about compassion as being able to feel and empathise with another person who is struggling. The second part of compassion is to feel moved to want to help the person feel better. Often people can be compassionate to others but find it harder to do this for themselves. We think self-compassion may be linked to better outcomes for informal carers and want to find out what people understand by this term to develop better services.

Why have I been asked to take part?

You have been invited to take part as you identify as somebody who currently cares for a person who is living with dementia. We are also interested if you previously cared for a person with dementia who died in the last 6-12 months. Much of the research in this topic area has been done with paid staff carers (often called 'formal' carers). We think that the experiences of paid staff carers are likely to be very different to people caring (unpaid) for their loved ones. This study would like to research informal carers for a person living with dementia and their experiences of caregiving. We hope to involve 10-15 people in the research, to get a range of different experiences.

Do I have to take part?

You are not required to take part in this research study and if you decide not to take part, this is completely understandable, and your decision will be respected. Participation in the study is **voluntary** and if you do decide to take part in the research, you are **free to withdraw** your participation up until the data is anonymised. Should you withdraw from the study, you do not need to provide an explanation to the researcher and this will not affect the care and support you or your loved one receive.

What will happen if I take part?

If you decide to take part in the research, the researcher Marsha Mawson (Trainee Clinical Psychologist) will contact you to arrange an appointment at an NHS site or at your home address depending on your preference. During the appointment, we will go through the information again and you will be given the opportunity to ask questions before signing the Consent Form. The researcher will then start the interview and ask you some questions about your experiences of caring and understanding of self-compassion. It is estimated that the consent process and interview will last approximately 60-90 minutes. We will record the interview with a digital recorder and you can pause, rewind or delete any audio recordings should you wish to during the course of the interview session. Audio data will be transferred to a transcription service and transcribed in an encrypted format. The transcription service uses a confidentiality agreement to ensure that no-one can share your information with anyone other than the researcher.

The researcher will aim to interview all participants between February – July 2019. You don't have to answer all questions in the interview but can choose not to answer specific questions. After the interview, you will have some time to talk through the experience of the interview with the researcher. Next the researcher will anonymise all transcripts (removing names, ages or locations which may identify you) and then look for themes in all of the transcripts. The researcher will then contact you later to feedback what the analysis found and to see whether the findings fit with your experiences. You will then be asked if you would like to receive a written summary sheet at the end of the study. If you would like a written summary, the researcher will email or post this to you during August 2020 to feedback final reports.

How will my data be used?

The University of Liverpool is the sponsor for this study based in the United Kingdom. We will be using information from you in order to undertake this study and will act as the data controller for this study. This means that we are responsible for looking after your information and using it properly. Your rights to access, change or move your information are limited, as we need to manage your information in specific ways in order for the research to be reliable and accurate. If you withdraw from the study, we will keep the information about you that we have already obtained. To safeguard your rights, we will use the minimum personally-identifiable information possible.

Mersey Care NHS Foundation Trust, Mossley Hill Hospital will use your name, NHS number and contact details to contact you about the research study, and make sure that relevant information about the study is recorded for your care, and to oversee the quality of the study. Individuals from The University of Liverpool and regulatory organisations may look at your medical and research records to check the accuracy of the research study.

Mossley Hill Hospital will pass these details to The University of Liverpool along with the information collected from you. The only people in The University of Liverpool who will have access to information that identifies you will be people who need to contact you to arrange an appointment for an interview or to audit the data collection process. The people who analyse the information will not be able to identify you and will not be able to find out your name, NHS number or contact details. The University of Liverpool will keep identifiable information about you from this study for 10 years after the study has finished.

You can find out more about how we use your information by contacting Dr Sarah Butchard: butchard@liverpool.ac.uk

Further information on how your data will be used can be found in the table below:

How will my data be collected?	Through a one to one, face to face interview using a digital recorder to audio record.
How will my data be stored?	On an electronic computer and anonymised.
How long will my data be stored for?	10 years.
What measures are in place to protect the security and confidentiality of my data?	Personal data will be stored on secure NHS/university computers in password-protected files with only the research team having access.
Will my data be anonymised?	Yes. Any identifiable information will be removed, and you will be given a pseudo name.
How will my data be used?	Data will be used to develop a theoretical model to explain what is understood by the term 'self-compassion'. This will be presented in a thesis report for academic purposes and in a paper which will aim to be published in an online scientific journal (Aging and Mental Health).
Who will have access to my data?	Th research team: Dr Sarah Butchard (Clinical Psychologist / Academic Supervisor), Dr Katy Lobely (Clinical Psychologist / Academic Supervisor) and Marsha Mawson (Trainee Clinical Psychologist / Student.
Will my data be archived for use in other research projects in the future?	Yes.
How will my data be destroyed?	Dr Sarah Butchard will delete your data from the electronic files after 10 years.

Expenses

You will be able to claim reasonable expenses for mileage, parking or public transport costs if travel is part of your participation in the study. You will be reimbursed with 45p per mile if you travel by car.

Are there any risks in taking part?

Throughout the interview, the researcher will be asking questions about the emotional responses that can come with caregiving. For example, things that you find hard or upsetting or rewarding about caring for your loved one. Therefore, as the questions may include sensitive topics this could impact upon how you are feeling or feel upsetting for you. The researcher will offer pauses or the option to stop the interview if you feel this is best. The researcher is a Trainee Clinical Psychologist and is used to talking with people who are upset or finding things difficult and will be able to be sensitive and helpful if you do start to find the interview difficult. The researcher can provide you with The Alzheimer's Society contact number (**0300 222 1122**) should you wish to have ongoing support.

Also, there is a possibility that talking about caring for a person with dementia and emotional responses could raise safeguarding concerns. This is where the researcher may be worried about the safety of you or the person with dementia. If this is the case the researcher will discuss this with you and would then need to contact the appropriate safeguarding team for further information. This could result in a referral being made to Care Line to get more help, should anyone be at risk.

Are there any benefits in taking part?

There are no direct benefits to taking part in the study and any possible benefits will be different for different individuals. For example, some people may find it helpful to take part in the research as it will hopefully help the support of other carers in the future. Also, some people may find it helpful to talk about their experiences to somebody and to have somebody listen to them. The interviews are not designed for therapeutic benefit.

What will happen to the results of the study?

The results will be put into a theoretical model which will be in a visual (diagram) and written form. The diagram and written explanation of the model will be put into a thesis report for academic purposes. Also, this information will form a written article that will be submitted for publication to a scientific journal called Dementia.

This can be accessed online through the internet through subscription to the journal article. Your personal details will not be included into the results, so you will not be identifiable in the research findings.

What will happen if I stop taking part?

You have the right to withdraw your participation and information given up until the point of anonymisation. After the data has been anonymised, your data will not be able to be withdrawn from the study. If you wish to withdraw your participation and / or your results (interview data) please contact the researcher Marsha Mawson by email: Marsha.Mawson@liverpool.ac.uk

What if I am unhappy or if there is a problem?

If you are unhappy, or if there is a problem, please feel free to let us know by contacting **Dr Sarah Butchard on 01517945530** and we will try to help. If you remain unhappy or have a complaint which you feel you cannot come to us with then you should contact the Research Ethics and Integrity Office at ethics@liv.ac.uk or on 0151 7948290. When contacting the Research Ethics and Integrity Office, please provide details of the name or description of the study (so that it can be identified), the researcher(s) involved, and the details of the complaint you wish to make.

The University strives to maintain the highest standards of rigour in the processing of your data. However, if you have any concerns about the way in which the University processes your personal data, it is important that you are aware of your right to lodge a complaint with the Information Commissioner's Office by calling 0303 123 1113.

Who can I contact if I have further questions?

Dr Sarah Butchard (Clinical Psychologist), University of Liverpool, Doctorate in Clinical Psychology Programme, Whelan Building, Brownlow Hill Liverpool, L69 3GB, 01517945530.

Contact details of investigatory team

Dr Katy Lobley (Clinical Psychologist), University of Liverpool, Doctorate in Clinical Psychology Programme, Whelan Building, Brownlow Hill Liverpool, L69 3GB, 01517945530.

Marsha Mawson (Trainee Clinical Psychologist), University of Liverpool, Doctorate in Clinical Psychology Programme, Whelan Building, Brownlow Hill Liverpool, L69 3GB, 01517945530.

Appendix 11

Consent form

Participant consent form

Version number & date: 2, 08/02/2019

Research ethics approval number:

Title of the research project: Self-compassion in informal carers for people living with dementia

Name of researcher(s): Marsha Mawson, Dr Sarah Butchard and Dr Katy Lobely

Please initial box

1. I confirm that I have read and have understood the information sheet dated 08/02/2019 for the above study, or it has been read to me. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐
2. I understand that taking part in the study involves an audio recorded interview. ☐
3. I understand that my participation is voluntary and that I am free to stop taking part and can withdraw from the study at any time without giving any reason and without my rights being affected. In addition, I understand that I am free to decline to answer any particular question or questions. ☐
4. I understand that anonymised quotes will be used in the thesis report and paper. ☐
5. I understand that I can ask for access to the information I provide and I can request the destruction of that information if I wish at any time prior to anonymisation. I understand that following anonymisation I will no longer be able to request access to or withdrawal of the information I provide. ☐
6. I understand that the information I provide will be held securely and in line with data protection requirements at the University of Liverpool until it is fully anonymised and then deposited in the archive for sharing and use by other authorised researchers to support other research in the future **(optional).** ☐
7. I understand that signed consent forms, original audio recordings and a transcript of my interview will be retained in The University of Liverpool, Whelan Building, Department of Clinical Psychology with only the research team having access to it until August 2030 **(optional).** ☐
8. I agree to take part in the above study. ☐

___________________________ __________ ______________________

Participant name Date Signature

___________________________ __________ ______________________

Name of person taking consent Date Signature

Principal Investigator

Dr Sarach Butchard

University of Liverpool, Doctorate in Clinical

Psychology Programme, Whelan Building

Brownlow Hill Liverpool, L69 3GB

01517945530

Butchard@liverpool.ac.uk

Student Investigator

Marsha Mawson

University of Liverpool, Doctorate in Clinical

Psychology Programme, Whelan Building

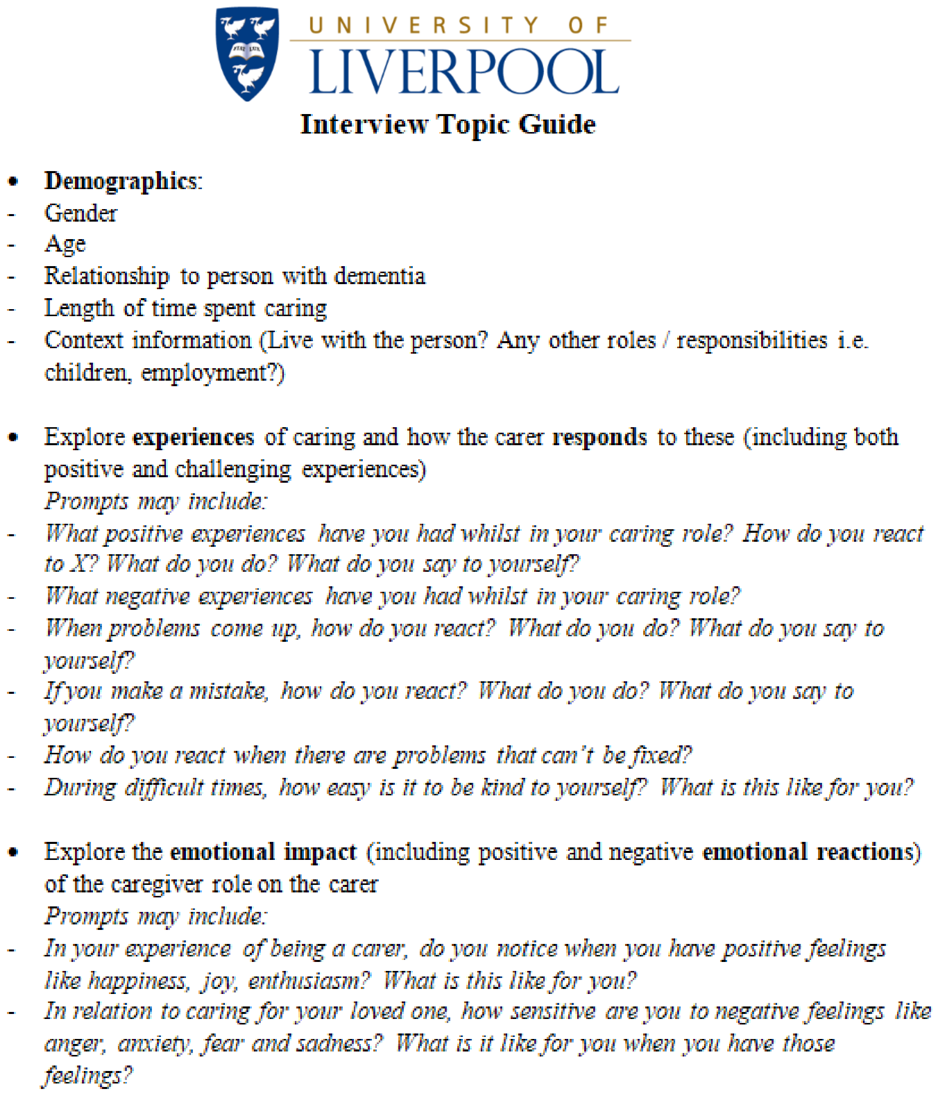
Brownlow Hill Liverpool, L69 3GB

01517945530

Marsha.Mawson@liverpool.ac.uk

Appendix 12

Interview topic guide



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Interview Topic Guide

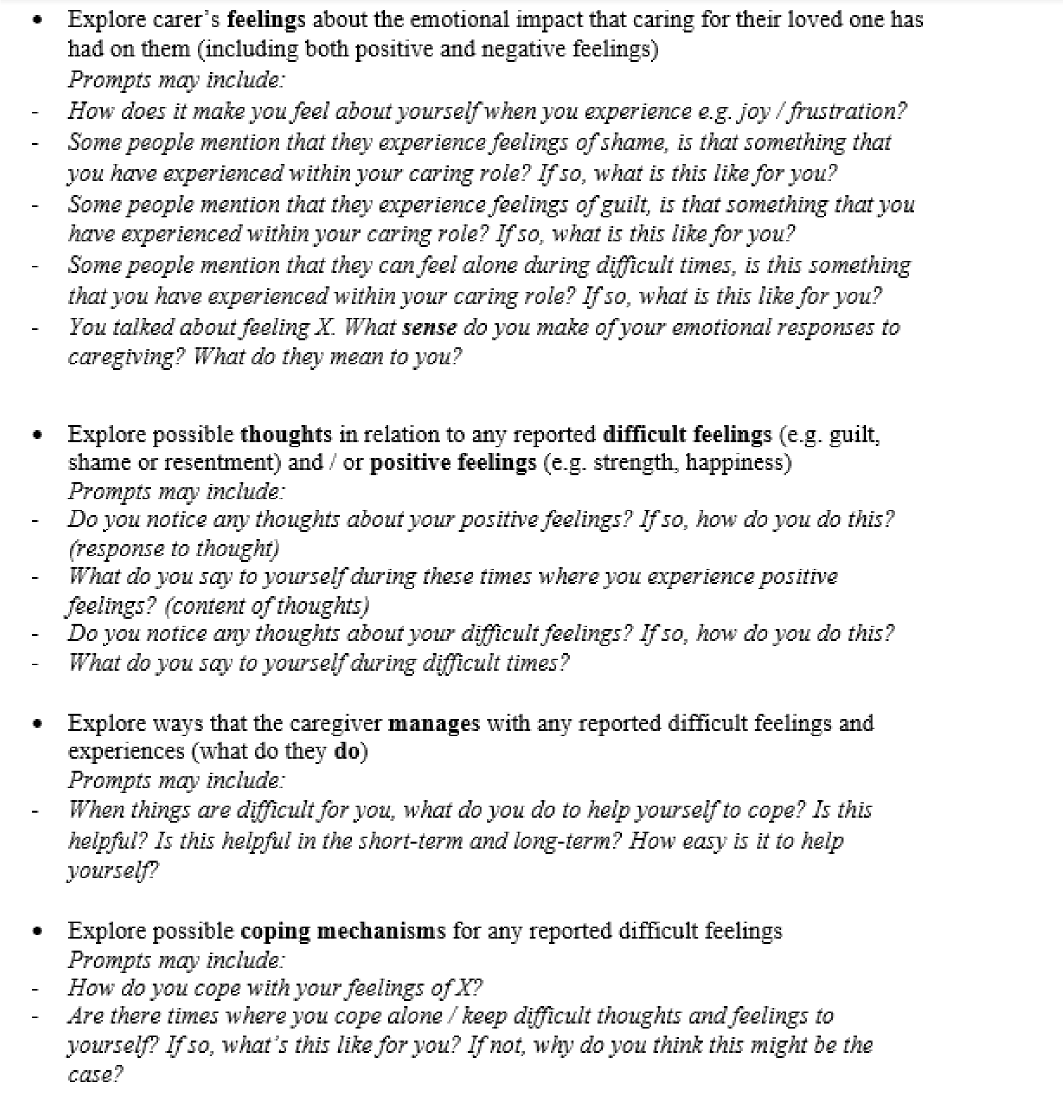
- **Demographics**:
- Gender
- Age
- Relationship to person with dementia
- Length of time spent caring
- Context information (Live with the person? Any other roles / responsibilities i.e. children, employment?)

- Explore **experiences** of caring and how the carer **responds** to these (including both positive and challenging experiences)

  Prompts may include:
- *What positive experiences have you had whilst in your caring role? How do you react to X? What do you do? What do you say to yourself?*
- *What negative experiences have you had whilst in your caring role?*
- *When problems come up, how do you react? What do you do? What do you say to yourself?*
- *If you make a mistake, how do you react? What do you do? What do you say to yourself?*
- *How do you react when there are problems that can't be fixed?*
- *During difficult times, how easy is it to be kind to yourself? What is this like for you?*

- Explore the **emotional impact** (including positive and negative **emotional reactions**) of the caregiver role on the carer

  Prompts may include:
- *In your experience of being a carer, do you notice when you have positive feelings like happiness, joy, enthusiasm? What is this like for you?*
- *In relation to caring for your loved one, how sensitive are you to negative feelings like anger, anxiety, fear and sadness? What is it like for you when you have those feelings?*



- Explore carer's **feelings** about the emotional impact that caring for their loved one has had on them (including both positive and negative feelings)

  Prompts may include:
- *How does it make you feel about yourself when you experience e.g. joy / frustration?*
- *Some people mention that they experience feelings of shame, is that something that you have experienced within your caring role? If so, what is this like for you?*
- *Some people mention that they experience feelings of guilt, is that something that you have experienced within your caring role? If so, what is this like for you?*
- *Some people mention that they can feel alone during difficult times, is this something that you have experienced within your caring role? If so, what is this like for you?*
- *You talked about feeling X. What **sense** do you make of your emotional responses to caregiving? What do they mean to you?*

- Explore possible **thoughts** in relation to any reported **difficult feelings** (e.g. guilt, shame or resentment) and / or **positive feelings** (e.g. strength, happiness)

  Prompts may include:
- *Do you notice any thoughts about your positive feelings? If so, how do you do this? (response to thought)*
- *What do you say to yourself during these times where you experience positive feelings? (content of thoughts)*
- *Do you notice any thoughts about your difficult feelings? If so, how do you do this?*
- *What do you say to yourself during difficult times?*

- Explore ways that the caregiver **manages** with any reported difficult feelings and experiences (what do they **do**)

  Prompts may include:
- *When things are difficult for you, what do you do to help yourself to cope? Is this helpful? Is this helpful in the short-term and long-term? How easy is it to help yourself?*

- Explore possible **coping mechanisms** for any reported difficult feelings

  Prompts may include:
- *How do you cope with your feelings of X?*
- *Are there times where you cope alone / keep difficult thoughts and feelings to yourself? If so, what's this like for you? If not, why do you think this might be the case?*

- *Are there times where you relate / share your experiences to other people? If so, what's this like for you? If not, why do you think this might be the case?*

- Explore the ways that positive feelings have impacted upon the caregiving role and the caregivers' life.
  Prompts may include:
- *When you feel e.g. joy, or happiness how does this impact upon your caregiving role? How does this impact upon your life?*

- Explore what the caregiver has learnt from their positive feelings in relation to caring.
  Prompts may include:
- *What have you learnt about yourself as a caregiver? What have you learnt about your life?*

Appendix 13

Updated interview topic guide

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Interview Topic Guide

- **Demographics**:
- Gender
- Age
- Ethnicity
- Relationship to person with dementia
- Length of time spent caring
- Context information (Live with the person? Any other roles / responsibilities i.e. children, employment?)

- Explore **experiences** of caring and how the caregiver **responds** to these
  Prompts may include:
- *In the early weeks and months after the diagnosis, how did you cope with any worries or difficulties that you had?*
- *Do you think that the way you have coped emotionally within your caring role has changed over time?*
- *When problems come up, how do you react? What do you do? What do you say to yourself?*
- *If you make a mistake, how do you react? What do you do? What do you say to yourself?*
- *How do you react when there are problems that can't be fixed?*
- *During difficult times, how easy is it to be kind to yourself? What is this like for you?*

- Explore the **emotional impact** (including positive and negative **emotional reactions**) of the caregiver role on the caregiver
  Prompts may include:
- *In your experience of being a carer, do you notice when you have pleasant feelings like happiness, joy, enthusiasm? What is this like for you?*
- *In relation to caring for your loved one, do you notice when you have distressing feelings like anger, anxiety, fear and sadness? What is it like for you when those feelings arise?*
- *Are there things that you try not to think about or feel? If so, how do you do this? Do you distract yourself or try to put it out of your mind?*
- *Do you find it hard to think about the more difficult stuff? What are some of the risks of dwelling on things?*

- Explore caregivers' **feelings** about the emotional impact that caring for their loved one has had on them (including both positive and negative feelings)
  Prompts may include:
  - *How does it make you feel about yourself when you experience e.g. joy / frustration?*
  - *Some people mention that they experience feelings of guilt, is that something that you have experienced within your caring role? If so, what is this like for you?*
  - *Some people mention that they can feel alone during difficult times, is this something that you have experienced within your caring role? If so, what is this like for you?*
  - *You talked about feeling X. What* ***sense*** *do you make of your emotional responses to caregiving? What do they mean to you?*
  - *What's it like to talk about you and your feelings?*

- Explore ways that the caregiver **manages** with any reported difficult feelings and experiences (what do they **do**)
  Prompts may include:
  - *Do you think it is important for carers to look after themselves?*
  - *Are you able to prioritise your own needs? If so, how do you do this?*
  - *When things are difficult, how do you look after yourself? How easy is it to help yourself?*

- Explore possible **coping mechanisms** for any reported difficult feelings
  Prompts may include:
  - *Do you feel any pressures to cope? If so, where do these pressures come from?*
  - *Are there any sources that you refer to about how you think you should be as a carer? E.g. other carers, the media. What messages do you take from these?*
  - *Are there times where you cope alone / keep difficult thoughts and feelings to yourself? If so, what's this like for you? If not, why do you think this might be the case?*
  - *Are there times where you relate / share your experiences to other people? If so, what's this like for you? If not, why do you think this might be the case?*

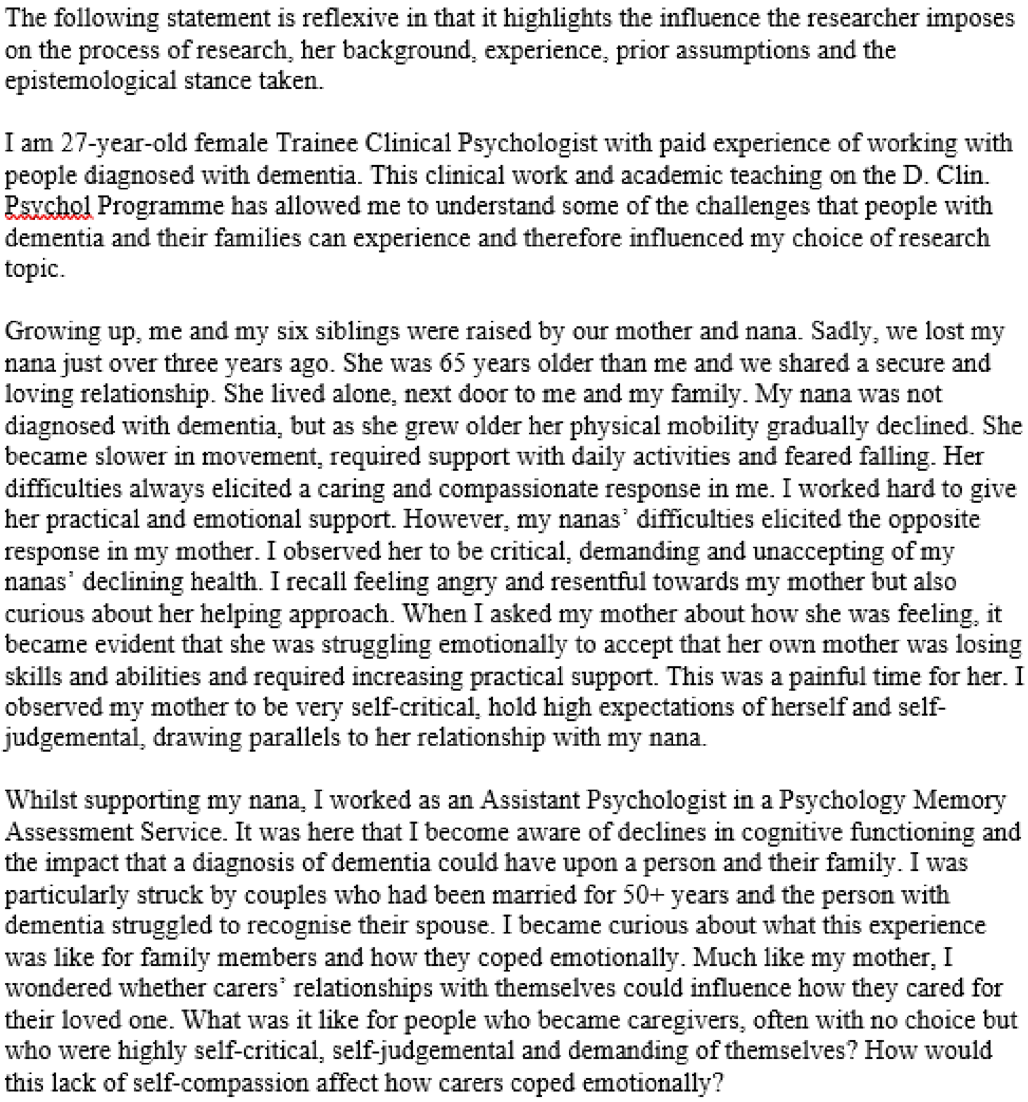
- What do you think about the **concept self-compassion**, what is your understanding of this?
  - *What do you associate with the concept self-compassion?*
  - *Do you think there are any benefits to showing compassion towards yourself?*
  - *Are there any difficulties or fears about being compassionate towards yourself?*
  - *Can you notice distress within yourself? If you do, how do you look after yourself? What do you do?*
  - *If you don't do compassion, what do you do instead?*
  - *How do you balance looking after your loved one and looking after yourself?*

- Explore what the carer has learnt from their caregiving role

  Prompts may include:
  - *What have you learnt about yourself as a caregiver? What have you learnt about your life?*

Appendix 14

Reflexive statement



The following statement is reflexive in that it highlights the influence the researcher imposes on the process of research, her background, experience, prior assumptions and the epistemological stance taken.

I am 27-year-old female Trainee Clinical Psychologist with paid experience of working with people diagnosed with dementia. This clinical work and academic teaching on the D. Clin. Psychol Programme has allowed me to understand some of the challenges that people with dementia and their families can experience and therefore influenced my choice of research topic.

Growing up, me and my six siblings were raised by our mother and nana. Sadly, we lost my nana just over three years ago. She was 65 years older than me and we shared a secure and loving relationship. She lived alone, next door to me and my family. My nana was not diagnosed with dementia, but as she grew older her physical mobility gradually declined. She became slower in movement, required support with daily activities and feared falling. Her difficulties always elicited a caring and compassionate response in me. I worked hard to give her practical and emotional support. However, my nanas' difficulties elicited the opposite response in my mother. I observed her to be critical, demanding and unaccepting of my nanas' declining health. I recall feeling angry and resentful towards my mother but also curious about her helping approach. When I asked my mother about how she was feeling, it became evident that she was struggling emotionally to accept that her own mother was losing skills and abilities and required increasing practical support. This was a painful time for her. I observed my mother to be very self-critical, hold high expectations of herself and self-judgemental, drawing parallels to her relationship with my nana.

Whilst supporting my nana, I worked as an Assistant Psychologist in a Psychology Memory Assessment Service. It was here that I become aware of declines in cognitive functioning and the impact that a diagnosis of dementia could have upon a person and their family. I was particularly struck by couples who had been married for 50+ years and the person with dementia struggled to recognise their spouse. I became curious about what this experience was like for family members and how they coped emotionally. Much like my mother, I wondered whether carers' relationships with themselves could influence how they cared for their loved one. What was it like for people who became caregivers, often with no choice but who were highly self-critical, self-judgemental and demanding of themselves? How would this lack of self-compassion affect how carers coped emotionally?

I did not have an in-depth understanding of how families emotionally coped, as I had not reviewed any of the literature in this field. I assumed that a vast evidence based already existed. Following briefly reviewing the literature, it came to light that much of the research on dementia care focused on formal carers (paid healthcare professionals) and compassionate care being showed to service users. I learnt from the literature that some researchers believe that to give authentic compassion to others requires compassion to the self.

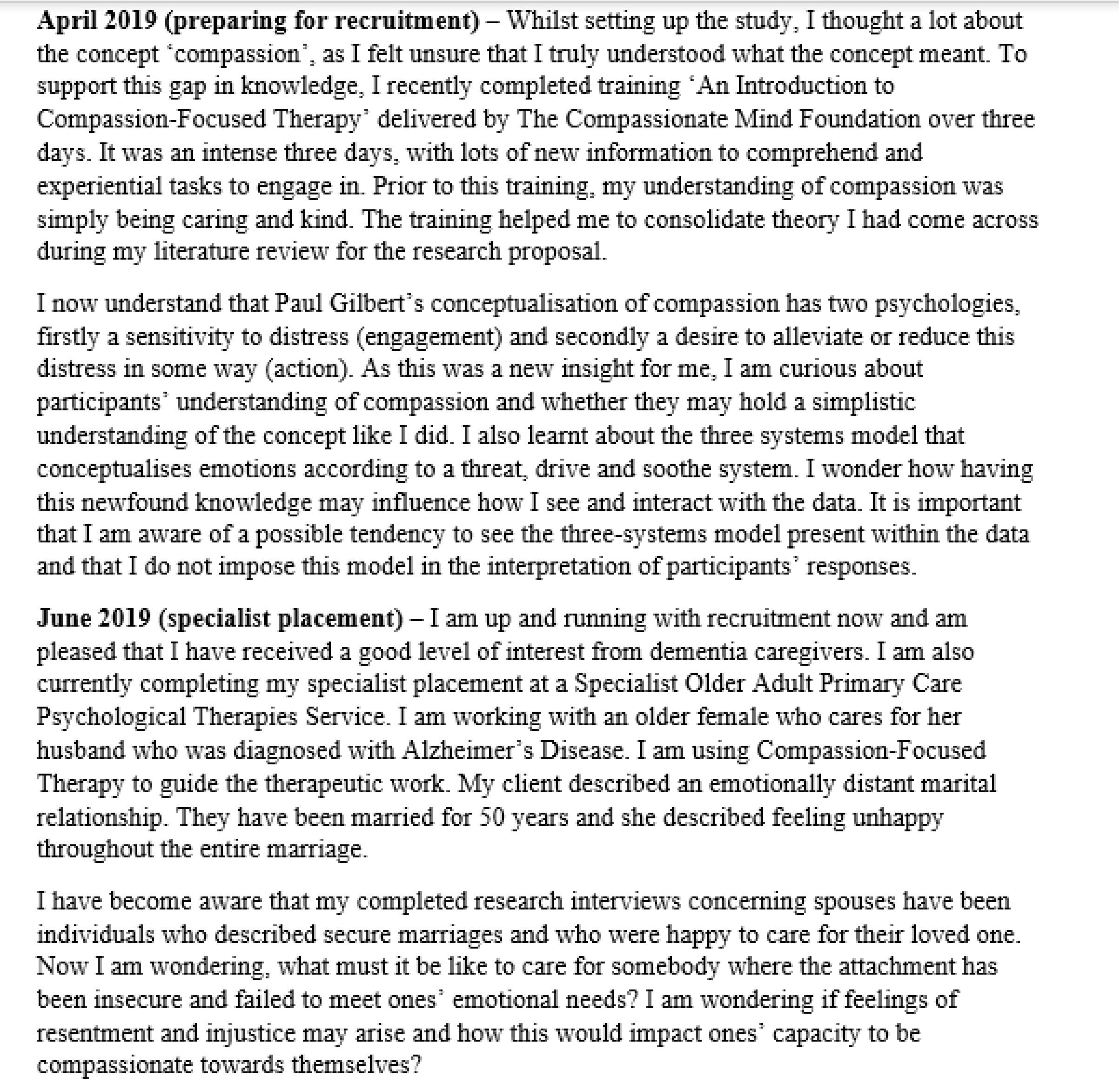
There appeared to be no models exploring self-compassion in informal caregivers for people diagnosed with dementia. Consequently, I felt that a Grounded Theory Approach to build a model would hopefully capture informal caregivers' experiences of self-compassion in the context of the caring relationship. The aim of using Grounded Theory is to become aware of pre-conceived ideas, which will enable me to think about how participants are creating meaning of the world and my interpretation of this.

My initial assumptions are that informal caregivers for people with dementia will find caring for themselves challenging. I expect there may be differences in gender in relation to caregivers looking after themselves. I wonder if male participants may be affected by societal stereotypes such as the "alpha male" or being "macho" and possibly hide their feelings. I wonder if female participants may be more emotionally expressive. I expect that current caregivers may be more self-critical and self-blaming, and I wonder if these processes may shift for bereaved caregivers. I expect that there will be a mix of experiences for caregivers whose loved ones no longer live with them.

I will need to revisit this page of preconceptions to ensure that participants narratives and the theory is grounded in caregivers lived experiences. It might be that I expect certain responses or over interpret responses to align with my assumptions about what I might find. Line by line coding, personal reflective memos, revisiting this statement and research supervision will help to minimise subjectivity and bias. I will keep a journal to reflect on new information that appears from interviews and consider how caregivers are making sense of their experiences.

Appendix 15

Examples from research diary



April 2019 (preparing for recruitment) – Whilst setting up the study, I thought a lot about the concept ‘compassion’, as I felt unsure that I truly understood what the concept meant. To support this gap in knowledge, I recently completed training ‘An Introduction to Compassion-Focused Therapy’ delivered by The Compassionate Mind Foundation over three days. It was an intense three days, with lots of new information to comprehend and experiential tasks to engage in. Prior to this training, my understanding of compassion was simply being caring and kind. The training helped me to consolidate theory I had come across during my literature review for the research proposal.

I now understand that Paul Gilbert’s conceptualisation of compassion has two psychologies, firstly a sensitivity to distress (engagement) and secondly a desire to alleviate or reduce this distress in some way (action). As this was a new insight for me, I am curious about participants’ understanding of compassion and whether they may hold a simplistic understanding of the concept like I did. I also learnt about the three systems model that conceptualises emotions according to a threat, drive and soothe system. I wonder how having this newfound knowledge may influence how I see and interact with the data. It is important that I am aware of a possible tendency to see the three-systems model present within the data and that I do not impose this model in the interpretation of participants’ responses.

June 2019 (specialist placement) – I am up and running with recruitment now and am pleased that I have received a good level of interest from dementia caregivers. I am also currently completing my specialist placement at a Specialist Older Adult Primary Care Psychological Therapies Service. I am working with an older female who cares for her husband who was diagnosed with Alzheimer’s Disease. I am using Compassion-Focused Therapy to guide the therapeutic work. My client described an emotionally distant marital relationship. They have been married for 50 years and she described feeling unhappy throughout the entire marriage.

I have become aware that my completed research interviews concerning spouses have been individuals who described secure marriages and who were happy to care for their loved one. Now I am wondering, what must it be like to care for somebody where the attachment has been insecure and failed to meet ones’ emotional needs? I am wondering if feelings of resentment and injustice may arise and how this would impact ones’ capacity to be compassionate towards themselves?

I am also currently running a coping carers group based on a Cognitive-Behavioural framework to support caregivers' emotional well-being whilst caring for a loved one diagnosed with dementia. Each week I feel that there is a tension between supporting caregivers to reflect upon their own emotional needs and caregivers wishing to talk about the difficulties their loved one has. It seems difficult for caregivers to reflect upon and express their own emotional needs. Do they perceive their own needs as important? Or would it be too painful for them to truly reflect upon their own emotional wellbeing?

July 2019 (completion of first five interviews) – After the initial interviews, I am starting to wonder what the model will look like and the concepts that will capture participants' experiences. Following discussions with my research supervisors there seems to be a running storyline across responses that explains a connection between caring demands (e.g. living with the person with dementia, levels of social support) and the capacity for self-compassion. At times, I have found it challenging to get participants to talk about themselves and their own emotional needs. All participants have wished to tell me about the events leading up to the diagnosis and the difficulties that their loved ones have. I feel like this is mirroring my experiences in the coping carers group. I can feel myself being self-critical wondering if it's something to do with my interviewing style.

September 2019 (first draft of model) – I have finally finished a first draft of the model. I feel pleased with it and am wondering how it may change / evolve with further interview data. The model is currently based on four marital relationships, one parental relationship and all participants live with the person with dementia. I am wondering if bereaved caregivers and caregivers who live separately from the person with dementia have similar or different narratives. I wonder what self-compassion looks like for them. We have decided in supervision to aim to recruit bereaved and caregivers who live separately to hopefully fill this gap in knowledge and to enrich the evolving model.

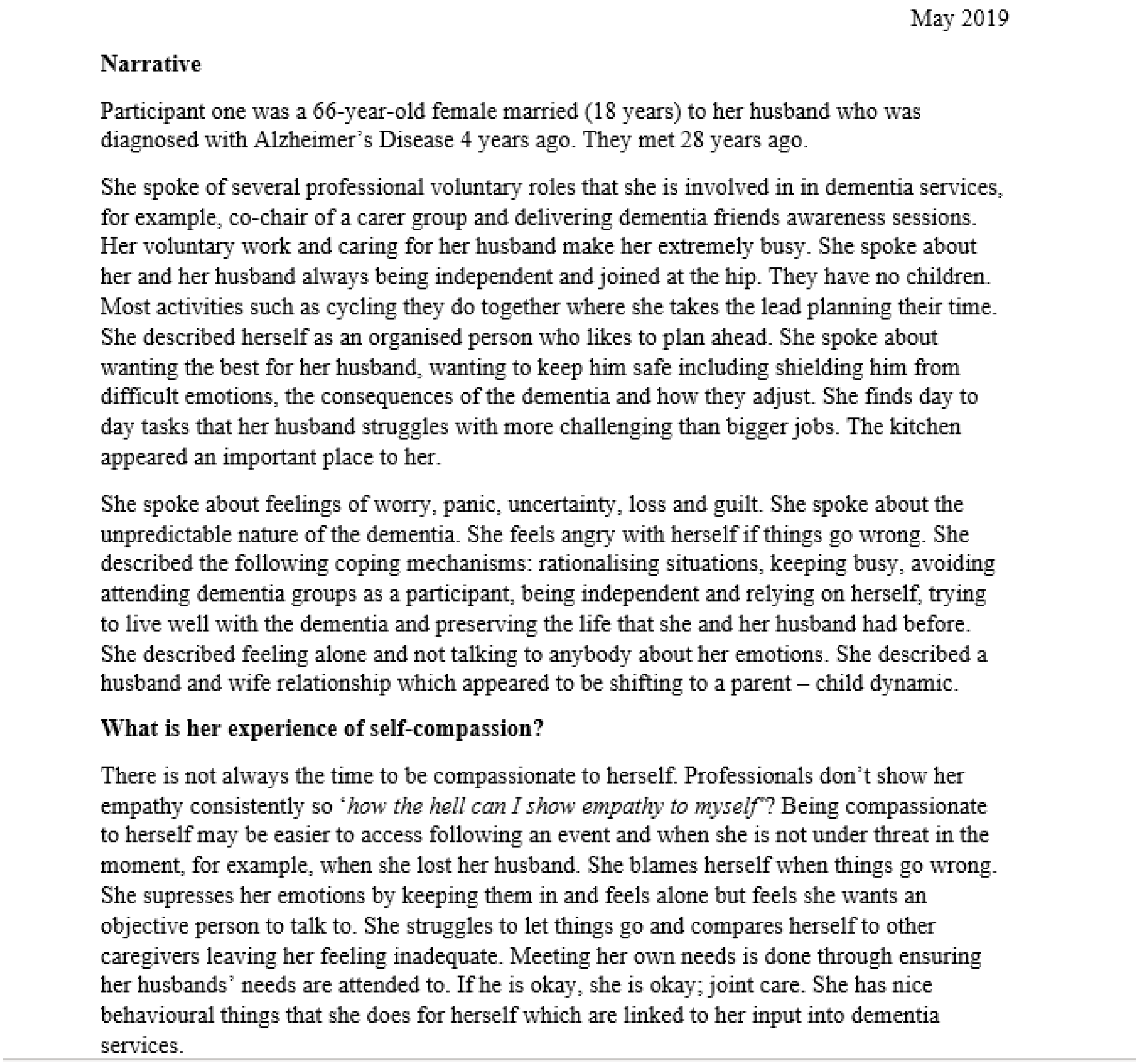
January 2020 (completion of recruitment and data analysis) – I have now completed 10 interviews. Following the 8th interview, during data analysis and discussions in research supervision, it was felt that minimal / no new themes were emerging from participant interviews and therefore we were approaching data saturation. This influenced our decision to complete recruitment following the 10th interview. I have now finalised the model to hopefully incorporate the main themes from all participants' narratives reflecting factors that influence an enhanced or reduced capacity for self-compassion, giving the model explanatory power. I am curious and eager to receive feedback from the caregivers who took part in the research study.

February 2020 (Carer feedback session) – Myself and primary research supervisor met with six participants and one person diagnosed with dementia (care recipient). The remaining four participants were unable to attend the session and were therefore consulted over email. It felt great to see all caregivers again, I felt really privileged that participants shared their narratives with me and were interested to hear what the study found. I felt excited but anxious to share the findings, as I was aware that I really wanted caregivers to feel that I had truly captured their stories well.

I shared a narrative summary and visual model with participants who all shared valuable insights about the research findings. There seemed to be a consensus amongst caregivers that they could recognise themselves in different parts of the diagram including both the enhanced and reduced capacity for self-compassion. This helped clarify the model in my mind in that it is not a static model but a fluid one depending on different variables. Additionally, their feedback supported me to understand that any position on the diagram is neither right nor wrong but more of an adaptive survival response. Furthermore, as participants reported that the model accurately reflected their experiences, I feel that this enabled the model to have face validity and supported ideas in relation to clinical implications.

Appendix 16

Participant reflective summary and diagram



May 2019

Narrative

Participant one was a 66-year-old female married (18 years) to her husband who was diagnosed with Alzheimer's Disease 4 years ago. They met 28 years ago.

She spoke of several professional voluntary roles that she is involved in in dementia services, for example, co-chair of a carer group and delivering dementia friends awareness sessions. Her voluntary work and caring for her husband make her extremely busy. She spoke about her and her husband always being independent and joined at the hip. They have no children. Most activities such as cycling they do together where she takes the lead planning their time. She described herself as an organised person who likes to plan ahead. She spoke about wanting the best for her husband, wanting to keep him safe including shielding him from difficult emotions, the consequences of the dementia and how they adjust. She finds day to day tasks that her husband struggles with more challenging than bigger jobs. The kitchen appeared an important place to her.

She spoke about feelings of worry, panic, uncertainty, loss and guilt. She spoke about the unpredictable nature of the dementia. She feels angry with herself if things go wrong. She described the following coping mechanisms: rationalising situations, keeping busy, avoiding attending dementia groups as a participant, being independent and relying on herself, trying to live well with the dementia and preserving the life that she and her husband had before. She described feeling alone and not talking to anybody about her emotions. She described a husband and wife relationship which appeared to be shifting to a parent – child dynamic.

What is her experience of self-compassion?

There is not always the time to be compassionate to herself. Professionals don't show her empathy consistently so '*how the hell can I show empathy to myself*'? Being compassionate to herself may be easier to access following an event and when she is not under threat in the moment, for example, when she lost her husband. She blames herself when things go wrong. She supresses her emotions by keeping them in and feels alone but feels she wants an objective person to talk to. She struggles to let things go and compares herself to other caregivers leaving her feeling inadequate. Meeting her own needs is done through ensuring her husbands' needs are attended to. If he is okay, she is okay; joint care. She has nice behavioural things that she does for herself which are linked to her input into dementia services.

Hypotheses / ideas / questions

- Small day to day things are experienced as more frustrating than bigger jobs in the house. Why? Does this mean more work for caregivers, more mess for carers to tidy up? Does this represent loss?
- It is important to preserve the life they had prior to the dementia diagnosis and to hold onto what's important, for example, retirement plans. How does this affect the emotional adjustment process?
- Prioritising the person with dementias' needs leads to a suppression in caregivers' emotional needs and therefore carer's needs become unmet.
- Spouses find it easier to care for their partner than their parent. Why? Is there more of a choice with their partner, moral dilemmas with parent?
- Protecting the person with dementia is important to keep them safe. If they are not safe then it's the caregivers' fault, they feel inadequate, to blame and that they should be better. Leads to striving. Does she acknowledge her role when things go well?
- There is no time for self-care, no time or psychological space for caregivers.
- It is important to caregivers how they are perceived or held in the mind of others. Why?
- Being an organised and controlling person clashes with the unpredictable nature of dementia.
- Providing practical support for the person with dementia is easier than providing emotional support. Practically caregivers don't feel alone but emotionally they feel alone.
- It's harder for caregivers to identify positive experiences of caring and things that help their emotional wellbeing and easier to access the more negative experiences of caring.
- Negative experiences of other caregivers such as listening to '*horror stories*' has a negative impact on carer's emotional well-being, increasing worries about the future.
- If caregivers don't perceive the people around them showing them empathy, this makes it challenging to show empathy to themselves.
- Rationalising when things go wrong does not shift the emotion.
- Caregivers evaluate their experiences of caring in relation to perceptions of other carer's experiences. Comparing themselves to other caregivers perceived as less fortunate leads to feelings of gratitude (downward comparison). Comparing themselves to other caregivers perceived as coping and functioning well leads to feelings of inadequacy and criticism (upward comparison).

- Caregivers protect others by not criticising them, but it is more acceptable to criticise themselves.
- Caregivers are good at pretending things look neat and tidy but inside everything is a mess (like the kitchen cupboards).
- If caregivers attend to the person with dementias' needs, then they feel that their needs are also attended to. Joint care.
- Working in a professional dementia role can lead to carers feeling like they lose their informal carer identity.

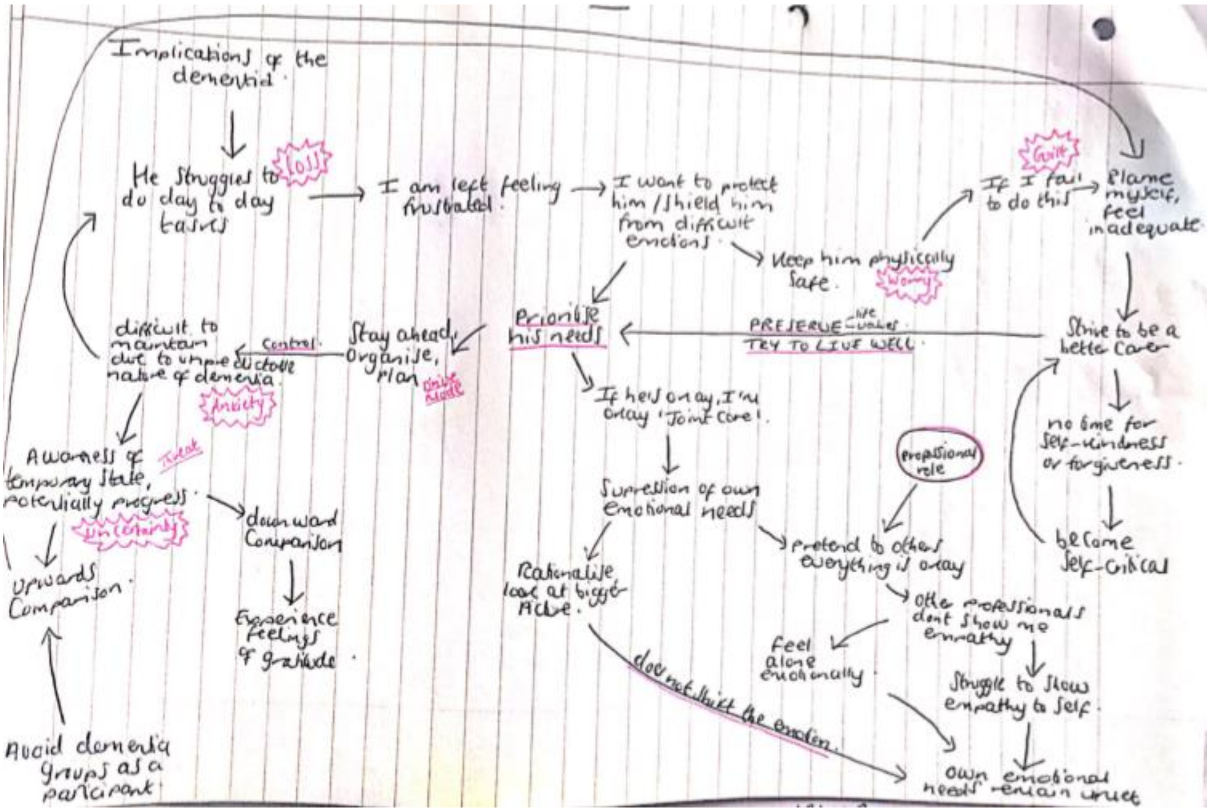
Reflections / What have I learnt?

The participant spoke at great length and at times it felt hard to structure the interview and move onto other questions. I wondered whether this was reflective of her having minimal opportunities to talk about and express her emotions. It appeared a struggle for her to access her cognitions about herself. It felt as if she doubted herself at times and was unsure what being compassionate to herself truly means.

At times I could feel myself wanting to slip into 'therapist' mode as opposed to 'researcher' mode, particularly as we were talking about her difficult emotions. I felt an urge to provide emotional support in attempt to alleviate some of her distress.

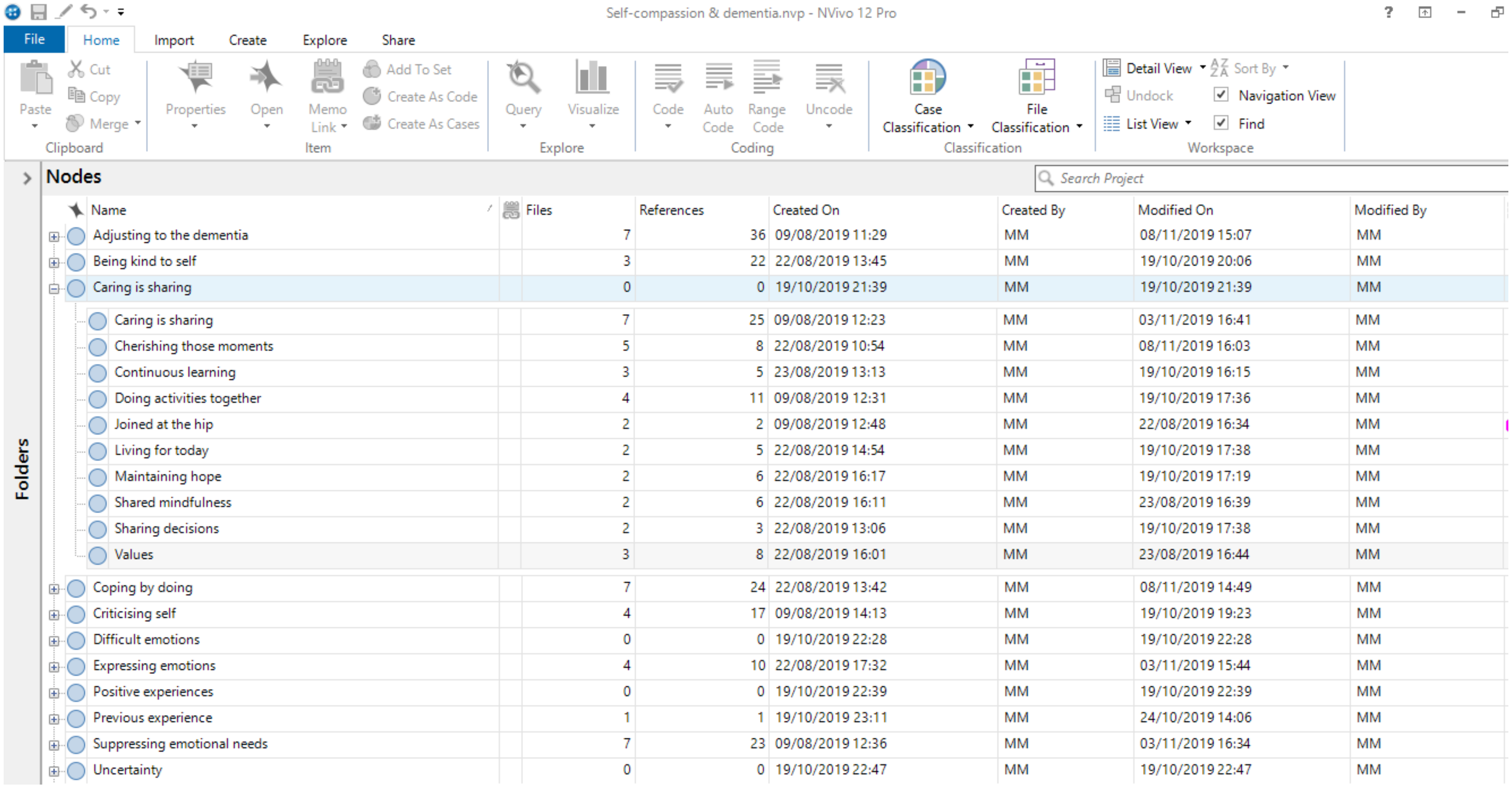
I noticed that I had an assumption that being in professional roles contributing to dementia services would have positive impacts for her wellbeing. To my surprise, this lady spoke about feeling as if other professionals had forgotten she had a husband with dementia, expected a lot from her and did not display empathy consistently. This seemed to impact on her self-to self-relationship in relation to being able to show herself empathy. This helped me to think about the possible consequences of working in professional roles whilst caring.

From my clinical experience most carers have found meeting other carers a positive experience. This lady spoke about avoiding dementia groups as she found it unhelpful talking about dementia a lot of the time and hearing other carer's '*horror stories*'. I have learnt that common humanity in the context of dementia caring may not always be helpful to the individual.



Appendix 17

Example of NVIVO coding



Name	Files	References	Created On	Created By	Modified On	Modified By
Adjusting to the dementia	7	36	09/08/2019 11:29	MM	08/11/2019 15:07	MM
Being kind to self	3	22	22/08/2019 13:45	MM	19/10/2019 20:06	MM
Caring is sharing	0	0	19/10/2019 21:39	MM	19/10/2019 21:39	MM
Caring is sharing	7	25	09/08/2019 12:23	MM	03/11/2019 16:41	MM
Cherishing those moments	5	8	22/08/2019 10:54	MM	08/11/2019 16:03	MM
Continuous learning	3	5	23/08/2019 13:13	MM	19/10/2019 16:15	MM
Doing activities together	4	11	09/08/2019 12:31	MM	19/10/2019 17:36	MM
Joined at the hip	2	2	09/08/2019 12:48	MM	22/08/2019 16:34	MM
Living for today	2	5	22/08/2019 14:54	MM	19/10/2019 17:38	MM
Maintaining hope	2	6	22/08/2019 16:17	MM	19/10/2019 17:19	MM
Shared mindfulness	2	6	22/08/2019 16:11	MM	23/08/2019 16:39	MM
Sharing decisions	2	3	22/08/2019 13:06	MM	19/10/2019 17:38	MM
Values	3	8	22/08/2019 16:01	MM	23/08/2019 16:44	MM
Coping by doing	7	24	22/08/2019 13:42	MM	08/11/2019 14:49	MM
Criticising self	4	17	09/08/2019 14:13	MM	19/10/2019 19:23	MM
Difficult emotions	0	0	19/10/2019 22:28	MM	19/10/2019 22:28	MM
Expressing emotions	4	10	22/08/2019 17:32	MM	03/11/2019 15:44	MM
Positive experiences	0	0	19/10/2019 22:39	MM	19/10/2019 22:39	MM
Previous experience	1	1	19/10/2019 23:11	MM	24/10/2019 14:06	MM
Suppressing emotional needs	7	23	09/08/2019 12:36	MM	03/11/2019 16:34	MM
Uncertainty	0	0	19/10/2019 22:47	MM	19/10/2019 22:47	MM

Appendix 18

Coding matrix

	1	2	3	4	5	6	7	8	9	10
Difficult emotions	Overlooks	Acknowledges	Acknowledges	Mainly overlooks	Overlooks	Acknowledges	Overlooks	Overlooks	Acknowledges	Acknowledges
Uncertainty of dementia	Struggles to tolerate	Tolerates	Tolerates	Struggles to tolerate	Struggles to tolerate	Tolerates	?	?	Tolerates	Tolerated
Surrounding network / support	No – no family, minimal friends, professionals - rejecting	Yes – family, friends - Supporting	Yes – family, friends - Supporting	Yes – family, friends, professionals - Supporting	Yes – family, professionals but copes independently Friends - rejecting	Some – attends carer group but lives alone Family & friends - rejecting	No – family & professionals - rejecting	Yes – family, other carers - supporting	Yes – other carers, professionals - supporting	Yes – family, friends, professionals - supporting
Understanding of self-compassion	For both Unsure of meaning	For self Deserving	For self Deserving	For both Deserving	For others ?	For self Sacrificing?	For both ?	For others Sacrificing	For self Deserving	For self Deserving
Self-care	No	Yes	Yes	Yes	No	Yes	No	No	Yes	Yes
Emotional Expression	No	Yes	Yes	Sometimes	No	No	No	No	Sometimes	Yes
Ways of coping	Restricted	Diverse	Diverse	Diverse	Restricted	Diverse	Restricted	Restricted	Diverse	Diverse
Caring is sharing	No - Always prioritise PwD	Yes	Yes	Yes	No – Always prioritise PwD	Yes – tries to put own needs first	No – Prioritised PwD	?	Yes	Yes
Critical of self	Yes	No	No	No	Yes?	Sometimes	Sometimes	No?	Sometimes	No
Emotional suppression	Yes	No	No	Sometimes	Yes	Yes	Yes	Yes	Sometimes	No
Defend against emotional pain	Yes	No	No	Sometimes	Yes	No	Yes	Yes	Sometimes	No

Appendix 19

Mapping focused codes onto theoretical codes

Theoretical codes
Focused codes
Initial codes

Transitioning into dementia world (including re-evaluation of life goals & values)
Loss process
Experiencing emotional pain
Experiencing grief
Experiencing loss
Experiencing a sense of injustice
Implications of the dementia
Loss of relationship
Witnessing physical decline

Becoming the leader
Adjusting process
Investing in new roles
Medical complications
Protecting the person with dementia
Risk situations
Providing practical support
Taking the lead
Transitioning to parent-child dynamic

Becoming the visitor
Contemplating long-term care
Feeling free
Feeling obligated
Feeling relief
Transitioning to long-term care
Visiting the person with dementia

Re-evaluating life
Importance of giving to dementia services
Life changing
Living on borrowed time
Living well with dementia
Preparing for the future
Relating to the dementia as the norm
Time is a healer
Thinking about death

Positive experiences
Acknowledging positive moments
Appreciating new opportunities
Protective characteristics

Feeling reconnected with family
Feeling socially connected to others

<u>Influencing processes</u>

Uncertainty of dementia (tolerate or struggle)
Feeling uncertain about the future
No control over the progression
Thinking about own future health
Unpredictable nature of dementia

Difficult emotions (acknowledge or overlook)
Experiencing carer burden
Experiencing shame
Feeling alone
Feeling anxious
Feeling attacked
Feeling defeated
Feeling demanded of
Feeling frustrated with the person with dementia
Feeling guilty
Feeling inadequate
Feeling misunderstood by others
Feeling of entrapment
Feeling regret
Feeling resentful
Feeling responsible for the person with dementia
Feeling restricted
Feeling threatened
Feeling unappreciated

Surrounding network (supportive or rejecting)
Battling with services
Being socially rejected
Being mistreated by others
Being rejected by family
Experiencing deceit
Experiencing power struggles
Difficult family dynamics
Just the two of us
Pressure from family
Receiving carer support
Receiving family support
Receiving professional support
Secure relationship with the person with dementia

Understanding of self-compassion (deserving or sacrificing)
Both needs as one
Compassion is for others

Feeling sorry for self
Prioritising own needs
Recognising own needs
Questioning the meaning of self-compassion

Enhanced capacity for self-compassion

Self-care & openness
Accepting of help
Accepting of the situation
Awareness of common humanity
Being kind to the self
Recognising own efforts
Recognising own limits
Self-reflection

Emotional expression
Expressing internal feelings
Seeking support
Seeking proximity

Ways of coping
Correcting my actions
Doing mindful activity
Experiencing gratitude
Externalising the dementia
Having time for self
Having respite
Looking at the bigger picture
Making downward comparisons
Needing something for self
Prior caring experience
Rebuilding my life
Taking each day as it comes
Putting boundaries in place
Using knowledge to understand

Caring is sharing
Caring is sharing
Continuous learning
Cherishing those moments
Doing activities together
Joined at the hip
Living for today
Maintaining hope
Shared mindfulness
Shared decision making
Values

Reduced capacity for self-compassion

Self-criticism
Criticising self
Blaming self
Doubting self
Disappointed with self
Making upwards comparisons
Perceiving judgement
Putting expectations on self
Rumination
Social comparisons
Thinking about how others perceive me

Emotional suppression
Supressing emotional needs
Avoiding burdening others
Avoiding difficult emotions
Initial denial
No shift in emotion
Struggling to accept

Defending against emotional pain
Avoiding carer groups
Blocking things out
Keeping busy
Living by family cultural values
Preserving life
Prioritising the person with dementias' needs
Professional approach
Rationalising
Safety Planning
Seeking reassurance
Stiff upper lip
Striving
Thinking positively
Unmet emotional needs
Using masculinity

Appendix 20

Narrative summary for participants at feedback session

Research findings: self-compassion in informal caregivers for people diagnosed with dementia

Thank you for volunteering in the research project looking at self-compassion in informal caregivers for people diagnosed with dementia. Offering your time to take part in the interview and to talk about your experiences of caring allowed the research to take place and to discover some important findings. The research included ten informal caregivers in total, all who offered a unique contribution to the study.

All participants talked about **transitioning** or adjusting to the dementia diagnosis and therefore their caring role. Many talked about experiencing a sense of **loss** as a result of the dementia, which included feelings of grief and a sense of injustice. Participants reflected on needing to take the **lead** in relation to daily activities and decisions. Some talked about investing in new roles such as cooking, attending to household duties and managing finances. Other caregivers (living separately) spoke about becoming a **visitor** to their loved one and regularly visiting them in a care home. Most caregivers explained that the dementia diagnosis represented a huge change in their ideas and hopes for their future, and a need to **re-evaluate** their priorities considering decisions such as possible future care for their loved one. A small number of caregivers spoke about **positives** that came with their caring role. This included families reconnecting and having new opportunities such as travelling or working in a professional role to input into dementia services.

All participants spoke about trying to tolerate the **uncertainty of dementia**. This included reflecting on the day to day unpredictable nature of dementia, having no control over the progression and therefore feeling uncertain about the future. Some caregivers had **different ways of coping** with this uncertainty such as using knowledge to understand dementia, doing mindful activity, having time for themselves, externalising the dementia (*'it's not her fault, it's the dementia'*), taking each day as it comes and having gratitude. Having varied ways of coping fostered a mindset of "*I am doing my best*". Some caregivers talked about finding it difficult to tolerate the uncertainty of dementia and would put much of their energy into **keeping busy**, prioritising their loved one and "*just getting on with it".* We hypothesised that keeping busy may have protected caregivers from experiencing overwhelming emotions.

All participants spoke about experiencing **difficult emotions** within their caring role including, anxiety, worry, guilt, frustration and many more. Some caregivers explained that they would **seek emotional support** from the people around them including family, friends, other caregivers and healthcare services and **express how they were feeling**. This tended to have a good impact upon their emotional wellbeing, leaving caregivers feeling supported and understood. Other caregivers talked about **avoiding talking about their emotions** with the people around them and therefore **suppressing difficult feelings**. This was often driven by a fear of burdening others and for some not seeing their own emotional needs of worthy of being heard. We hypothesised that this had the unintended consequence of leaving caregivers feeling **threatened and alone**.

A key finding of the study was caregivers' **surrounding network**. Some reported **supportive** and **nurturing** relationships around them which would support them in their caring role.

Caregivers in this position tended to relate to themselves with self-care and forgiveness, recognising "*I am only human*". Also, having support from others allowed caregivers to have some respite and time for themselves. Others talked about **critical** and **rejecting** experiences with others including family, friends and services. Caregivers in this position sometimes related to themselves with **self-criticism**, blaming themselves for difficult times, comparing themselves to other caregivers and beating themselves up. Caregivers **understanding of self-compassion** appeared to be influenced by the people around them as to whether they perceived self-compassion as something they deserved for themselves or something that was for other people.

The model proposes that tolerating the uncertainty of dementia, acknowledging difficult emotions, having support from others and a positive view of self-compassion, leads to an **enhanced capacity for self-compassion;** which is made up of self-care, expressing ones' emotions and varied ways of coping. On the other hand, struggling to tolerate the uncertainty of dementia, overlooking difficult emotions, having negative experiences with others and a negative view of self-compassion, leads to a **reduced capacity for self-compassion;** which is made up of self-criticism, supressing ones' emotions and keeping extremely busy. An enhanced capacity for self-compassion was linked to **caring is sharing**. This was a category that represents joint care including caregivers and the person with dementias' needs being met.

The model is fluid and therefore people can move to different places on the model depending on the influencing processes. We welcome any feedback from you.

Clinical implications to support caregivers' psychological needs:

- Support caregivers to develop distress tolerance skills specifically related to dementia.
- Support caregivers to develop or enhance their awareness of their internal world including difficult emotions and acknowledge their presence.
- Provide caregivers with positive and supporting relationships through services, allowing caregivers to internalise a compassionate and caring way of relating to themselves.
- Support the understanding of self-compassion, working through possible fears, blocks, or resistances to engaging in this motivation and consider extending education on compassion to family members and healthcare staff (e.g. in care homes).