Living with Aggression: Exploring the Experiences of Spouses Caring for a Partner with Dementia

By

Charlotte Kelland

A thesis submitted to the University of Birmingham for the degree of DOCTOR OF CLINICAL PSYCHOLOGY

Centre for Applied Psychology
School of Psychology
The University of Birmingham
MAY 2023

Thesis Overview

This thesis is submitted in partial fulfilment of the requirements for the degree of Doctor of Clinical Psychology (ClinPsyD) at the University of Birmingham. This thesis comprises of three chapters.

Chapter one consists of a literature review that presents a qualitative meta-ethnography examining how informal caregivers of people with dementia experience changes to their self-identity through the caregiving experience. It further explores how perceived identity changes can affect an individual's self-esteem and in turn their psychological well-being.

The second chapter is an empirical study exploring the experiences of spousal caregivers looking after a partner with dementia-related aggressive behaviours, with a specific focus on how these behaviours impact on the spousal relationship.

The third chapter presents a public domain document (i.e., a press release) providing an overview of the literature review and the empirical paper.

Acknowledgements

First and foremost, I would like to thank Gerry Riley for supervising my research. Thank you for your support, patience, expertise, and guidance throughout this process. Thank you for your reassurance and for helping me to stay calm during the storms of research.

I would also like to thank Andy Fox and Darrelle Villa for teaching me everything I know about writing a meta-synthesis, and for always knowing (or helping me to find) the answers to my many (many) queries. Thank you to the entire Doctor of Clinical Psychology Course team at the University of Birmingham for the unwavering support throughout the last three years.

I would like to say a big thank you to my participants for taking the time and having the courage to share your story with me. This research would not have been possible without you.

Thank you to my family, Scott, and my best friends Jessica Stewart and Lucy Peden for helping me get here and for never letting me give up. You have believed in me far more than I believed in myself. Thank you to Emily Compton-Smith for proofreading my work and for always being my biggest cheerleader and my best friend. Thank you to my cohort, I could not have done this without you, especially to Elizabeth Maund for coming on the double qual journey with me and to Angharad Chidgey for the daily debriefs and endless cups of tea. Lastly, a special mention to those who helped me through the challenging times and held me up along the way: Philippa McQuilton, Elizabeth Maund, Cat Gercs, Ben Jackson, and Bekky Harrison. You have been a very important part of my doctorate journey and your support means the world to me.

Dedications

I dedicate this thesis to my mum, my dad, my brother Luke and my sister Rachael for their unconditional love and support. I would also like to dedicate this thesis to my Godson George. You are my ray of sunshine, my inspiration, and my beacon of hope. Thank you for being you.

Table of Contents

A)

1. Chapter One: Literature Review

2. Chapter Two: Empirical Project

Figures

Literature Review

Empirical Research Paper

Tables

Literature Review

Empirical Project

CHAPTER ONE

HOW DOES CAREGIVING FOR A LOVED ONE WITH DEMENTIA IMPACT ON AN INDIVIDUALS SELF-IDENTITY AND SELF-ESTEEM? A META-ETHNOGRAPHY.

Abstract

Aims: This meta-ethnography aimed to examine the existing qualitative literature uncovering how caregiving for a loved one with dementia can impact on one's self-identity. The secondary aim was to synthesise any findings from these studies regarding associated effects on self-esteem and psychological well-being.

Method: A systematic literature search was conducted on four databases, which identified 12 qualitative papers from peer reviewed journals. The papers were appraised using a methodological quality framework. The papers were synthesised using Noblit and Hare's (1988) meta-ethnographic approach, which involved findings similarities and differences across papers and translating papers into each other to develop shared meanings.

Results: Three main themes (in bold) and six sub-themes (in italics) were identified that capture the experiences of caregivers: **1. Personality changes – "who am I?**, *Perceived negative changes, Upskilling and personal growth.* **2. Changes in relational and social identity**, *Changes in relationship with care receiver, Changes in other relational roles*. **3. The relationship between the caregiving identity and self-esteem**, *Not feeling like a good enough caregiver, Boosting self-esteem.*

Conclusion: The findings highlighted that caregiving for a loved one with dementia can have an adverse impact on an individual's self-identity and self-esteem. This was found to occur when the 'caregiving' identity began to overwhelm and replace pre-existing aspects of one's identity, which could negatively alter the way individuals perceived themselves. The possible impact of such on one's psychological well-being is discussed. Recognising ways to help caregivers preserve their identity may be an important factor of consideration for health care services.

Introduction

Dementia is becoming a growing challenge in an ever-aging population (Cross et al., 2018). In the UK, it is estimated that around 850,000 people currently have dementia, with this figure predicted to continue rising (National Health Service [NHS] England, 2022). In their latest report, NHS England (2022) predict the economic costs of dementia in the UK to stand at around £23 million a year.

The rise in prevalence rates has seen an increase in the number of family and friends providing informal care to loved ones with dementia (Richardson et al., 2013). Research has found that caregivers of people with dementia can experience varying degrees of adverse psychosocial problems (Joling et al., 2010), and compared to the general population, are more likely to experience increased stress, physical health problems, psychosomatic disorders, and reduced overall well-being (Pinquart & Sörensen, 2004). As such, dementia care has become one of the most importance health and social care issues in the UK and is a key priority for both NHS England and the government (‘Challenge on Dementia 2020’, 2015; NHS England, 2022).

In 2015, the prime minister launched the “Challenge on Dementia 2020” plan which proposed to enhance dementia care and support in England, including supporting research into dementia with the aim to inform treatment pathways and interventions. Exploring caregivers’ experiences of looking after loved ones with dementia may help educate us about how to enhance positive health outcomes (Crellin et al., 2014). Improvements in caregivers’ quality of life may result in better quality of care being delivered to loved ones, which may reduce or delay the necessity for residential care or hospitals, reducing economic pressures (Rosness et al., 2011). Therefore, there is a pressure to understand caregiver’s individual experiences and needs by considering the factors that can influence their well-being (Chattillion et al., 2013).

A review of the literature conducted by Schluz and Martire (2004) identified numerous studies that highlighted the adverse impacts of caring for a loved one with dementia on caregivers’ psychological well-being. Mallya and Fiocco (2018) conducted a quantitative study comparing the Quality of Life (QOL), stress, and depression, in 57 informal caregivers and 97 non-caregivers. Results found that dementia caregivers experienced significantly more stress (p=<.001), reduced QOL (p=<.001) and higher rates of depression (p=<.001) than their counterparts.

Research has detected many ways in which caring for a loved one with dementia can impact on psychological well-being (Lindeza et al., 2020). One area in which there is growing interest, yet sparse evidence is the impact that caregiving can have on one's self-identity and self-esteem, and how this can affect one's psychological well-being.

The concepts of Self-Identity and Self-esteem

Identity is described by Erikson (1963) in his Psychosocial Development Theory as one's ability to experience themselves as something that has "continuity and sameness, and to act accordingly" (p.42). Within the literature, different models emphasise the importance of different aspects of identity, however all are united in that the primary function of identity is to provide oneself with a sense of inner coherence and continuity (Pilarska, 2020). Identity has been understood as a multifaceted phenomenon that includes one's inner thoughts and feelings, their uniqueness, coherence, and self-worth (Pilarksa, 2020). According to personality theories, the construction of a stable identity is an imperative part of personal well-being (Erikson, 1980; Waterman, 2007).

Oyserman (2001) stated that self-identity provides answers to the basic questions of 'who am I?'. According to Higgins (1987) self-discrepancy theory, a person withholds multiple perspectives of themselves. The *actual self* describes the attributes and traits a person genuinely has, the *ideal self* refers to attributes one would like to have or has potential to have, and the *ought self* reflects the attributes one feels they should have. Self-discrepancies are perceived differences between the actual, the ideal, and the ought self. Higgins (1987) theorised that discrepancies between the actual and the ideal self can predict sadness and depression, whereas discrepancies between the actual and the ought self can trigger anxiety and guilt.

Self-esteem is defined by Thoits (1999) as one's understanding of their quality as a person, including how good or bad they are and how valuable they are. In essence, self-esteem is an evaluation of one's identity and as such provides a link between self-identity and psychological well-being: psychological well-being suffers if an individual does not feel satisfied with themselves, or if they feel disliked or undervalued by others (Sharma & Sharma, 2010).

Self-identity, Self-esteem, and Psychological Well-being

It is unified across psychological models and theories that psychological well-being is greatly influenced by a positive self-perception and high self-esteem. Psychological disorders are in turn believed to be partly attributed to inadequate identity development, identity loss, and threats to self-esteem (Sharma & Sharma, 2010).

Research exploring the impact of self-identity on psychological well-being in dementia caregivers is sparse. However, there is evidence from research in other domains that suggests that identity disruption can lead to low self-esteem, which can in turn predict poorer psychological well-being. Matheson et al. (2015) explored this concept through in-depth interviews with 41 women who had experienced intimate partner violence. Participants discussed how their identities had been deconstructed through their experiences, and their self-esteem had been damaged. Damages to self-esteem and self-identity were found to predict persistent negative effects on individuals' mental well-being, with many participants experiencing depression. A quantitative study by Henriguez et al. (2021) examined the relationship between identity variables (identity fusion, collective self-esteem, and ethnic identity) and psychological well-being in an immigrant population. Results from 887 participants found that ethnic identity and collective self-esteem (aspects of self-esteem related to belonging to a social group) both had significant positive relationships with psychological well-being. The authors concluded that maintaining a positive social identity helps to increase self-esteem and in turn, support psychological well-being.

Identity Disruption in Dementia Caregiving

Dementia caregiving has been found to lead to identity disruption (Cooper, 2021; Montgomery & Kosloski, 2012) and low self-esteem (Lamont et al., 2019). Identity disruption is said to occur amongst caregivers when personal experiences do not align with one's view of their self, and when there is an incongruence between one's caregiver role, and their previous identity (Montgomery & Kosloski, 2012). Eifert et al. (2015) describe the concept of 'role engulfment' which occurs when the pressures of caregiving overtake other social roles and start to shape one's identity. The authors explain that caregivers generally have less time for other activities or behaviours that previously defined them, and thus the role of "caregiver" becomes their dominant identity. Cooper (2021) elaborates that as the caregiving role becomes more demanding, caregivers may start to make sense of their identity in the context of caregiving, and this may overtake other aspects of oneself. Other research has emphasised that other aspects of the social self and relational roles (e.g., parent, neighbour, sibling) are relegated as the demands of caregiving take over (Sabat, 2001) and identity can be negatively impacted when people are no longer able to engage in previously enjoyed hobbies and interests that helped to define them (Wilcock, 1999).

Montgomery and Kosloski (2012) discuss how caregiving often develops in the context of existing familial roles (i.e., daughter, son, spouse), yet the caregiver may start to perform tasks and responsibilities that are incongruent with the existing relational role (i.e., feeding, washing). This may impact on the caregiver's relational identity as they come to perceive themselves as more of a "parent" or "carer", than as a partner (Hayes et al., 2009; Miller et al., 2008).

Identity disruption is theorised to be more intense when it does not align with one's expectations, or when they have little time to adjust to the caregiving role (Cash et al., 2019). Cash et al. (2019) propose that spouses may experience less identity disruption, because it is accepted that caring for your partner in old age is part of the spouse role. Identity disruption can be protected when family caregivers incorporate the role of caregiving into their existing identities, rather than replacing one for another (Montgomery & Kosloski, 2012).

Self-esteem and Psychological Well-being in Dementia Caregivers

A UK study sampling 1283 dementia caregivers by Lamont et al. (2019) found that higher levels of self-esteem were associated with better psychological well-being in dementia caregivers. Conversely, low levels of self-esteem were detected as risk factors for poorer psychological well-being. A cohort study by Lethin et al. (2017) sampling 1223 dementia caregivers found that caregivers with better psychological well-being reported higher levels of self-esteem. Caregivers with better psychological well-being reported less caregiver burden, more positive experiences of caregiving, and better quality of care being delivered to their care recipient.

Aims of Review

Psychological well-being has been uncovered to be an imperative issue for dementia caregivers. Disrupted self-identity and low self-esteem have been found to predict poor psychological well-being in other domains, however this is relatively unexplored in relation to dementia caregivers. Although research has separately detected identity disruption, reduced self-esteem, and poor psychological well-being in dementia caregivers, it is important to better understand how these concepts interrelate.

As noted, although issues of self-identity have emerged in qualitative studies with dementia caregivers, this has rarely been the focus of the study. Consequently, there is a lack of overarching detailed accounts. The primary aim of this review is therefore to synthesise findings from these qualitative accounts as a preliminary step in providing a more detailed overview of the impact of caregiving for a loved one with dementia on an individual's self-identity. The secondary aim is to synthesise any findings from these studies regarding associated effects on self-esteem, and any links with psychological well-being.

Method

Over the past two decades, there has been an emergence of qualitative studies conducted in health research focusing on the subjective experiences and perspectives of the population (Atkins et al., 2008; Harden et al., 2004). As such, there is an increasing interest in research that synthesises qualitative papers, known as a meta-synthesis (Thomas & Harden, 2008). A meta-synthesis presents a systematic review and integration of findings from qualitative research (Lachal et al., 2017). Synthesising evidence from primary qualitative studies can help generate more comprehensive and generalisable theories by adding more breadth and depth to existing literature and providing insight into personal experiences that can better inform care and treatment pathways (Atkins et al., 2008; Campbell et al., 2011; Dalton et al., 2017). A meta-ethnography is a widely used approach to synthesising qualitative evidence in health research (Sattar et al., 2021). Originally developed by Noblit and Hare (1988), meta-ethnographies use a structured process to compare and analyse themes gathered from multiple perspectives.

A qualitative review was selected for the current paper to allow valuable insight into the lived experiences of caregivers regarding the impact of caregiving on one's self-identity and self-esteem. This hoped to generate rich and in-depth findings that cannot be achieved using quantitative methods. Qualitative evidence in this domain is sparse and there is little existing literature discussing this phenomenon from the perspectives of caregivers themselves. It was therefore hoped that this research could contribute new, useful findings that may pave the way for future research and allow the voices of dementia caregivers to be heard.

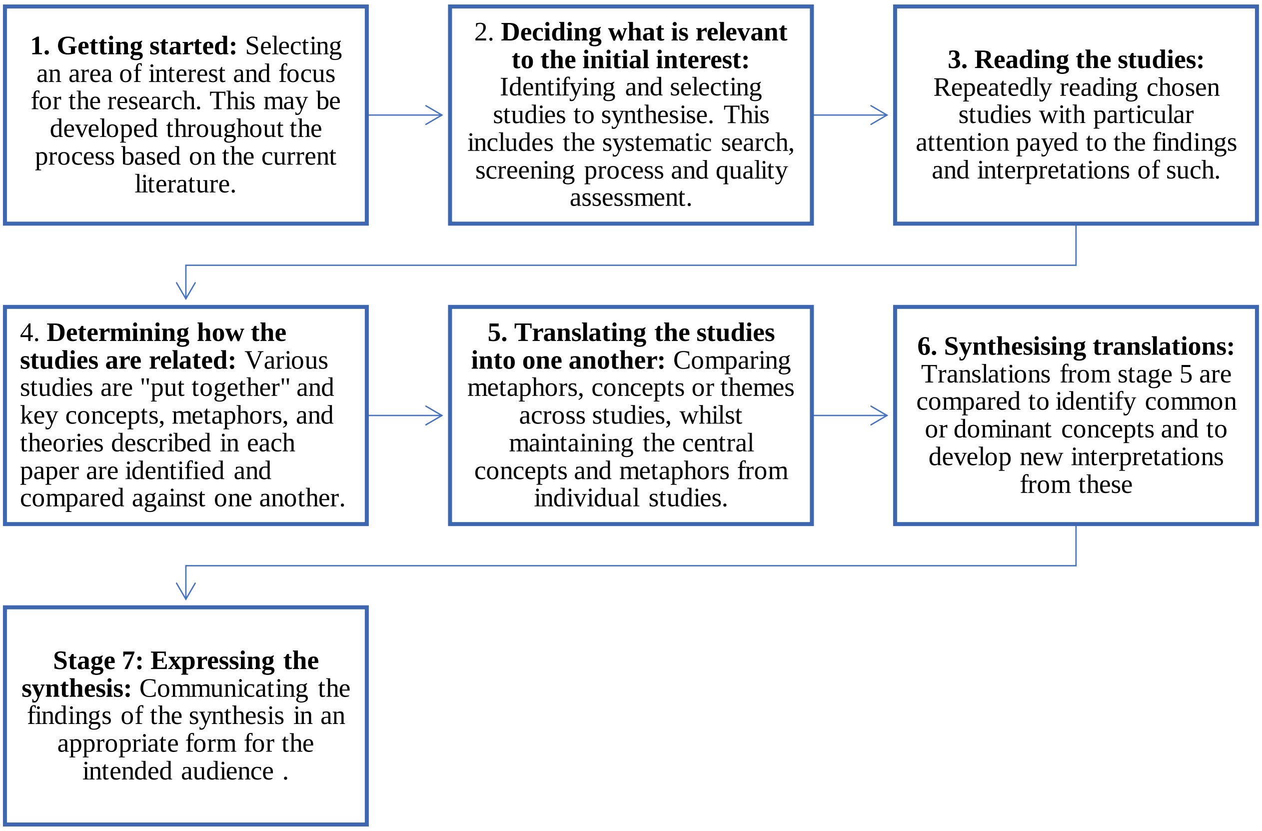
A meta-ethnographic approach was deemed most appropriate due to the nature and quality of the papers included in the synthesis. Only half of the papers selected explored self-identity as a main aim or focus of their study. For the other six papers, themes around self-identity were explored in part or presented as an additional finding. The analysis of data was therefore conducted by the researcher using mostly first order constructs (direct quotes from participants) and third order constructs (the current researcher's interpretations of the data), and less so using existing themes and subthemes from papers, and second order constructs (interpretations made by authors of each paper). A meta-ethnography allows this approach to data analysis and considers the position and influence of the current researcher (Thomas & Hardy, 2008), which was imperative to this analysis. As such, the steps and stages of a meta-ethnographical approach presented a better fit for data analysis than other qualitative methods.

This research adopted an inductive approach to data analysis and aimed to openly explore a new phenomenon with no existing theory or hypothesis. A meta-ethnographical method supports an inductive approach to data analysis and is particularly suited to developing new conceptual models and theories (Sattar, 2021), further indicating the appropriateness of this approach for the current review.

This meta-ethnography was guided by Noblit and Hare's (1988) seven phases of synthesising qualitative research which provides clear guidance for the process of systematic comparisons and translations of qualitative literature. These phases are outlined in Figure 1.1

Figure 1.1

The Seven Guiding Principles of Conducting a Meta-ethnography by Noblit and Hare (1988: p.26-29).



1. Getting started: Selecting an area of interest and focus for the research. This may be developed throughout the process based on the current literature.

2. **Deciding what is relevant to the initial interest:** Identifying and selecting studies to synthesise. This includes the systematic search, screening process and quality assessment.

3. Reading the studies: Repeatedly reading chosen studies with particular attention payed to the findings and interpretations of such.

4. **Determining how the studies are related:** Various studies are "put together" and key concepts, metaphors, and theories described in each paper are identified and compared against one another.

5. Translating the studies into one another: Comparing metaphors, concepts or themes across studies, whilst maintaining the central concepts and metaphors from individual studies.

6. Synthesising translations: Translations from stage 5 are compared to identify common or dominant concepts and to develop new interpretations from these

Stage 7: Expressing the synthesis: Communicating the findings of the synthesis in an appropriate form for the intended audience .

Stage 1 and 2

Search Strategy

A topic area was chosen based on gaps in the existing literature as discussed in the introduction section of this paper. The topic for the empirical paper presented in chapter two of this report was determined prior to the topic for the literature review and thus inspired the topic for this chapter. It was important to the researcher that the topics for both papers complemented each other and supported the researcher's endeavour to give a voice to dementia caregivers.

A systematic search of four databases (PsycInfo, Embase, Web of Science, and Scopus) was performed between January 2022 and March 2022. This search was repeated in June 2022 to identify any new papers. The databases detected research published between January 1987 and the 7th of May 2022. These databases were chosen as they were deemed to be most relevant to the research area of dementia, as decided by the researcher and research supervisor. A final search was conducted in Google scholar to detect any potential papers that had been missed. The results from the searches were exported into EndNote software, to enable an efficient screening process. Duplicates were removed prior to the systematic screening process.

Search terms were initially devised based on terms used in existing literature and were then consolidated following a consensus discussion between the primary researcher and the research supervisor, and an initial scoping review. Table 1.1 shows the search terms and truncations used.

Table 1.1

Search Terms used for Database Search.

Caregiver (keyword/topic, title, abstract)	**Dementia (Keyword/topic, title, abstract)**	**Identity (Keyword/topic, title, abstract)**
"Family carer"	Dementia	"Sense of self"
"Family caregiver"	Alzheimer*	"self-identity"
"Spous* care*"		personhood
Partner		identity
Son		"Social-identity"
Daughter		"self-image"
Relative		
"Loved one"		

Note. An Asterix after a search term is a 'wildcard' that enables all terms that begin with the preceding characters to be used in the search.

Inclusion/Exclusion Criteria

Following the completed searches, the screening process began by removing duplicates. A screening of the papers via title and abstract was then conducted based upon the inclusion/exclusion criteria outlined in Table 1.2. Abstracts with too little information to apply criteria were kept for further review. For this review, informal caregivers were defined as any family member who self-identified as the primary caregiver (e.g., dedicated the greatest number of hours to caregiving) for a loved one with dementia. Papers were only included if they reported quotes from participants themselves discussing the impact of caregiving on their self-identity and/or self-esteem. Papers that only included authors interpretations or theories of such were excluded.

Table 1.2

Inclusion and Exclusion Criteria

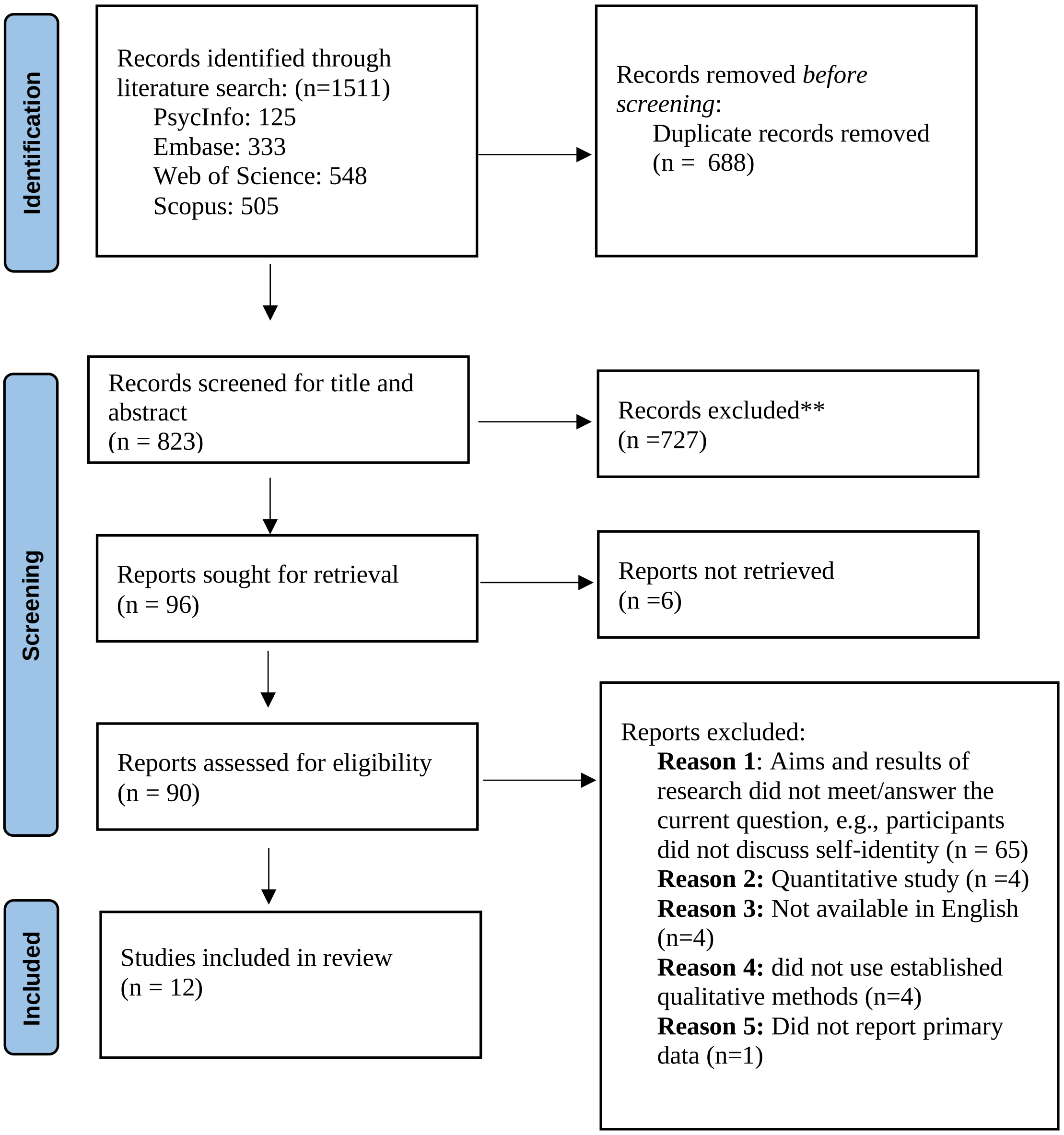
Inclusion Criteria	**Exclusion criteria**	**Rationale**
Qualitative papers and mixed method papers.	Quantitative only papers, papers that do not use an established qualitative analysis method (e.g., no formal analysis conducted).	Meta-ethnography is a technique aimed at synthesising qualitative literature. Non-formal analysis methods may not produce reliable findings which may impact the validity and usefulness of the synthesis.
Papers focusing on the identity of informal caregivers caring for a family member/close friend with dementia. Papers must include findings where participants directly discuss the impact of caregiving on their identity.	Papers focusing on professional caregivers/ care home staff. Papers focusing on identity of the person with dementia, more so than that of the caregiver, were also excluded.	The synthesis is examining the impact of caregiving for a loved with one with dementia on an individuals' self-identity and self-esteem.
Papers must be original and primary in nature	Articles using secondary data, e.g., review articles.	Meta-ethnography synthesises primary data and relies on quotes from participants and the interpretations made by the original authors as a basis for analysis.
Peer reviewed journal articles	Undergraduate or post graduate thesis/dissertations, review articles, research theory articles, opinion articles, books.	Peer reviewed journal articles are most likely to present higher quality of evidence and are therefore more reliable.
Papers are published and accessible in the English Language	Papers not available in the English language.	The synthesis will be completed in English. Translating between languages may lose the meaning rooted in the language.

Systematic Screening Process

Inclusion and exclusion criteria were applied to papers retained for full text review. Reference lists of all eligible papers were screened for relevant studies not identified via the database. Reports that were unavailable, or where full papers could not be accessed were recorded as "reports not retrieved" and were excluded from the analysis. Figure 1.2 illustrates the systematic screening process that was followed, showing the total number of papers from each database, and demonstrating at which stage of the process papers were removed or selected for inclusion. The Preferred Reporting Items for Systematic Review and Meta-Analyses (PRISMA) model (Moher et al., 2009) was used to demonstrate this.

Figure 1.2

PRISMA Flowchart Demonstrating the Process of Exclusion and Selection at Each Stage of the Screening and Review Process (Moher et al., 2009)



Following the screening process, 12 papers were selected for the synthesis. The selected papers are summarised in table 1.3.

Table 1.3

Summary Table of Studies Included in the Final Synthesis Following the Systematic Selection Process

Title, author, year of publication, country	**Aim(s) of study**	**Participants**	**Data collection and analysis**	**Key findings (only those relevant to current synthesis are recorded) including main themes (in bold italics) and subthemes (in regular italics).**
Caregivers' deepest feelings in living with Alzheimer's disease Bursch and Butcher (2012) USA (IOWA)	To develop an understanding of how emotions and thought processes experienced in the caregiver's journey influences caregivers' self-esteem and ability to function in their role.	27 caregivers of people living with Alzheimer's disease took part in this study: Female: (n=22) Male: (n=5) Spouse: (n=16) Child: (n=9) Other relation: (n=2) All of white ethnicity. Age range: 45 → 80	This study analysed journals written by participants: Written in never → twice a year: (n=10) Written in every few months → twice per month: (n=3) Written in once a week: (n=1) Written twice a week → every day: (n=4) NVivo software was used to manage data. Data was analysed using a Hermeneutic phenomenology method.	There were three main themes and one subtheme drawn from the data: ***1. Questioning own self-worth*** – feeling forgotten, experiencing new or stronger emotions that are different to pre-caregiver self (e.g., anger). ***2. Experiencing loss of authenticity after becoming a caregiver*** – sometimes good (e.g., being 'obsessive' was helpful in caregiving), but most participants assumed caregiver role out of necessity not choice, grieving loss of previous self, sense of distance from their past self, resulted in participants being self-critical. ***3. Struggling for self-esteem: strategies to find self-esteem*** – feeling like a good person through caregiving, knowing others would be proud of them,

				Threats to self-esteem – hurtful behaviour of partner and others not understanding this, anger towards care receiver which can spill over into caregiving, and this makes caregivers angry at themselves.
A qualitative study of the process by which carers of people with dementia derive meaning from caring. Cherry et al. (2019) UK	To further explore the processes by which caregivers of people living with dementia derive meaning from caring for their loved one.	20 caregivers participated. Female (n=11) Male (n=9) Spouses (n=11), Sons (n=3), Daughters (n=6). 19 participants were white British, and the ethnicity of the final participant is not stated.	Semi-structured interviews were used to collect data. Data was analysed in two parts: a constant comparative approach drawn from grounded theory was first used to read and code data. A pluralistic methodological approach (Donnellan et al., 2015) was then used to further analyse the data whereby transcripts were read and coded in the context of what was said elsewhere in that interview and in other interviews.	Two main themes were identified from the data: 1. ***Maintenance of sense of self*** (identity)- does caring fit with who they think they are? Having to leave jobs for caring responsibilities. Some maintained a sense of self through compartmentalisation of caregiving role (e.g., having a life separate from caregiving role). 2. ***Perceived social connectedness*** – some did feel socially connected and experienced supportive interactions with others around their identity as a carer. Others felt socially isolated and not belonging in society, losing touch with friends.
Everyday occupation, well-being, and identity: The experience of caregivers in families with dementia Hasselkus and Murray (2007)	To gain an understanding of the nature of the daily occupations of caregivers for family members with dementia as related to the caregiver's perceptions of well-being.	33 caregivers of adults with dementia participated in this study. Women (n= 27) Men (n=6)	In depth telephone interviews were conducted following an interview method used in an earlier study by the same authors. Interviews were 35→45 minutes long.	Two main themes were identified from the data: 1. ***The caregivers state of being*** – participants discussed the impact of caregiving on their well-being, including their level of competence with performing the caregiving role. Some caregivers derived satisfaction

USA (Wisconsin)	“Occupation” in this study relates to the day-to-day management and ‘work’ of caring for a loved one with dementia.	Daughters (n=17) Daughter in law (n=3) Wives (n=7) Sons (n=4) Husbands (n=2) Age range = 34→56 All participants lived in Wisconsin, USA Care receiver diagnosis: Vascular Dementia (4) Alzheimer’s (13) Mixed (3)	Narrative analysis method was used to analyse data.	from the caregiving role and this satisfaction often came from care-receiver’s positive emotions (e.g., excitement, joy). Things that were detrimental to caregivers’ well-being were disrupted occupations and hobbies, and a sense of discontinuity with their life before caregiving. 2. ***The search for relationship*** **–** participants discussed trying to hold on to some normalcy and retain a relationship with their loved one. Caregivers attempted to maintain links with the past.
Caring for a loved one with dementia at end of life: An emergent theory of rediscovery Lewis (2015) USA (Vermont)	To discover a substantive theory that identifies the main problems caregivers of loved ones with dementia face at the end of life and the basic social processes by which they resolve that problem.	Purposive sample of caregivers of loved ones who have passed away in the last 10 years. 83 caregivers Male (n=11) Female (n=72) Sample contained, adult children of PWD and spouses.	Interviews were conducted either online or in person with caregivers. 26 books written by caregivers were analysed and observations of 18 caregivers were completed. Grounded theory methodology & Constant comparative analysis.	Six main themes were discussed, described as “stages” of rediscovery: 1. ***Role entrapment****:* feeling they cannot escape the care role because it was their duty, *2.* ***Missing the past****.* 3. ***Sacrificing self****:* lost carers, homes, time spent with other family, friends, holidays etc, described “putting life on hold”, not being able to fulfil other roles (e.g., as a daughter). 4. ***Yearning for escape*** – caregivers discussed wanting the caregiving experience to be over.

		Dementia Diagnosis of care receiver: Alzheimer's (53) Fronto-Temporal Dementia (5) Lewy Body (7) Parkinson's disease (1) Vascular (6) Wernicke - Korsakoff (1) Mixed (3) Unknown (8)		5. ***Reclaiming identity*** – participants discussed being compassionate to themselves and the importance of seeking help and support to allow them a break from caregiving. This included doing things they used to do and engaging in other social roles. 6. ***Finding joy*** – As a consequence of reclaiming identity, caregivers were able to find joy in their role as a caregiver. This included finding activities they could do together.
Exploring the role of occupation for spouse-carers before and after the death of a spouse with dementia. Mattock and McIntyre (2016) UK	To explore whether the occupations of spouse-carers contribute in the transition to the post-care period.	Nine spousal carers of a PWD who had passed away, who were between 1 and 5 years post-bereavement. Female (n=7) Male (n=2) Ages 68→91	Semi-structured interviews were conducted with participants. A reflective diary was also used to reflect the response of researchers following each interview. Template analysis was used to analyse data.	Three main themes were identified from the data: 1. ***Continuity*****:** less continuation in previous hobbies/friendships. 2. ***Roles and occupations****:* reduced social life which impacted on sense of self, but many participants-maintained hobbies and interests where they could. 3. ***Support and change and transition***: joining groups was helpful for social identity and learning new skills (positives of caregiving).
Self-identifying as a caregiver: Exploring the positioning process. O'Connor (2007) Canada – Vancouver	To explore how people come to self-identify as a caregiver, what it means to be a caregiver, and how does their sense of self-identity as a caregiver influence how	Participants consisted of 33 family members of people with dementia. 23 females Wives (n=7)	Personal, open-ended, in-depth interviews were conducted. A content analysis of all transcripts was conducted followed by a cross case analysis and then an	Four main themes were identified from the data: 1. ***The process of beginning to self-identify as a caregiver*** – discussing the transition to caregiver – being unnoticed/just part of being a husband

	they care for their relatives	Daughters (n=13) Sisters (n=2) Friend (n=1) 10 males Husbands (n=8) Sons (n= 2) Age range 45→85 Caucasian = 82% (27) Chinese = 18% (6)	interpretive qualitative description of data.	or wife vs more awareness and loss of self. 2. ***Caregiver as socially constructed*** **-** other people defining them as a caregiver (mostly professionals) which triggered their realisation of such. 3. ***The benefits of taking up this position*** **-** a sense of connection with others, increased ease at accessing services supporting caregivers, and respect gained from others for being a caregiver – social admiration. 4. ***Tensions and contradictions associated with caregiver*** **-** neglecting own needs, distance created between caregiver and care receiver, and power imbalances in that relationship.
Exploring online identity construction for the caregivers of adults living with dementia and the value of interactions with health and social care professionals (Prato et al. 2022) UK (one participant living in America).	To identify how identity is constructed online and how health and social care interactions can influence constructions amongst carers of individuals living with dementia.	16 online web blogs of people caring for loved ones with dementia were analysed. Sons (n=3) Daughters (n=7) Granddaughter (n=1) Husbands (n=2) Wife (n=2) Partner (n=1)	Analysed web blogs from appropriate web pages (caregivers of people with dementia) Principles of discourse analysis were applied. A coding framework was then applied based on a model of identity (Eifert et al., 2015).	Seven main themes were drawn from the data: 1. ***Changing family role*** – transitioning to role of carer in family, own identity feels “lost” or “replaced”. 2. ***Powerful expert social campaigner*** – campaigning to raise awareness based on the fact they have expert knowledge (positive identity change, new part of them, new focus) 3. ***Being an advocate*** **–** the informal caregiver identity is partly constructed by being an advocate for their loved one – developing strong advocacy skills based on negative experiences with HC professionals. 4. ***Wider community member both online and in real life*** – being a

				member of a health and social care team network enabled caregivers to develop their understanding of their new identity including new skills and abilities. 5. ***Guardian of their relative's self-hood*** – a focus on retaining the personhood (because their sense of self links to the caregivers) of their loved one, the blogs were used as a place to reminisce about their loved one. 6. ***Sustaining creative and spiritual identity*** – importance of accessing hobbies and interests away from caregiving and keeping part of themselves, vital to continued individuality of the caregiver. 7. ***Wider community member in virtual and real life*** – other roles they played as part of caregiver role: health and social care network, support groups, informal caregiver networks – joining all these new groups formed part of their 'new' identity.
The experience of self and threats to sense of self among relatives caring for people with Alzheimer's disease. Skaalvik et al. (2016). Norway	The study aimed to explore how aspects of self were impacted amongst close relatives to people with AD. Based on Harre's social constructionist theory of self-hood:	Study was part of a longitudinal, controlled study "*identity preserving care of people with Alzheimer's disease and their family".* Conducted in	Interview data (individual interviews with family) from the start of the original study. Interviews lasted 50-90 minutes. Unclear on method to analyse data: data was divided into content areas	Findings were divided into two main themes, with one subtheme, relating to the "two selves" from Harre's social constructionist theory of self-hood. 1. ***Self-2: The preservation and use of attributes with the best of intentions*** – trying to make the best out of a situation, not recognising oneself, having to change certain attributes

	"self-2": related to persons past, present and future attributes, this includes their life stories (in this study, looks at the way relationship informal caregiving supports or diminishes their valued mental and physical attributes). "self-3": the way people display their selves, self-3 is developed via encounters with others, self-3 describes how we position ourselves and how others position us (people can have multiple self 3's and this may change depending on who they are with, e.g., different self-3 at work to at home (in this study self-3 looks at the persons valued social persona constructed by themselves and others).	Norway. They used interview data from this study. 20 participants, pairs of 2 from the same family (10 families sampled overall) Daughters (n=5) Sons (n=4) Husbands (n=3) Wives (n=3) Sisters (n=2) Sister in laws (n=2) Daughter in law (n=1)	using Harre's social construct theory of selfhood. Abstractions were made to determine the participants descriptions of how they revealed their selfhood had been affected in relation to self-2 and self-3 from Harre's theory.	about yourself (e.g., being outspoken, being active, losing optimistic outlook), taking over tasks the loved one had done before (spouses mostly), having to adjust your personality to suit the needs of your loved one. *The experience of conflicting emotion:* feeling sad, angry, loving, resentful, caring towards loved one. 2. ***Self-3: change in job roles, change in physical health*** (e.g., increase in migraines), reduced social activity, caring responsibilities conflicting with job, needing psychological help to deal with changes in relationship with the loved one, abandoning that relationship.
Supporting and sustaining care at home: Experiences of adult daughters who support a parent with dementia to remain in their own home.	To better understand how daughters a) navigated the competing demands of their situation and b) their perception of the impact of this role on their physical and psychological well-being.	Eight adult daughters of people with dementia. Opportunistic sampling was used through personal contacts in the	Semi-structured interviews were used and photo elicitation (using photographs to encourage comments from participants about the issue being studied- participants were invited	Four key themes were found: 1. ***Impact on Identity*** **–** having a sense of self separate from caregiving was important for participants, role reversal of parent/child, juggling other responsibilities and parts of life that contributed to sense of self.

Smith and Rodham (2022) UK		health and social care field. Ages 36→53	to bring photographs to interview that represented their care experience) Thematic analysis (Braun & Clark, 2006) was used – explained well in paper. Transcripts were analysed by both authors and notes compared.	2. ***Continuity and change –*** change in the person with dementia and the relationship between them, not all participants were negative about this and some were able to hold on to aspects of the relationship. Some were able to maintain a routine (quotes not given), some felt they had grown stronger because of caregiving. 3. ***Stepping up to the challenge –*** pervading sense of responsibility, discusses some of the difficult practical elements of caregiving, making decisions for parent. 4. ***Finding help – 'it's a minefield'*** - feeling unsupported by health services. Seeking help took time away from their other roles (e.g., employment).
Is living well with dementia a credible aspiration for spousal carers? Tolhurst et al. (2019) UK (Chester)	To explore the experiences of those caring for a loved one with dementia, to discover the challenges associated with caring. This aims to critically evaluate the feasibility of the UK's "living well" policy for people with dementia and their families.	16 spousal carers of people with dementia, Female (n=15) Male (n=1) All white British. Ages 52 → 84. Care receiver diagnosis: Alzheimer's (13) Lewy body (1) Vascular (1) Mixed (1)	Semi-structured interviews were used. Mean duration of 70 minutes. Thematic analysis was used.	Three key themes were identified, and these themes were then related to the 'living well' agenda. 1. ***Identity subsumed under care responsibilities*** – not going out anymore, no time to do things for self, not being able to have any time alone, Positives were also found in greater sense of connection to wider community, existence solely defined by caring, taking on extra responsibilities. 2. ***The couple as an isolated family unit*** – lack of help/support from other family members including children, pressure to cope self-sufficiently,

				3. ***Barriers to professional support*** – shame of seeking support meant you can’t cope with responsibilities, not prioritising own need, pressure to live up to caring responsibilities and be the best carer.
Lived experiences of caregivers of persons with dementia and the impact on the sense of self: A qualitative study in Singapore Tuomola et al. (2016) Singapore	To explore the lived experience of caregivers of dementia patients in Singapore, and the impact this has on their sense of self.	Six participants, all Chinese ethnicity, all female spousal caregivers, average age 61.83. Purposive sampling method used from a hospital in Singapore.	Semi-structured interviews were conducted. Interviews lasted between 45 – 60 minutes. Interpretive Phenomenological Analysis (IPA) was used to analyse data.	Four main themes and eight subthemes were identified. ***1. Impact of caregiving*** *Multiple responsibilities* – impacting role as parent as having to care for partner, *Influence on lifestyle* – affected work, social and personal life, yearning for old lifestyle, not enough time for self, 2. ***Emotional burden*** – overwhelmed by stress of caring, embarrassed of partners behaviour in public, guilt for getting frustrated at partner 3. ***Acceptance of destiny: resignation of fate*** *Fulfilment of the duty of a wife* – seeing caregiving as the responsibility of their role. Accepting their partners diagnosis and that they would have to care for them for life, changes in dreams for the future. ***4. Taking Control: Active coping*** – actively engaged in coping strategies, using support networks,

				using connections with others to cope, using faith, focusing on work. *A sense of empowerment* – doing things that they didn’t do before because their husband did it so feeling empowered that they could do more and be independent, *Changing roles* – taking head of household, switching roles with partner, like caring for a child. **5.** ***View of self*** **–** positive changes of ‘growing up’, negative changes of feeling incompetent, negative view of self as a carer (not good enough), changes in personality (e.g., grumpy), others views of them changing too (being told they’re doing a good job).
Supporting sustainable occupational lives for partner caregivers of people with dementia Yong et al. (2020) UK	To gain a deeper understanding of UK partner caregiving and how it may impact on partners occupational lives. To understand any impact or changes to daily activities	UK study Recruited through a local Alzheimer’s group. 10 participants. Females (n=7) Males (n=3) Wives (n=6) Husbands (n=2) Partners (n=2) Age range 63→88.	One to one semi-structured interviews were conducted, interviews were 50-60 minutes each. NViVo software used for analysis – steps from Braun and Clark’s (2006) thematic Analysis were used.	Four main themes were drawn, with five subthemes. 1. ***Losing occupational activities and roles, daily life overtaken by care receiver’s needs.*** *Occupational loss* – hard to maintain meaningful activities for themselves, loss of social time, never being alone. *Internal struggles and limitations impacting on caring abilities* – worries about future, own

				ageing that further narrowed occupational activities. 2. ***Adapting to a new occupational life: attempting to achieve new occupational balance*** – maintaining contact with family and friends via internet, joint activities with partner blended into carer role (e.g., walk). 3. ***Attempting to maintain control of daily occupational life*** – keeping routines. 4. ***Adjusting to a new relationship with partner:*** *Managing loss of previous life together* – loss of intimacy, miss being a couple, sadness in accepting changes. *Attempting to maintain and preserve partners sense of self* – impact on social situations (having to withdraw), helping them do as much independently as possible. *Gaining meaning from the caregiver role* – sense of duty, responsibility is part of life-bond to partner.

The studies were conducted across several different countries, with the majority being based in the United Kingdom (UK) (n=6) and the United States of America (USA) (n=3). Others were undertaken in Canada (n=1), Norway (n=1) and Singapore (n=1). Sample sizes varied from the smallest being six (Tuomola et al., 2016) to the largest being 83 (Lewis, 2015). All studies split male to female participants, and combined the studies represented 221 females and 52 males. One participant's gender was not stated. Most studies (n=11) stated the relationship of the caregiver to the person with dementia. This included spouses/partners (n=113), children (n=81), daughter in laws (n=4), sisters (n=4) grandchildren (n=1), sister in laws (n=2), friend (n=1), and other relations not stated (n=2). One study (Lewis, 2015) did not report specific relational roles but stated their sample included spouses and adult children of people with dementia. Only three studies reported the specific type of dementia included in their studies, with the majority caring for a loved one with Alzheimer's (n=79). Other diagnoses included Lewy Body Dementia (n=8), Vascular Dementia (n=11), Fronto-Temporal Dementia (n=5), mixed (n=7), and other (n=2). Eight were unknown. From the ages of participant's provided, these ranged from 34 to 91.

Less than half of the studies reported the ethnicity of participants (n= 5). Of those that did, majority of participants identified as White/Caucasian (n=89), or Chinese (n=12).

Several different analytical methods were employed across the 12 studies. The most common techniques used were Thematic methods (n=3). Others used were content analysis, grounded theory, constant comparative analysis, interpretive phenomenological analysis (IPA), template analysis, hermeneutic phenomenology, pluralistic methodology, discourse analysis and narrative analysis. Skaalvik et al. (2016) analysed their data according to a specific social constructionist theory.

Quality Appraisal

Assessing the quality of papers selected is important as it allows the researcher to consider any potential methodological biases and avoid drawing unreliable conclusions (Thomas & Harden, 2008). There is currently a lack of consensus around the use of quality frameworks for qualitative research (Toye et al., 2013; Sattar et al., 2021). However, it is argued that a good meta-synthesis should record the quality of its papers to provide trustworthy findings that will offer more useful and valid information to support the development of health care services (Finfgeld-Connet & Johnson, 2013).

Considering the above, this review assessed the quality of papers selected to ensure that conclusions were drawn based on good quality research, increasing the credibility and subsequent usefulness of the overall synthesis. An adapted quality appraisal framework was developed by the researcher, primarily based on the National Institute for Health and Care Excellence (NICE, 2012) quality appraisal checklists for qualitative research (see Appendix A). The researcher added synthesis specific criteria, such as whether there was a clinical diagnosis of Dementia and whether the aims of the paper align with the aims of the current review.

The papers were reviewed and marked using the NICE (2012) checklist guidance. Where criteria have been fully or mostly met, a '++' rating was given. Studies that partially meet criteria are rated with a '+' and a '-' is awarded when criteria was sparsely met, or not at all. The quality framework applied to the 12 papers can be found in Table 1.4.

Table 1.4

Quality Framework as Applied to Included Studies.

Papers	Q1. Is a qualitative approach appropriate?	Q2: Is the study clear in what it seeks to do?	Q3: How defensible/ rigorous is the research design/methodology?	Q4: How well was data collection carried out?	Q5: Is the role of the researcher clearly described?	Q6: Is the context clearly described?	Q7: Were the methods reliable?	Q8:Is the data analysis sufficiently rigorous?	Q9: Is the data 'rich'?	Q10: Is the analysis reliable?	Q11: Are the findings convincing?	Q12: Are the findings relevant to the aims of the study?	Q13: Conclusions -Is there adequate discussion of any limitations encountered?	Q14: How clear and coherent Is the reporting of ethics?	Overall Quality
Bursch and Butler (2012)	Appropriate	Mixed	Defensible	Appropriately	Not described	Clear	Not sure: thorough data collection method but no triangulation.	Rigorous	Rich	Not reported	Convincing	Relevant	Not sure – reports some limitations but minimal detail provided.	Not reported	(+)
Cherry et al. (2019)	Appropriate	Clear	Defensible	Appropriately	Unclear – no account of reflexivity/ positionality but does include researcher explanation to participants	Not sure: some characteristics described by no information on ethnicity or context bias.	Reliable	Rigorous	Rich	Reliable	Convincing	Relevant	Adequate	Appropriate	(++)
Hasselkus and Murray (2007):	Appropriate	Clear	Defensible	Appropriately	Clearly described	Not sure: some characteristics described by no information on	Reliable	Rigorous	Rich	Reliable	Convincing	Relevant	🟥	🟩	(++)

						ethnicity or context bias.							Inadequate	Appropriate	
Lewis (2015):	Appropriate	Clear	Defensible	Appropriately	Not described	Clear	Reliable	Rigorous	Rich	Reliable	Convincing	Relevant	Adequate	Appropriate	(++)
Mattock and McIntyre (2016)	Appropriate	Clear	.Defensible	Appropriately	Unclear – description given as to how the research was explained to participants but no consideration of researcher position or relationship with participants provided. Notes reflective diary but no example given.	Not sure: some characteristics described by no information on ethnicity or context bias.	Reliable	Rigorous	Rich	Reliable	Convincing	Relevant			(++)

	🟩	🟩	🟩	🟩	🟨	🟨	🟩	🟩	🟩	🟩	🟩	🟩	Adequate	Appropriate	
O'Connor (2007) Self-identifying as a caregiver: exploring the positioning process	Appropriate	Clear	Not sure – good detail given on method but no justification/reasoning for chosen methods provided	Appropriately	Not described	Clear	Not sure – not clearly stated but assume one researcher interpreted data independently.	Rigorous	Rich	Not sure participants fed back on data to identify gaps and clarify findings – but only one researcher.	Convincing	Relevant	Adequate	Not reported	(+)
Prato et al. (2022)	Appropriate	Clear	Defensible	Appropriately	Not described	Unclear – no characteristics provided	Reliable	Rigorous	Rich	Reliable	Convincing	Relevant	Adequate	Appropriate	(+)
Skaalvik et al. (2016)	Appropriate	Clear	Not sure – design described but limited detail and no	Inadequately reported – limited detail given on data	Not described	Not sure – only age and gender of participants reported.	Not sure – no discussion of triangulation.	Not sure – limited information given	Rich	Not reported	Convincing	Relevant	🟩	🟩	(+)

	🟩	🟩	justifications/reasons given	collection method.	🟥	Context bias not considered.	🟨	🟨	🟩	🟨	🟩	🟩	Adequate	Appropriate	
Tolhurst et al. (2019)	Appropriate	Clear	Defensible	Appropriately	Clearly described – discussed how researchers gender (male) may have influenced the dynamic of interviews.	Clear – discusses context bias and observations made in variety of circumstances but omitting data on ethnicity/other individual characteristics.	Not sure – no mention of triangulation and only used one method (interview)	Rigorous	Rich	Not reported	Convincing	Relevant	Adequate	Appropriate	(+)
Tuomola et al. (2016)	Appropriate	Clear	Defensible	Appropriately	Not described	Clear	Reliable	Rigorous	Rich	Reliable	Convincing	Relevant	Adequate	Appropriate	(++)

Smith & Rodham (2022)	Appropriate	Clear	Defensible	Appropriately	Not described	Clear	Reliable	Rigorous	Rich	Reliable	Convincing	Relevant	Adequate	Appropriate	(++)
Yong et al. (2020)	Appropriate	Clear	Defensible	Appropriately	Clearly described – discussed positionality (critical realism). Reflective journal used (but not reflected upon)	Clear – but no note of ethnicity.	Reliable – two authors analysed data and reflective journal was referenced	Not sure – reported but limited detail/explanation given regarding steps of thematic A	Rich	Reliable	Convincing	Relevant	Adequate – good discussion of limitations and implication.	Appropriate	(++)

Note. For the ease of the reader, individual criteria are colour coded into green (criteria met), yellow (criteria partially met), amber (criteria mostly unmet), and red (criteria unmet).

Overall, the studies were judged to be of good quality, with seven out of 12 being awarded a '++' rating, and the five receiving a '+'. No studies were deemed to be of poor quality. An area of weakness highlighted across majority of studies was the reporting of demographics of participants, with ethnicity of participants being noticeably absent. Seven out of the 12 papers omitted this information and of the five that did record ethnicity, only one study (O'Connor, 2007) sampled participants from more than one ethnic group. However, the role of ethnicity on participants experiences was not discussed by the authors.

In other areas of weakness, only three papers discussed the positionality of the researcher regarding how data was collected, analysed, and interpreted. In qualitative research it is important to consider how the role of the researcher may have influenced the data to account for any potential biases that may otherwise limit the credibility of the interpretation (Braun & Clark, 2022).

Stage 3

The 12 papers were read in their entirety. The results sections were read multiple times to familiarise the researcher with key concepts, themes, and metaphors from within and across studies. These were often presented as themes and subthemes identified by the authors of each paper, with corresponding quotes to support each theme. The themes and subthemes from each paper were extracted into a separate grid in readiness for the analysis stage (see appendix B). First order constructs are quotes evidencing each theme. Second order constructs are the primary authors interpretation of the primary data. Third order constructs represent the current reviewer's interpretations, based on an analysis of the first and second order constructs. The majority of themes from the papers were included in the extraction grid, including those that were not explicitly related to self-identity but provided some relevant findings to the current synthesis. Themes that were entirely unrelated to the aims of the current review are not presented.

Stage 4

To determine how studies are related, Noblit and Hare (1988) suggest creating a list of themes or metaphors and juxtaposing them. Grids and tables are also commonly used to display concepts and themes (Atkins et al., 2008) and this approach was employed in the current synthesis (see Appendix C). The first step involved identifying common concepts, themes and subthemes concerning the impact of caregiving on one's identity. As included papers did not all have ‘identity’ as the focus, at times this involved taking parts of themes and subthemes that added to the overall understanding of these experiences.

Noblit and Hare (1988) describe the process of ‘reciprocal translations’ whereby one must understand one study’s findings in relation to another which involves the comparison and ‘matching’ of themes across papers, ensuring that a key theme captures similar themes from different papers (Atkins et al., 2008). Identified themes and corresponding papers were placed into a grid and compared against each other to determine where themes reoccurred across different papers. Themes that were found to be common across more than two papers were kept for further analysis. Themes were shared with the research supervisor and with a peer in a meta-synthesis support group which helped to refine them and ensure that they were inclusive and representative of the overall dataset. Authors of the papers included in this meta-synthesis provided interpretations and developed theoretical ideas about identity based on their findings. The current analysis predominantly focuses on concepts and ideas provided directly by participants through quotes.

Stages 5 and 6

To translate one study to another, a thematic analysis of themes was used. For each study, issues relating to each theme were examined in detail to ensure all relevant data was included. As the process of comparing studies continued, the initial broader grouping of themes was refined by merging and collapsing categories to result in final and overarching themes and relevant subthemes (See Appendices D). This helped to determine which themes better represented the cases in their entirety, and which themes better countered the overarching aims and questions of the review.

Throughout all stages of the synthesis process, the researcher’s positionality and how this may influence the review was considered. The researcher kept a reflexive journal that documented their practical and emotional experiences, and their reflections on the process throughout the data collection and analysis stages. The researcher was a young, trainee clinical psychologist with no caregiving responsibilities. As such, the researcher was far removed from the position of caregiver themselves and had mostly been exposed to such experiences through clinical practice, theoretical knowledge, and societal discourses around caregiving. Therefore, the researcher naturally held pre-conceived knowledge, ideas, and assumptions regarding caregiving experiences and these assumptions may have led the researcher to interpret the meaning behind participant quotes differently to how it was meant by participants themselves. Furthermore, the data analysis stage of the review was conducted simultaneously with the data collection of the empirical project presented in chapter two of this report. Discussions with participants in the interviews for the empirical paper highlighted certain aspects of dementia caregiving that the researcher recognised influenced the development of themes for the literature review. For example, feeling more like a caregiver than a partner was a dominant topic in interviews with participants and this may have influenced the researcher's decisions when collapsing and merging themes for the meta synthesis. Employing a critical realism ontology, the researcher therefore recognises that the findings and interpretations presented in this report do not represent objective truths and realities but display a version of possible truths and realities that are influenced by the unique experience of the participants coupled with the individualities of the researcher. As this explores unique experiences that are personal to each individual, it is acknowledged that within the realities uncovered may lie many variations and nuances.

Results

Table 1.5 demonstrates the themes that were derived from the meta-ethnography. Three main themes, and six subthemes were found.

Table 1.5

Summary of Themes

Main Theme	Sub-Themes
Theme 1: Personality Changes – "who am I?"	1. Perceived Negative Changes. 2. Upskilling and Personal Growth
Theme 2: Changes in Relational and Social Identity	1. Changes in Relationship with Care-receiver 2. Changes in Other Relational and Occupational Roles
Theme 3: The Relationship between the Caregiving Identity and Self-esteem	1. Not Feeling Like a Good Enough Caregiver 2. Boosting Self-esteem

Personality Changes – "who am I?"

Perceived Negative Changes

It was found across papers that participants noted changes in their personality after embracing the caregiver role (Bursch & Butler, 2012; Hasselkus & Murray, 2007; Lewis, 2015; O'Connor, 2007; Prato et al., 2022; Skaalvik et al., 2016; Tuomola et al., 2016; Smith & Rodham, 2022). Participants described that this led them to feel "unrecognisable" from their previous selves and left them questioning "who am I?" (Prato et al., 2016, p 299). Participants described this experience as losing part of themselves. Caregiving wives in Bursch and Butlers (2012) study expressed: "I am grieving my loss of self, the person I knew as me is going, fading away" (p 212). Another commented: "I feel a loss, loss of me, waste of myself" (p 213). Similar feelings were identified in Tuomola et al's (2016) study with one wife expressing: "I cannot find myself" (p 166).

A husband from Skaalvik et al. (2016) discussed how his "hard working" and "optimistic and positive attitude" was challenged when he became a caregiver to his wife, stating: "I see all as insurmountable. I don't recognise myself" (p 471). Another discussed having to be more "assertive" in his role as a caregiver than he is as a husband (p 471).

Caregivers discussed purposefully changing parts of their natural character to protect their loved one. For example, a husband from Skaalvik et al. (2016) described that he had always been “outspoken”, however now had to be “very careful” with what he said as to not upset his wife (p 471). From the same study, a wife discussed having to adjust her natural conduct and control strong headed parts of her personality because she worried her husband may be hurt by her true nature: “I have become quieter, and I don’t tell my husband as much as I used to” (p 473).

Caregivers elicited an unkind opinion of themselves in response to the changes in their personality, which suggests an impact on their self-esteem. These opinions often addressed changes to their personality that they perceived to be negative, as one wife described: “I am not a good person, I am not a good caregiver […] sometimes I cannot find myself, I [am] grumpy. I do not smile as much as I used to” (Tuomala et al., 2016, p 166). Another shared:

> I am no longer a happy person […] I hope when this is all over, I still have friends, and a husband. I hope my children still have a mom with a sense of humour, and I hope my happiness gene reappears intact (Lewis, 2015, p 492).

Further demonstrating the impact that perceived personality changes may have on one’s self esteem, participants in Bursch and Butler (2012) elicited self-blaming statements and feelings of “anger” towards themselves in response to the loss of their previous self. One wife shared: “I am angry at me[…] I’m a mop […] I am disturbed by the constant anger I feel” (p 213). Another felt similarly: “I am angry that I am allowing this [personality changes] to happen to me” (p 212). Whilst discussing feeling isolated and abandoned by family and friends, two participants attributed this to their personal inadequacies. One wife shared: “When I’m lonesome I start to wonder what’s wrong with me. Do I offend, am I boring or what?” (Bursch & Butler, 2012, p 211). Another wife from the same study commented: “They say there is no rest for the wicked and sometimes, I feel I am the wickedest person in the world” (p 213).

Upskilling and Personal Growth

Changes in personal characteristics were not always perceived as negative, and caregivers also discussed areas of personal growth, or new aspects of their personalities that they were proud of (Bursch & Butler, 2012; Mattock & McIntyre, 2016; O’Connor, 2007; Prato et al., 2022; Skaalvik et al., 2016; Tolhurst et al., 2019; Tuomola et al., 2016; Smith & Rodham, 2022). A daughter discussed positive changes to her personality of being more “empathetic” and “sensitive” towards other caregivers:

> Caregiving in general has really opened my eyes to a lot of things that, unless you experience it, you don't know what it's like. And so now I have a lot more sympathy and empathy for anybody that has an ill parent or is looking after somebody that needs a lot of help. I am just more sensitive to things (O'Connor, 2007, p 171).

Discussing her experience of caring for her husband, one wife acknowledged that "you come out of it a different person", however she reflected on this positively, describing caregiving as a "growing experience" (O'Connor, 2007, p 171). A caregiving daughter discussed personal growth and described herself as becoming "stronger" and "wiser" through the caregiving experience (Smith & Rodham, 2022, p 86).

One husband discussed that caring for his wife had become his occupation and he enjoyed learning new skills in being a carer. He described feeling "proud" of himself for his caregiving abilities (Mattock & McIntyre, p 74). Another daughter discussed that the caregiver role gave her a sense of purpose and improved her opinion of herself, demonstrating a positive impact on her self-esteem: "Caring for my mother has made me realise that no matter what anyone thinks or says to me, I am a good person" (Bursch & Butler, 2012, p 212).

Another common finding was that participants discussed the advantages of taking on roles previously completed by their partners, and how this helped them develop new skills and foster a positive sense of self (Mattock & McIntyre, 2016; Prato et al., 2022; Skaalvik et al., 2016; Tolhurst et al., 2019; Tuomola et al.,2016; Smith & Rodham, 2022). Participants described that this made them feel "strong" and "able to withstand diversity". One wife from Tuomola et al. (2016) shared a newfound sense of independence: "Nowadays I learn so many things. Anything that I want to do, I can. I can think over and do on my own" (p 165). Another wife similarly discussed developing new skills:

> You do learn a lot, I mean he used to do such a lot years ago. I never picked a screwdriver up. But then you learn to pick a screwdriver up […] so you learn all different things you've never learnt before (Tolhurst et al., 2019, p 60-61).

Changes in Relational and Social Identity

Changes in Relationship with Care Receiver

There was a noticeable impact on caregivers' identity within their relational role as they began to take on tasks that did not align with their pre-existing role (e.g., partner, child)

(Bursch & Butler, 2012; Hasselkus & Murray, 2007; Lewis, 2015; Mattock & McIntyre, 2016; Prato et al., 2022; Tuomola et al., 2016; Smith & Rodham, 2022; Yong et al., 2020). As discussed in the literature, there was a shift from the original relational role to that of a “parent” or “carer”, and this altered how individuals defined themselves. This was found across both partners and children caring for loved ones. One wife described: “I hate being his mother and he dislikes it even more” (Bursch & Butler, 2012, p 212). Another wife expressed similar feelings: *“*I’m no longer their partner/lover, I haven’t been for a very long time. I have said before I am the carer first” (Prato et al., 2022, p 299). One wife described feeling more like a “mother” to her husband, and compared her experiences of caregiving to that of parenting: “I think if you have been a mother and brought children up, you take on that role... There is no sexual [aspect] or anything, that sort of thing, it is more a loving... motherly feeling towards them” (Mattock & McIntyre, p 73).

An acknowledgment that the caregiving role had overtaken the relational role was also experienced by adult children caring for parents with dementia. One daughter commented: “The role reversal from daughter to caregiver had defined me” (Lewis, 2015, p 492). Others from Lewis (2015) felt similarly: “I was so busy being a caregiver for my mum that I often didn’t have the energy or capacity to be a daughter” (p 492). Another participant described feeling more like a parent or an advocate, than a daughter: “I’m almost her parent but also the person trying to make sure she’s got the best life she can have and it’s not sometimes… so it’s an advocate role rather than a daughter role” (Smith & Rodham, 2022, p 85).

Those caregiving for parents often found that the role of parent/child became reversed. Participants who had previously had a strong bond with their parent discussed a sense of loss and reflected on how this impacted their identity as a son/daughter (Cherry et al., 2019; Hasselkus & Murray, 2007; Lewis, 2015; Smith & Rodham, 2022). One daughter described feeling like she “didn’t have a mother anymore” (Hasselkus & Murray, 2007, p 16). Two daughters shared a sense of loss of the pre-dementia relationship: “I felt like a child, chasing my mother as she walked away. I just wanted to be loved, for her to take an interest in me, her daughter” (Lewis, 2015, p 492). Another shared: “Well people go to their mum for support and advice and we’ve always had quite a good relationship, an emotional relationship, and that’s just gone” (Smith & Rodham, 2022, p 85).

A possible explanation as to why some caregiver’s identities felt more protected than others could be because they viewed caring for their loved one as part of their “duty”, or an inherent aspect of their pre-existing relational role (Cherry et al., 2019; Mattock & McIntyre, 2016; O'Connor, 2007; Prato et al., 2022; Yong et al., 2020). These caregivers often still referred to themselves within their pre-existing role (e.g., wife, husband, son) rather than as a caregiver, and they tended to reflect more positively on the experience of caregiving. A caregiving wife expressed: "I care for him because I'm his wife and I love him. I would've cared for him anyway. He'd have cared for me" (Cherry et al., 2019, p 71). Another also referred to caregiving being "part of" marriage: "I just do this because it's part of marriage, you take care of each other" (O'Connor, 2007, p 170). This experience was shared by caregiving husbands. One husband expressed "I don't resent it [caregiving] it's part of the contract I entered into when I got married" (Yong et al., 2020, p 600). One husband described caregiving to be a "natural" part of marriage: "looking after Gwen* became a natural thing to do cause we had a good marriage... and after Gwen had gone... that sort of continued... and in my case it hasn't gone away" (Mattock & McIntyre, 2016, p 74), and he was not alone in this experience: "I mean, I was looking after my wife, I never gave myself a title or anything like that. She was, I was her husband, it was up to me to look after her" (O'Connor, 2007, p 168).

This was also experienced by adult children, who reported a sense of duty to care for their parents as their parents once cared for them, with one son explaining: "The role's reversed and so you just take care of somebody" (Cherry et al., 2019, p 71).

O'Connor (2007) noted that when speaking of their loved ones, participants would use medical terms or refer to them as "Alzheimer's patient" and not "mum" or "dad", "husband" or "wife", particularly when discussing more difficult parts of the caregiving role (e.g., personal care, aggressive behaviours). This may have enabled them to protect the pre-existing relational role, and their identity within this relationship, by creating emotional distance between their new (caregiver) and pre-existing (relational role) identity. This was specifically highlighted by one participant, with the author stating that others alluded to similar sentiments:

> I think being able to abstract oneself – or myself – from my personal circumstances and look at my parents in a kind of dispassionate sort of way […] to see them as people who are needing help and not be all wrapped up in all of the sort of little emotional things that happen with families (p 172).

Changes in Other Relational and Occupational Roles

It was found that caregivers often discussed how aspects of their identity within other relational roles (e.g., mother, spouse, friend) were overtaken as they prioritised their caregiving role (Bursch & Butler, 2012; Cherry et al., 2019; Lewis, 2015; Mattock & McIntyre, 2016; O'Connor, 2007; Tolhurst et al., 2019; Tuomola et al., 2016; Smith & Rodham, 2022; Yong et al., 2020). One participant looking after her husband described having to "let go" of her role as a mother because the demands of looking after her husband took up too much of her time: "Because I have to help the father, so I let go of my son and tell him he has to help himself*"* (Tuomola et al., 2016, p 163). Another daughter reflected on trying to juggle different relational roles to protect other elements of her identity: *"*So I'm not just mum's carer, I'm a teacher. Umm, I think part of my identity as well is that I'm a wife, I'm a mother and trying to support all these things*"* (Smith & Rodham, 2022, p 84).

A common theme found across the papers was that caregivers felt they had "sacrificed", "given up on" or lost parts of their previous identity (Bursch & Butler, 2012; Cherry et al., 2019; Hasselkus & Murray, 2007; Lewis, 2015; O'Connor, 2007; Skaalvik et al., 2016; Tolhurst et al., 2016; Smith & Rodham, 2022; Yong et al., 2020). The loss of occupational, social, and other familial roles often made caregivers feel that they were "just a carer", and that other aspects of themselves had disappeared. Caregivers spoke of how their role of caregiver had "replaced" other roles, and they had no time to be themselves. As such, some felt that their identity was now defined by the role of caregiver. One wife expressed: "Everything is just rotated around caregiving, you can't just do what you want to do" (Yong et al., 2020, p 598). A daughter from Lewis' (2015) study reported a similar experience: "I had no life outside of my role as a caregiver, my life, was her life" (p 492). This notion was commonly experienced by both partners and adult children. One daughter commented: "It's just a matter of sometimes you want to get out on your own and just be you. You know, and you can't be you because you're a carer" (Tolhurst et al., 2019, p 60). Another expressed:

> I'll be talking about my mum and one of the girls will say "well, how about you? How are you?" Or "what have you done for yourself?" you know. And you do, you tend after a while when you're the caregiver, you tend to get that you, you know, everything sort of revolves about her (O'Connor, 2007, p 171).

A wife from Tolhurst et al. (2019) discussed a similar experience:

> You’ve got no free time to be yourself if that’s the right word. There are all the jobs to do, every single thing that’s done, it’s up to the person caring rather than anybody else […] he [husband] doesn’t take responsibility for anything. So, everything is left to me (p 60).

One daughter discussed how this could be exacerbated by other family members also seeing her as “just a carer”. She described: “I just wish the rest of my family would see that I need to be loved and to be understood. Sometimes I feel like all they want is for me to do something” (Bursch & Butler, 2012, p 211).

Participants reflected on finding it hard to focus on other responsibilities outside of their care role and found they made adaptations to their lives which further distanced them from their previous roles. A husband described: “She does not like to be separated from me… it’s difficult to do any work because there are constant interruptions. I do find that I don’t have time to do anything of my own” (Yong et al., 2020, p 598). Other caregivers similarly shared:

> I didn’t have any life of my own. I’d take him with me wherever I went, like if we went grocery shopping. That’s all we did, grocery shopping and church […] I didn’t go anywhere, I didn’t do anything except look after him. It was plain hell (Hasselkus & Murray, 2007, p 14)
>
> Another thing I noticed when you’re caring is you lose touch with a lot of friends, because whereas people might ring you and ask you to go to things of a night and that I’ve always had to say “Oh I can’t, I’ve got no one to mind my mum” […] eventually you just get stopped asking to go to things (Cherry et al., 2019, p 73).

The Relationship Between the Caregiving Identity and Self-Esteem

Not Feeling Like a Good Enough Carer

One of the ways in which participants self-esteem was found to be negatively impacted within their identity as a caregiver was that they felt inadequate at care giving or questioned their ability to do the right thing for their loved one (Bursch & Butler, 2012; Cherry et al., 2019; Hasselkus & Murray, 2007; Tolhurst et al., 2016). Participants would use unkind words about themselves such as “selfish” and “bad” that suggested a dampened view of oneself (Bursch & Butler, 2012; Hasselkus & Murray, 2007).

One wife shared feeling inadequate as a caregiver: “Maybe I don’t love him enough to care the way some people do—visiting all the time when the person is not even ‘there’—I’m afraid I am inadequate to the caring part” (Bursch & Butler, 2012, p 212). Another partner expressed feeling that someone else could care for her husband better than she could: “I’m not too good at all and I feel incredibly guilty that somebody else can cope with it and I can’t. It’s all guilt – it’s vile, horrid” (Tolhurst et al., 2016, p 62). A caregiving son described feeling like a “very bad son”, explaining that this came from feeling an inadequate caregiver: “I don’t think I ever felt satisfied with what I could do for her. I think that was a real sad part of my life” (Hasselkus & Murray, 2007, p 13). Self-esteem was also impacted for caregiving wives for similar reasons. One wife commented she felt “selfish” for putting her own needs first at times: “I’m feeling apprehensive about our move. He won’t like it at all. How can I do this to him? Am I selfish? I feel so guilty—and yet I know I must do something to save myself” (Bursch & Butler, 2012, p 213). Another wife discussed her perceived flaws and how this made her believe her husband would be better cared for by someone else:

> But it’s my lack of patience—and I don’t know what the answer is there. [His forgetfulness] really aggravates me a lot. He doesn’t need a minder, but he does need someone who is gentler and calmer than I (Bursch & Butler, 2012, p 212).

Boosting Self-esteem

Although many participants identified ways in which their caregiving role had hindered their self-esteem, others highlighted ways in which becoming a caregiver had improved their self-esteem (Bursch & Butler, 2012; Hasselkus & Murray, 2007; O’Connor, 2007; Tuomola et al., 2016). In addition to the upskilling and personal growth discussed above, some participants noted feeling good in themselves for embracing and performing their role of caregiver, and others commented that being complimented by others for their caregiving abilities helped to boost their self-esteem. One participant from Hasselkus and Murray (2007) shared: “It’s satisfying that I can take care of her; that brings us closer together. I don’t think we’ve ever been as close as we are right now” (p 14). Participants from other studies discussed similar experiences:

> I have become more patient, [and] exercise more self-control, which I am still learning. I feel that [going] through a harder life tends to make you a better person. This is the hard way of learning about life (Tuomola et al., 2016, p 163).

> Some of them have said ‘wow, I really respect you for that’, you know. But, but it's just, uh, surprise mostly. Yeah, so, that's an interesting side because it makes me feel good to hear that feedback. You know, it always makes you feel good when people give you some praise for, for things” (O’Connor, 2007, p 171).

Discussion

This review aimed to synthesise findings from 12 qualitative studies investigating how informal caregivers of people with dementia (PWD) experience changes to their self-identity through the caregiving experience. It further aimed to develop a preliminary understanding of how perceived identity changes can affect an individual’s self-esteem and in turn their psychological well-being. Highlighting the importance of exploring this relationship, disrupted self-identity and low self-esteem have been found to be linked to poorer psychological well-being and increased likelihood of psychological disorders (Matheson et al., 2015; Lamont et al., 2019; Sharma & Sharma, 2010). It is suggested that a better understanding of the experiences of informal caregivers, and the identification of factors that can influence their well-being can help educate health care services on the types of support that may be offered to caregivers to enhance positive health outcomes (Crellin et al., 2014).

Summary of Findings

Oyserman (2001) stated that self-identity provides an answer to the question “who am I?”, a question that this synthesis found to be challenged in partners and adult children caring for a loved one with dementia. In support of the existing literature (Cooper, 2021; Montgomery & Kosloski, 2012; Lamont et al., 2019), the synthesis highlighted ways in which caregiving could lead to identity disruption, and low self-esteem. The synthesis found that one way this occurred was through perceived personality changes that distanced caregivers from who they supposed themselves to be before becoming a caregiver, and this made them feel “unrecognisable” from their previous self. Personality changes were commonly experienced as negative, with participants eliciting unkind opinions of their “new” identities, which left them “grieving” their previous selves, suggesting a negative impact on their self-esteem and psychological well-being. For example, participants from Bursch and Butlers (2012) study discussed feeling “angry” and “disturbed” by their change of self, with one caregiver referring to themselves as becoming “a mop”, and another viewing themselves as “the wickedest person in the world”.

According to Higgins (1987) self-discrepancy theory, discrepancies between the actual and ought self can trigger anxiety and guilt, and discrepancy between the actual and ideal self can lead to depression. Personality changes may have distanced caregivers from their "ought" and "ideal" selves (previous selves/a good caregiver), which may then have impacted on their self-esteem and in turn their psychological well-being. In relation to the ought and ideal self, participants discussed feeling that they were "inadequate" as caregivers, and that others would be able to look after their partners better. As Higgins (1987) theory explained, this could activate feelings of anxiety and guilt, as one participant from Tolhurst et al. (2016) described: "I feel incredibly guilty that someone else can cope with it and I can't. It's all guilt". This may also have triggered feelings of depression, as one participant described caregiving to be a "very sad part of my life" (Hasselkus & Murray, 2007) with another expressing "I am no longer a happy person" (Lewis, 2015).

Caregivers discussed taking on tasks that were not coherent with their pre-existing relational role which impacted on their identity within those roles. As predicted in the literature by Miller et al., (2008) and Hayes et al., (2009), there was a shift from the pre-existing relational role to that of a "parent" or "carer", and this altered how caregivers defined themselves. It was found that caregivers often discussed how aspects of their identity within other relational roles (e.g., mother, spouse, friend) were overtaken as they prioritised their caregiving role and lost remnants of their identities tied up in other roles. This may be explained by Eifert et al's (2015) concept of 'role engulfment' whereby participants described how the demands of caregiving took time and energy away from other social and occupation roles and as result they felt that had to "sacrifice" these parts of their identity. Hinting at the impact this may have on one's psychological well-being, a participant from Hasselkus and Murray's (2007) study described giving up social occupations as being like "prison", and "like hell" (p 14). According to behavioural theories of depression, losing access to established sources of meaning and a reduction in positive reinforcements can result in a decline in valued activities, which can increase the risk of depression (Carvalho & Hopko, 2011; Lewinsohn, 1974). Caregivers prolonged lack of engagement with positive behaviours (e.g., previously enjoyed hobbies and occupations) may refuse them the chance to attain a sense of pleasure or achievement, which can sustain and worsen depressive symptoms (Carvalho & Hopko, 2011). Social isolation is significantly and positively associated with lower self-esteem (Henriguez et al., 2021; Preston & Rew, 2022) and increased risk of depression (Bosacki et al., 2007). The reduction in social activities may have hindered caregivers' sense of belonging, acceptance, and connectedness that is gained from positive interactions with others (Baldwin & Sinclair, 1996; Lee & Robbins, 1995), and as such may have further impacted on their self-esteem and psychological well-being.

Cash et al. (2019) and Montgomery and Kosloski (2012) proposed that identity disruption may be protected for caregivers who viewed caregiving as part of their "duty", or an inherent aspect of their pre-existing relational role. This was supported in the current synthesis and appeared to be more protective of one's self-esteem and psychological well-being; participants who discussed caregiving as being part of their pre-existing relational role, and therefore less disruptive to their identity, also discussed a more positive experience of the caregiving role, and of themselves. In some cases, viewing caregiving as part of their pre-existing relational role protected caregiver's sense of continuity within the marital relationship, with one husband describing that his "good" marriage "hasn't gone away" and another commenting he did not "resent" his caregiving role as it was part of the "contract" of marriage. Others discussed having pride in their role as a caregiver and feeling that they were fulfilling this well. Demonstrating the influence of relationship continuity on the caregiving experience, a study by Riley et al. (2018) sampling 71 spouses of PWD found that higher levels of relationship continuity on the Birmingham Relationship Continuity Measure (BRCM) (Riley et al., 2013) were correlated with fewer negative emotional reactions to caregiving on the Zarit Burden Interview (ZBI) (Zarit et al., 1980) and higher positive reactions on the Positive Aspects of Caregiving questionnaire (PAC) (Tarlow et al., 2004). It is therefore hypothesised that perceiving the care-giving role as part of one's pre-existing identity and therefore maintaining relationship continuity with the PWD may serve as a protective function for an individual's psychological well-being.

In a more positive light, some caregivers were found to embrace the caregiving role, and identified ways in which the role had helped them develop new skills and areas of growth to their personality. Highlighting a positive impact on self-esteem, participants commented on feeling stronger, wiser, and like "a good person". Other research has detected similar psychological benefits of caregiving. In a survey conducted by the National Opinion Research Centre (2014) family caregivers reported positive experiences of caregiving including the satisfaction of providing good care and increased meaning and purpose in one's life. As such, not all identity changes were perceived to be negative which adds new insight to the existing literature which currently predominantly focuses on negative aspects of identity change.

Strengths and Limitations

This was the first review of its kind to synthesise qualitative literature exploring identity change in informal caregivers of people with dementia. As such, it provides novel insight into this phenomenon that may offer helpful insight into the needs of caregivers and path the way for future research.

One limitation of this review is that of the 12 papers examined, only half explored self-identity as a main aim or focus of their study. For the other six papers, themes around self-identity were explored in part or presented as an additional finding. These papers were included due to the limited number of qualitative studies specifically exploring this topic and as such the current author did not want to omit valuable or meaningful data. However, this limited the depth of data provided and the evidence used to support findings (e.g., quotes), leaving findings more open to interpretation, reducing the reliability and credibility of conclusions drawn.

The reviewed studies combined represent a mostly white population, limiting the representativeness and generalisability of the sample population to other ethnic or cultural backgrounds. This is of particular importance in this topic area as other research has highlighted how differences in cultural norms, values, and rituals can impact on one's experience of caregiving (Connell & Gibson, 1997). Future research would benefit from exploring this phenomenon across different cultural backgrounds to produce more generalisable findings that better represent the population affected. Further, half of the studies either did not record how many authors analysed findings or used only one researcher's judgement. This may reduce the reliability and validity of findings from these papers, as they rely on the subjective judgement of one researcher and other possible interpretations may not be presented.

The current review is also limited by having only the first author complete the screening and analysis process. This depicts a risk of researcher bias, as the author may have unintentionally interpreted first order (quotes) and second order (authors interpretations) constructs in favour of supporting the research topic. It is also possible that the researcher's individual experiences, values and beliefs may have impacted on the interpretation of meaning from the papers. As the researcher has not been in the position of caring for a loved one with dementia, it is possible that they interpreted meaning differently to someone who has been in the caregiving position, reducing the credibility of interpretations and conclusions drawn. The current review could have been strengthened by having another author complete the screening and analysis process, and for interpretations to be discussed and agreed upon, producing more reliable and less biased interpretations.

Lastly, the studies reviewed included different types of informal caregivers, comprising adult children and spouses. It was decided to include studies that sampled any informal caregivers due to the limited number of papers found for each subgroup. However, this may have confounded different perspectives and issues. It has been reported that the impact of the caregiving experience between spouses and adult children differs due to their distinct expectations and stages of life (Chappell et al., 2014; Raschick & Ingersoll-Dayton, 2004). Future research would benefit from exploring the impact on the identity of adult children and spouses separately to produce more useful findings that will better inform clinical practice.

Other types of informal caregivers (e.g., grandchildren, siblings) were included in some of the reviewed studies, however evidence from these participants was sparse and not relevant to the current synthesis, hence were not used in this review.

Implications and Recommendations

These findings indicate that a positive self-identity and higher levels of self-esteem may predict better psychological well-being for informal caregivers of PWD. This suggests that identifying ways to help individuals preserve their identity whilst taking on the role of caregiver may be an important factor of consideration for health care services.

Considering the limitations of this study, more primary research adopting a qualitative approach is needed to further explore the impact of caregiving on one’s self-identity and self-esteem. It would be helpful to focus specifically on these issues to gain a richer and deeper understanding. It would be recommended to repeat this synthesis when more primary sources are available that focus specifically on this phenomenon to attain a more informed conclusion.

The findings of the review indicate that informal caregivers of people with dementia would benefit from support from health care professionals to help them maintain a positive self-identity. Recognising and understanding the impact of caregiving on self-identity is important for health care professionals so that they can help caregivers anticipate them and validate them when they do occur. Helping caregivers to maintain a positive self-identity may involve steps to allow caregivers to continue with other occupations, hobbies, and outlets that are important to their pre-existing identity (Glasby & Thomas, 2018). Yong et al. (2020) highlighted the value of providing support with time management and adapting environments to encourage caregivers to engage in personally meaningful occupations. This may help caregivers feel more empowered and regain some autonomy to lead a life that better resembles that of their pre-dementia life.

Findings of this synthesis indicate that one’s identity within their relationship (relationship continuity) is also an important factor to consider when supporting informal caregivers. Interventions may therefore also want to consider methods to help caregivers maintain continuity within their relationships. This may include supporting caregivers to sustain shared activities with their loved one, which may involve adapting previously enjoyed tasks to consider the caregiver’s and care receiver’s skills, interests, and safety (Yong et al., 2020).

References

Atkins, S., Lewin, S., Smith, H., Engel, M., Fretheim, A., & Volmink, J. (2008). Conducting a meta-ethnography of qualitative literature: Lessons learnt. *BMC Medical Research Methodology*, *8*, 1–10. https://doi.org/10.1186/1471-2288-8-21

Baldwin, M. W., & Sinclair, L. (1996). Self-esteem and "If … Then" contingencies of interpersonal acceptance. *Journal of Personality and Social Psychology*, *71*(6), 1130–1141. doi:10.1037/0022-3514.71.6.1130

Bosacki, S., Dane, A., Marini, Z., & Youth, L. C.-C U. R. A. (2007). Peer relationships and internalizing problems in adolescents: mediating role of self-esteem. *Emotional & Behavioural Difficulties, 12*(4), 261–282. https://doi.org/10.1080/13632750701664293

Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology, 3*(2), 77–101. https://doi.org/10.1191/1478088706qp063oa

Bursch, H. C., & Butcher, H. K. (2012). Caregivers' deepest feelings in living with alzheimer's diseas: A ricoeurian interpretation of family caregivers' journals. *Research in Gerontological Nursing*, *5*(3), 207–215. https://doi.org/10.3928/19404921-20120605-03

Campbell, R., Pound, P., Morgan, M., Daker-White, G., Britten, N., Pill, R., Yardley, L., Pope, C., & Donovan, J. (2011). Evaluating meta-ethnography: Systematic analysis and synthesis of qualitative research. *Health Technology Assessment*, *15*(43). https://doi.org/10.3310/hta15430

Cash, B., Warburton, J., & Hodgkin, S. (2019). Expectations of care within marriage for older couples. *Australasian Journal on Ageing*, *38*(1), E19–E24. https://doi.org/10.1111/ajag.12590

Carvalho, J. P., & Hopko, D. R. (2011). Behavioral theory of depression: Reinforcement as a mediating variable between avoidance and depression. *Journal of Behavior Therapy and Experimental Psychiatry*, *42*(2), 154–162. https://doi.org/10.1016/j.jbtep.2010.10.001

Chappell, N. L., Dujela, C., & Smith, A. (2014). Spouse and adult child differences in caregiving burden. *Canadian Journal on Aging*, *33*(4), 462–472. https://doi.org/10.1017/S0714980814000336

Chattillion, E. A., Ceglowski, J., Roepke, S. K., von Känel, R., Losada, A., Mills, P. J., Romero-Moreno, R., Grant, I., Patterson, T. L., & Mausbach, B. T. (2013). Pleasant events, activity restriction, and blood pressure in dementia caregivers. *Health Psychology, 32*(7), 793–801. https://doi.org/10.1037/a0029412

Cherry, M. G., Ablett, J. R., Dickson, J. M., Powell, D., Sikdar, S., & Salmon, P. (2019). A qualitative study of the processes by which carers of people with dementia derive meaning from caring. *Aging and Mental Health, 23*(1), 69–76. https://doi.org/10.1080/13607863.2017.1393792

Connell, C.M., & Gibson, G.D. (1997). Racial, Ethnic, and Cultural differences in dementia caregiving: Review and analysis. *Gerontologist, 37*(3), 355-364. https://doi:10.1093/geront/37.3.355

Cooper, R. A. (2021). “I Am a Caregiver”: Sense-making and Identity Construction through Online Caregiving Narratives. *Journal of Family Communication*, *21*(2), 77–89. https://doi.org/10.1080/15267431.2021.1889554

Crellin, N. E., Orrell, M., McDermott, O., & Charlesworth, G. (2014). Self-efficacy and health-related quality of life in family carers of people with dementia: A systematic review. *Aging and Mental Health, 18*(8), 954–969. https://doi.org/10.1080/13607863.2014.915921

Cross, A. J., Garip, G., & Sheffield, D. (2018). The psychosocial impact of caregiving in dementia and quality of life: a systematic review and meta-synthesis of qualitative research. *Psychology and Health, 33*(11), 1321–1342. https://doi.org/10.1080/08870446.2018.1496250

Dalton, J., Booth, A., Noyes, J., & Sowden, A. J. (2017). Potential value of systematic reviews of qualitative evidence in informing user-centered health and social care: findings from a descriptive overview. *Journal of Clinical Epidemiology, 88*, 37-46. https://doi.org/10.1016/j.jclinepi.2017.04.020

Department Of Health. (2015). *Prime Ministers Challenge on Dementia 2020.* *https://www.gov.uk/government/publications/prime-ministers-challenge-on-dementia-2020/prime-ministers-challenge-on-dementia-2020*

Donnellan, W. J., Bennett, K. M., & Soulsby, L. K. (2015). What are the factors that facilitate or hinder resilience in older spousal dementia carers? A qualitative study. *Aging and Mental Health*, *19*(10), 932–939. https://doi.org/10.1080/13607863.2014.977771

Eifert, E. K., Adams, R., Dudley, W., & Perko, M. (2015). Family Caregiver Identity: A Literature Review. *American Journal of Health Education*, *46*(6), 357–367. https://doi.org/10.1080/19325037.2015.1099482

Erikson, E. H. (1963). *Childhood and society*. WW Norton & Company.

Erikson, E. H. (1980). Identity and the life cycle. New York: W. W. Norton.

Finfgeld-Connett, D., & Johnson, E. D. (2013). Literature search strategies for conducting knowledge-building and theory-generating qualitative systematic reviews. *Journal of Advanced Nursing*, *69*(1), 194–204. https://doi.org/10.1111/j.1365-2648.2012.06037.x

Glasby, J., & Thomas, S. (2018). Understanding and responding to the needs of the carers of people with dementia in the UK , US and beyond. *Social Care Collection*, 1–28. https://www.birmingham.ac.uk/Documents/college-social-sciences/social-policy/carers-of-people-with-dementia.pdf

Harden, A., Garcia, J., Oliver, S., Rees, R., Shepherd, J., Brunton, G., & Oakley, A. (2004). Applying systematic review methods to studies of people's views: An example from public health research. *Journal of Epidemiology and Community Health*, *58*(9), 794–800. https://doi.org/10.1136/jech.2003.014829

Hasselkus, B. R., & Murray, B. J. (2007). Everyday occupation, well-being, and identity: The experience of caregivers in families with dementia. *American Journal of Occupational Therapy*, *61*(1), 9–20. https://doi.org/10.5014/ajot.61.1.9

Hayes, J., Boylstein, C., & Zimmerman, M. K. (2009). Living and loving with dementia: Negotiating spousal and caregiver identity through narrative. *Journal of Aging Studies*, *23*(1), 48–59. https://doi.org/10.1016/j.jaging.2007.09.002

Henriquez, D., Urzúa, A., & López-López, W. (2021). Indicators of Identity and Psychological Well-Being in Immigrant Population. *Frontiers in Psychology*, *12*(October). https://doi.org/10.3389/fpsyg.2021.707101

Higgins, E. T. (1987). Self-discrepancy: A theory relating self and affect. *Psychological Review*, *94*(3), 319–340. https://doi.org/10.1037/0033-295X.94.3.319

Joling, K.J., Schellevis, F.G., van der Horst, H.E., Scheltens, P., & van Marwijk, H.W.J. (2010). Incidence of Depression and Anxiety in the spouses of Patients With Dementia: A Naturalistic Cohort Study of Recorded Morbidity With a 6- year Follow-up. *American Journal of Geriatric Psychiatry*, *18*(2), 146-153. https://doi:10.1097/JPG.0b013e3181bf9f0f

Lachal, J., Revah-Levy, A., Orri, M., & Moro, M. R. (2017). Metasynthesis: An original method to synthesize qualitative literature in psychiatry. *Frontiers in Psychiatry*, *8*(DEC). https://doi.org/10.3389/fpsyt.2017.00269

Lamont, R. A., Quinn, C., Nelis, S. M., Martyr, A., Rusted, J. M., Hindle, J. V., Longdon, B., & Clare, L. (2019). Self-esteem, self-efficacy, and optimism as psychological resources among caregivers of people with dementia: Findings from the IDEAL study. *International Psychogeriatrics*, *31*(9), 1259–1266. https://doi.org/10.1017/S1041610219001236

Lee, R. M., & Robbins, S. B. (1995). Measuring Belongingness: The Social Connectedness and the Social Assurance Scales. *Journal of Counseling Psychology*, *42*(2), 232–241. https://doi.org/10.1037/0022-0167.42.2.232

Lethin, C., Renom-Guiteras, A., Zwakhalen, S., Soto-Martin, M., Saks, K., Zabalegui, A., Challis, D. J., Nilsson, C., & Karlsson, S. (2017). Psychological well-being over time among informal caregivers caring for persons with dementia living at home. *Aging and Mental Health*, *21*(11), 1138–1146. https://doi.org/10.1080/13607863.2016.1211621

Lewinsohn, P. M. (1974). A behavioral approach to depression. In R. J. Friedman, & M. M. Katz (Eds.), *The psychology of depression: Contemporary theory and research* (pp. 157-178). John Wiley & Sons.

Lewis, L. F. (2015). Caregiving for a Loved One with Dementia at the End of Life: An Emergent Theory of Rediscovering. *American Journal of Alzheimer's Disease and Other Dementias*, *30*(5), 488–496. https://doi.org/10.1177/1533317514559829

Lindeza, P., Rodrigues, M., Costa, J., Guerreiro, M., & Rosa, M. M. (2020). Impact of dementia on informal care: A systematic review of family caregivers' perceptions. *BMJ Supportive and Palliative Care*, 1–12. https://doi.org/10.1136/bmjspcare-2020-002242

Mallya, S., & Fiocco, A. J. (2018). Impact of informal caregiving on cognitive function and well-being in Canada. *International Psychogeriatrics, 30*(7), 1049-1055. https://doi.org/10.1017/S1041610217002605

Matheson, F. I., Daoud, N., Hamilton-Wright, S., Borenstein, H., Pedersen, C., & O'Campo, P. (2015). Where Did She Go? The Transformation of Self-Esteem, Self-Identity, and Mental Well-Being among Women Who Have Experienced Intimate Partner Violence. *Women's Health Issues*, *25*(5), 561–569. https://doi.org/10.1016/j.whi.2015.04.006

Mattock, S., & McIntyre, A. (2016). Exploring the role of occupation for spouse-carers before and after the death of a spouse with dementia. *British Journal of Occupational Therapy*, *79*(2), 69–77. https://doi.org/10.1177/0308022615608638

Miller, K. I., Shoemaker, M. M., Willyard, J., & Addison, P. (2008). Providing Care for Elderly Parents: A Structurational Approach to Family Caregiver Identity. *Journal of Family Communication*, *8*(1), 19–43. https://doi.org/10.1080/15267430701389947

Moher, D., Liberati, A., Tetzlaff, J., & Altman, D. G. (2009). Reprint - Preferred reporting items for systematic reviews and meta-analyses: The PRISMA statement. *Physical therapy*, *89*(9), 873–880.

Montgomery, R.J.V., & Kosloski, K.D. (2012). Pathways to a Caregiver Identity and Implications for Support Services. In RC Talley &RJV Montgomery (Eds.). *Caregiving across the lifespan*. (pp. 131-156). Springer.

National Health Service. (2022). Dementia. NHS. https:www.england.nhs.uk/mental-health/dementia/

National Institute for Health and Care Excellence. (2012). Appendix H Quality Appraisal Checklist -qualitative studies. *Methods for the development of NICE public health guidance (third edition).* www.nice.org.uk/process/pmg4

National Opinion Research Centre. (2014). *Long term care in America: expectations and reality. Htpps://www.longtermcarepoll.org/wp-content/uploads/2017/11/AP-NORC-Long-term-Care-2014_Trend_Report.pdf*

Noblit, G., & Hare, R. (1988). *Meta-ethnography: Synthesizing Qualitative Studies (Qualitative Research Methods).* SAGE Publications Inc.

O'Connor, D. L. (2007). Self-identifying as a caregiver: Exploring the positioning process.

Journal of Aging Studies, *21*(2), 165–174. https://doi.org/10.1016/j.jaging.2006.06.002

Oyserman, D. (2001). *Oyserman, D. (2001). Self-concept and identity. In A. Tesser & N. Schwarz,*. 499–517.

Pilarska, A. (2020). Sense of identity and self-control: The mediating role of goal characteristics. *Psihologijske Teme*, *29*(2), 291–310. https://doi.org/10.31820/pt.29.2.5

Pinquart, M., & Sörensen, S. (2004). Associations of caregiver stressors and uplifts with subjective well-being and depressive mood: A meta-analytic comparison. *Aging and Mental Health*, *8*(5), 438–449. https://doi.org/10.1080/13607860410001725036

Prato, L., Abley, C., & Adamson, J. (2022). Exploring online identity construction for the caregivers of adults living with dementia and the value of interactions with health and social care professionals. *Health and Social Care in the Community*, *30*(1), 295–306. https://doi.org/10.1111/hsc.13403

Preston, A. J., & Rew, L. (2022). Connectedness, Self-Esteem, and Prosocial Behaviors Protect Adolescent Mental Health Following Social Isolation: A Systematic Review. *Issues in Mental Health Nursing*, *43*(1), 32–41. https://doi.org/10.1080/01612840.2021.1948642

Raschick, M., & Ingersoll-Dayton, B. (2004). The costs and rewards of caregiving among aging spouses and adult children. *Family Relations*, *53*(3), 317–325. https://doi.org/10.1111/j.0022-2445.2004.0008.x

Richardson, T. J., Lee, S. J., Berg-Weger, M., & Grossberg, G. T. (2013). Caregiver health: Health of caregivers of Alzheimer's and other dementia patients topical collection on geriatric disorders. *Current Psychiatry Reports*, *15*(7). https://doi.org/10.1007/s11920-013-0367-2

Riley, G. A., Evans, L., & Oyebode, J. R. (2018). Relationship continuity and emotional well-being in spouses of people with dementia. *Aging and Mental Health*, *22*(3), 299–305. https://doi.org/10.1080/13607863.2016.1248896

Riley, G. A., Fisher, G., Hagger, B. F., Elliott, A., Serve, H. Le, & Oyebode, J. R. (2013). The Birmingham Relationship Continuity Measure: The development and evaluation of a measure of the perceived continuity of spousal relationships in dementia. *International Psychogeriatrics*, *25*(2), 263–274. https://doi.org/10.1017/S1041610212001743

Rosness, T. A., Mjrud, M., & Engedal, K. (2011). Quality of life and depression in carers of patients with early onset dementia. *Aging and Mental Health*, *15*(3), 299–306. https://doi.org/10.1080/13607861003713224

Sabat, S.R. (2001). *The Experience of Alzheimer's Disease: Life Through a Tangled Veil*. Blackwell.

Sattar, R., Lawton, R., Panagioti, M., & Johnson, J. (2021). Meta-ethnography in healthcare research: a guide to using a meta-ethnographic approach for literature synthesis. *BMC Health Services Research*, *21*(1), 1–13. https://doi.org/10.1186/s12913-020-06049-w

Schluz, R., & Martire, L.M. (2004). Family Caregiving of Persons with Dementia: Prevalence, Health Effects, and Support Strategies. *The American Journal of Geriatric Psychiatry, 12*(3), 240-249. https://www.proquest.com/scholarly-journals/family-caregiving-persons-with-dementia/docview/195982798/se-2

Sharma, S., & Sharma, M. (2010). Self, social identity and psychological well-being. *Psychological Studies*, *55*(2), 118–136. https://doi.org/10.1007/s12646-010-0011-8

Skaalvik, M. W., Norberg, A., Normann, K., Fjelltun, A. M., & Asplund, K. (2016). The experience of self and threats to sense of self among relatives caring for people with Alzheimer's disease. *Dementia*, *15*(4), 467–480. https://doi.org/10.1177/1471301214523438

Smith, G., & Rodham, K. (2022). Supporting and sustaining care at home: Experiences of adult daughters who support a parent with dementia to remain in their own home. *Health and Social Care in the Community*, *30*(1), 81–90. https://doi.org/10.1111/hsc.13373

Tarlow, B.J., Wisniewski, S.R., Belle, S.H., Rubert, M., Ory, M.G., & Gallagher-Thompson, D. (2004). Positive aspects of caregiving: Contributions of the REACH Project to the development of new measures for Alzheimer's caregiving. *Research on Aging, 26,* 429–453. doi:10.1177/ 0164027504264493

Thoits, P.A. (1999). Self, identity, Stress and mental health. In CS Aneshensel & JC Phelam (Eds.). *Handbook of the sociology of mental health.* (pp. 345–368). Springer.

Thomas, J., & Harden, A. (2008). Methods for the thematic synthesis of qualitative research in systematic reviews. *BMC Medical Research Methodology*, *8*, 1–10. https://doi.org/10.1186/1471-2288-8-45

Tolhurst, E., Carey, M., Weicht, B., & Kingston, P. (2019). Is living well with dementia a credible aspiration for spousal carers? *Health Sociology Review*, *28*(1), 54–68. https://doi.org/10.1080/14461242.2018.1475249

Toye, F., Seers, K., Allcock, N., Briggs, M., Carr, E., Andrews, J., & Barker, K. (2013). “Trying to pin down jelly” - Exploring intuitive processes in quality assessment for meta-ethnography. *BMC Medical Research Methodology*, *13*(1), 1–12. https://doi.org/10.1186/1471-2288-13-46

Tuomola, J., Soon, J., Fisher, P., & Yap, P. (2016). Lived Experience of Caregivers of Persons with Dementia and the Impact on their Sense of Self: A Qualitative Study in Singapore. *Journal of Cross-Cultural Gerontology*, *31*(2), 157–172. https://doi.org/10.1007/s10823-016-9287-z

Waterman, A. S. (2007). Doing well: The relationship of identity status to three conceptions of well-being. *Identity*, *7*(4), 289–307. https://doi.org/10.1080/15283480701600769

Wilcock, A. A. (1999). Reflections on doing, being and becoming. *Australian Occupational Therapy Journal*, *46*(1), 1–11. https://doi.org/10.1046/j.1440-1630.1999.00174.x

Yong, A. S. L., Price, L., Napier, F., & Matthews, K. (2020). Supporting sustainable occupational lives for partner caregivers of people with dementia. *British Journal of Occupational Therapy*, *83*(9), 595–604. https://doi.org/10.1177/0308022619898080

Zarit, S.H., Reever, K.E., & Bach-Peterson, J. (1980). Relatives of the impaired elderly: Correlates of feelings of burden. *Gerontologist, 20*, 649–655

Zhang, Y. (2021). “Cinderella Men”: Husband-and Son-Caregivers for Elders with Dementia in Shanghai. *Anthropology and Aging*, *42*(2), 6–20. https://doi.org/10.5195/AA.2021.356

CHAPTER TWO

LIVING WITH AGGRESSION: EXPLORING THE EXPERIENCES OF SPOUSES CARING FOR A PARTNER WITH DEMENTIA

Abstract

Introduction: There is a growing interest in how different aspects of dementia can impact on the relationship continuity between people with dementia (PWD) and their spouses. One area that has received little attention is the impact of dementia-related aggressive behaviours. This study therefore aimed to examine how aggressive behaviours in dementia can undermine the relationship between PWD and their spousal caregivers, using relationship continuity as a framework. It further sought to examine what factors may moderate this impact.

Method: Semi-structured interviews were conducted with seven spousal caregivers of PWD who were displaying dementia-related aggressive behaviours. The interviews were analysed using a Reflexive Thematic Analysis technique (Braun & Clark, 2022).

Results: Findings demonstrate that aggressive behaviours in dementia can result in a loss of love and affection between the couple, and greater feelings of hostility. Different responses to the aggression could be explained by how individuals made sense of the aggression, and how far removed these were from the pre-dementia relationship. Developing a better understanding of the aggression and learning effective ways to manage behaviours was found to be protective of the relationship.

Conclusions: This study indicates that relationship continuity between PWD and their spousal caregivers can be negatively impacted by aggression. However, the study also detected different factors that can moderate this impact, and ways in which couples can preserve relationship continuity under challenging circumstances. Further research is needed to provide a richer understanding of this phenomenon.

Introduction

This research aimed to explore how aggressive behaviours undermine the relationship between people with dementia (PWD) and their partner, using relationship continuity as a framework for understanding this impact. It further sought to examine whether and how some carers can protect the relationship against the undermining effects of aggression.

To address these aims, two key questions were covered in interviews with spousal carers of individual's living with dementia:

1. How does the aggression impact on the experience of continuity in the relationship?
2. What moderates that impact?

Relationship continuity refers to a continuation of the pre-dementia relationship whereby the relationship still feels like a romantic and loving partnership (Riley et al., 2013). When this is not achieved, Riley et al. (2013) explain that individuals may experience relationship discontinuity, whereby the relationship no longer feels like a partnership but is replaced by a caregiver and care-receiver relationship. Riley et al. (2013) propose that relationship continuity comprises of a cluster of five connected relationship domains: (1) *Relationship redefined*, the relationship is viewed as a continuation of the pre-dementia relationship, or it is now replaced with a new type of relationship. (2) *Same/different person,* the person with dementia is viewed as the same person despite dementia-related changes. (3) *Same/different feelings,* the spouse experiences the same love and affection for the person as before, or these feelings have been replaced with feelings such as protectiveness, emotional distance or dislike. (4) *Couplehood,* the spouse feels that they are still one member of a couple. (5) *Loss*, feeling a sense of loss for the person with dementia or the relationship. Research on relationship continuity predominantly focuses on the continuation of a loving relationship that has been undermined by dementia (Riley et al., 2018). However, in some cases the pre-dementia relationship may be unsatisfactory and the way in which aggression impacts on these relationships also merits attention.

Aggressive Behaviours in Dementia

Dementia related aggressive behaviours are characterised as destructive actions aimed at others, objects, or the self (Khan et al., 2018). These behaviours can include verbal (e.g., shouting, cursing, threatening), and physical (e.g., hitting, pushing, kicking, biting) actions (Kinskey & Buchanan, 2018). Aggressive behaviours in adults with dementia have been highlighted as one source of difficulty in the relationship between PWD and their spousal carers (Vugt et al., 2003; Gibbons, 2018; Riley et al., 2019; Spector et al., 2016). To date, this is mostly evidenced in quantitative research. In a study sampling 53 spousal caregivers of PWD, Vugt et al. (2003) examined the relationship between behavioural problems in the PWD and the quality of the marital relationship, using the Neuropsychiatric Inventory (NPI) (Cummings et al., 1994) and items from the Three General Families measure of positive affect (Mangen et al., 1988). Regression analysis determined that behavioural problems were significantly associated with the deterioration in the quality of the relationship between PWD and their spousal carer. Findings were supported by more recent research by Spector et al. (2016) who compared results from the 'Quality of Caregiver and Patient Relationship (QCPR) (Spruytte et al., 2002) and the NPI (Cummings et al., 1994) in 50 couples, where one member had dementia. Results demonstrated a significant association between behavioural disturbances (including aggression and agitation) and reduced quality of patient-carer relationship. However, these studies do not specifically investigate relationship continuity and the impact of aggressive behaviours on relationship continuity in romantic relationships is largely unexplored.

Polenick et al. (2017) conducted a study using in-depth focus group data from 26 family caregivers to uncover strategies for managing behavioural and psychological symptoms of dementia, including aggression. Caregivers discussed using strategies such as selfcare, maintaining a sense of humour, and social support. Although findings provide a useful insight into strategies for caregivers to manage behaviours and protect their emotional well-being, it does not focus specifically on aggression, and does not touch upon how caregivers may attempt to protect their relationship with the PWD.

Relationship Continuity

Research exploring the experiences of caring for a loved one with dementia has found considerable variations in how partners experience the relationship. Some report fewer changes from the pre-dementia relationship, and others report that they no longer feel like they are part of a couple (Lewis & Riley, 2021). Relationship continuity, measured by the Birmingham Relationship Continuity Measure (BRCM) (Riley et al., 2013) has been found to be associated with a reduced sense of burden and greater satisfaction from the care-giver role (Riley et al., 2019). Relationship continuity has further been associated with a more empathic and person-centred approach to caregiving which increases the quality of care and subsequent emotional well-being of the PWD and the caregiver (Walters et al., 2020). In contrast, Walters et al. (2010) found that discontinuity was linked to greater control and restriction. Supporting this notion, Riley et al. (2020) explored the link between person-centred care and relationship continuity in a quantitative study sampling 25 spousal caregivers of PWD. Results found that caregivers who reported higher levels of continuity on the BRCM (Riley et al., 2013) recounted more person-centred attributions to caregiving. The reasons as to why some people experience continuity and others do not are so far undetermined. However, given the potential benefits of continuity, this is an important area of exploration.

In a qualitative study investigating the impact of aggression on marital relationships, Gibbons (2018) interviewed five spousal carers of PWD. Findings indicated that aggression disrupted the couple's ability to maintain a continuous relationship. Gibbons hypothesised that aggression may threaten continuity because of the hostility it can create, that weakens feelings of love and affection. However, Gibbons found that some spouses were able to separate aggression from the person and see it as something external. This appeared to help the carer to maintain the experience of a continuous and loving relationship. Gibbons small sample size hindered the ability to explore this connection further or make any generalisations. However, findings were supported in a quantitative study by Lewis and Riley (2021) sampling 35 participants. Scores from BRCM (Riley et al., 2013), the Revised Memory and Behaviour Checklist (Teri et al., 1992) and the Relationship Assessment Scale (Hendrick, 1998) were correlated and found a significant negative correlation between continuity and challenging behaviour. Lewis and Riley (2021) offered explanation in that if the pre-dementia relationship was loving, aggressive behaviours may seem very inconsistent with the person and the relationship as they were before, making it difficult to maintain a sense of continuity. Although useful for identifying trends, quantitative data does not allow in-depth insight into the personal experiences of participants and thus does not provide explanatory information of the reasons behind these trends, limiting its usefulness in informing clinical practice. Gibbons (2018) and Lewis and Riley (2021) concluded that further qualitative research with a larger sample is needed to explore the complex nature of this connection.

In qualitative research exploring the impact of behavioural changes on relationship continuity in other neurological conditions, Bodley-Scott and Riley (2015) conducted a study investigating how partners experience personality changes after a traumatic brain injury. They found that aggressive behaviours elicited strong emotional responses of fear and stress in participants which resulted in some participants becoming avoidant of being around their partner. This predicted a loss of positive interactions, including affection, which was perceived to be incongruent with the pre-injury relationship and as such hindered relationship continuity. The study did not focus solely on aggression and as such the specific impact of this was not fully explored, however it provided novel insight into the impact of aggressive behaviours on relationship continuity in neurological conditions.

A qualitative study by Band-Winterstein and Avieli (2019) compared the experiences of dementia-related aggression on women who had experienced lifelong inter partner violence (IPV) with women whose partner's violent behaviours had first appeared during the dementia process. Findings demonstrated that women who had experienced lifelong IPV viewed the behaviours as a continuation of their partners previous self. Women who had not experienced IPV before understood the behaviours to be part of the dementia. As such, dementia-related aggressive behaviours were interpreted in accordance with the couples' previous relationships. Women who experienced lifelong IPV expressed feeling more burdened by negative emotions and they had less compassion for their partner. Contrastingly, women who had not experienced IPV before spoke more positively of their experiences and expressed more empathy for their partner.

In response to the government's "Challenge on Dementia 2020" (Department of Health, 2015) plan, a recent review recognised that more research is needed to aid understanding of carers experiences (Department of Health and Social Care, 2019). The review concluded that it is important to understand how specific elements of dementia can impact on the relationship and how these in turn affect the experience of living with dementia. An improved understanding may support the development of interventions that support couples to maintain and enhance positive aspects of their relationship and preserve continuity, with an overarching aim to improve the emotional well-being and QOL of caregivers and PWD (Lewis & Riley, 2021).

This research therefore aimed to examine the impact of aggression on the relationship between the person living with dementia and their spousal caregiver, using continuity/discontinuity framework as a theoretical guide; and to explore what moderates this impact.

Method

Ethics

This research study was reviewed and received full ethical approval from the University of Birmingham Research and Governance committee (see Appendix E). In line with the British Psychological Society *Code of Ethics and Conduct* (2018), participants were required to provide written informed consent once they had been given sufficient time to consider their participation in the study and had discussed any queries. All names and identifiable information presented in this paper, including the appendices, have been changed to ensure anonymity.

Recruitment and Participants

The sample size was chosen based on guidelines by Braun and Clarke (2013, p. 50), which recommended that for small projects involving interviews, six to twelve participants are sufficient to generate enough data to demonstrate patterns whilst ensuring that there is not too much data to manage. This was also deemed a realistic target in consideration of the time limit imposed upon this research, and with consideration of the specific nature of participants required (i.e., participants partners must be displaying aggressive behaviour). The inclusion/exclusion criteria are described in Table 2.1.

Table 2.1

Inclusion and Exclusion Criteria

Inclusion criteria	**Exclusion criteria**
Participants must be caring for a partner who has been diagnosed with dementia at least 6 months prior to the study.	Non-English speaking and/or unable to read English
Participants must have been in the relationship for a minimum of two years prior to diagnosis, to ensure a good comparison of the 'before' relationship.	Caregiver has cognitive difficulties themselves.
Participants must have capacity to give informed consent and reflect meaningfully upon their experiences.	
Participants must have experienced aggressive behaviours in the relationship.	
Participants must be aged 60+	

A purposive sample method was used to enable the researcher to gather appropriate information from sources related to the 'lived experience' the research is investigating (Horsburgh, 2003). This method invites critique in that it lacks randomness and representativeness. However, in qualitative research the relevance and production of necessary knowledge in the understanding of the phenomenon is more important that its ability to represent a population (Popay et al., 1998).

Participants were recruited from 'Join Dementia Research' (JDR). JDR is an online platform whereby individuals can register themselves to volunteer to participate in research relating to dementia. An application form was completed and submitted to JDR outlining the key details of this study and the inclusion/exclusion criteria. The study was approved by the organisation and advertised on their website. Volunteers were 'matched' with the study if they fit the criteria. Recruitment took place between June 2022 and December 2022. Identified matches who were over 60 years old (n=136) were sent an information sheet via email providing further details of what participation would entail and asking them to contact the researcher via email if they were interested in participating (see Appendix F). Of the 50 responses received from volunteers, 14 declined to participate with no explanation given. 25 were not eligible as they were caring for a relative who was not a spouse, or their spouse did not display aggressive behaviours. 11 volunteers expressed interest. Two did not respond to any further emails. One volunteer withdrew because their partner's health had declined.

A total of eight people were originally recruited for this study. One participant withdrew from the study before the interview due to ill health. Seven people participated in the study, including six wives and one husband. Table 2.2 provides a summary of participant details; pseudonyms have been used to ensure anonymity. All participants were white British. Participants ages ranged from early 60's to late 70's. All participants identified as the 'main carer' for their loved one. Although Rupert's wife moved to a care home last year, he had been her main carer for several years prior to this. Polly's husband passed away in early 2021 and had lived in a care home for a few months prior to this. Polly had been his main carer for the first few years of his diagnosis. As such, Rupert and Polly report retrospective accounts of their experiences of when their spouses were living with them. All participants reported experiencing incidents of verbal aggression and three also reported acts of physical aggression from their spouse.

Table 2.2

Demographic and Contextual Information for Participants Included in the Study

Pseudonym	Age	Relationship to PWD	Length of relationship (years)	Type of Dementia	Years since diagnosis (years spent caring)	Aggressive Behaviours	Living with PWD?	BCRM score
May	Early 70's	Wife	35	Alzheimer's	5 years	**Verbal:** shouting, swearing. **Physical:** hitting, squeezing, kicking.	Y	32
Elsa	Late 60's	Wife	49	Alzheimer's	1.5 years	**Verbal:** cursing, shouting, and snapping at others. **Physical:** none	Y	47
Polly	Early 60's	Wife	30	Early Onset Dementia	3 years. Polly's husband passed away in 2021	**Verbal:** threatens physical violence, shouting, cursing. **Physical**: pushing, shoving, hitting, kicking.	N	38
Rupert	Late 70's	Husband	44	Semantic Dementia	5 years	**Verbal:** accusations of adultery, hurtful comments, swearing. **Physical:** none	N	51
Jane	Early 70's	Wife	44	Alzheimer's- being reassessed at time of interview	9 years	**Verbal:** making accusations, threatening physical aggression, name calling, shouting, swearing. **Physical:** standing over Jane in a threatening manner.	Y	65

Anna	Late 60’s	Wife	38	Alzheimer’s	2.5 years	**Verbal:** accusations, shouting, saying untrue and unkind things to Anna. **Physical:** none	Y	51
Helen	Mid 60’s	Wife	42	Early Onset Dementia	2 years	**Verbal:** making accusations, taunting, “belittling”, saying “nasty” things, criticising, shouting. **Physical:** standing over Helen in threatening manner, throwing things.	Y	44

Procedure

After confirming their willingness to partake in the study, a pre-interview meeting was conducted where participants met the researcher, signed consent forms (see Appendix G) and completed the Birmingham Relationship Continuity Measure (BRCM) (Riley et al., 2013). The BRCM measures relationship continuity and includes items that assess the five key dimensions of continuity. The questionnaire comprises 23 statements that participants answer on a five-point Likert scale of ‘agree a lot’ to ‘disagree a lot’. Higher scores indicate higher levels of relationship continuity. Based on a normative sample of spousal caregivers of PWD, the mean score for the BRCM is 57.90 (Riley et al., 2013). Scores for participants are presented in table 2.2. Jane scored above the mean BRCM score, indicating higher levels of continuity in her relationship. All other participants scored lower than the mean score, indicating lower levels of relationship continuity compared to a normative sample of dementia caregivers.

Completing the BRCM gathered important data from participants that saved time in the main interview. The BRCM highlighted topic areas that were more/less significant for participants and allowed the researcher to focus on topics pertinent to each participant in the interviews. For example, if a participant scored lower in a certain domain, the researcher focused more on this in the interview to try to attain a better understanding of the causality and impact of such. In higher scoring domains, the researcher prompted conversations ascertaining what has helped participants maintain this aspect of the relationship. The BRCM was predominantly used to aid the design and development of the current research and was not aimed to be part of the main analysis. Therefore, it is not presented as such in this report, however certain findings are provided in the results section if they support the qualitative data.

The pre-interview meeting further provided participants with a chance to build rapport with the researcher; this aimed to help participants to feel comfortable discussing sensitive information in the research interview and increase the likelihood of gathering rich information necessary to meet the aims of this study. Three participants chose to have this meeting remotely due to time and convenience. The questionnaire and consent forms were sent in the post to these participants to complete and return.

The research interviews took place in face-to-face and remote settings, based on participant choice. For three participants, the interviews were conducted at the University of Birmingham. Two participants interviewed in their homes. Two participants completed their interviews remotely using the Zoom platform. Interviews did not have a strict time limit as the researcher wanted to obtain as much information as participants were willing to share. Interviews ranged from between 40 and 124 minutes.

The interview was recorded on an encrypted Dictaphone that was hired from the University of Birmingham. Interviews were transcribed using the Silverman (2011) transcription guide.

Data Collection

To meet the aims of this research, a qualitative method was deemed necessary as it enables access to in-depth knowledge and insight into the unique experiences and emotions of others (Creswell, 2009). A qualitative approach was useful to generate rich and valuable discussions regarding the impact of aggressive behaviours on relationship continuity for people living with dementia and their spousal carers.

The research predominantly adopts a deductive approach in that previous findings and theories relating to relationship continuity have driven the aims of the research and were used to guide the interview questions and the analysis. However, there was an inductive element as the research aimed to explore ideas about the connection between aggression and the relationship that have not yet been uncovered.

Data was collected via semi-structured interviews. Semi-structured interviews provide direction for the interview and ensure necessary questions are asked, yet enable participants to speak freely, allowing access to extra information (Bryman, 2012).

It was important that the genuine perspectives of the participants on the impact that aggression has had on their relationship was attained. However, the use of spontaneous questions was non-restrictive and hoped to encourage participants to tell their own story. An interview guide with questions on pre-determined topics was developed prior to interviews (see Appendix H).

The interview guide was initially devised based on the dimensions of relationship continuity outlined by Riley et al. (2013). It intended to gather an enriched understanding of domains covered in the BRCM (Riley et al., 2013), that are relevant to the research question. The topics for the interview fell into three categories, (1) Questions that provided contextual information about the aggression (e.g., whether it was physical, verbal, or both), (2) Broad questions about what sense they made of the aggression and how it impacted on them, physically and emotionally, and (3) Questions that related more specifically to dimensions of relationship continuity/discontinuity that previous research suggested might be affected by the aggression, e.g., what impact the aggression had on their perception of their loved one. The schedule changed and expanded throughout the process and was shaped and influenced by each individual interview. Follow up questions were tailored to individual participant responses, to clarify and expand on areas of importance to them. For example, a participant's response that they feel scared by their partners aggression may have been followed by questions such as: "What do you do in response to feelings of being scared?" or "How do you feel this impacts on the way you interact with your partner?". The researcher reflected that the experience of interviews was different in face-to-face vs remote settings, with face-to-face interviews often lasting longer and provoking more thoughtful, emotive conversations, than those conducted remotely.

Data Analysis

Reflexive Thematic Analysis (RTA) was deemed appropriate as it is acknowledged to be useful for questions related to people's experiences and perceptions (Braun & Clark, 2013). It also recognises the potential for both inductive (data-driven) and deductive (theory driven) analysis (Braun & Clarke, 2021). This was appropriate for this study given the use of a theoretical framework (relationship continuity) to guide the interviews and the analysis, and the interest in exploring existing ideas about how aggression might undermine the relationship.

This research adopts a critical realism ontology and a constructionist epistemological approach to the data. Critical realism supports the notion that a social reality exists, however we can only ever partially know it because human experiences are unique and interpretations of such are individualised to the participants and/or the researcher (Braun & Clark, 2022). A constructionist position examines how participants make sense of their own experiences, and the meaning and significance they place on the impact of these experiences, whilst remaining aware that this may not apply to all individuals who experience the same phenomenon (Byrne, 2022). RTA provides access to a situated, interpreted reality of participants, whilst accepting that this may not produce simple or whole truth as it cannot encapsulate the reality of all individuals caring for a loved one with dementia. Critical realism acknowledges that each participant has a different “truth” and that qualitative research is searching for where these truths may overlap to create common trends, whilst recognising that there will be many variations within those trends. The analysis was focused on content, rather than the language or expression used.

At the start of the research process, as advised by Braun and Clark (2022), the researcher completed a reflective piece of work that explored the researcher’s positionality (e.g., gender, occupation, social class, etc.) and how these positions may impact on the data collection and data analysis process. This allowed the researcher to remain conscious of their impact on the data process and to use the reflexive journal to monitor and reflect on this. The reflexive journal highlighted how each participant provoked different emotions in the researcher that may have altered the way the researcher interpreted these conversations, and how elements of the data that stood out to the researcher shaped the content of future interviews. For example, a conversation in the first interview around the impact of the quality of the pre-dementia relationship stood out to the researcher and this became a topic explored in all future interviews. Critical realism accepts that a researcher’s individualities will influence the data process and findings. As such, no two researchers would produce the exact same results and this research presents the current authors interpretation and version of events based on the realities of seven people who are experiencing a common phenomenon.

The traditional six-step method of reflexive analysis was used to analyse the data (Braun & Clark, 2022). This process is described in Table 2.3.

Table 2.3

The Six-Step Method to Reflexive Thematic Analysis (Braun and Clark, 2022)

Step 1: Familiarising yourself with the dataset: The interview transcribes were read and re-read to enable the researcher to become familiar and engaged with the data. Initial notes were made regarding any ideas or insights formed from within and between participant datasets that may be of relevance to the research question. A reflexive journal was used to enhance this process.
Step 2: Coding: Features of the data that were relevant and meaningful to the research question were given code labels. A constructive and interpretive epistemology and ontology were addressed by considering both the meaning constructed and interpreted by the participant (semantic codes), and the interpretation of meaning by the researcher (latent codes). Datasets were coded individually, with each new data set introducing new codes. To organise and combine codes, an Excel spreadsheet was created that included all codes and matching data extracts for each participant (see Appendix I). In the initial stages of coding, each line of transcript was coded individually and thoroughly, creating narrow and specific codes (e.g., biting as an act of physical aggression, kicking as an act of physical aggression). In the second stage of coding these were clustered into broader codes (e.g., physical acts of aggression) for ease of data management. From the broader clusters, a master list of codes was then created combining all seven transcripts and this was developed into a coding framework by the researcher and their supervisor (see Appendix J). All datasets were coded twice to ensure all relevant information was captured. On the second round of coding all datasets were coded using the new coding framework.
Step 3: Generating theme ideas: Codes that shared a core idea or concept and were deemed to be meaningful to the research question were compiled and clustered to identify *shared* patterned meaning across the datasets. These were collated to develop candidate themes (An initial clustering of codes and a potential theme that requires further exploration) and subthemes (see Figure 2.1). This involved collapsing codes that shared a similar underlying concept into one single code. Codes that were felt to be representative of

an over-arching narrative within the data and were meaningful to the research question were then promoted to a theme or subtheme. Any codes that did not fit with the data or were not felt to be relevant to the question were discarded.

In this stage, the researcher printed code labels and created visual maps, grouping together similar codes that formed together to make candidate themes. Based on advice by Braun and Clark (2022), the researcher revisited and revised these maps every few days for a two-week period and code labels were moved around and discarded until the researcher felt that the remaining themes were representative of the data set and told a coherent narrative that addressed the research question.

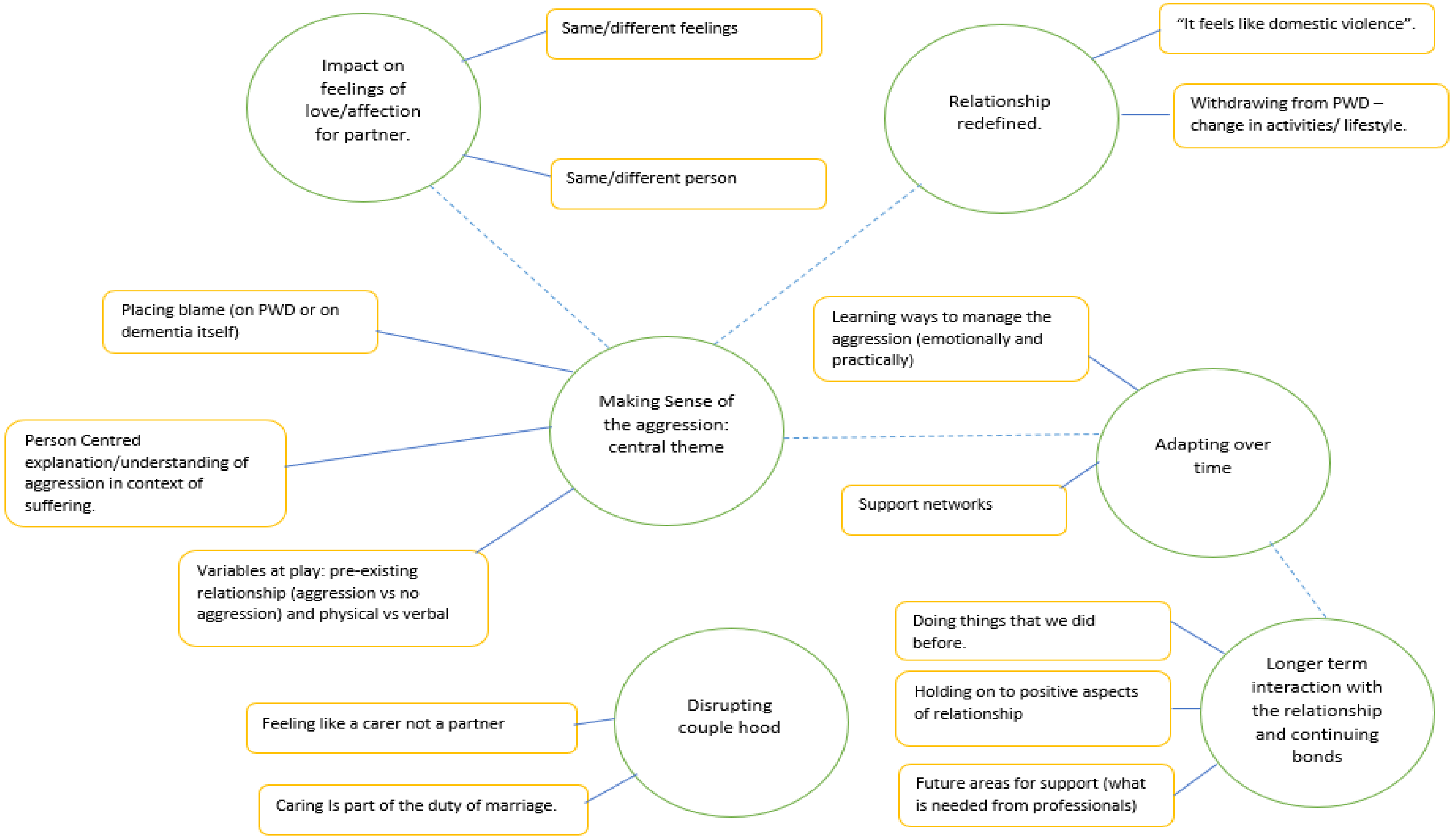
Step 4: Developing and reviewing themes: Candidate themes were reviewed to assess how well they fit the data and if they presented a convincing story about an important pattern of shared meaning related to the dataset The reflexive journal, at this stage, highlighted the researcher's discomfort dismissing data that felt important to participants but was less relevant to the research question. To ensure the data presented was relevant to the question and not kept based on the researchers desire to tell the story of individual participants, the researcher continuously referred back to the aims of the research to determine how well each theme explored the impact of aggressive behaviours on the relationship, and/or moderating factors. The researcher also considered how well supported each theme was with evidence, and which may be more based on assumption/interpretation. Candidate themes were collapsed, refined, and discarded to generate more meaningful themes. In this stage**,** themes were divided into those that explored the impact of aggression, and those that addressed moderating factors (see Figure 2.2).

Step 5: Defining and Naming themes: An analysis was written up of each theme identifying the story each theme captured (see Appendix K). This enabled the researcher to clearly define themes and discard of any that were less relevant to the overall narrative. This process solidified how each theme and subtheme fit with the overall data set and how well they answer the research question (Terry et al., 2017). At this stage, concise and appropriate names for each theme and subtheme were given.

Step 6: Once the above five steps were complete, the final step involved producing the report by writing up themes to produce a clear, coherent, logical**,** and interesting account of the story the data tells, within and across themes (Braun & Clark, 2006).

Figure 2.1

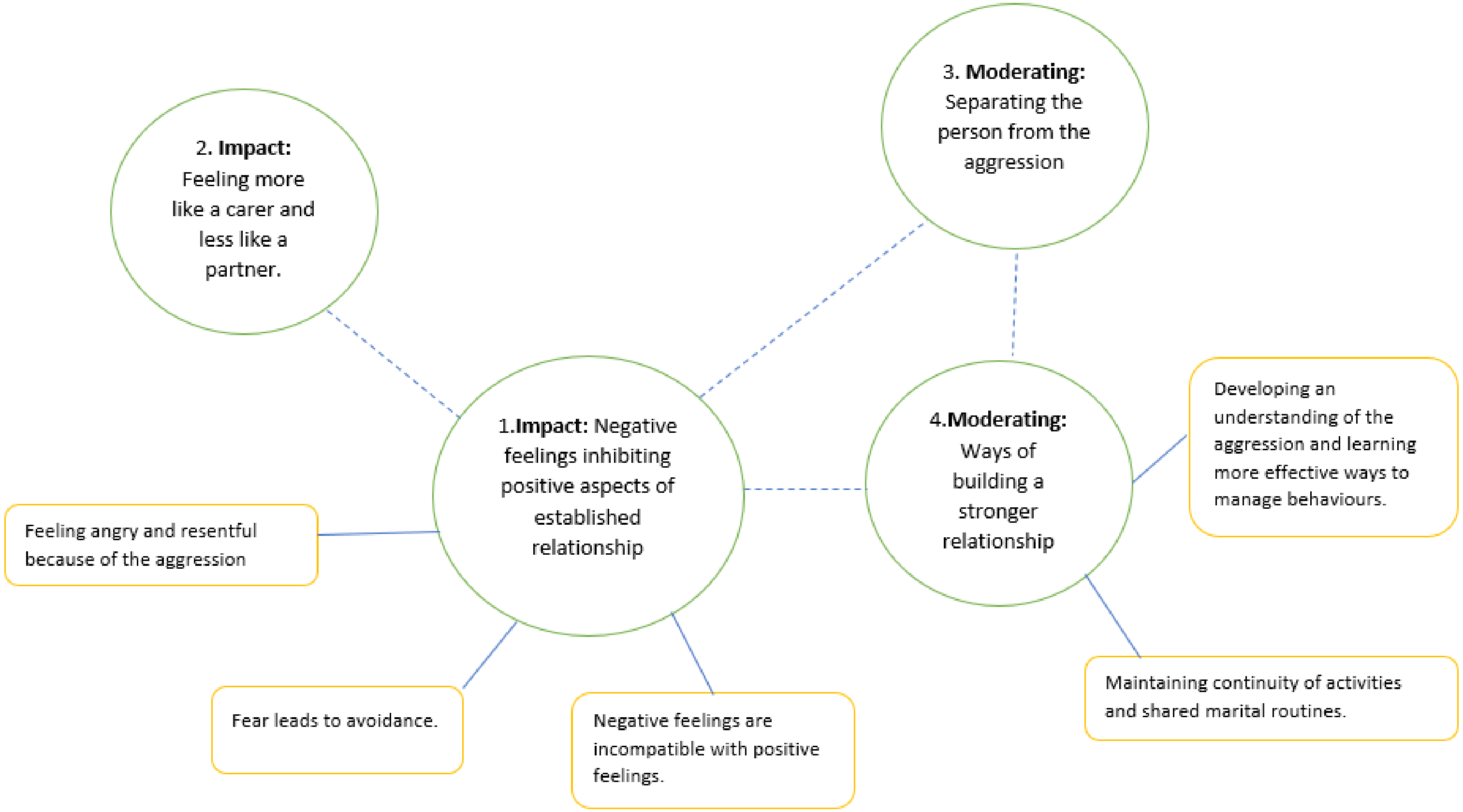
Initial Thematic Map of Candidate Themes



Note. Circle = main theme, Rounded rectangle = subtheme, Full line = link between theme and subtheme, Dotted line = relationship between themes.

Figure 2.2

Thematic Map of Themes Refined.



Reflexivity and Quality Appraisal

To ensure the quality of the research, a quality checklist devised by Braun and Clark (2023) specifically aimed at Reflexive Thematic Analysis was used (see Appendix L). Braun and Clark (2023) stipulate that it is important that the research entails a reflexive consideration of the researcher's positionality and role in shaping the research. The first author kept a reflexive journal to allow time and space for thoughtful and creative data engagement. Journal entries were made after interviews and during initial stages of analysis. These included reflections on the relationship between participant and researcher, the participants, and the researcher's emotions, and intriguing items that stood out from the data. An example is given in Appendix M. Through this process the researcher's positionality was highlighted which gave opportunity to reflect on the impact they were having on the research. For example, the researcher's position as a trainee clinical psychologist equipped them with skills of empathy and communication that supported the rapport building process with participants. However, this position occasionally saw participants seeking therapeutic support during interviews and at times participants steered conversation away from relevant topics to focus on aspects related to their own mental health. The researcher remained mindful to separate their clinical and research persona and not offer a service beyond the remit of this research. It was important to support participants to tell their own stories whilst not steering too far from the research questions. The reflexive journal allowed the researcher to remain conscious of this and reflect upon it in supervision. Journal entries further helped shape and influence future interviews (e.g., adding and adjusting questions) by recognising important aspects of one's experiences that may relate to another's.

Steps Taken to Enhance Credibility

To minimise risk of bias, the researcher and supervisor met after each interview to reflect on the quality of interviews being conducted and ensure that questions were not being led by the researcher's assumptions, or that the researcher was not unintentionally steering participants towards dimensions of continuity by asking leading questions. After each interview initial findings were discussed, and it was determined together how this may shape and influence future interviews. During the data analysis phase, a sub-set of transcripts were coded separately by the researcher supervisor and the first author. These were then discussed and compared, and a template for coding was collaboratively devised to be applied to the whole data set. Within the report, direct quotes from participants have been used to evidence themes. Themes and subthemes were reviewed and refined throughout the analytical process by the first author and the researcher supervisor to ensure that they were appropriate and provided a narrative that was representative and truthful to the story of participants.

Results

In this section of the report, themes are organised under two headings addressing both aims of the study. (1) How does aggression impact on the experience of continuity in the relationship, and (2) What moderates that impact? Table 2.4 shows the themes and subthemes that are presented in this section.

Table 2.4

Themes and Subthemes

Part 1: Impact of Aggression	**Subthemes**
1. Negative feelings inhibiting the positive aspects of established relationship.	1. Feeling angry and resentful because of the aggression 2. Fear leads to avoidance (relationship re-defined) 3. Negative feelings are incompatible with positive feelings
2. Feeling more like a carer and less like a partner	
Part 2: Moderation of Impact	
3. Separating the person from the aggression	
4. Ways of building a stronger relationship	1. Developing an understanding of the aggression and learning more effective ways to manage behaviours. 2. Maintaining continuity of activities shared and marital routines

Part 1: Impact of Aggression

Two overarching themes were found addressing the impact of the aggression. (1) Negative feelings inhibiting the positive aspects of established relationship. (2) Feeling more like a carer and less like a partner.

Negative Feelings Inhibiting the Positive Aspects of Established Relationship

One of the ways in which it became apparent that aggression impacted on the relationship continuity between participants and their spouses was that it impacted on the way they felt towards their partner. Relating to the *same/different feelings* aspect of relationship continuity, participants discussed feeling less loving towards their partners, and they elicited more negative feelings towards them because of the way the aggression made them feel.

Feeling Angry and Resentful because of the Aggression

Participants described feelings of anger and resentment that weakened feelings of love for their partners. Rupert expressed a strong feeling of "hatred" towards his wife because of the accusations of adultery that she made against him. He shared that her behaviours made him "not love her so much". Discussing her husband's behaviour, May described: "I think there was ongoing resentment and I think I was quite angry with him". Anna also acknowledged a change in loving feelings: "It does change my feelings towards him because I haven't got that loving partner there". Similarly, others described how the aggression had generated negative feelings for their partner that interfered with loving feelings:

> I don't forgive easily. I never really have done. Umm, or maybe I don't forget easily, rather than forgive. I don't feel particularly unsafe now, but I just feel that this is a new part of him that I don't particularly like. When he's aggressive it's very hard to feel anything but anger I suppose umm anger and sadness. (Elsa)

> I very rarely think I love him even now I don't, I'm not going around grieving. No there are periods where he's, he's kind of, the old him but I suppose there's part of me that thinks he's less lovable because of things we're going through. (Helen)

> Oh yeah I hated her. I hated, well she wasn't the same person was she, and in fact, I still now.. I now say, I would say to you now, my wife died in 2017. In fact, if I'm honest, I wish she was dead. I wish she was not here. What's the point? It makes you not love them so much doesn't it. (Rupert)

The change in feelings towards their partners was supported by quantitative findings on the BRCM (Riley et al., 2013) whereby all seven participants agreed to some extent that although they cared for their partners, they did not love them in the same way they used to (Q4).

It is also interpreted that negative feelings for their partners could cause a general dislike of being around them. Some participants discussed wanting to be away from their spouse, or not enjoying spending time with them. May shared: “I booked an extra carer for the evening so I didn’t have to do the evening cares. If a carer was here I would breathe a sigh of relief and go out”. Anna similarly discussed: “In the moment I was frustrated too and I just want to either get out of the room, or him to get out of the room or whatever”. Others described related experiences:

> Then towards the end, very much towards the end, with my condition and her situation we’d get back after dinner and I’d think “Oh thank god for that”. We’d got through that day, and I’d managed to take her to all those places, and I didn’t feel great and didn’t want to do it. (Rupert)
>
> A friend of mines husband came to pick him up in the morning and take him to a day centre. Umm, so he would come, and I would just be clock watching until he came at quarter to eight in the morning. I can remember when I’d organised him to go into care and we were waiting for them to do an assessment and I was just counting down the days until he went. (Polly)

Fear Leads to Avoidance (Relationship Redefined)

Participants acknowledged feeling afraid of their partners in response to the aggressive behaviour. Throughout the interviews participants described feeling “frightened”, “scared”, “uneasy”, and “wary” of their partners. All but May and Helen acknowledged that they had never felt this way before the onset of dementia. Fear was found to lead participants to avoid their partner or hinder the enjoyment in spending time with them. It is interpreted that avoidance may have undermined the sense of continuity because couples were no longer engaging in everyday joint activities and communications that served to bond them together. Participants discussed avoiding conversations that may trigger aggression, or purposefully avoiding spending time with partners to evade the repercussions of the aggression. Helen shared: “Yes there is an element of me actually now tiptoeing around him and avoiding him because it’s so frightening and I just don’t want to trigger it”. Jane described: “Sometimes, I almost don’t start a discussion because I know he won’t be able to follow it and then he can get frustrated". Polly also shared: "I was scared of him and scared to be honest with him. You know I couldn't be honest with him, I couldn't tell him anything anymore, I couldn't ask his advice for anything". Others felt similarly:

> We would always watch the news together before but depending a little bit on how he is that day I might avoid that now because I think that might spur him into shouting and getting more angry or more frustrated. (May)
>
> There's the odd time where I will go upstairs and watch television because he's having a go. Having a moan. So I just go upstairs. When he's walking round now.. […] when he's walking round opening and slamming doors and drawers I know he's lost something or he's looking for something, so I avoid him. (Jane)

Rupert discussed how this impacted on he and his wife's social life which was an important aspect of their pre-dementia relationship: "We were always out with other people. We were a sociable couple". Rupert explained that he felt uncomfortable being around other women with his wife present in case this led to her making accusations against him:

> Well I have to be very careful if there are any women in the room, and I sometimes forget. I could not do it [speak] with women in front of Amy and get away with it, there would always be an issue […] so we stopped going out.

Polly and Jane both discussed that they had to sleep separately from their husbands because of their fear of the aggression, which was a change to their marital routine and pre-dementia relationship. Jane shared: "We now sleep in separate beds because um he's very agitated at night". Polly explained:

> I couldn't sleep there [in the marital bed] because I could hear him breathing or snoring you know and I'd think "oh he's going to wake up, he's going to wake up", um and one time he did and he punched a pillow because I didn't wake up and when he'd wake you don't know which Paul* you're going to get, it was just… you'd no idea what was coming next. It was terrifying.

Some participants acknowledged that they felt "safer" being with their partners when around others because of the aggression. It is hypothesised that this may have created feelings of discontinuity, as this impacted on quality time participants and their partners spent together as a couple and created further distance from the pre-dementia relationship. May discussed feeling safer at home since having a live in carer: "For the last 10 days now or more than that, I’ve had a live in carer and that makes a huge difference because there is somebody there”. Of similar vein, Polly stated: “I got to the stage where I wouldn’t go out with him on my own. I needed somebody else to come. You know I couldn’t do it on my own". Helen also stated: “If we’re socialising, I would normally say that in fact becomes a kind of safe environment”. Helen rationalised these feelings based on a recent incident she had experienced whilst out at the theatre with her husband where he had become aggressive:

> He accused me of not looking after him well enough and then on the steps back up to the theatre he was shouting at me which was really unusual that he was still shouting even though there were people around, usually he would temper it, um and somebody just called out to me am I alright.. and that was just so lovely. I was kind of relieved to be among normal people. I thought well you know this can’t continue while there are other people around. I felt it was a safe place, so I was quite happy to go back to the theatre.

Negative Feelings are Incompatible with Positive Feelings

Another way in which negative feelings were interpreted to be disruptive to the relationship was that they were incompatible with positive feelings normally experienced in relationships, such as affection. It was commonly discussed how the aggressive behaviour had made participants feel and behave less affectionately towards their spouse. When comparing their relationship and feelings now to their pre-dementia state, Helen described: “Um, I find it hard to be affectionate now because he’s really putting us, putting me through the mill. I almost cringe when he kisses me, which is terrible”. Anna shared:

> Well yes it is less attractive to be honest, it is, um, it’s very hard to feel warmth for somebody who is agitated and being aggressive, or being verbally aggressive and accusing, it’s very hard to feeling loving towards them in that moment, it is.

Rupert described he and his wife to be “very close and affectionate” before the aggression. However, his wife’s accusations of disloyalty changed this:

> I avoided anything like that so how can I be affectionate with Amy... you know verbally affectionate, when I know that every time I try something, or every time I speak to somebody else, she made it difficult for me.

Elsa discussed her husband being less affectionate towards her because he was often “sulking” which she viewed to be part of his aggressive behaviours. When asked if there was a change in affection between them, she responded:

> When he’s being aggressive yes. I can’t remember many nights when we haven’t either gone to bed or woke up […] where we haven’t lay in bed and had a cuddle either before going to sleep or when we wake up, umm, and there have been more nights recently probably because he’s sulking, and he’s took himself off to bed.

Feeling More Like a Carer and Less Like a Partner

Conversations with participants suggested that due to the avoidance of spending time with their partners and as such missing out on positive interactions, majority of interactions between participants and their partners became focused on care-related activities. This may have contributed to the sense of the relationship starting to feel more like a care-giver and care-receiver relationship, rather than a partnership. The exclusive focus on providing care, and the loss of positive interaction and quality time, may have contributed to the sense that this was a burdensome job they had to endure, rather than a relationship to enjoy. This may have caused a sense of discontinuity in the relationship. May and Anna discussed this experience:

> I no longer felt his wife, I felt I was his carer and I was caring for this difficult old man, he was a difficult client and everything was a battle […] I think it did change the relationship because in my mind I was now looking after this aggressive bloke you know, rather than my husband. (May)
>
> I’m more increasingly just seeing “well this is my job now” you know, I retired a few years ago, this is now my job. This is what I do. You know if he does get frustrated and he spirals down, that, that has an impact on me as well for the next few hours unless I distract him and we go and do something else, so, I do see myself as a wife, but I am a carer. (Anna)

Helen described feeling “tormented” by her husband’s behaviour, and she explained how this impacted on how she felt as a wife, referring to her marriage as a “contract” suggesting she viewed the marriage to be like a job: “I feel more like some servant who’s been bound to a master more than a carer. It’s you know, a contract you can’t get out of”. When discussing her attempts to manage her partner’s aggression, Polly also highlighted the change from feeling like a wife to a carer: "I just felt like that was my existence now, that's my role, that's my role you know. I didn't feel like a wife for a long time to be honest".

This notion was supported by results from the BRCM (Riley et al., 2013) where all participants answered either "agree a lot" or "agree a little" to the statement "I feel like his/her carer now, not his/her partner" (Q6), suggesting this was a universal experience.

Part 2: Moderation of Impact

Two main themes discussed factors that moderated the impact of aggression on relationship continuity, (1) Separating the person from the aggression, and (2) Building a stronger relationship.

Commonly experienced by participants was that over time, and in the right circumstances, participants experienced improvements in their relationship as the aggression became more understandable and more manageable. Participants discussed going through a journey of developing an understanding and acceptance of their partners behaviour which enabled them to be more empathic and feel more compassionate towards them.

Separating the Person from the Aggression

One factor that was found to moderate the impact of the aggression was the way in which individuals made sense of the behaviour. Understanding the aggression as part of the dementia, rather than understanding it in personalised terms, enabled caregivers to separate the person from the aggression. Being able to make this separation made it possible for caregivers to be more empathetic, and this lessened the negative feelings engendered by the aggression. This was found to be harder for those who experienced aggression in their relationship before the onset of dementia.

May and Helen discussed how their husbands had shown tendencies to be aggressive before their dementia diagnosis:

> It's not totally out of character, he was always a person who shouted. Yes he would always shout, if he was upset he'd shout, um, so, and he's always been a person who likes to be in control of things […] and liked to be right. (May)

> I think on reflection, there have been moments of the behaviour he's eclipsing now in the past, I think they have been right since getting married actually. There have been little flash points…he used to threaten to tell my parents how rubbish I was. Um, so

> sort of belittling things. He did have a way of sort of humiliating, just occasionally, but this is now coming round as a frequent occurrence. Previously he had little sort of um tantrums and I suppose sort of even as soon as we got married, they are, they're something that really shocked me. Umm when we were first married and um he threw a bowl of my soup across and the room and said um, you know, "call this lunch?" sort of thing and um, um he threw a ramekin that I'd got from my sister he sort of smashed it against the wall, um sort of things like that, he sort of flipped. (Helen)

Both participants explained how this helped them make sense of their husband's current aggression as being part of who they were yet understanding that the dementia could have exacerbated the aggression, or brought it to the surface. Helen explained: "I think if you know this is the pure form of it, and I just saw the diluted form that he managed to suppress it down to before". May also described:

> It's quite hard to separate the person from the illness [...] I sort of think.. 'you've always been a shouty person', it's just what you would have been like but you put the stops to it before.

Both acknowledged that the behaviours had worsened since the dementia diagnosis and as such the relationship still felt different to the pre-dementia relationship. They both understood their partner's aggression as something they were doing on purpose, and that they had control over, with May commenting she believed her husband could "help it". Helen felt her husband was predominantly in control of his behaviour:

> I think in his mind he's, he's, he's doing it on purpose at the time, um I can't see the point in why he'd do it otherwise [laughs]. He's not, you know, he's not been taken over by anything, he's not in a trance he's still stringing his words together.

May and Helen discussed how the inability to separate their husband from the aggression had impacted on their feelings towards them. For May, this heightened her sense of fear as it brought back distressing feelings from her past. For Helen it triggered feelings of regret for staying in her marriage and heightened negative feelings towards her husband.

> When he first shouted at me again it made me sort of back into the feelings which kind of you know made me feel sort of hot and cold you know because I thought "oh god the shouting is going to start again... when he started to shout again after not being shouty at all for a couple of years made me feel so scared. (May)

> It’s really colouring my view and I really really hope that this calms down soon or something resolves it because it’s really making me quite sad about the number of years we’ve been married. I’m not going around grieving thinking “oh where is that lovely man that I used to be with”. I’m actually quite still angry about it all because I’ve been robbed of that. I’m not sure I could have resolved it anyway other than leaving the marriage earlier but that’s me taking a particularly dark view at the moment. (Helen)

For the other five participants whose partners had not been aggressive before the dementia, they made sense of the aggression as being part of the dementia. Polly attributed her husband’s behaviour to the dementia, and in turn did not blame him: “He was ill and it wasn’t his fault”. Similarly, Jane described her husband’s aggression as a “side effect” of dementia, stating: “That’s part of it. Part of the package [of dementia]”. In general, these participants were less blaming towards their partners, and viewed them as not being in control of their behaviour:

> I don’t think he has any control over it because it’s so unlike him. He’s still Tim*, he’s not aware of it. I think, I don’t know, I don’t know what part of the brain is affected but he, it’s somethings that just seems to take over. And its uncontrollable. (Jane)

> If he had any control he wouldn’t say it, because he’s never never or I can’t ever remember him … once before we were married he swore in front of me and he was mortified. He wouldn’t do it deliberately, I don’t think he realises how he does it. I don’t blame him. He was never like this before. (Elsa)

> I know how much he loves me, and I know that before he was ill that would just never ever have happened, at all, no I’m still able to separate it, um, he’s not an aggressive person. (Anna)

> I don’t think she realised, there was never a control on it […] I tried all the time to say in my head that it was the illness because that what my pragmatic self would tell me, my psychiatrist friend would tell me, my other son would tell me, everybody told me “it’s not you Rupert, Amy* loves you. You never hate her because you know it’s actually not her. (Rupert)

When participants attributed blame outside of the person, this elicited more feelings of sympathy and empathy. It was commonly noted by many that they "felt sorry" for their loved one, and they described feeling more empathic towards them. Polly stated: "It must have been terrifying, I just felt sorry for him. I have a lot of sympathy for him". Jane also expressed empathy: "If he could be on the outside and see it, he'd be devastated. I get upset for him", and Anna discussed feeling sorry for her husband: "I feel very sad, and I stop and think "*what must that be like for him*". I just feel very sad for him".

In contrast, when they attributed blame to the person, they were more likely to express feeling angry at them, and more feelings of distain towards them. May acknowledged feeling "ongoing resentment" for her husband during the times she blamed him for the aggression. However, at times when she felt less blaming towards him, she expressed she felt "very sad" and "a lot of sympathy" for him. Similarly, Helen described feelings of anger and a "dislike" for her husband when she believed him to be in control of his behaviours, however when acknowledging that the aggression may in part be caused by the dementia, she expressed more empathy towards her husband's situation, stating: "It really is tragic, this whole thing".

Ways of Building a Stronger Relationship

One way in which participants discussed being able to rebuild strength in their relationship was by developing a better understanding of their partners aggression. This enabled them to rationalise the behaviour and hold a more empathic and compassionate stance towards their partner. Learning ways to better manage the aggression enabled participants to reconnect with their partners by spending more time with them and/or feeling more affectionate towards them.

Developing a Better Understanding of the Aggression and Learning Ways to Manage Behaviours

At the initial stages of caregiving, participants discussed living with the aggression both taxing on themselves, and on their relationship. They discussed how they often responded to the aggression in unhelpful or uncompassionate ways which created unpleasant or "hostile" environments and created further discord in the relationship. May discussed how she used to threaten her husband with punishment: "I have said things to him like […] if you carry on.. I'll call the police". She also recalled how at times she would say things out of anger that may have unintentionally humiliated him: "I'd say things like "well it's not very nice for me to have to do this, I hate doing it, but I've got to do it because you've messed yourself". Helen discussed a similar response in wanting to shame her husband:

> yeah and I have reached to record things on our audio a few times because I sort of think.. I don't even think that I would ever know um I should listen to that or or you know, I think in the past if it was domestic abuse you might be inclined to say "this is what you sounded like last night look how terrible it was don't do it again".

Others discussed that feeling angry at their partner prompted them to respond to aggression by being verbally aggressive back. Polly described "threatening" her husband: "I had to literally threaten him, I said "look I'm going to stay with my brother" […] you know, I did scream and shout". Elsa also shared:

> When he gets aggressive I say to him "you can't do this, I just, I usually just say "don't talk to me like that…and if you ever tell me do that [go away] again one of these days I might". I really snapped at him once and was quite sharp with him.

Demonstrating a contrast from their initial responses, participants shared how they had started to think about their partners behaviour in context with their suffering, developing a more person-centred understanding. Polly stated: "he just didn't understand the world, it was, he didn't know where he was, he didn't know who we were, it must have just been terrifying". Others shared:

> I think being aggressive is his only way to be in control of things because he's not in control of his life anymore and I think he's scared. He often says he wants to go home and I think that's um I think that's just a way of him saying he wants to be safe. So I think he feels unsafe, frightened, out of control maybe, maybe a bit sort of ashamed you know [..]that someone else is having to wipe his bottom and do all of these very personal things. (May)

> He gets defensive, I think that's part of it as well umm but he doesn't like being told you know, he's quite stubborn, he's always been stubborn so yeah, he doesn't want to be looked after umm, he really doesn't think he needs to be looked after. (Elsa)

> Yeah the decision making and the ability to understand things has gone and as a consequence of that he gets very frustrated because he feels left out […] so, he feels a failure and that makes him feel very frustrated. And that makes him feel not equal in

> the relationship, so he doesn't act equally. Most of his frustration is at himself but it comes out because I'm here it's directed towards me. (Anna)

> I think a lot of it is his frustration, frustrations with it, because he was high functioning before, um that now not being able to string two thoughts together is extremely frustrating and he, he would just find that the ready person to blame it on is right beside him. (Helen)

Participants reflected on how having a better understanding of their partners behaviour and triggers for aggression, and being able to think more compassionately towards them helped them to learn more effective ways of managing the behaviour. Polly shared: "that was the best thing to do you know say "come on we're going for a walk, shoes" you know "get your shoes on" and whatever the weather just go for a walk up the road". Others also shared strategies:

> He doesn't like people shouting back at him. It's much better to back off. Withdrawing from him is a good way of calming him down, and then coming back and saying you know "I know you're upset but we have to do this" […] and avoid the triggers as much as possible. Some days will go by and he won't have um lashed out because we've managed it. (May)

> I learnt that sometimes it's easier to just walk away and let him get on with it and quite often he'll go out for a walk, and he comes back and he's in a better mood. I usually tend to go for a walk with him because it does do him good, and it does calm him down. (Elsa)

> I think, I've noticed that if, sometimes he gets a story in his head, there's a grain of truth in it, and then I can see where this stories come from, so he will be absolutely convinced about something and there will be a grain of truth that I can pick out and then I say "look this is what's happened, I think you've got the rest muddled up but this is what happened". (Anna)

Participants highlighted the benefit of seeking help and support from others in managing their partners aggression. Better management of the aggression helped reduce feelings of distress, fear, and anger, which in turn enabled participants to enjoy spending more time together. May and Rupert discussed how professional help from paid carers supported this process.

May stated that having a live in carer made a “huge difference” to her experience of caregiving because she feels “less frightened” of her husband:

> I’m not scared now of him or the behaviours I mean sometimes if were both changing him and he’s grabbing my arm I might be scared that he will, that he will hurt, but you know, the bruises have gone now but I had all these bruises from being squeezed, squeezed tight, so , but I’m less, I’m definitely less scared in general and I’m hardly scared in the moment really.

May explained how this had helped improve her relationship with her husband by allowing her to spend more quality time with him, and lessening feelings of anger:

> Since I’ve had Tom* here I now feel that it’s actually far more his responsibility to look after him and I help [...] I probably spend more time with him now. I’ll go and sit in the room with George* and whether he’s asleep or not but I might have my lunch in there or I might read a bit of the paper and I wasn’t doing that I was you know just caring […] I can sit next to him and now if he’s shouting I can still go, cause I will hear him shouting and I’ll still go in there and I might try and then calm him rather than get angry at him and I think that’s changed, that dynamic has changed a bit.

Rupert described a similar experience after his wife went into a care home. He spoke about the difference in their relationship before and after the move, and how the affection between them has improved:

> There were lots of times if I was with Amy* I’d look at her and I’d think.. and I loved her, a lot, yeah I do, and I’d just hold her hand, now that’s all I wanted to do just say “Amy hold my hand” and she wouldn’t do it, but now she wants to do it all the time because I think she’s settled […]I think definitely the aggression made it worse, because now she doesn’t have the aggression since being in the home, the affection is better.

He explained how the reduction in aggression has enabled him to spend more time with his wife:

> It’s made my mood swings go and it’s made hers go and therefore when I do go to see her, which I do, I’d say I try most weeks to go either two or three times a week, when I go I spend a lot of time there, I spend about four or five hours there now.

Elsa described how health care professionals involved in her husband’s care have helped improve her confidence in caring for him. She described: “They’ve been brilliant, very supportive and they helped me through any problems, and I know what I’m doing now”. She also explained how professional support had helped her understand her husband’s behaviours:

> We had a dementia nurse at the hospice where I work and I did speak to her quite a lot and she did urm a seminar on dementia which I went to um it was an online thing and I asked her if my daughter could join umm and she did and we both found it really useful.

Others discussed how support from friends and family was invaluable in helping them manage the aggression and their emotional well-being:

> What I have tried and does work is bringing him into the car and taking him to a friend’s house, we’ve had a cup of hot chocolate and then came home again, and that completely switched the mood […] I’ve got a friend’s house I can escape to. If we’re socialising that sort of becomes a safe environment. (Helen)

> I ring a friend at 5 o’clock every morning because he’s got a problem with his wife who’s poorly and he has to tend to her, and we have a cognitive behavioural therapy session every morning at five o’clock. He gives me advice. We’ve done it for two years […] Its good and I look forward to it. (Rupert)

Some participants however felt that there is a lack of professional support for aggressive behaviours, with suggestions that this may be an area of focus for health care services:

> I found it hard.. I mean I did try and tell people that to start with and then nobody understood they just don’t know you, it just gets me annoyed they don’t understand. I don’t think anybody understood, you know the psychiatrist never really got it because you couldn’t talk to him without my husband being there, and then he’d, well you can’t have an open conversation. (Polly)

> I’ve got nowhere to go with it. I think there’s a massive gap for carers to have somewhere to go with this stuff, you know when stuff happens and you’re thinking, you’re either very frustrated, I’m very frustrated or very sad, or embarrassed sometimes. I think there’s a big gap for, well for people with dementia and for carers. (Anna)

> umm, I've sought advice wherever I can, um, I haven't found any single person yet who can directly help me. It [aggressive behaviour] needs someone to appear and intervene. (Helen)

Maintaining Continuity of Shared Activities and Marital Routines

Findings demonstrated the importance of couples maintaining activities and routines from the pre-dementia relationship. In contrast to others, Jane and Elsa expressed determination to continue with routines and activities completed as a couple. Jane and Elsa described more continuous relationships than others, and scored higher on the BRCM (Riley et al., 2013), demonstrating the potential importance of maintaining habits and spending time together to protect relationship continuity. It is hypothesised that this may have helped relationships to feel more continuous, as they start to feel more recognisable with the pre-dementia relationship. For Jane and Elsa, continuation of activities was important in keeping them connected to their partner, despite the aggression:

> I try to make sure we still do things together and you know umm like we're going on holiday together tomorrow and you know, um, so yeah I try to make sure we still do things both together and with other people. I try just to, you know, keep some of our old normality I suppose. (Elsa)

> I've accepted it now and it's a deteriorating thing that will only get worse so while he's okay um we try and enjoy it. I mean this year I've worked as hard as we can so we've had as many holidays as we can I wouldn't stop, we won't stop. (Jane)

Rupert also discussed dancing with his wife when he visited her at her care home, and he reminisced on enjoying this together as a couple before his wife's diagnosis. He recognised that this is something they still enjoy together now that feels like a remnant of their old relationship:

> I tell you now, if I go in and I love the music myself, but I mean but you know I am really childish when the music's on with Amy and she is dancing all the time. She's in a different world and when the music is on I get up and dance with her in front of everybody.

Anna also reflected on how spending more time with her partner helped generate more positive feelings towards him, as it allowed her opportunities to see parts of his pre-dementia characteristics come through:

> Then on another day when it’s a good day, and Fred* had a great sense of humour, it was one of the things that attracted me to him he was very funny, and you know that occasionally happens […] if there is a flashback to his sense of humour, it’s lovely.

Rupert discussed having a similar experience when his wife went into care, where there were subsequently less incidents of aggression, which made spending time together more enjoyable: “I see a little bit of Amy that I used to love when I see her do certain things, she still makes me laugh, and she still does things and I think “god that’s the old Amy that””.

May described that when she started to spend more time with her husband she enjoyed “nice moments” where she could “sit and cuddle” him. Polly also described moments of calm felt like she “got bits of him [husband] back” and could “give him a hug” which she described as joyful moments between them.

Discussion

This study aimed to explore how aggressive behaviours can undermine the relationship between individuals with dementia and their partner, using the relationship continuity framework (Riley et al., 2013). It sought to examine how aggression impacted on the experience of continuity in spousal relationships, and what factors moderate this impact. Seven spousal caregivers of individuals with dementia-related aggressive behaviours completed semi-structured interviews where they shared and reflected upon their experiences of caring for their partner.

Summary of Findings

The Impact of Aggression

Findings supported an existing hypothesis that aggression can interrupt couples’ ability to maintain a continuous relationship (Gibbons, 2018; Lewis & Riley, 2021). As Gibbons (2018) and Lewis and Riley (2021) theorised, one of the ways in which this occurred was that aggressive behaviours resulted in a loss of love and affection between the couple, and greater feelings of anger and resentment in the caregiver (*same/different feelings*). Findings complement existing evidence that aggressive behaviours resulting from neurological conditions can cause negative feelings that predict a loss of positive interactions (Bodley-Scott & Riley, 2015). Majority of participants discussed feeling less loving towards their partner and being less affectionate with them because of these negative emotions. Bodley-Scott and Riley (2015) hypothesised that it may be difficult for individuals to switch off negative feelings which then override or suppress more positive feelings of love and intimacy. As suggested by Lewis and Riley (2021), the loss of loving feelings experienced by participants may make it difficult to retain a sense of continuity with the pre-dementia relationship.

It was identified that the aggressive behaviours themselves, and the negative feelings derived from these, impacted on the time couples spent together and were found to be disruptive to the maintenance of previously shared activities and marital routines (*relationship redefined)*. Spending less time with their partners and missing out on positive interactions resulted in relationships becoming more care-focused and as such participants discussed starting to feel more like caregivers than partners, demonstrating relationship discontinuity (Riley et al., 2013). It may be plausible that disconnecting from the relationship serves a protective function for caregivers. Viewing the caregiving role as a "job" may reduce feelings of hurt, anger, and shame related to persistent aggressive behaviours, making it easier for caregivers to cope with the emotional consequences of such.

Moderation of Impact

In relation to factors that moderated the impact of aggression, the way individuals made sense of the behaviour, and their ability to separate their partner from the aggression was key.

Supporting research by Band-Winterstein and Avieli (2019) who found that the context of the pre-existing relationship impacted on the way individuals made sense of aggressive behaviours, May and Helen who had experienced violence in the pre-dementia relationship, attributed the aggression to their partner's character, and not to the dementia. Although in these cases some of the aggressive behaviours were a continuation of their previous relationship, this still appeared to impact continuity as it increased feelings of hostility and anger because they perceived their partners to be in control of their behaviour. In contrast, the other five participants who had not experienced aggression pre-dementia attributed the aggression to the dementia and were less blaming of their partners. Further in line with findings by Band-Winterstein and Avieli (2019), May and Helen demonstrated less compassion and empathy for their husbands, and they held a more negative perception of them, indicating a less continuous relationship. This was supported by scores on the BRCM (Riley et al., 2013) where May and Helen reported lower scores of relationship continuity than other participants.

This finding may be further explained by Weiner's (1985) attributional model of helping behaviours. Weiner (1985) proposed that when a challenging behaviour and subsequent need for help is perceived to be uncontrollable by the care recipient, this leads to significantly more sympathy and compassion from caregivers. In contrast, if the behaviour and need is attributed to controllable causes, then anger is the dominant emotional response (Meyer & Mulherin, 1980; Weiner, 1985). The model may explain the difference in emotional responses from participants, as May and Helen perceived their husband's behaviour to be within their control and consequently their behaviours were often met with feelings of anger and resentment, and less compassion. The other five participants who perceived their partner's behaviour to be outside of their control displayed more compassion and sympathy, which may have protected them from more negative feelings.

Developing an understanding of the aggression and learning effective ways to manage behaviours was found to lessen its impact. It was important that couples maintained shared activities and routines to allow the relationship to greater resemble that of the pre-dementia relationship. Participants discussed going through a journey of developing an understanding of their partners behaviour which enabled them to be more empathic and compassionate towards them. Participants discussed preserving their relationship through actively trying to spend time with their loved one and maintain parts of the routines they had together before, including routines of affection. This enabled them to hold onto positive aspects of the person and the relationship.

Findings from the current study build upon quantitative research by Riley et al. (2020) who identified a link between relationship continuity and person-centred approaches to caregiving. Riley et al. (2020) offered that when relationships are continuous, spousal caregivers may be better able to understand challenging care needs and behaviours from the PWD's perspective by considering what may be happening internally for them, using their existing knowledge of that person. The authors continue that a person-centred understanding may predict a person-centred response to caregiving, by employing care strategies that consider personalised needs. The current participants described this process, discussing that overtime they developed a person-centred understanding of their partner's behaviour which enabled them to develop more person-centred strategies to manage the behaviour, e.g., doing things the PWD enjoys and empathising with their distress. Expanding on findings from the quantitative literature, all participants shared that a person-centred approach did not happen initially but was a process that evolved overtime and was influenced by other factors, such as external support.

Developing a strong support network including both professionals and family/friends was highlighted by May, Rupert, Elsa, Helen, and Polly as an important part of the process of understanding and managing their partners aggression. Learning to manage the aggression helped reduce feelings of distress, fear, and anger, which in turn enabled participants to enjoy being around their partners and spend more time together, helping to continue the bonds of the relationship.

It may be important to note that May and Helen who experienced greater difficulties in their relationship had partners who displayed more physically aggressive behaviours. Polly also experienced physical aggression and reported greater feelings of fear and behaviours of avoidance. All three scored lower than others on the BRCM (Riley et al., 2013). An assumption may therefore be made that the nature of the aggression may determine the degree of impact this has on the relationship. Although beyond the scope of the current research, looking at the differences between the impact of physical and verbal aggression may be an important area for future research.

In support of the qualitative data that highlighted the specific impact of aggression on relationship continuity, all participants except for Jane, scored lower on the BRCM (Riley et al., 2013) than the general population based on a normative sample of caregivers of PWD (Riley et al., 2013). This hints that aggression may impact relationship continuity to a greater degree than the dementia alone. The current sample size is too small to make generalisable or reliable conclusions, however these results do support findings from a quantitative study by Lewis and Riley (2021) sampling 35 spousal caregivers who similarly found that challenging interpersonal behaviours were more strongly associated with lower relationship continuity scores on the BRCM (Riley et al., 2013) than most other aspects of dementia.

Strengths and Limitations

This research successfully addressed a gap in the literature by providing introductory findings exploring the impact of aggression on relationship continuity between individuals with dementia and their spousal caregivers. One strength of the research design was that the pre-interview meeting helped familiarise participants to the researcher and the project which supported the rapport building process. This may have prompted more open, honest, and comfortable discussions that enhanced the richness of data provided.

The flexible approach to the interview procedure was another strength. The option to conduct the interviews remotely, or at the participant's home, and at a time that was determined by participants, was less disruptive to caregiver’s routines and duties, and minimised any potential stress or disadvantages of taking part.

Of importance, participants expressed having benefited from the interviews and reflected that they had enjoyed feeling listened to and heard, which offered them a different experience to what they had received so far in their dementia journey. Participants expressed gratitude for the opportunity to discuss their experience and stated it had encouraged them to take part in other research projects relating to dementia care.

All participants were recruited from Join Dementia Research (JDR) which comprises individuals who have willingly volunteered to participate in research. This holds ethical strengths in that it can be assumed all participants were motivated and emotionally able to engage in research. However, this method also holds a bias in that participants may not be representative of all caregivers, some of whom may be experiencing more distress and hardship, and consequently are less able to dedicate time or emotional energy to participate in research. To increase the reliability, representativeness, and validity of data, it may be useful for future research to recruit participants from other avenues, such as through NHS services. This may provide a participant pool who are more representative of a population of spousal caregivers that will aid a more widespread understanding of the nature and impact of this phenomenon.

A further limitation was that it became apparent throughout the conversations that it was difficult for caregivers to differentiate between, and separate, which aspects of the relationship were impacted specifically by the aggression, and which were caused by the dementia in general, potentially impacting the credibility of the interpretation that has been provided. To provide a more credible account of the impact of aggression on spousal relationships, it may be helpful for future research to compare and explore the differences in relationship continuity between people caring for loved ones with and without dementia-related aggressive behaviours.

There is a cultural bias in that all participants were white British. It cannot therefore be assumed that experiences are representative of those from other ethnic backgrounds, where there are known to be differences in cultural expectations and relationship values that may impact on the experiences being explored in this research (Yuan et al., 2023). Six out of the seven participants were female, and it is important to consider evidence that suggests that the caregiving experiences of men may be different (Zhang, 2021).

Due to the qualitative nature of this research design and the difficulties experienced with recruitment and retention, the sample size is smaller than desired, and findings from this study should not be overgeneralised. A larger scale study sampling a wider range of participants from different ethnic backgrounds and genders would provide more generalisable findings.

The research is further limited by having one key author who analysed and interpreted the data, risking researcher bias as the researcher may have unintentionally interpreted data to fit with pre-conceived ideas related to relationship continuity. Although the findings were discussed with the researcher supervisor, they are also invested in the research topic, and it may have increased reliability by having a third unrelated researcher analyse the findings.

Using the relationship continuity framework helped to shape the interview schedule, and supported the process of narrowing and refining themes, allowing the researcher to "let go" of themes that felt important to the participants story but were less relevant to the research question. It also offered an explanatory framework to make sense of what participants were saying about the impact of the aggression on their relationship, allowing suggestions to be made about the ways in which aggression may impact on the relationship and how people may counteract that impact. In limitation, the use of a theoretical framework was restrictive in that important findings exploring the general impact of aggression on caregivers were ignored. Employing other theoretical lenses may have produced other useful findings that could inform clinical practice. Examples of such include gender (e.g., exploring differences in experiences of aggression between men and women), and power imbalances (e.g., a Foucauldian discourse analysis that explored the data in the context of societal discourses about relationships, power, and aggression). It may be interesting for future research to analyse the dataset using different theoretical lenses or adopt a more inductive approach to data analysis by employing an idiographic method, such as an Interpretive Phenomenological Approach (IPA).

Implications of Findings

The research findings suggest that it will be important for dementia-related aggressive behaviours to be considered when conducting assessments and developing treatment plans for PWD and their caregivers. As suggested by Band-Winterstein and Avieli (2019), it may be helpful to ascertain information regarding the pre-dementia relationship on assessment and remain mindful of the ways this may impact on the caregiver's response and management of the aggressive behaviours. This research also suggests that services should screen for aggressive behaviours in assessments and should consider how these may be impacting on both the caregiver's emotional well-being, and on the relationship.

Relationship continuity was found to be protected when participants held a more person-centred understanding of their partner's aggression. Desai et al. (2017) support the importance of promoting person-centred care in dementia caregiving. It may be helpful for health care services to educate caregivers on potential behaviours associated with dementia, such as aggression, and help caregivers understand their partner's behaviours. This may help reduce blame and stigma associated with challenging behaviours.

Interventions could support couples to maintain parts of their marital routine or adapt previously enjoyed activities where possible and safe to do so, to enable the caregiver and their spouse to spend time together and protect relationship continuity. Life story work has been incorporated into dementia care interventions over the past few decades and is designed to help caregivers and care receivers recognise and remember positive aspects of their partner and of their relationship, to help them hold on to loving feelings (Frances, 2016). Considering the current findings, this may be of particular importance for individuals caring for a loved one with dementia-related aggression as positive aspects of the relationship may have been disparaged due to the challenges of dealing with adverse behaviour and the hostility it can create.

Three participants (Polly, Anna, and Helen) commented that there is lack of support for caregivers, with Helen describing this as a "clear gap" in dementia care. It was agreed amongst participants that more emotional and social support is needed for dementia caregivers, and more consideration of their needs as well as the needs of their loved one. Participants who had received professional support noted that this was helpful in enhancing their understanding and management of their partner's behaviour, and the emotional toll it had had on them. It was noted that speaking to professionals was easier than speaking to loved ones as participants often discussed not wanting to "burden" friends and family who are already emotionally invested in the caregiver and the PWD. A space for caregivers to reflect upon, process and manage their experiences and associated emotions in a therapeutic setting may be an important part of interventions. It may be worthwhile to implement and offer this to caregivers as a fundamental and standard service within dementia care. This may offer caregivers containment for their difficult emotions, and help them feel heard, which was established by participants to be imperative for their own emotional well-being. Lastly, some participants appreciated the support of loved ones to help manage practical and emotional risks associated with dementia-related aggression. Establishing support networks and encouraging caregivers to utilise these, or taking a systemic approach to treatment by inviting the participation of close others, may help protect caregivers and their relationships from some of the adverse effects of aggressive behaviours.

References

Band-Winterstein, T., & Avieli, H. (2019). Women coping with a partner's dementia-related violence: A Qualitative Study *Journal of Nursing Scholarship*, *51*(4), 368–379. https://doi.org/10.1111/jnu.12485

Bodley-scott, S. E. M., & Riley, G. A. (2015). How partners experience personality change after traumatic brain injury – Its impact on their emotions and their relationship. *Brain injury*, *16*(3), 205–220. https://doi.org/10.1017/BrImp.2015.22

Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, *3*(2), 77–101. https://doi.org/10.1191/1478088706qp063oa

Braun, V., & Clarke, V. (2013). *Successful qualitative research: A practical guide for beginners.* SAGE publications

Braun, V., .& Clarke, V. (2021). Can I use TA? Should I use TA? Should I not use TA? Comparing reflexive thematic analysis and other pattern-based qualitative analytic approaches. *Counselling and Psychotherapy Research*, *21*(1), 37–47. https://doi.org/10.1002/capr.12360

Braun, V., & Clarke, V. (2022). *Thematic Analysis A Practical Guide.* SAGE publications.

Braun, V., & Clarke, V. (2023). Is thematic analysis used well in health psychology? A critical review of published research, with recommendations for quality practice and reporting. *Health Psychology Review*, 1–24. https://doi.org/10.1080/17437199.2022.2161594

British Psychological Society. (2018). *BPS Code of Human Research Ethics*. https://www.bps.org.uk/sites/www.bps.org.uk/files/Policy/Policy - Files/BPS Code of Ethics and Conduct %28Updated July 2018%29.pdf

Bryman, A. (2012). *Social Research Methods* (4th ed.). Oxford University Press INC.

Byrne, D. (2022). A worked example of Braun and Clarke ' s approach to reflexive thematic analysis. *Quality & Quantity*, *56*(3), 1391–1412. https://doi.org/10.1007/s11135-021-01182-y

Creswell, J.W. (2009). *Research Design, Qualitative, Quantitative, and Mixed Methods Approaches* (3rd ed.). SAGE Publications.

Cummings, J.L., Mega, M., Gray, K., Rosenberg-Thompson, S., Carusi, D.A., & Gornbein, J. (1994). The Neuropsychiatric Inventory: comprehensive assessment of psychopathology in dementia, *Neurology*, *44,* 2308–2314. https://doi.org/10.1212/WNL.44.12.2308

Department Of Health. (2015). *Prime Ministers Challenge on Dementia 2020. https://www.gov.uk/government/publications/prime-ministers-challenge-on-dementia-2020/prime-ministers-challenge-on-dementia-2020*

Department of Health and Social Care. (2019). *Dementia 2020 Challenge: 2018 Review Phase 1*. *February 2019*, 2–18.

Desai, A., Wharton, T., Struble, L., & Blazek, M. (2017). Person-centered primary care strategies for assessment of and intervention for aggressive behaviors in dementia. *Journal of Gerontological Nursing*, *43*(2), 9–17. https://doi.org/10.3928/00989134-20170111-07

Frances, Y. (2016). Improving care for people with dementia : development and initial feasibility study for evaluation of life story work in dementia care, *National Institute for Health Research*, *23*(4), . https://doi.org/10.3310/hsdr04230

Gibbons, H.L. (2018). *Aggression in dementia: Associated factors and impact on spousal relationships* [Doctorate Thesis, University Of Birmingham].

Hendrick, S. S. (1988). A generic measure of relationship satisfaction. *Journal of Marriage and the Family*, *50*(1), 93. https://doi.org/10.2307/352430

Horsburgh, D. (2003). Evaluation of qualitative research studies. *Evidence-Based Nursing*, *6*(2), 36–40. https://doi.org/10.1136/ebn.6.2.36

Join Dementia Research. (n.d.). *Welcome to Join Dementia Research. A place to register your interest in taking part in vital dementia research.* https://www.joindementiaresearch.nihr.ac.uk

Khan, S. S., Ye, B., Taati, B., & Mihailidis, A. (2018). Detecting agitation and aggression in people with dementia using sensors—A systematic review. *Alzheimer's and Dementia*, *14*(6), 824–832. https://doi.org/10.1016/j.jalz.2018.02.004

Kinskey, C., & Buchanan, J.A. (2018). Non-Pharmacological interventions for aggression in persons with dementia: A 10 year follow-up review of the literature. *Clinical nursing studies, 6*(3), 8-18. https://doi.org/10.5430/cns.v6n3p8

Lewis, M. A., & Riley, G. A. (2021). Are spousal carers' perceptions of continuity and discontinuity within the relationship influenced by the symptoms of dementia? *Dementia*. https://doi.org/10.1177/1471301221994311

Mangen, D. J., & McChesney, K. Y. (1988). Intergenerational cohesion: A comparison of linear and nonlinear analytical approaches. *Research on Aging*, *7*(1), 121-136

Meyer, J. P., & Mulherin, A. (1980). From attribution to helping : An analysis of the mediating effects of affect and expectancy. *Journal of Personality and Social Psychology, 39*(2), 201–210.

Polenick, C. A., Struble, L. M., Stanislawski, B., Turnwald, M., Broderick, B., Gitlin, L. N., & Kales, H. C. (2020). "I've learned to just go with the flow": Family caregivers' strategies for managing behavioral and psychological symptoms of dementia. *Dementia, 19*(3), 590–605. https://doi.org/10.1177/1471301218780768

Popay, J., Rodgers, A., & Williams, G. (1998). Rationale and Standards for the Systematic Review of Qualitative Literature in Health Services Research. *Qualitative Health Research, 8 (3), 341-351*

Riley, G. A. (2019). Relationship Continuity/Discontinuity—A Framework for investigating the role of relationships in the experience of living with dementia. *American Journal of Alzheimer's Disease and Other Dementias, 34*(3), 145–147. https://doi.org/10.1177/1533317518813557

Riley, G. A., Achiampong, J., Hillberg, T., & Oyebode, J. R. (2020). Relationship continuity and person-centred care in how spouses make sense of challenging care needs. *Aging and Mental Health*, *24*(2), 242–249. https://doi.org/10.1080/13607863.2018.1531380

Riley, G. A., Evans, L., & Oyebode, J. R. (2018). Relationship continuity and emotional well-being in spouses of people with dementia. *Aging and Mental Health*, *22*(3), 299–305. https://doi.org/10.1080/13607863.2016.1248896

Riley, G. A., Fisher, G., Hagger, B. F., Elliott, A., Serve, H. Le, & Oyebode, J. R. (2013). The Birmingham Relationship Continuity Measure: The development and evaluation of a measure of the perceived continuity of spousal relationships in dementia. *International Psychogeriatrics*, *25*(2), 263–274. https://doi.org/10.1017/S1041610212001743

Silverman, D. (2011). *Interpreting Qualitative Data* (3rd ed.). SAGE Publications.

Spector, A., Orrell, M., Charlesworth, G., Marston, L., Spector, A., Orrell, M., Charlesworth, G., & Marston, L. (2016). Factors influencing the person – carer relationship in people with anxiety and dementia. *Aging and Mental Health*, *20*(10), 1055-1062. https://doi.org/10.1080/13607863.2015.1063104

Spruytte, N., Audenhove, C. Van, Lammertyn, F., & Storms, G. (2002). The quality of the caregiving relationship in informal care for older adults with dementia and chronic psychiatric patients. *Psychology and Psychotherapy: Theory, Research, and Practice*, *75*, 295–311. https://doi/pdfdirect/10.1348/147608302320365208

Teri, L., Truax, P., Logsdon, R., Uomoto, J., Zarit, S., & Vitaliano, P. P. (1992). Assessment of behavioral problems in dementia: The revised memory and behavior problems checklist. *Psychology and Aging*, 7(4), 622-631. https://doi:10.1037/0882-7974.7.4.622

Terry, G., N. Hayfield, V. Clarke, and V. Braun. (2017). "*Thematic Analysis*." In The SAGE Handbook of Qualitative Research in Psychology, edited by C. Willig and W. S. Rogers, 17–73. SAGE Publications.

Vugt, M. E. De, Stevens, F., Aalten, P., Lousberg, R., Jaspers, N., Winkens, I., Jolles, J., & Verhey, F. R. J. (2003). Behavioural disturbances in dementia patients and quality of the marital relationship. *International Journal of Geriatric Psychiatry*, *18*, 149–154. https://doi/pdfdirect/10.1002/gps.807

Walters, A. H., Oyebode, J. R., & Riley, G. A. (2010). The dynamics of continuity and discontinuity for women caring for a spouse with dementia. *Dementia*, *9*(2), 169–189. https://doi.org/10.1177/1471301209354027

Weiner, B. (1985). An Attributional Theory of Achievement Motivation and Emotion. *Psychological Review*, *92*(4), 548–573.

Yuan, Q., Zhang, Y., Samari, E., Jeyagurunathan, A., Goveas, R., Ng, L. L., & Subramaniam, M. (2023). Positive aspects of caregiving among informal caregivers of persons with dementia in the Asian context: a qualitative study. *BMC Geriatrics*, *23*(1), 1–11.

https://doi.org/10.1186/s12877-023-03767-8

Zhang, Y. (2021). “Cinderella Men”: Husband-and Son-caregivers for elders with dementia in Shanghai. *Anthropology and Aging*, *42*(2), 6–20. https://doi.org/10.5195/AA.2021.356

CHAPTER THREE: PUBLIC DISSEMINATION DOCUMENT

Press release for Literature Review

Losing Oneself in Dementia Caregiving

According to a new meta-ethnography produced by the University of Birmingham, caring for a loved one with dementia can impact on an individual's self-identity and their self-esteem. This is believed to happen when the 'caregiving' identity starts to overwhelm and replace pre-existing aspects of one's identity, including other relational and social roles.

Highlighting the importance of exploring this topic, previous research in other domains has found that losing one's sense of identity and having low self-esteem can have a detrimental impact on an individual's psychological well-being, which may have implications for local health care providers and our National Health Service (NHS). The prevalence rates of people living with dementia in the UK is rising, as is the economic cost of the condition. This rise in prevalence has seen a rise in informal caregivers looking after family members with dementia. Existing evidence demonstrates that the stresses and demands of caregiving can have a detrimental impact on caregivers physical and emotional well-being, and a need for support for this population has been identified. In 2015, the prime minister launched the "Challenge on Dementia 2020" plan which proposed to enhance Dementia care and support in England, including supporting research into dementia with the aim to inform treatment pathways and interventions for both people with dementia and their loved ones. The current review emphasises the importance of this and provides insight into factors that can impact on the experience of informal caregivers that may provide some direction for health care services, and the government, to provide necessary support to this population.

This qualitative literature review brought together the current research on how caregivers of people with dementia experienced a disruption to their self-identity and self-esteem through the caregiving process. It is the first of its kind to focus specifically on the impact of caregiving on self-identity, and to uncover ways in which this can impact on one's self-esteem and in turn, their psychological well-being.

The review compared 12 qualitative papers, with a mix of studies predominantly from the United Kingdom (UK) and the USA. All participants involved in studies were caring for a loved one with dementia, mostly comprising spouses and adult children. Majority of participants were of white ethnicity. The papers utilised several different qualitative analysis techniques, with the most common being thematic methods whereby similarities and differences between individual experiences are compared.

Results highlighted that through the process of caregiving, some caregivers perceived negative changes in their personality because of the stress and burden of the caregiving experience. This had an adverse impact on their self-esteem as they expressed a ‘dislike’ for who they have become. Contrastingly, others perceived positive changes in their self-identity discussing a sense of ‘growth’ through taking on a meaningful role and learning new skills, which could improve self-esteem. Majority of participants experienced changes in their social and relational identities due to the time-consuming nature of caregiving which left little time for previously enjoyed social or occupational activities. On a more positive note, methods of boosting self-esteem were also uncovered, and participants found that appreciation from others, and internal praise from helping their loved one was protective of their self-esteem and psychological well-being. Another important discovery was that self-identity and self-esteem were better protected when individuals saw caregiving as part of their “duty” as a partner, or as a son/daughter. For spousal caregivers, viewing caregiving as part of their pre-existing relationship role also protected caregiver’s sense of continuity within the marital relationship.

It is important to note that there were methodological flaws in the synthesis that somewhat limit the credibility of conclusions drawn and further research is required to support and expand upon the current findings. However, preliminary findings from this research suggest that identifying ways to help individuals preserve their identity whilst taking on the role of caregiver may be an important factor of consideration for health care services.

Lead author Charlotte Kelland concluded: “A larger evidence base and a greater understanding of this experience may aid health care providers to access more funding and resources to provide crucial support to informal caregivers. More research is needed to better understand these experiences so we can ensure the right support is available to help and protect those who need it most”.

Press release for Empirical Project

Living with Aggression in Dementia Caregiving

According to research by the University of Birmingham, dementia-related aggressive behaviours can impact on relationship continuity between people with dementia (PWD) and their spousal caregivers. The current research used a qualitative method to build upon findings from quantitative studies that aggression interrupts couples' ability to maintain a continuous relationship whereby the relationship between PWD and their spousal caregiver resembles the pre-dementia relationship. When a relationship is discontinuous, the spouse may experience a change in feelings towards their partner, and/or towards their relationship, and the sense of being one half of a couple is lost. This paper explored the complex nature of the connection between aggressive behaviours and relationship continuity, and uncovered novel ideas about ways relationship continuity may be protected when aggressive behaviours are present for PWD. Highlighting the importance of research in this domain, previous studies have found links between relationship continuity and psychological well-being in both the caregivers and care-receivers, and relationship continuity has been associated with better quality of care. It is therefore imperative that we understand the factors that may impact on relationship continuity to inform health care services of what needs to be done to support affected couples.

In this study, the researcher interviewed seven spousal caregivers of PWD who were displaying verbal and/or physical aggressive behaviours. The interview focused on the way individuals made sense of their loved one's aggression, how it had impacted on their feelings towards the person and the relationship, and the factors that moderated this impact.

The results showed that relationship continuity between PWD and their spousal caregivers is negatively impacted by aggression. Aggressive behaviours were discussed to result in a loss of love and affection between the couple, and greater feelings of hostility. Some participants discussed avoiding spending time with their partner due to fear or resentment of the aggressive behaviours. However, all hope was not lost. Other participants discussed less disruption in the relationship, and they told of how they worked hard to ensure they continued to spend time with their partner and maintain marital routines. Different responses to the aggression could be explained by the varying degrees of frequency and severity of aggressive behaviours, and how far removed these are from the pre-dementia relationship. In more positive findings, it was identified that developing a person-centred understanding of the aggression in the context of their loved one's suffering helped caregivers feel more empathic and compassionate towards their partners. This helped some couples rebuild parts of the relationship over time that had been lost to the aggression, as they learnt to better manage the behaviours which enabled them to spend more time with their partner. Seeking help and support from professionals and close others helped increase feelings of safety which further permitted couples to spend more time together. Suggestions for health care services and future research were discussed.

Lead author Charlotte Kelland commented: “It was interesting to hear about the unique and meaningful experiences of participants and I am grateful to all those who took part. It was clear that individual characteristics of the relationship and the aggression shaped and determined each experience in different ways. However, similarities were found in the ways the aggression impacted on the relationship and these require consideration from health care services to determine how we can better support people with dementia and their spousal caregivers and help them foster and maintain healthy relationships”.

APPENDICES: CHAPTER ONE

Appendix A: NICE Qualitative Checklist (2012)

Study identification: Include author, title, reference, year of publication.

Guidance topic:

Key research question/aim:

Checklist completed by:

Theoretical approach

1. Is a qualitative approach appropriate?

For example:

- Does the research question seek to understand processes or structures, or illuminate subjective experiences or meanings?
- Could a quantitative approach better have addressed the research question?

Appropriate

Inappropriate

Not sure

Comments:

2. Is the study clear in what it seeks to do?

For example:

- Is the purpose of the study discussed – aims/objectives/research question/s?
- Is there adequate/appropriate reference to the literature?
- Are underpinning values/assumptions/theory discussed?

Clear

Unclear

Mixed

Comments:

Study design

3. How defensible/rigorous is the research design/methodology?

For example:

- Is the design appropriate to the research question?
- Is a rationale given for using a qualitative approach?
- Are there clear accounts of the rationale/justification for the sampling, data collection and data analysis techniques used?
- Is the selection of cases/sampling strategy theoretically justified?

Defensible

Indefensible

Not sure

Comments:

Data collection

---

4. How well was the data collection carried out?

For example:

- Are the data collection methods clearly described?
- Were the appropriate data collected to address the research question?
- Was the data collection and record keeping systematic?

Appropriately

Inappropriately

Not sure/inadequately reported

Comments:

Trustworthiness

---

5. Is the role of the researcher clearly described?

For example:

- Has the relationship between the researcher and the participants been adequately considered?
- Does the paper describe how the research was explained and presented to the participants?

Clearly described

Unclear

Not described

Comments:

---

6. Is the context clearly described?

For example:

- Are the characteristics of the participants and settings clearly defined?
- Were observations made in a sufficient variety of circumstances
- Was context bias considered

Clear

Unclear

Not sure

Comments:

---

7. Were the methods reliable?

For example:

- Was data collected by more than 1 method?
- Is there justification for triangulation, or for not triangulating?
- Do the methods investigate what they claim to?

Reliable

Unreliable

Not sure

Comments:

Analysis

---

8. Is the data analysis sufficiently rigorous?

For example:

- Is the procedure explicit – i.e. is it clear how the data was analysed to arrive at the results?
- How systematic is the analysis, is the procedure reliable/dependable?
- Is it clear how the themes and concepts were derived from the data?

Rigorous

Not rigorous

Not sure/not reported

Comments:

9. Is the data 'rich'?

For example:

- How well are the contexts of the data described?
- Has the diversity of perspective and content been explored?
- How well has the detail and depth been demonstrated?
- Are responses compared and contrasted across groups/sites?

Rich

Poor

Not sure/not reported

Comments:

10. Is the analysis reliable?

For example:

- Did more than 1 researcher theme and code transcripts/data?
- If so, how were differences resolved?
- Did participants feed back on the transcripts/data if possible and relevant?
- Were negative/discrepant results addressed or ignored?

Reliable

Unreliable

Not sure/not reported

Comments:

11. Are the findings convincing?

For example:

- Are the findings clearly presented?
- Are the findings internally coherent?
- Are extracts from the original data included?
- Are the data appropriately referenced?
- Is the reporting clear and coherent?

Convincing

Not convincing

Not sure

Comments:

---

12. Are the findings relevant to the aims of the study?

Relevant

Irrelevant

Partially relevant

Comments:

---

13. Conclusions

For example:

- How clear are the links between data, interpretation and conclusions?
- Are the conclusions plausible and coherent?
- Have alternative explanations been explored and discounted?
- Does this enhance understanding of the research topic?
- Are the implications of the research clearly defined?

Is there adequate discussion of any limitations encountered?

Adequate

Inadequate

Not sure

Comments:

Ethics

---

14. How clear and coherent is the reporting of ethics?

For example:

- Have ethical issues been taken into consideration?
- Are they adequately discussed e.g. do they address consent and anonymity?
- Have the consequences of the research been considered i.e. raising expectations, changing behaviour?
- Was the study approved by an ethics committee?

Appropriate

Inappropriate

Not sure/not reported

Comments:

Overall assessment

As far as can be ascertained from the paper, how well was the study conducted? (see guidance notes)

++

+

–

Comments:

Notes on the use of the qualitative studies checklist

Section 1: theoretical approach

This section deals with the underlying theory and principles applied to the research.

1. Is a qualitative approach appropriate?

A qualitative approach can be judged to be appropriate when the research sets out to investigate phenomena which are not easy to accurately quantify or measure, or where such measurement would be arbitrary and inexact. If clear numerical measures could reasonably have been put in place then consider whether a quantitative approach may have been more appropriate. This is because most qualitative research seeks to explain the meanings which social actors use in their everyday lives rather than the meanings which the researchers bring to the situation.

2. Is the study clear in what it seeks to do?

Qualitative research designs tend to be theory generative rather than theory testing; therefore it is unlikely that a research question will be found in the form of a hypothesis or null hypothesis in the way that you would expect in conventional quantitative research. This does not mean however that the paper should not set out early and clearly what it is that the study is investigating and what the parameters are for that. The research question should be set in context by the provision of an adequate summary of the background literature and of the study's underpinning values and assumptions.

Section 2: study design

Considers the robustness of the design of the research project.

3. How defensible is the research design?

There are a large number of qualitative methodologies, and a tendency in health to 'mix' aspects of different methodologies or to use a generic qualitative method. From a qualitative perspective, none of this compromises the quality of a study as long as:

The research design captures appropriate data and has an appropriate plan of analysis for the subject under investigation. There should be a clear and reasonable justification for the methods chosen.

The choice of sample and sampling method should be clearly set out, (ideally including any shortcomings of the sample) and should be reasonable. It is important to remember that sampling in qualitative research can be purposive and should not be random. Qualitative research is not experimental, does not purport to be generalisable, and therefore does not require a large or random sample. People are usually 'chosen' for qualitative research based on being key informers.

Section 3: data collection

4. How well was the data collection carried out?

Were the method of data collection the most appropriate given the aims of the research? Was the data collection robust, are there details of:

how the data were collected?

how the data were recorded and transcribed (if verbal data)?

how the data were stored?

what records were kept of the data collection?

Section 4: trustworthiness

Assessing the validity of qualitative research is very different from quantitative research. Qualitative research is much more focused on demonstrating the causes of bias rather than eliminating them, as a result it is good practice to include sections in the report about the reflexive position of the researcher (what was their 'part' in the research?), about the context in which the research was conducted, and about the reliability of the data themselves.

5. Is the role of the researcher clearly described?

The researcher should have considered their role in the research either as reader, interviewer, or observer for example. This is often referred to as 'reflexivity'. It is important that we can determine: a clear audit trail from respondent all the way through to reporting, why the author reported what they did report, and that we can follow the reasoning from the data to the final analysis or theory.

The 'status' of the researcher can profoundly affect the data, for example, a middle aged woman and a young adult male are likely to get different responses to questions about sexual activity if they interview a group of teenage boys. It is important to consider age, gender, ethnicity, 'insider' status (where the interviewer/researcher is part of the group being researched or has the same condition/illness, for example). The researcher can also profoundly influence the data by use of questions, opinions and judgments, so it is important to know what the researchers' position is in that regard and how the researcher introduced and talked about the research with the participants.

6. Is the context clearly described?

It is important when gauging the validity of qualitative data to engage with the data in a meaningful way, and to consider whether the data are plausible/realistic. To make an accurate assessment of this it is important to have information about the context of the research, not only in terms of the physical context – for example, youth club, GP surgery, gang headquarters, who else was there (discussion with parents present or discussion with peers present are likely to cause the participant to position himself very differently and thus to respond very differently) – but also in terms of feeling that the participants are described in enough detail that the reader can have some sort of insight into their life/situation. Any potential context bias should be considered.

7. Were the methods reliable?

It is important that the method used to collect the data is appropriate for the research question, and that the data generated map well onto the aims of the study. Ideally, more than 1 method should have been used to collect data, or there should be some other kind of system of comparison which allows the data to be compared. This is referred to as triangulation.

Section 5: analysis

Qualitative data analysis is very different from quantitative analysis. This does not mean that it should not be systematic and rigorous but systematicity and rigour require different methods of assessment.

8. Is the data analysis sufficiently rigorous?

The main way to assess this is by how clearly the analysis is reported and whether the analysis is approached systematically. There should be a clear and consistent method for coding and analysing data, and it should be clear how the coding and analytic strategies were derived. Above all, these must be reasonable in light of the evidence and the aims of the study. Transparency is the key to addressing the rigour of the analysis.

9. Are the data rich?

Qualitative researchers use the adjective 'rich' to describe data which is in-depth, convincing, compelling and detailed enough that the reader feels that they have achieved some level of insight into the research participants experience. It's also important to know the 'context' of the data, that is, where it came from, what prompted it and what it pertains to.

10. Is the analysis reliable?

The analysis of data can be made more reliable by setting checks in place. It is good practice to have sections of data coded by another researcher, or at least have a second researcher check the coding for consistency. Participants may also be allowed to verify the transcripts of their interview (or other data collection, if appropriate). Negative/discrepant results should always be highlighted and discussed.

11. Are the findings convincing?

In qualitative research, the reader should find the results of the research convincing, or credible. This means that the findings should be clearly presented and logically organised, that they should not contradict themselves without explanation or consideration and that they should be clear and coherent.

Extracts from original data should be included where possible to give a fuller sense of the findings, and these data should be appropriately referenced – although you would expect data to be anonymised, it still needs to be referenced in relevant ways, for example if gender differences were important then you would expect extracts to be marked male/female.

12–13. Relevance of findings and conclusions

These sections are self-explanatory.

Section 6: ethics

14. How clear and coherent is the reporting of ethics?

All qualitative research has ethical considerations and these should be considered within any research report. Ideally there should be a full discussion of ethics, although this is rare because of space limitations in peer-reviewed journals. If there are particularly fraught ethical issues raised by a particularly sensitive piece of research, then these should be discussed in enough detail that the reader is convinced that every care was taken to protect research participants.

Any research with human participants should be approved by a research ethics committee and this should be reported.

Section 7: overall assessment

15. Is the study relevant?

Does the study cast light on the review being undertaken?

16. How well was the study conducted?

Grade the study according to the list below:

++ All or most of the checklist criteria have been fulfilled, where they have not been fulfilled the conclusions are very unlikely to alter.

+ Some of the checklist criteria have been fulfilled, where they have not been fulfilled, or not adequately described, the conclusions are unlikely to alter.

– Few or no checklist criteria have been fulfilled and the conclusions are likely or very likely to alter.

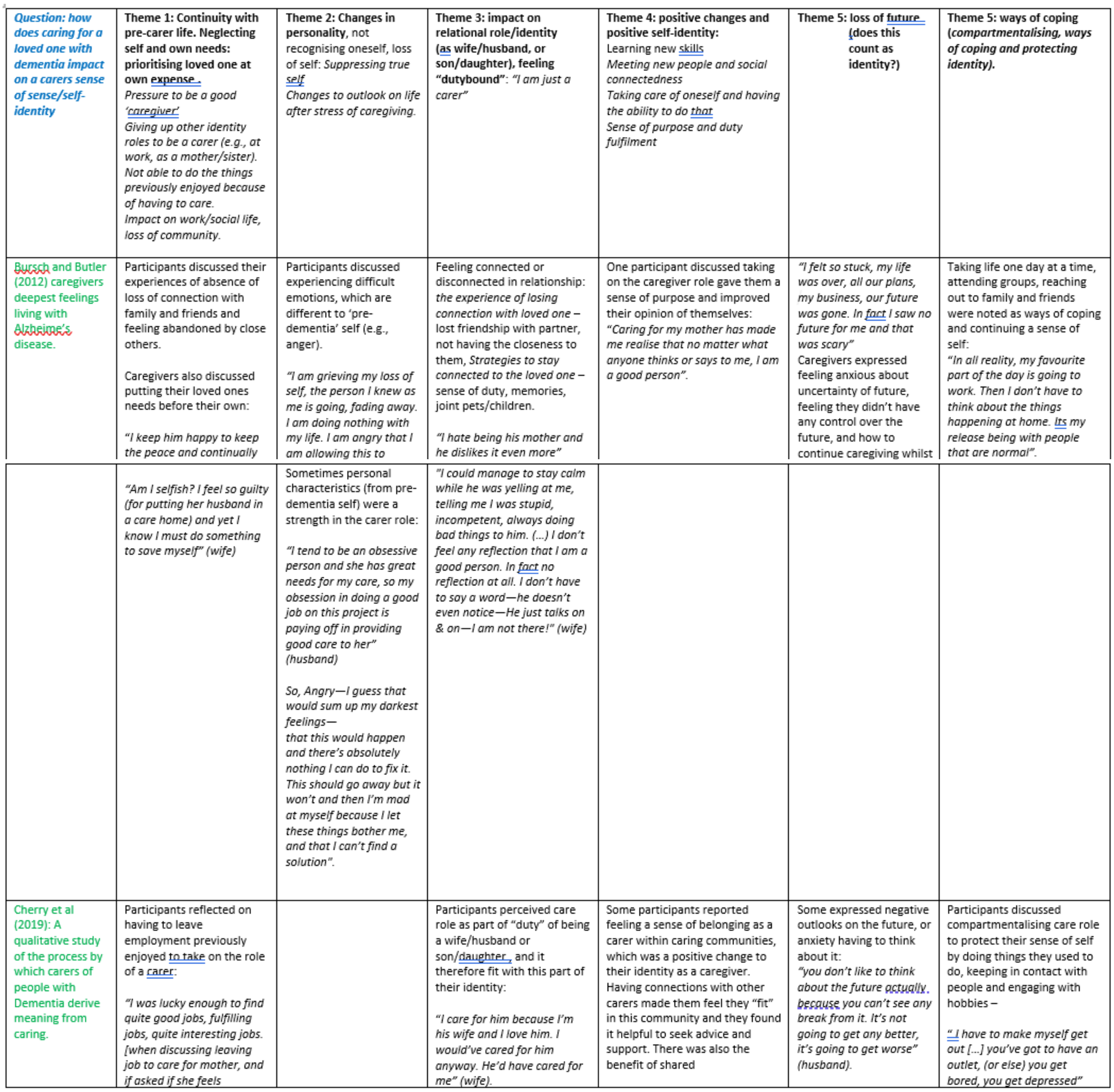
Appendix B: Example of Extraction Grid with First, Second, and Third Order Constructs

Paper	Theme and subthemes	First order (participant quotation)	Second order (Authors interpretation)	Third order (my interpretations of the authors i
Paper 1:Bursch and Butler (2012) caregivers deepest feelings living with Alzheime's disease.	1. **Feeling connected or disconnected in friendship**: the experience of losing connection to the care recepient, strategies to stay connected, friendships with family, questioning own self worth. 2. **Trying to find authenticity for self and care recepient**: witnessing the care receivers loss of authenticity , experiencing loss of authenticity after assuming the role of caregiver. 3. **Struggling for self-esteem**: strategies to find self-esteem, experiencing threats to self esteem. 4. **Suffered capacity to act: the experince of not being able to act autonomously, the experience of autonomy in changing settings of care, worrying about the future, trying to reclaim capacity to act.**	"This past week, my husband has wanted to give me a kiss. This gives me pleasure and warmth. Somehow, working with him is easier for a time" (quote 1) "J. truly does not like having me talk to him and says so. He spends all his time with his books and music, only appears when he needs help. The isolation is killing me. I feel a terrible void." (wife) "He is pleasant and happy and even charming, but he does not make me feel special or worth while or even competent. I feel he takes me for granted" (wife) "When I'm lone some I start to wonder what's wrong with me. Do I offend, am I boring or what?" (Son/daughter- not stated). "I tend to be an obsessive person and she has great needs for my care, so my obsession in doing a good job on this project is paying off in providing good care to her" (husband). "I am grieving my loss of self, the person I knew as me is going, fading away. I am doing nothing with my life. I am angry that I am allowing this to happen to me". "Caring for my mother has made me realise that no matter what anyone thinks or says to me, I am a good person" (daughter). "I could manage to stay calm while he was yelling at me, telling me I was stupid, incompetent, always doing bad things to him. (...) I don't feel any reflection that I am a good person. In fact no reflection at all. I don't have to say a word—he doesn't even notice—He just talks on & on—I am not there!" (wife). "I feel God has abandoned me and other times, I know that he is there for me. They say there is no rest for the wicked and sometimes, I feel I am the wickedest person in the world."(not stated). ""The changes that have happened in my life because	The authors interpreted that participants were experiencing resentment, depression and anger, and that those feelings were attributed to low self-esteem from loss of friendship and autonomy. Caregivers generally mourned the loss of friendship with their loved one and grieved for the loss of the person they knew. Feeling isolated led caregivers to question their own selfworth. Whilst some caregivers were able to embrace caregiving because they felt it matched their personality, others had assumed the role out of necessity, not choice, and they acknowledged that caregiving made that act inauthentically to themselves. Caregivers presented an altered past and present self and demonstrated struggling with their own authenticity in life. It hindered their self-esteem as they felt they should be better people/carers. Some caregivers got self-esteem from their caregiving skills (e.g., acknowledging they are a good carer) but all other sources of esteem came from their relationships with others outside of their caregiving role. Autonomous acts for present and future were profoundly restrained for most caregivers due to the demands of caregiving and the physical and emotional consequences of such. Caregivers lacked a sense of control over the future. Keeping a journal was identified as a coping strategy for caregivers.	Participants experienced **changes in their personality** as a result of the strain and demands of caring for loved ones with Dementia - this impacted how they felt about themselves and how they recognised theirselves (loss of sense of self). The **changes in participants lifestyles**, and perceived negative changes in themselves **led to low self-esteem and impacted on their emotional well-being.**
Paper 2: Cherry et al (2019): A qualitative study of the process by which carers of people with Dementia derive meaning from caring.	1. **Perceived relational symmetry:** caring feels fair and right within the context of the carers own life cycle and their relationship with the person with dementia. 2. **Maintenance of sense of self:** Carers experience caring as congruent with their sense of self, and/or are able to preserve their sense of self by boundarying the care relationship spatially, temporarily and/or cognitively. 3. **Perceived social connectedness**: Carers experience mutually supportive and satisfying social interactions with others around the identity as carers	"I care for him because I'm his wife and I love him. I would've cared for him anyway. He'd have cared for me" (wife). "The role's reversed and so you just take care of somebody" (son). "you're just trapped and you do get angry. I would argue with people who say 'oh but I love him' and all the rest of it because sometimes you don't, because it's not that person [...] in the beginning I was really thinking of leaving" (wife). "I was lucky enough to find quite good jobs, fulfilling jobs, quite interesting jobs. [when discussing leaving job to care for mother, and if asked if she feels resentful].. I did. I mean there was a certain amount of emotional blackmail at one point". (daughter). I have to make myself get out. Not only are you going to get depressed yourself, you're going to put weight on and all this. So you've got to have an outlet. That's the only thing I can think of as you get bored, you'd get depressed, you do the same thing, and then you'd end up arguing with your wife. Especially when you can't say 'We'll go here or did you see that yesterday orthat was a good programme last night'. You can't say anything like that because she doesn't know (husband). "I want to retain me, my social life, and that's (caring role) just something that's part of what I do, I don't want it to become me, or over take me" (daughter). "I am on the backburner for now I think... I am not looking out for anything for me it's always about her really" (daughter). 3. It [the carer support	The authors interpretated that there were two main reasons why participants found it difficult to gain a sense of meaning from their care role, that impacted on their ability to adopt an identity as a caregiver ; they viewed caring as continuing relationships from previously negative relationships (e.g., the difficult pre-dementia relationship between husband and wife/ parent and child), or they were no longer able to see their relative as the same person. Protecting the sense of self, or being coherent with their previous self, was a source of meaning in caring for loved ones with dementia. Things that made it hard to maintain a sense of self were: giving up previous hobbies, employment and activities that defined their sense of self to perform the care role, and being unable to boundary caring responsibilities due to time consuming demands of care role. The authors concluded that creating boundaries when caregiving to allow time to engage in previously enjoyed activities may protect the sense of self. Feeling socially connected help to reduce feelings of isolation and helped them normalise roles as carers, as they felt a sense of belonging amongst other caregivers.	**Being part of a community of caregivers** helped protect a sense of self as caregivers could build a new part of their identity as a "caregiver" and this was seen as a more positive change to identity and this helped them adapt better to this role. **There is an element of relational roles where people felt "duty bound" to perform care for their loved one, either because it was felt to be the responsibility of a spouse, or adult children felt they owed it to their parent to care for them as they had when they were children**. Having to reduce time spent on own interests and hobbies seemed detrimental to ones emotional well-being, though the impact on identity isn not directly discussed. Participants did alude to not looking after themselves of paying much attention to their needs, though didnt elaborate on if they felt this has changed them as a person, or how they felt about themselves in relation to their role to others. **Social identity was found to be an important protective aspect of caregiving.**

Note: Different colours represent different themes for each paper and corresponding first and second order constructs. The items highlighted in colour in the third order constructs represent the authors initial thoughts on themes (e.g., pink highlights were items corresponding to the theme "personality changes"). Third order constructs were added and adapted throughout the different stages of the analysis process.

Appendix C: Example of Initial Theme Identification and Development Grid

Themes changed throughout the analysis process, and these were not the final themes presented. This process was conducted for all 12 studies. The themes were merged, defined, and discarded through the analytical process and after supervision. For example, theme 5 “loss of future” was discarded as it was decided between the researcher and the supervisor that this did not explicitly or directly address the research question of the impact of caregiving on self-identity or self-esteem.



Question: how does caring for a loved one with dementia impact on a carers sense of sense/self-identity	**Theme 1: Continuity with pre-carer life. Neglecting self and own needs: prioritising loved one at own expense .** *Pressure to be a good ‘caregiver’* *Giving up other identity roles to be a carer (e.g., at work, as a mother/sister).* *Not able to do the things previously enjoyed because of having to care.* *Impact on work/social life, loss of community.*	**Theme 2: Changes in personality**, not recognising oneself, loss of self: *Suppressing true self* *Changes to outlook on life after stress of caregiving.*	**Theme 3: impact on relational role/identity (as wife/husband, or son/daughter), feeling “dutybound”**: *“I am just a carer”*	**Theme 4: positive changes and positive self-identity:** Learning new skills *Meeting new people and social connectedness* *Taking care of oneself and having the ability to do that* *Sense of purpose and duty fulfilment*	**Theme 5: loss of future (does this count as identity?)**	**Theme 5: ways of coping (*compartmentalising, ways of coping and protecting identity).***
Bursch and Butler (2012) caregivers deepest feelings living with Alzheime’s disease.	Participants discussed their experiences of absence of loss of connection with family and friends and feeling abandoned by close others. Caregivers also discussed putting their loved ones needs before their own: *“I keep him happy to keep the peace and continually*	Participants discussed experiencing difficult emotions, which are different to ‘pre-dementia’ self (e.g., anger). *“I am grieving my loss of self, the person I knew as me is going, fading away. I am doing nothing with my life. I am angry that I am allowing this to*	Feeling connected or disconnected in relationship: *the experience of losing connection with loved one* – lost friendship with partner, not having the closeness to them, *Strategies to stay connected to the loved one* – sense of duty, memories, joint pets/children. *“I hate being his mother and he dislikes it even more”*	One participant discussed taking on the caregiver role gave them a sense of purpose and improved their opinion of themselves: *“Caring for my mother has made me realise that no matter what anyone thinks or says to me, I am a good person”.*	*“I felt so stuck, my life was over, all our plans, my business, our future was gone. In fact I saw no future for me and that was scary”* Caregivers expressed feeling anxious about uncertainty of future, feeling they didn’t have any control over the future, and how to continue caregiving whilst	Taking life one day at a time, attending groups, reaching out to family and friends were noted as ways of coping and continuing a sense of self: *“In all reality, my favourite part of the day is going to work. Then I don’t have to think about the things happening at home. Its my release being with people that are normal”.*
	“Am I selfish? I feel so guilty (for putting her husband in a care home) and yet I know I must do something to save myself” (wife)	Sometimes personal characteristics (from pre-dementia self) were a strength in the carer role: *“I tend to be an obsessive person and she has great needs for my care, so my obsession in doing a good job on this project is paying off in providing good care to her” (husband)* *So, Angry—I guess that would sum up my darkest feelings—* *that this would happen and there’s absolutely nothing I can do to fix it. This should go away but it won’t and then I’m mad at myself because I let these things bother me, and that I can’t find a solution”.*	*“I could manage to stay calm while he was yelling at me, telling me I was stupid, incompetent, always doing bad things to him. (…) I don’t feel any reflection that I am a good person. In fact no reflection at all. I don’t have to say a word—he doesn’t even notice—He just talks on & on—I am not there!” (wife)*			
Cherry et al (2019): A qualitative study of the process by which carers of people with Dementia derive meaning from caring.	Participants reflected on having to leave employment previously enjoyed to take on the role of a carer: *“I was lucky enough to find quite good jobs, fulfilling jobs, quite interesting jobs. [when discussing leaving job to care for mother, and if asked if she feels*		Participants perceived care role as part of “duty” of being a wife/husband or son/daughter , and it therefore fit with this part of their identity: *“I care for him because I’m his wife and I love him. I would’ve cared for him anyway. He’d have cared for me” (wife).*	Some participants reported feeling a sense of belonging as a carer within caring communities, which was a positive change to their identity as a caregiver. Having connections with other carers made them feel they “fit” in this community and they found it helpful to seek advice and support. There was also the benefit of shared	Some expressed negative outlooks on the future, or anxiety having to think about it: *“you don’t like to think about the future actually because you can’t see any break from it. It’s not going to get any better, it’s going to get worse” (husband).*	Participants discussed compartmentalising care role to protect their sense of self by doing things they used to do, keeping in contact with people and engaging with hobbies – *“ I have to make myself get out […] you’ve got to have an outlet, (or else) you get bored, you get depressed”*

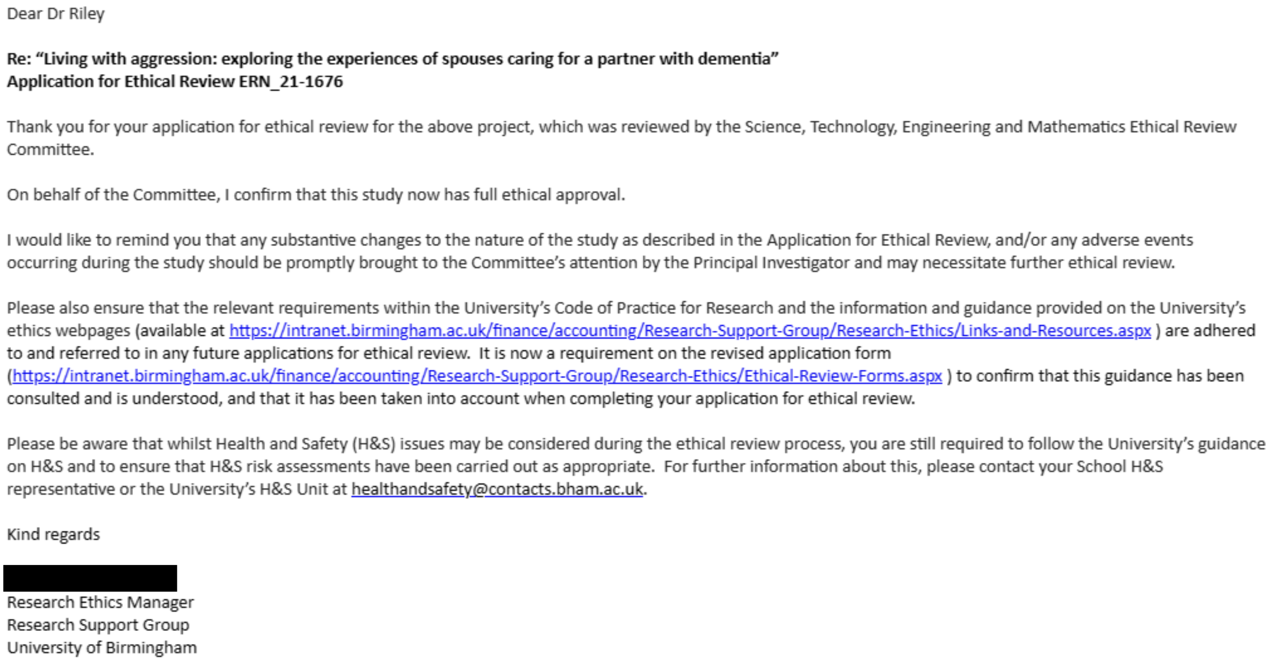
Appendix D: Example of final translations grid

Themes (3rd order construc	Papers that contributed	Quotes (first order constructs)
Theme 1:Changes in personality: Subthemes: perceived negative changes, upskilling and personal growth	Bursch and Butler (2012), Hassulkus and Murray (2007), Lewis (2015, O'Connor (2007), Prato et al (2022), Skaalvik et al (2016), Tuomola et al (2016), Smith and Rodham (2022)	"I am grieving my loss of self, the person I knew as me is going, fading away. I am doing nothing with my life. I am angry that I am allowing this to happen to me". "I feel a loss, loss of me, waste of myself" "I am angry at me[…] I'm a mop […] I am disturbed by the constant anger I feel" "I tend to be an obsessive person and she has great needs for my care, so my obsession in doing a good job on this project is paying off in providing good care to her" (husband) . "I hope when this is all over I still have friends, and a husband. I hope my children still have a mom with a sense of humour, and I hope my happiness gene reappears intact" (daughter). "I see all as insurmountable. I don't recognise myself". "Growing up" and becoming "more caring towards others"."I am not a good person, I am not a good caregiver […] sometimes I cannot find myself, I [am] grumpy. I do not smile as much as I used to" . "I am grieving my loss of self, the person I knew as me is going, fading away. I am doing nothing with my life. I am angry that I am
Theme 2: Changes in relational and social identity ***S ubthemes****: changes in relationship with care receiver, changes in other relational and social roles.*	Bursch & Butler (2012), Cherry et al (2019), Hassulkus and Murray (2007), Lewis (2015), Mattock and McIntyre (2016), O'Connor (2007), Prato et al (2022), Skaalvik et al (2016), Yong et al., (2020), Tolhurst et al (2019), Tuomola et al (2016), Smith and Rodham (2022)	"because I have to help the father, so I let go of my son and tell him he has to help himself". "I hate being his mother and he dislikes it even more" (wife). "I care for him because I'm his wife and I love him. I would've cared for him anyway. He'd have cared for me" (wife). "He is pleasant and happy and even charming, but he does not make me feel special or worth while or even competent. I feel he takes me for granted" (wife) "The role's reversed and so you just take care of somebody" (son) you're just trapped and you do get angry. I would argue with people who say 'oh but I love him' and all the rest of it because sometimes you don't, because it's not that person […] in the beginning I was really thinking of leaving". "I don't think I ever felt satisfied with what I could do for her. I think that was a real sad part of my life […] I was a very bad son at that point" (Son). "It was like I didn't have a mother anymore" . "You're told and you're told 'This is not your mother anymore and don't like of her like that' but how do you turn that off? I can't. I'm sorry. I cannot. This is still the woman I remember as a child, and that I remember at my wedding" (daughter) . "I felt like a child, chasing my mother as she walked away. I just wanted to be love, for her to take an interest in me, her daughter" (daughter). "I was so busy being a caregiver for my mum.. that I often didn't have the energy or capacity to be a daughter". "The role reversal from daughter to caregiver had defined me". "He's just a mumbling old man, he weren't john"(wife). "There is no sexual [aspect] or anything, that sort of thing, it is more a loving… motherly feeling towards them". "I mean, I was looking after my wife, I never gave myself a title or anything like that. She was. I was her husband. it was up to me to look

*Note***.** Colours correspond to the study the quotes belong to.

APPENDICES CHAPTER TWO

Appendix E: Ethical Approval Confirmation



Dear Dr Riley

Re: "Living with aggression: exploring the experiences of spouses caring for a partner with dementia"
Application for Ethical Review ERN_21-1676

Thank you for your application for ethical review for the above project, which was reviewed by the Science, Technology, Engineering and Mathematics Ethical Review Committee.

On behalf of the Committee, I confirm that this study now has full ethical approval.

I would like to remind you that any substantive changes to the nature of the study as described in the Application for Ethical Review, and/or any adverse events occurring during the study should be promptly brought to the Committee's attention by the Principal Investigator and may necessitate further ethical review.

Please also ensure that the relevant requirements within the University's Code of Practice for Research and the information and guidance provided on the University's ethics webpages (available at https://intranet.birmingham.ac.uk/finance/accounting/Research-Support-Group/Research-Ethics/Links-and-Resources.aspx) are adhered to and referred to in any future applications for ethical review. It is now a requirement on the revised application form (https://intranet.birmingham.ac.uk/finance/accounting/Research-Support-Group/Research-Ethics/Ethical-Review-Forms.aspx) to confirm that this guidance has been consulted and is understood, and that it has been taken into account when completing your application for ethical review.

Please be aware that whilst Health and Safety (H&S) issues may be considered during the ethical review process, you are still required to follow the University's guidance on H&S and to ensure that H&S risk assessments have been carried out as appropriate. For further information about this, please contact your School H&S representative or the University's H&S Unit at healthandsafety@contacts.bham.ac.uk.

Kind regards

[redacted]
Research Ethics Manager
Research Support Group
University of Birmingham

Appendix F: Participant information sheet

Living with aggression: Exploring the experiences of spouses caring for a partner with Dementia.

Participant Information Sheet

I would like to invite you to take part in my research study exploring the impact of aggression on relationships for people living with dementia and their spousal carers, from the perspective of the carer.

Before you decide whether or not you would like to take part, you will need to understand why I am conducting this research and what taking part would involve for you. Please read this information sheet carefully. You will have an opportunity to ask me any further questions in a telephone call that will be arranged for anyone who may be willing to take part.

What is the purpose of this study?

I am interested in your experience of caring for a spouse or partner with dementia who is engaging in aggressive behaviours that were not present before their diagnosis of dementia. In particular, I am interested in how you make sense of and understand your partners behaviour, how the behaviours have impacted on your relationship, and how this may make you feel and behave differently towards your partner.

Do I have to take part?

Participation in this research is entirely voluntary and you are free to decline to take part. You have the right to withdraw from the study up until 14 days after your interview. If you choose to withdraw, all of your personal information and recordings will be deleted, and your interview data will not be included in the analysis or write up of the report. If you ask to withdraw after the 14 days then your data may still be included as analysis will have begun, however direct quotations from you will not be included in the report.

What does taking part involve?

If you choose to take part, you will be contacted by the researcher (Charlie Kelland) by telephone to explain the study in more detail and arrange a pre-interview meeting. During the initial telephone call, you will have the opportunity to ask any questions or discuss any concerns regarding participation in the research. In the pre-interview meeting you will be asked to sign the consent forms and complete the Birmingham Relationship Continuity Measure (BRCM) questionnaire. This is a 23-item questionnaire that is designed to assess how carers experience their relationship with a partner with dementia. This meeting will take place either at your home or at The University of Birmingham, depending on your preference.

If at this point you are still willing to participate, we will then arrange a research interview that will last between 60-90 minutes and will be conducted either at your home or at the university, again upon your choosing. For interviews conducted at your home or online, it will be important that you have a safe and private space to speak freely about your experiences and that your partner is not able to hear the conversation.

This interview will explore your experiences of caring for a loved one with dementia who is engaging in aggressive behaviours, and the impact this may have had on your relationship. You will be able to pause or stop the interview at any time.

What will happen to the information I provide?

With your permission, the interview will be audio-recorded on a secure device and will be later transcribed (i.e., typed out). The audio recording will be erased once the transcribing process is complete. Transcripts will be kept on a secure data base at the university that only the researcher and the researcher’s supervisor have access to. In the transcript, you will be given a pseudonym (a false name) and any information that might identify you (such as the names of other people) will be omitted or changed.

The transcript will be analysed by the researcher and then written up in a report. This report may include quotations from your interview, however these will all be anonymised. If you wish, you will be able to receive a summary of findings from the report. I will need to keep personal details including your name and address so I can post this to you.

All records of personal data such as your name and address will be deleted once it is no longer required.

It is possible that someone authorised by the University of Birmingham to conduct a research audit may be given access to your data, including your interview transcript and your consent form.

What are the possible risks and benefits of taking part?

Due to the research being about aggression, it is possible that you may discuss incidents that raise concern about your safety or the safety of others. If this occurs, the researcher will implement safe-guarding procedures in line with the University of Birmingham safe-guarding policies. This may involve notifying adult safeguarding services. If I do notify them, I will inform you that I am going to do so.

In response to the COVID-19 pandemic, the researcher will follow government and university guidance regarding conducting face-to-face interviews at the time in which the interviews take place. If it is not safe to conduct the interviews in person, there will be an option for an online interview.

The interview focuses on a sensitive and potentially upsetting topic. If you do get upset, the interview will be stopped and you will be given a choice about what to do (withdraw from the interview, reschedule for another day, take a break or carry on). Information about sources of additional support are provided at the end of this information sheet.

There are no direct benefits for taking part, however your participation may offer valuable insight into the experiences of caring for a loved one with dementia. This may support the development of future interventions and benefit others encountering similar experiences in the future.

Will my data be kept confidential?

Yes, all data will be kept confidential and will be anonymised to protect your identity. The only time that confidentiality may be breached is if there is a concern for your safety or the safety of others around you in which case I will be obliged to contact the responsible authorities.

Anonymised interview transcripts will be kept on a secure data store by the university for 10 years after the completion of the project. After 10 years all data will be erased.

What will happen with the results from the study?

The results from the study will be analysed and written up in a report, forming part of the researcher's doctorate thesis. Separate reports may also be written up for publication in professional journals, or be presented at professional conferences. A summary of findings will be written up and made available to those participants who request it.

Who has reviewed the study?

The study has been reviewed by the University of Birmingham's Science, Technology, Engineering and Mathematics Ethical Review Committee. This ensures it meets all the standards of fairness and protects you as a participant.

What if there is a problem?

If you have any concerns you can contact me at any time by email at [redacted] and I will do my best to address any concerns and answer any questions. If you would feel more comfortable speaking to someone else, you can contact the research supervisor Gerry Riley on [redacted], or by telephone on [redacted].

What happens next?

I will contact you using the contact details you have provided over the next two weeks to discuss your interest and willingness to participate in this study.

Who can I contact for more information

You can contact the researcher on [redacted] or the research supervisor [redacted].

Details of researcher

Charlotte Kelland
Trainee Clinical Psychologist
University of Birmingham
[redacted]

Details of supervisor

Gerard Riley
Clinical Psychologist and Senior lecturer at the University of Birmingham.
[redacted]

Resources for emotional and psychological support:

1. Age UK for free information and advice on: 0800 678 1602 (9am – 7pm)
2. Samaritans, to talk about anything that is upsetting you: 116 123 (open 24 hours)
3. Saneline, if you are experiencing a mental health problem or supporting someone else who is: 0300 304 7000 (4:30pm-10:30pm)
4. Birmingham MIND for support for people experiencing emotional distress: 0121 262 3555 OR help@birminghammind.org – 24 hours a day, 7 days a week.
5. Solihull MIND support for people experiencing emotional distress: 0121 742 4941 OR contact@solihullmind.org.uk
6. Alzheimer's Society support line: 0333 150 3456.

If you feel you need urgent support you should see your GP.

Thank you for taking the time to read this information.

Appendix G: Consent Form

UNIVERSITY OF BIRMINGHAM

Consent form

Living with aggression: exploring the experiences of spouses caring for a partner with dementia.

Name of researcher: **Charlotte Kelland**

Please note that your data will be treated in accordance with the requirements of the Data Protection Act (2018).

Please initial boxes below

1. I confirm that I have read and understand the participant information sheet provided for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐
2. I understand that my participation is voluntary and that I am free to withdraw up until 14 days after my interview. . ☐
3. I understand that if I withdraw later than 14 days following my interview, my data may still be used as analysis may have been completed. ☐
4. I understand that all data I provide will be treated as confidential, and that it will be stored securely and in an anonymised form. ☐
5. I agree to audio-recording and note taking of the interview and to its transcription. Transcripts will be anonymised. Audio recordings will be erased following transcription. ☐
6. I agree to anonymised quotations being used in reports of the study and in the promotion of the study findings. ☐
7. I understand that my data may be used in a clinical audit by persons authorised by the University of Birmingham. ☐
8. I agree to take part in the above study. ☐
9. I wish to receive a summary report of the findings and I therefore consent for my contact details to be kept in order for this to be posted to me (leave blank if you do not wish to receive the summary). ☐

Name of Participant:	Signature:	Date:
…………………………………	………………………………………	……………………..

Appendix H: Semi-structured Interview Schedule

Living with aggression: exploring the experiences of spouses caring for a partner with dementia

Interview Template

Things for the interviewer to bear in mind are in red.

Context

1. Their life together before the dementia: How long have you been together, any children, what jobs did you both do?

2. About the dementia: When did it start, what problems does your spouse have, how much assistance to they need with daily living, what are the care and support arrangements?

3. About the aggression:
    - In what ways is your spouse aggressive (verbal, physical to objects, physical to others)? When did it start and how often does it occur? Who are they aggressive to, and are they directly aggressive towards you?
    - Can you describe some recent examples – what sparked it off and what happened?
    - How did you manage these situations? How generally do you try to manage the aggression?
    - Was your spouse ever aggressive before the dementia started? Is the aggression very out of character?
    - Does your spouse ever apologise afterwards for being aggressive?

4. Help: Have you had any help from others in relation to dealing with the aggression? What advice were you given? Is it helpful?

Making sense of the aggression

5. What is your understanding of why your spouse is aggressive?

6. Thinking of the recent examples you described, what do you think was going on there? Why did your spouse become aggressive in those situations?

7. What explanations have other people given (e.g. doctors, people at the Alzheimer's Society)? What do you make of their explanations?

8. [If they don't mention dementia in their answers] Do you think that the aggression is connected to the dementia? How do you think it might be connected?

9. [If they don't mention the personality or identity of the person with dementia, or take the perspective of the person with dementia] What do you think was in your spouse's mind when they are being aggressive? For example, in the XX situation you described to me,

what do you think your spouse was thinking and feeling in that situation? Why were they thinking and feeling those things?

10. How much control do you think they have over their aggressive behaviour? Do you think they know what they are doing? Do you blame them for not making more of an effort to control the aggression? Do you ever think it's their fault when they are aggressive?

11. Do you ever feel that they are deliberately trying to upset you or hurt you?

Emotional reactions

12. How does it make you feel when your spouse is aggressive?

13. In the XX situation you described to me, how did it make you feel at the time when your spouse was aggressive?

14. Do you get angry at that moment when your spouse is being aggressive?

15. [If yes] Do those feelings of anger stay with you? Do you find them hard to switch off? Is there ongoing resentment because of the aggression? Are you able to forgive them for being aggressive?

16. Is it frightening at that moment when your spouse is being aggressive?

17. [If yes] Do you generally feel on edge with your spouse because of the aggression? Are you scared of them?

18. Is there anything you tell yourself to make yourself feel better about the aggression? Is there any explanation of the aggression that makes it easier and less upsetting for you?

Behavioural reactions

19. Have you changed what you do together as a couple because of the aggression?

20. Are there any activities that you avoid in case your spouse does become aggressive? Are these things that you used to enjoy doing together?

21. Do you think you generally spend less time with your spouse because of the aggression? Do you ever keep out of their way to avoid them getting aggressive?

General feelings towards the person with dementia

22. Do you think the aggression has changed your feelings towards your spouse? [If yes] Why do you think this is?

23. Do you think it is harder to feel love and affection to them because they are aggressive? [If yes] Why do you think this is?

Perception of the person with dementia

24. Do you think of the aggression as part of who they are now? Are they, in your mind, an aggressive person now? Or do you see the aggression as something separate from who they really are?

25. Does the aggression make it hard to think of them as the same person as they were before the dementia started? [If yes] Why do you think that is?

Perception of impact on the relationship

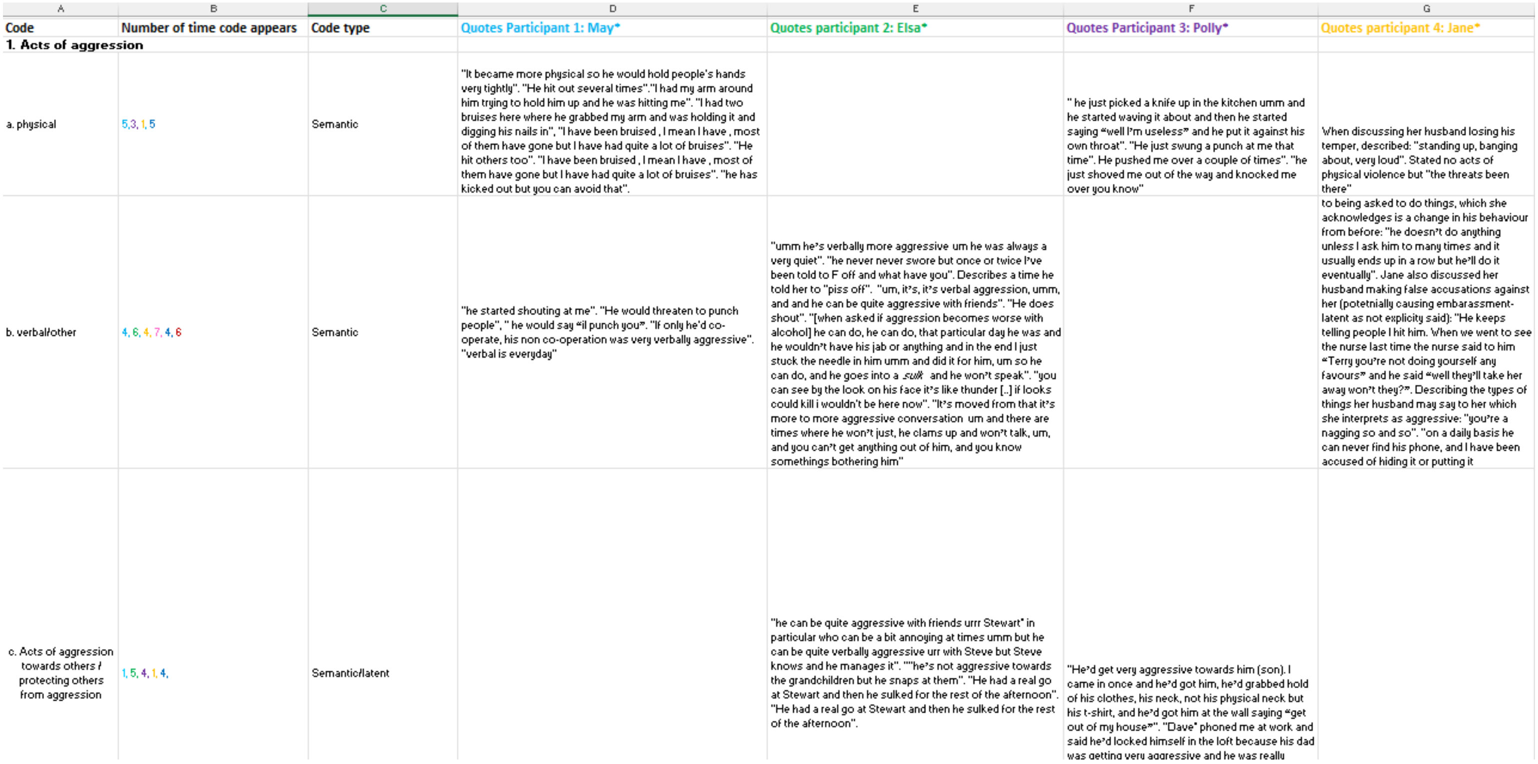
26.Generally, what effect do you think the aggression has had on your relationship? [If they suggest something, explore how they think it has had this impact?]

Moderating factors

27 . Is there anything you think has helped you to better manage the aggression?

28. Is there anything you think has helped protect the relationship between you and your partner?

Appendix I: Example Excel Coding Spreadsheet



A	B	C	D	E	F	G
Code	**Number of time code appears**	**Code type**	**Quotes Participant 1: May***	**Quotes participant 2: Elsa***	**Quotes Participant 3: Polly***	**Quotes participant 4: Jane***
1. Acts of aggression						
a. physical	5,3, 1, 5	Semantic	"It became more physical so he would hold people's hands very tightly". "He hit out several times"."I had my arm around him trying to hold him up and he was hitting me". "I had two bruises here where he grabbed my arm and was holding it and digging his nails in", "I have been bruised , I mean I have , most of them have gone but I have had quite a lot of bruises". "He hit others too". "I have been bruised , I mean I have , most of them have gone but I have had quite a lot of bruises". "he has kicked out but you can avoid that".		" he just picked a knife up in the kitchen umm and he started waving it about and then he started saying "well I'm useless" and he put it against his own throat". "He just swung a punch at me that time". He pushed me over a couple of times". "he just shoved me out of the way and knocked me over you know"	When discussing her husband losing his temper, described: "standing up, banging about, very loud". Stated no acts of physical violence but "the threats been there"
b. verbal/other	4, 6, 4, 7, 4, 6	Semantic	"he started shouting at me". "He would threaten to punch people", " he would say "il punch you". "If only he'd co-operate, his non co-operation was very verbally aggressive". "verbal is everyday"	"umm he's verbally more aggressive um he was always a very quiet". "he never never swore but once or twice I've been told to F off and what have you". Describes a time he told her to "piss off". "um, it's, it's verbal aggression, umm, and and he can be quite aggressive with friends". "He does shout". "[when asked if aggression becomes worse with alcohol] he can do, he can do, that particular day he was and he wouldn't have his jab or anything and in the end I just stuck the needle in him umm and did it for him, um so he can do, and he goes into a *sulk* and he won't speak". "you can see by the look on his face it's like thunder [..] if looks could kill i wouldn't be here now". "It's moved from that it's more to more aggressive conversation um and there are times where he won't just, he clams up and won't talk, um, and you can't get anything out of him, and you know somethings bothering him"		to being asked to do things, which she acknowledges is a change in his behaviour from before: "he doesn't do anything unless I ask him to many times and it usually ends up in a row but he'll do it eventually". Jane also discussed her husband making false accusations against her (potetnially causing embarassment- latent as not explicity said): "He keeps telling people I hit him. When we went to see the nurse last time the nurse said to him "Terry you're not doing yourself any favours" and he said "well they'll take her away won't they?". Describing the types of things her husband may say to her which she interprets as aggressive: "you're a nagging so and so". "on a daily basis he can never find his phone, and I have been accused of hiding it or putting it
c. Acts of aggression towards others / protecting others from aggression	1, 5, 4, 1, 4,	Semantic/latent		"he can be quite aggressive with friends urrr Stewart" in particular who can be a bit annoying at times umm but he can be quite verbally aggressive urr with Steve but Steve knows and he manages it". ""he's not aggressive towards the grandchildren but he snaps at them". "He had a real go at Stewart and then he sulked for the rest of the afternoon". "He had a real go at Stewart and then he sulked for the rest of the afternoon".	"He'd get very aggressive towards him (son). I came in once and he'd got him, he'd grabbed hold of his clothes, his neck, not his physical neck but his t-shirt, and he'd got him at the wall saying "get out of my house"". "Dave" phoned me at work and said he'd locked himself in the loft because his dad was getting very aggressive and he was really	

Appendix J: Final Coding Template

Codes/subcodes: Master list

1. Act of Aggression
    a. Physical
    b. Verbal/other
    c. Acts of aggression towards others

2. Contextual information
    a. Pre-dementia relationship: positive
    b. Pre-dementia relationship: discontinuity

3. Initial impact of aggression
    a. Emotional response to aggression
    b. Emotional response: empathy fear/anger/sadness/shame(negative)
    c. Initial behavioural response
    d. Feeling like domestic violence

4. Threats to relationship
    a. Withdrawing from/avoiding PWD
    b. Withdrawing from carer role
    c. No/less quality time with loved one
    d. Changes in activities/conversation as a couple
    e. Every interaction is a battle – no longer feeling like wife/husband – feels like a carer
    f. social embarrassment
    g. Feeling like I'm not a good enough carer/partner
    h. Negative feelings towards partner
    i. Discontinuity of the person
    j. Loss of love/affection towards partner
    k. No change in feelings of love/affection
    l. Caring is my duty of marriage
    m. Change in relationship with others
    n. Feeling scared of PWD/threatened
    o. Impact on caregiver self-esteem and emotional well-being

5. Making sense of the aggression
    a. Blaming the person/Blaming the Dement
    b. Person centred explanation- understanding aggression in context of their situation/suffering
    c. Appreciating impact of cognitive decline
    d. Separating the aggression from the person (aggression is part of dementia)

    e. Blaming person – unable to separate (belief they're in control/have some control)
    f. Aggression existed pre-dementia
    g. They are just an aggressive person
    h. Aggression did not exist pre-dementia
    i. Other explanation for aggression
    j. Blaming self for aggressive behaviour

6. Adapting over time - Learning ways to effectively manage the aggression and protect self/relationship
    a. Learning ways to cope emotionally
    b. Using things already known about the person
    c. practical measures to keep safe
    d. Colluding with dementia to reduce aggression
    e. Not knowing how to respond to aggression
    f. Following advice/information from professionals
    g. Reluctance to ask for support

7. Longer term interaction with the relationship (continuing bonds)
    a. Following advice/support from professionals
    b. Assistance, support, and lack of
    c. Feeling safer when around others
    d. Continuity: doing what we did before
    e. Empathy enables caregiver to see continuity in care receiver and this takes away some anger
    f. Positive aspects of the person/relationship still present – help caregiver separate loved one from aggression
and reduce negative emotions this elicits
    g. Less scared of partner now than before
    h. Relationship improved when partner went into care/had carer

8. Need for more support (future directions of care)
9. Impact on future – could it get worse?
10. Changes in relationship not caused by aggression (unrelated topics)

Appendix K: Analysis of Themes Summary

Part 1: The impact of aggression

Theme 1: Negative feelings inhibiting the positive aspects of the relationship.

One of the ways in which it became apparent that the aggression impacted on the relationship between participants and their loved ones was that it impacted on the way they felt towards their partner, and the way they viewed their partner as a person. Participants discussed feeling less loving towards their partner and being less affectionate towards them because of the way the aggression made them feel (e.g., feeling scared or angry). This was discussed in two separate subthemes due to the different emotions and responses being discussed. One subtheme discusses the emotional reactions to the aggression that inhibit the relationship *"feeling angry and resentful because of the aggression"* and another discusses the impact this then has on positive feelings and behaviours *"Negative feelings are incompatible with positive feelings"*. Some participants discussed not wanting to be around their partner, and not enjoying spending time with them. This was separated into a subtheme of *fear leads to avoidance.* Some participants spoke about finding it harder to view their partner as the same person, which made it difficult to feel the same way about them. This could impact on the couple's social activities too and their general way of life pre-dementia, creating more distance from the pre-dementia relationship and as such a greater sense of discontinuity.

Theme 2: Feeling More Like a Carer and Less Like a Partner.

This theme describes further disruption to the continuation of loving feelings towards partners in that caregivers began to feel more like carers, and less like a partner. This is thought to be caused by the lack of positive or intimate interactions with the PWD, resulting in activities within the relationship becoming 'care focused'. Participant's discussed caregiving to be more like a 'job' than a role they enjoyed.

Part 2: The moderation of impact

Theme 3: Separating the Person From the Aggression

This theme encapsulates the ways in which individual's understood their loved one's aggression, including their understanding of why the aggression was happening and where it was coming from. How participants made sense of the aggression could influence how they felt towards their partner and the relationship. Some participants understood the aggression to be part of the dementia, whereas others felt this was more attributed to the person. This theme also discovers that the context of previous relationship influences how people make sense of aggression now. Participants whose partners had demonstrated aggressive behaviour before the dementia tended to make sense of their partners aggression as being part of who they are, and not attributed to the dementia. This in turn predicted heightened negative feelings towards them and the relationship, and relationships were described to feel more discontinuous. Participants whose partners were not aggressive before the dementia attributed the aggression to the dementia, and in turn elicited more feelings of empathy towards their loved and less disrupted feelings.

Theme 4: Ways of building a stronger relationship.

This theme introduces ideas about ways participants were able to protect or strengthen their relationship. Participants discussed going through a journey of developing an understanding and accepting of their partners behaviour which enabled them to be more empathic and feel compassionate towards them. Participants discussed preserving their relationship through actively trying to spend more time with their loved one and maintain parts of the routines they had together before, including routines of affection (e.g., morning cuddles). This enabled them to hold onto positive aspects of the person and the relationship. Lastly, participants discussed learning ways to manage the aggression, both practically and emotionally, helped them to lessen negative feelings towards their partner and enjoy being around them more. This included seeking support. This theme is divided into two subthemes: *"Developing an understanding of the aggression and learning more effective ways to manage behaviours",* and *"Maintaining continuity of activities and shared marital routines".*

Appendix L: Braun and Clark (2023) Quality Appraisal guide for RTA

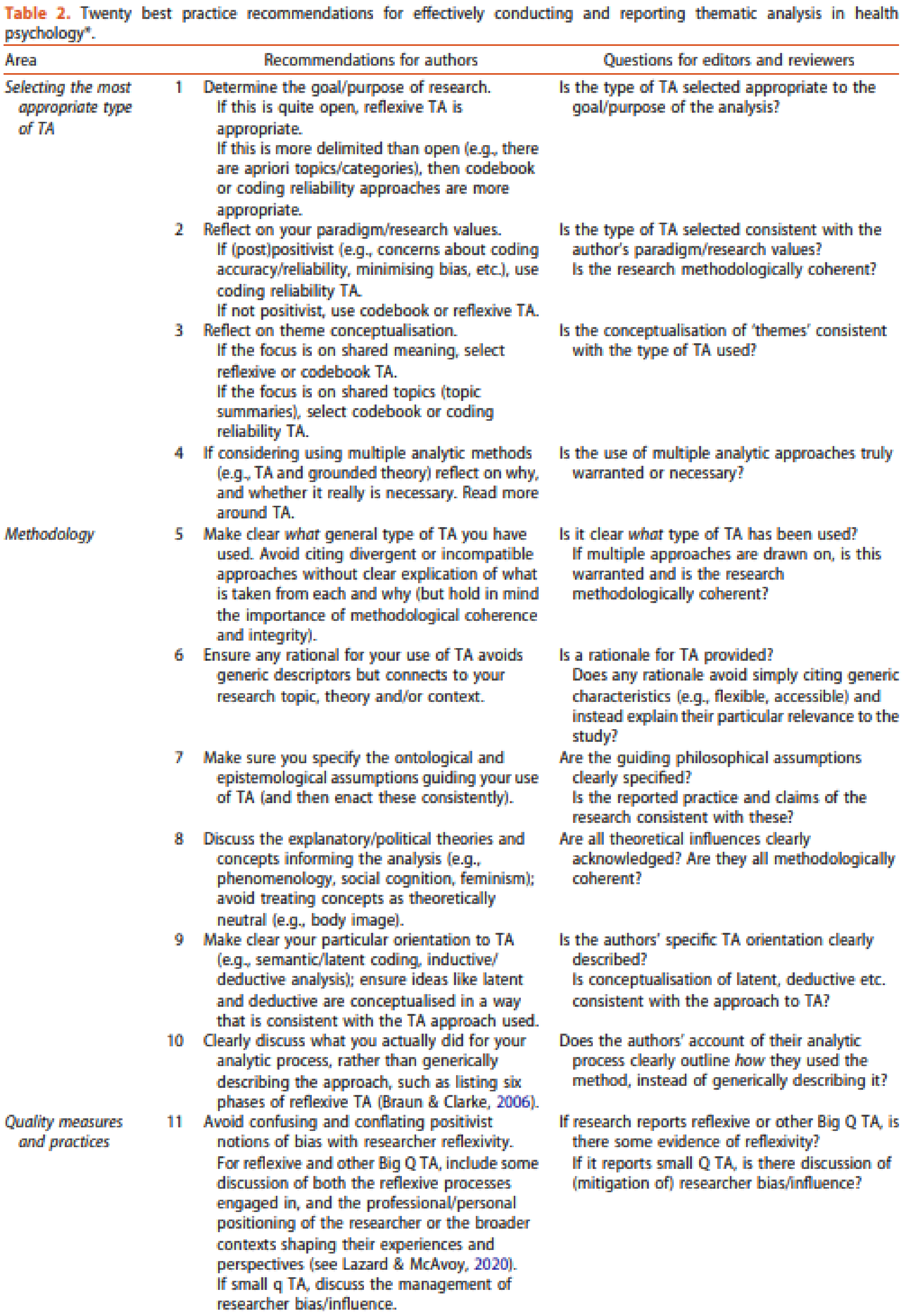


Table 2. Twenty best practice recommendations for effectively conducting and reporting thematic analysis in health psychology*.

Area		Recommendations for authors	Questions for editors and reviewers
Selecting the most appropriate type of TA	1	Determine the goal/purpose of research. If this is quite open, reflexive TA is appropriate. If this is more delimited than open (e.g., there are apriori topics/categories), then codebook or coding reliability approaches are more appropriate.	Is the type of TA selected appropriate to the goal/purpose of the analysis?
	2	Reflect on your paradigm/research values. If (post)positivist (e.g., concerns about coding accuracy/reliability, minimising bias, etc.), use coding reliability TA. If not positivist, use codebook or reflexive TA.	Is the type of TA selected consistent with the author's paradigm/research values? Is the research methodologically coherent?
	3	Reflect on theme conceptualisation. If the focus is on shared meaning, select reflexive or codebook TA. If the focus is on shared topics (topic summaries), select codebook or coding reliability TA.	Is the conceptualisation of 'themes' consistent with the type of TA used?
	4	If considering using multiple analytic methods (e.g., TA and grounded theory) reflect on why, and whether it really is necessary. Read more around TA.	Is the use of multiple analytic approaches truly warranted or necessary?
Methodology	5	Make clear *what* general type of TA you have used. Avoid citing divergent or incompatible approaches without clear explication of what is taken from each and why (but hold in mind the importance of methodological coherence and integrity).	Is it clear *what* type of TA has been used? If multiple approaches are drawn on, is this warranted and is the research methodologically coherent?
	6	Ensure any rational for your use of TA avoids generic descriptors but connects to your research topic, theory and/or context.	Is a rationale for TA provided? Does any rationale avoid simply citing generic characteristics (e.g., flexible, accessible) and instead explain their particular relevance to the study?
	7	Make sure you specify the ontological and epistemological assumptions guiding your use of TA (and then enact these consistently).	Are the guiding philosophical assumptions clearly specified? Is the reported practice and claims of the research consistent with these?
	8	Discuss the explanatory/political theories and concepts informing the analysis (e.g., phenomenology, social cognition, feminism); avoid treating concepts as theoretically neutral (e.g., body image).	Are all theoretical influences clearly acknowledged? Are they all methodologically coherent?
	9	Make clear your particular orientation to TA (e.g., semantic/latent coding, inductive/deductive analysis); ensure ideas like latent and deductive are conceptualised in a way that is consistent with the TA approach used.	Is the authors' specific TA orientation clearly described? Is conceptualisation of latent, deductive etc. consistent with the approach to TA?
	10	Clearly discuss what you actually did for your analytic process, rather than generically describing the approach, such as listing six phases of reflexive TA (Braun & Clarke, 2006).	Does the authors' account of their analytic process clearly outline *how* they used the method, instead of generically describing it?
Quality measures and practices	11	Avoid confusing and conflating positivist notions of bias with researcher reflexivity. For reflexive and other Big Q TA, include some discussion of both the reflexive processes engaged in, and the professional/personal positioning of the researcher or the broader contexts shaping their experiences and perspectives (see Lazard & McAvoy, 2020). If small q TA, discuss the management of researcher bias/influence.	If research reports reflexive or other Big Q TA, is there some evidence of reflexivity? If it reports small Q TA, is there discussion of (mitigation of) researcher bias/influence?

Table 2. Continued.

Area		Recommendations for authors	Questions for editors and reviewers
	12	Use language and a writing style consistent with your TA approach. For example, for *reflexive* TA, take care not to suggest that themes emerge, or were identified. Avoid language of bias and aim to write in the first person.	Is the general writing style and specific terminology around theme development/identification consistent with the TA approach?
	13	Use a reporting format and headings appropriate to your TA approach. For example, a combined results/discussion is often the best way to report analysis in reflexive TA.	Is the structure of the report and the section headings appropriate to the TA approach? Where relevant, does the report avoid unknowingly defaulting to a positivist norm?
	14	Ensure your quality practices are theoretically consistent both with your approach to TA, and with your ontological and epistemological assumptions Realism > respondent validation; triangulation. Positivism > multiple independent coders; interrater reliability; consensus coding/theme development. Big Q/nonpositivism > reflexive journaling; member reflections (Tracy, 2010).	Are the quality processes described theoretically consistent? Is the research methodologically coherent?
Reporting of analysis	15	Consider providing a clear overview of themes and thematic structure – such as a table or figure (depending on analytic complexity).	Is there a clear overview of the themes/thematic structure? Can you easily identify the themes within the paper?
	16	Make it clear how many themes (including any overarching themes and subthemes) will be reported.	Is the number of themes reported clear?
	17	Make sure themes are named appropriately. For example, names of shared meaning themes should ideally capture the key concept of the theme; in reflexive TA, avoid single word theme names.	Is the approach to theme names consistent with the underlying conceptualisation of a theme? Do theme names capture the core of each theme?
	18	Ensure what is reported within each theme aligns with method used. For example, in reflexive TA, themes need to be rich and complex, and capture more than one analytic insight/observation.	Is the depth and detail of each theme appropriate to the method used? If reflexive TA, are themes multifaceted?
	19	Ensure any fragmentation of thematic structure is appropriate to type of TA. If using reflexive TA, be wary of an overly fragmented thematic structure, as analytic quality requires depth in reporting, which fragmentation can preclude. Use subthemes only when desirable to highlight a particular facet of the central theme concept. Consider using supplementary materials or develop separate papers to report in depth.	Is any structural complexity (e.g., subthemes, overarching themes) necessary and appropriate? Is the number of theme levels justified and appropriate, and does it enhance the analysis? Is the thematic structure overly fragmented with lots of thin themes? If reflexive TA, are subthemes used appropriately?
	20	Make sure you appropriately use data to evidence themes and analytic observations and insights. Provide an analytic narrative that provides *interpretation* – in reflexive TA, for example, you ideally offer a rich, complex analytic narrative woven around the data extracts	Are themes appropriately evidenced with vivid and compelling data extracts? Is there a (rich) analytic narrative that *interprets* the data presented?

* These recommendations *may* clash with expectations or requirements of journals; we encourage discussion and reflection where that is the case. If some compromise, which doesn't infringe on integrity too deeply, is (ultimately) required, we recommend signalling such compromise(s) in your writing, so it doesn't come across as unknowing methodologically incoherent or poor practice.

Appendix M: Example of Reflexive Journal Entry

Diary Entry: May*, August 2022

I have felt sad and stressed since leaving May's house today. Her story was difficult to hear, particularly as the aggression is still something she is experiencing. I could feel her distress as her husband began to shout from the next room. There were moments I wanted to stop the interview and at one point I even wanted to offer to make her a cup of tea in her own house. I was thinking throughout how brave she is, and how sad this must be for her but how able she was to shut off those emotions to talk about it so frankly. She was very matter of fact in way of delivery, and I wonder if she has just become also immune to this now and the emotions perhaps get easier to deal with over time. I wonder if I will notice this in other participants. I was struck by how honest and open she was with me and how quickly she became comfortable in my presence. I wonder if it felt therapeutic for her to talk about her experiences. I also noticed that as she was speaking to me, she sort of seemed to make sense of her experience by talking through it, as a few times she seemed surprised by her own answers (e.g., thinking about things from the perspective of her husband). After we'd stopped recording she did comment that she was feeling more sympathetic towards him after our interview. I will remember to ask about this in later interviews – did this help the sense making process? Perhaps more so for someone who is naturally more avoidant of such emotions or is just "going through the motions" without stopping to really think about their experience. I imagine this will differ across participants. Another thing I observed throughout this, and my last interview, is that I am finding it difficult not to slip into "therapist" role and validate experiences and offer advice, especially when participants ask for it. I need to be mindful of this as I found myself falling into this trap occasionally and asking questions that were less driven by the research question but more by my concern for psychological impact it may be having on May and/or others. When I left, I made sure she has support in place and was feeling okay, which I think has given me some reassurance and will stop this playing on my mind.*