Factors affecting anxiety symptoms among family carers of people with dementia: A multifaceted approach

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ABSTRACT

Background: Dementia presents a significant public health challenge globally, with its prevalence expected to rise substantially in the coming decades. Family carers provide most of the care for individuals with dementia, often experiencing a range of psychological impacts including anxiety symptoms. Despite its high prevalence, anxiety among family carers is often overlooked in research. Understanding the factors affecting anxiety symptoms among family carers of people living with dementia is critical to inform future interventions. Therefore, this project aimed to investigate factors influencing anxiety symptoms among this population.

Methods: Three quantitative studies focused on examining the impact of contextual factors (carer demographics, patient-related stressors, and sleep quality) and individual factors (experiential avoidance and cognitive fusion) on carer anxiety. Two qualitative studies explored the impact of inter- and intrapersonal dynamics within caregiving relationships (emotional connection, communication engagement and sense of self) on carer anxiety.

Results: Quantitative studies revealed the significant direct effects of caregiving hours and sleep quality on carer anxiety and the moderating effect of experiential avoidance and cognitive fusion on the relationship between carer burden and carer anxiety. Qualitative findings demonstrated that a strong emotional connection (strong emotional bond between dyads) and a strong sense of self (having own identity and purpose) could lead to higher and lower levels of anxiety symptoms, respectively.

Conclusion: This project contributed to understanding the complex interplay of factors influencing anxiety symptoms among family carers of people living with dementia. Multi-component interventions incorporating acceptance, mindfulness, self-compassion-based approaches, boundary-setting techniques, and respite care services may be beneficial in targeting identified factors, consequently reducing anxiety symptoms. Further research is needed to address the methodological limitations identified in this project, such as the cross-sectional nature of quantitative studies and the limited diversity of samples in qualitative studies and incorporate insights gained from this project into intervention development.

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LIST OF ABBREVIATIONS

AAQ-II	Acceptance and Action Questionnaire-II
ACT	Acceptance and Commitment Therapy
CBT	Cognitive Behavioural Therapy
CBT-I	Cognitive Behavioural Therapy for Insomnia
CCI	Charlson Comorbidity Index
CCSS	Couples Communication Satisfaction Scale
CFI	Comparative Fit Index
CFQ	Cognitive Fusion Questionnaire
CI	Confidence Interval
EACQ	Experiential Avoidance Caregiving Questionnaire
EVH	Elien Van Hout
FRS	Frontotemporal dementia Rating Scale
GAD-7	Generalised Anxiety Disorder scale
GFI	Goodness-of-Fit Index
M	Mean
MBI-C	Mild Behavioural Impairment Checklist
MBSR	Mindfulness-Based Stress Reduction
MC	Milena Contreras
MEAQ	Multidimensional Experiential Avoidance Questionnaire
MR	Megan Riggey
MSc	Master of Science
n.s.	Not significant
NHS	National Health System
NK	Naoko Kishita
PhD	Doctor of Philosophy
PHQ	Patient Health Questionnaire
P-P	Probability Plot
PSQI	Pittsburgh Sleep Quality Index
QCA	Qualitative Comparative Analysis
RMSEA	Root Mean Square Error of Approximation
SD	Standard Deviation
SE	Standard Errors
SRQR	Standards for Reporting Qualitative Research
TROS	Tavistock Relationships Observational Scale

UK	United Kingdom
VIF	Variance Inflation Factor
ZBI	Zarit Burden Interview

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Does avoiding distressing thoughts and feelings influence the relationship between carer subjective burden and anxiety symptoms in family carers of people with dementia?. Alzheimer Europe Conference. Bucharest, Romania. October 2022.

Does avoiding distressing thoughts and feelings influence the relationship between carer subjective burden and anxiety symptoms in family carers of people with dementia?. South-West London Mental Health Carers Group. Online. April 2023.

Understanding the potential anxiety symptoms among women. NIHR Doctoral Training Camp. Crewe, United Kingdom. June 2023.

Anxiety in dementia caregiving: Targeting one factor at a time. HSC Seminar. [Public online seminar]. September 2023.

POSTER PRESENTATIONS ARISING FROM THIS THESIS

Examining the carer-related and patient-related factors predicting anxiety amongst family carers of people with dementia. Faculty of Medicine and Health Sciences PGR Online Conference. June 2021.

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CHAPTER 1:

GENERAL INTRODUCTION

Dementia

Dementia is a progressive chronic illness, categorised by disruptions in behaviour and a decrease in cognitive abilities (Zarepour et al., 2020), which can lead to a gradual decrease in a person's independence. In the United Kingdom (UK), approximately 850,000 people are living with dementia and this prevalence rate is expected to rise even further. By 2050, it is expected that worldwide more than 131 million people will be living with dementia (Xiong et al., 2020).

Most people with dementia live at home (Jütten et al., 2019) and almost 80 % of these individuals are supported by unpaid family carers, with most of them being older women (Lee et al., 2019). Together with an increase in the prevalence of dementia, the number of carers of people living with dementia is expected to rise from just over 700,000 in 2014, to approximately 1.7 million by 2050 in the UK (R. Smith et al., 2018). Home and the residential community will thus continue to be the core of our health care. In fact, informal carers are currently saving the UK economy £11 billion a year.

Anxiety symptoms among family carers of people living with dementia

Prevalence

Given the complex situation of caregiving, it can have both positive and negative impacts on family carers. Positive aspects may include an increase in carers' self-esteem, a stronger bond with the care recipient and an increase of meaning in life (Boerner et al., 2004; Frias et al., 2020). However, negative symptoms such as carer burden, anxiety, depression and lower wellbeing are also present and have a significant impact on the health of both carer and the person living with dementia (Frias et al., 2020).

Anxiety symptoms can be best described as a combination of different symptoms with the main symptoms being feelings of worry and fear, muscular tension, fatigue and insomnia (Cooper, Balamurali, & Livingston, 2007). It is well known that anxiety symptoms are highly prevalent among family carers of people living with dementia, with some studies suggesting that the prevalence is even greater than that of depressive symptoms (Cooper, Balamurali, & Livingston, 2007; Sallim et al., 2015). A systematic review demonstrated that the pooled prevalence of anxiety symptoms in family carers of people living with dementia is 32.1% (Kaddour & Kishita, 2020). This estimated prevalence of anxiety symptoms is greater than that among family carers of people with other conditions such as cancer (Friðriksdóttir et al., 2011) and stroke (Loh et al., 2017). Although anxiety symptoms are highly prevalent among family carers of people living with dementia, it is a somewhat neglected research topic in the carer literature (Kaddour & Kishita, 2020).

Interventions

Most research and existing interventions for dementia family carers are built around the outcome measures of depression and carer burden (Kishita et al., 2018). Moreover, anxiety symptoms are considered hard to treat among family carers and older people. One of the key reasons is the multiple comorbidities, often present in the older population, which complicate the detection and treatment of their anxiety symptoms (Bryant et al., 2008). Furthermore, some studies suggest that health-care professionals often tend to believe that worries are a part of the ageing process; thus, they are less likely to be seen as symptoms of anxiety (Alwahhabi, 2003; Kaddour & Kishita, 2020; Wyman et al., 2018). This all contributes to underestimated, undertreated and poorly studied anxiety disorders among older people, who are often the main population of family carers of people living with dementia (Kaddour & Kishita, 2020; Subramanyam et al., 2018).

Additionally, the efficacy of existing carer interventions on anxiety symptoms is also limited when compared to depression or carer burden (Kishita et al., 2018). Current evidence suggests that conventional Cognitive Behavioural Therapy (CBT), developed primarily to target depression, does not effectively treat anxiety symptoms among dementia family carers (Hopkinson et al., 2019; Kishita et al., 2018). Therefore, understanding the factors affecting anxiety symptoms among family carers of people living with dementia is critical to inform future interventions and this is the key goal of this PhD project.

Potential factors affecting anxiety symptoms

One of the well-established models, the sociocultural stress and coping model adapted to caregiving (Knight & Sayegh, 2010), suggests that stressors can directly influence the wellbeing of carers, but other individual factors (e.g., coping strategies) also contribute to explaining how carers are affected differently from distress caused by such stressors. Factors associated with anxiety symptoms among dementia family carers, including both stressors and individual factors, are understudied in the current literature (Puga et al., 2022). Furthermore, those small number of studies that do investigate factors affecting anxiety symptoms among carers report inconsistent findings. Thus, the current literature cannot draw a definitive conclusion about influencing factors to be targeted as part of carer interventions.

Contextual factors

The stressors often arise from the contextual factors, factors that are relevant to a specific population. Although the previous findings may be limited and inconsistent, in the context of dementia caregiving, these contextual factors refer to carer- and patient-related demographics and stressors. More specifically, they may include carer age (Brodaty & Donkin, 2009; Schoenmakers et al., 2010; Williams, 2005), carer gender (Frias et al., 2020; Kaddour & Kishita, 2020; Xiong et al., 2020), dementia severity (Watson et al., 2019) and behavioural and psychological symptoms of dementia (Chun et al., 2007; George et al., 2020; Schoenmakers et al., 2010; Watson et al., 2019). Carer burden, the physical and psychological strain experienced by individuals providing care to someone (George & Ferreira, 2020), is also considered as one of the key contextual factors affecting anxiety symptoms (Del-Pino-Casado et al., 2021). Furthermore, the previous literature demonstrates that dementia carers who provide more assistance (Kishita et al., 2020), which could lead to worse carer physical health (Mahoney et al., 2005) and poor quality of sleep (Alvaro et al., 2013; Jiménez-Gonzalo et al., 2021), have a higher risk of mental health problems.

Individual factors

Identifying individual factors or coping strategies that moderate the association between those contextual factors and anxiety symptoms in family carers of people living with dementia can aid in preventing clinically significant anxiety symptoms. Recent research highlights under-explored psychological dimensions influencing anxiety symptoms: experiential avoidance and cognitive fusion (Barrera-Caballero et al., 2021; Cookson et al., 2020; Kishita et al., 2020). Experiential avoidance is the attempt to alter the form, frequency or intensity of private experiences such as thoughts and feelings, even when doing so is costly, ineffective or unnecessary (Hayes et al., 2013). Cognitive fusion is the tendency to become entangled with thoughts and the inability to step back from such restricting beliefs (Hayes et al., 2013).

Both experiential avoidance and cognitive fusion significantly affect psychological wellbeing in family carers of people living with dementia (Barrera-Caballero et al., 2021; Cookson et al., 2020; Kishita et al., 2020). There is considerable evidence suggesting that experiential avoidance moderates the relationship between stressors and mental health outcomes in non-carer populations (Cabrera et al., 2022; Cookson et al., 2020; Trindade et al., 2021), and cognitive fusion mediates the relationship between experiential avoidance and depressive symptoms among family carers of people living with dementia (Kishita et al., 2022; Xiong et al., 2021). However, the moderating or mediating roles of these psychological factors in the association between stressors and anxiety symptoms in dementia family carers remains uncertain.

Relational factors

Dementia does not only impact individuals; it profoundly affects relationships (McGovern, 2011). Caregiving occurs within this relational context, playing a pivotal role in both the formation and continuation of caregiving. For example, a qualitative study on the motivational and relational aspects of dementia caregiving revealed that carers' ability to find meaning in their role and relationship significantly influences their motivation to provide quality care (Quinn et al., 2015).

Many theories within the dementia caregiving context, such as the grief-stress model of caregiving (Noyes et al., 2010), highlight the importance of considering interpersonal (i.e., relationship adjustment, communication engagement, and emotional connection between two individuals) and intrapersonal (i.e., loss of self within the context of relationship) dynamics when exploring the healthy relationship (Knobloch et al., 2019; Lyons & Lee, 2018; Rippon et al., 2020).

There is very limited literature that has explored the impact of these dynamics on mental health outcomes such as depression (Enright et al., 2020). Regarding their potential effect on anxiety symptoms, empirical research is even more scarce, primarily due to the inherent difficulty in quantifying these dynamics (Knobloch et al., 2019). In-depth explorations of such relational dynamics require qualitative studies. However, currently the body of qualitative studies focusing on dementia caregiving and anxiety symptoms is limited. A recent systematic review, which explored factors affecting the wellbeing of family carers of people living with dementia, included 51 studies, of which only three were qualitative (Farina et al., 2017).

Project Objectives

In summary, our current knowledge of factors affecting anxiety symptoms among family carers of people living with dementia is limited. These influencing factors may include contextual and individual factors as well as relationships (interpersonal and intrapersonal dynamics). Therefore, this PhD project will focus on understanding how these factors could potentially predict and moderate anxiety symptoms in family carers of people living with dementia. To achieve this objective, five different studies were conducted.

The first study (Chapter 2) focused on the contextual factors, more specifically carer- and patient-related factors that may be associated with anxiety symptoms. The study aimed to address which carer-related (i.e., carer age, gender, hours of caring per week, comorbidities and sleep quality) and patient-related (i.e., dementia severity and neuropsychiatric symptoms of dementia) demographics and stressors known to have an impact on carer depression predicted anxiety symptoms in family carers of people living with dementia. Since different aspects of sleep quality are considered to have a differential impact on the mental health of individuals (Del Rio João et al., 2018), this study also explored which aspects of sleep quality (i.e., subjective sleep quality, sleep duration, daytime dysfunction, sleep latency, habitual sleep efficiency, sleep disturbances and use of sleep medication) predict anxiety symptoms in family carers of people living with dementia.

Based on the findings from the first study which showed the strong association between carer burden and anxiety symptoms, the second (Chapter 3) and third (Chapter 4) studies focused on the psychological process that might moderate such association between carer burden and anxiety symptoms. The second study (Chapter 3) aimed to explore the moderating role of experiential avoidance in the relationship between carer subjective burden and anxiety symptoms using both, a generic and a domain-specific measure of experiential avoidance. The third study (Chapter 4) focused on examining the indirect effect of carer subjective burden on anxiety symptoms through experiential avoidance and cognitive fusion. In doing so, it aimed to examine these combined effects of carer subjective burden, experiential avoidance and cognitive fusion on anxiety symptoms in family carers of people living with dementia.

While studies 1 to 3 focused on quantitative explorations of contextual factors and individual factors, the fourth (Chapter 5) and fifth (Chapter 6) studies explored the impact of relationships (interpersonal and intrapersonal dynamics) on anxiety symptoms through qualitative explorations and mixed-method approaches. Study 4 (Chapter 5) aimed to explore the experiences of, and the meaning given to interpersonal (i.e., relationship adjustment, communication engagement, emotional connection) and intrapersonal dynamics (i.e., sense of self) in females taking care of their partner/spouse with dementia using a phenomenological approach. Study 5 (Chapter 6) aimed to determine what combination(s) of conditions (i.e., the degree of presence of communication engagement, emotional connection and/or sense of self) influenced anxiety symptoms using a qualitative comparative approach. These conditions were based on a robust framework of both the results of Study 4 and theoretical models.

Project Background

The PhD candidate started her course while the UK was still in the second phase of a national lockdown due to COVID-19. To minimise the impact of COVID-19, certain sections of the current PhD project (Chapters 1, 2, and 3) were embedded within larger research projects. The study outlined in Chapter 1 utilised the existing dataset of the iCARE project: 'Towards Integrated Support: The Role of Carer- and Patient-Level Characteristics on Family Carer Quality of Life at Different Stages of Dementia (iCARE).' The project received ethical approval from the NHS Research Ethics Committee and the Health Research Authority (17/LO/0564). The PhD candidate led formulating research questions, completing data analysis, and drafting the manuscript for publication.

Chapters 2 and 3 involved a secondary analysis of data collected as part of a large interventional study iACT4CARERS. The ethical approval was obtained from the NHS Research Ethics Committee (REC 20/LO/0025). The PhD candidate led participant recruitment and data collection, managed all research-related documentation, designed research questions and study aims for the two quantitative studies presented in Chapters 2 and 3, analysed the data, drafted the manuscripts for publication.

Furthermore, the qualitative study in Chapter 5 and the mixed-method study in Chapter 6 were independently designed by the PhD candidate to qualitatively examine the factors influencing anxiety symptoms among family carers. In both studies, the PhD candidate formulated research questions and study objectives, secured ethical approval, recruited participants, conducted interviews, led the data analysis, and drafted the manuscripts.

CHAPTER 2:

EXAMINING THE IMPACT OF DIFFERENT COMPONENTS OF SLEEP QUALITY ON ANXIETY AMONG FAMILY CARERS OF PEOPLE WITH DEMENTIA

Published manuscript

Introduction

There is considerable evidence supporting that caring for a person with dementia has a significant impact on the wellbeing of family carers (Frias et al., 2020; Qiu et al., 2019; Stall et al., 2019) and anxiety and depression are highly prevalent among this population (Barnes & Markham, 2018; Kaddour & Kishita, 2020; Mahoney et al., 2005). These prevalence rates are estimated to be much higher than in the general population (Somers et al., 2006). Furthermore, the estimated prevalence of anxiety in family carers of people with dementia is greater than in family carers of people with other conditions, such as cancer (Friðriksdóttir et al., 2011) and stroke (Loh et al., 2017).

Despite this, anxiety is somewhat neglected in the carer literature (Kaddour & Kishita, 2020). Most research and existing interventions for family carers are built around the outcome measures of carer depression and burden (Kishita et al., 2018; Spencer et al., 2019; Thompson et al., 2007). Current evidence suggests that Cognitive Behavioural Therapy (CBT), the most commonly used psychological approach in dementia carer research, is effective for targeting depression but does not effectively treat anxiety in family carers of people with dementia (Cooper, Balamurali, et al., 2007; Kishita et al., 2018). Understanding factors affecting anxiety can help refine existing carer interventions, and consequently, further improve the wellbeing of family carers of people with dementia.

Factors associated with anxiety among family carers of people with dementia are understudied in the current literature (Cooper, Balamurali, & Livingston, 2007). Those small number of studies that do investigate factors affecting carer anxiety report inconsistent findings (Brodaty & Donkin, 2009; Cooper, Balamurali, & Livingston, 2007; Kaddour & Kishita, 2020; Schoenmakers et al., 2010; Xiong et al., 2020). However, there is substantial evidence on common factors affecting other negative psychological outcomes, such as carer depression. Factors associated with greater depression include female carer gender (Frias et al., 2020; Xiong et al., 2020), younger carer age (Williams, 2005), greater hours of caring per week (Kishita et al., 2020), worse carer physical health (Mahoney et al., 2005), poor quality of sleep (Alvaro et al., 2013), greater dementia severity (Watson et al., 2019) and more behavioural and psychological symptoms of dementia (Chun et al., 2007; Schoenmakers et al., 2010).

However, little is known about whether these factors are associated with carer anxiety in the same way. For example, there is a study that demonstrated younger carers are more vulnerable to anxiety (Chang et al., 2001), while another study demonstrated that older carers have a higher chance of developing anxiety symptoms (Kaddour & Kishita, 2020). Thus, this study aims to investigate whether these demographic variables and carer stressors, known to have an impact on carer depression, affect anxiety in a multiple regression model.

The current study particularly focuses on the impact of sleep quality on carer anxiety. A strong relationship between sleep quality and anxiety has been established in previous studies among the general population (Alvaro et al., 2013; Roth et al., 2006) and dementia carers (Beaudreau et al., 2008; S. Liu et al., 2017). Generally, subjective sleep quality is described as a person’s perception on how well they sleep without any disturbances. Various aspects of the quality and patterns of sleep such as subjective sleep quality, sleep latency, sleep duration, habitual sleep efficiency, sleep disturbances, use of sleep medication and daytime dysfunction are considered to contribute to overall sleep quality, and these different aspects can be assessed using standardised measures such as the Pittsburgh Sleep Quality Index (PSQI; Buysse et al., 1989). Despite this, previous studies on sleep quality have often used unstandardised measures, such as one single question (Li et al., 2021) or short instruments with one to four questions (Ali et al., 2020) to assess the complex concept of sleep quality.

The different aspects of sleep quality are considered to have a differential impact on the mental health of individuals (Del Rio João et al., 2018). Previous studies demonstrated that higher values of sleep latency, sleep disturbances and daytime dysfunctions contributed to higher levels of psychological distress in comparison with other sleep aspects, such as the use of sleep medication and sleep efficiency (i.e., the ratio of total sleep to time in bed) among a non-clinical community sample (Del Rio João et al., 2018; Ramsawh et al., 2009) and carers of people with multiple sclerosis (Argyriou et al., 2011). Understanding the impact of different aspects of sleep quality can lead to the development of interventions targeting individuals with disturbances in different aspects of sleep quality (Buysse et al., 1989; Murawski et al., 2018). Although previous literature reports that more than half of family carers have poor sleep quality due to their caregiving role (Castro et al., 2009), the differential impacts of sleep quality in family carers of people with dementia have yet to be studied. In this regard, a recent systematic review on sleep interventions for family carers of people with dementia demonstrated that most existing interventions did not have significant effects on sleep health (Pignatiello et al., 2021).

Therefore, the current study aims to address the following two research questions:

1. Which carer-related (i.e., carer age, gender, hours of caring per week, comorbidities, sleep quality) and patient-related (i.e., dementia severity, neuropsychiatric symptoms of dementia) demographics and stressors known to have an impact on carer depression predict anxiety symptoms in family carers of people with dementia?
2. If sleep quality is found to be a significant predictor, which aspects of sleep quality (i.e., subjective sleep quality, sleep duration, daytime dysfunction, sleep latency, habitual sleep efficiency, sleep disturbances and use of sleep medication) predict anxiety symptoms in family carers of people with dementia?

Considering the well-established associations between demographic variables, caregiving-stressors and depression, we hypothesise that all proposed variables would correlate with carer anxiety (i.e., greater anxiety symptoms are associated with female carer gender, younger carer age, greater hours of caring per week, worse carer physical health, poor quality of sleep, greater dementia severity and more behavioural and psychological symptoms of dementia). Furthermore, based on studies investigating the impacts of different aspects of sleep quality in non-clinical community samples, we hypothesise that worse subjective sleep quality, greater sleep latency, greater sleep disturbances and more daytime dysfunctions would be significantly associated with greater anxiety symptoms.

Materials and Methods

Study design and sampling

This study is a secondary analysis of data from a cross-sectional study that aimed to identify factors affecting the quality of life in family carers of people with dementia. The original study took place between July 2017 and February 2020. Written consent was obtained from all participants involved. Full ethical approval was received from the NHS Health Research Authority and Research Ethics Committee (17/LO/0564).The participants had to be at least 18 years old and be unpaid carers with a first-degree relationship (parent, spouse/partner, sibling, or adult child) with a person with dementia. The original study recruited ninety-one family carers through clinician referrals from a local NHS mental health trust, referrals from other ethically approved dementia studies and Join Dementia Research, a UK-based online service for matching people with researchers looking for volunteers.

Procedure

Potential participants were contacted by the research team via telephone or email to check for eligibility. Participants meeting the eligibility criteria were sent an invitation letter and participant information sheet. An appointment for the assessment session was made at the participant's own home, the university or local NHS premises depending on the participant's preference. Participants completed all self-reported questionnaires in the presence of a researcher during the assessment session. The Frontotemporal Dementia Rating Scale (FRS), which is an interview-based measure, was conducted by researchers trained to administer the tool.

Measures

Demographic Information

Demographic information including the carer age, gender, relationship with the person with dementia and cohabitation status were collected to characterise the sample. Carers' gender was coded as: 1=female and 2=male. The cohabitation status was coded as: 1=carers living separately from the person with dementia and 2=carers living in the same house as the person with dementia.

Anxiety

The Generalised Anxiety Disorder Scale (GAD-7; Spitzer et al., 2006) is a 7-item self-report questionnaire that measures the severity of anxiety symptoms. Participants were asked how often during the last two weeks they had experienced common anxiety symptoms (e.g., 'worrying too much about different things'). The GAD-7 is rated on a 4-point scale ranging from 0 (not at all) to 3 (nearly every day). Depending on the sum of scores, the severity of symptoms can be categorised as minimal (0-4), mild (5-9), moderate (10-14) or severe (15-21). The GAD-7 has good psychometric properties with good internal consistency (Cronbach Alpha =.89) (Spitzer et al., 2006).

Number of Hours of Caring

The number of hours of caring per week was assessed using the following response options: 0-2h, 3-10h, 11-20h, 21-40h, 41-80h and 81 or more hours.

Physical Health

The Charlson Comorbidity Index (CCI; Charlson et al., 1987) is a measure that assesses comorbidities based on the presence or absence of certain medical conditions. The updated Charlson Comorbidity Index of 12 comorbidities (Quan et al., 2011) was used in an interview format to assess the physical health of the carers in this study. The 12 medical conditions included were: congestive heart failure, dementia, chronic pulmonary disease, rheumatologic disease, mild liver disease, diabetes with chronic complications, hemiplegia or paraplegia, renal disease, any malignancy, moderate or severe liver disease, metastatic solid tumour, and AIDS/HIV. Each condition represents a score (1, 2, 3, 4 or 6) in agreement with its weighted prognostic value. This risk-adjusted hazard ratio of the conditions could vary between ≥ 1.2 and ≤ 6. The calculated total number of these scores had a range from 0 to 24, with the highest score indicating higher comorbidity, higher risk for mortality, and thus worse physical health. The CCI has good psychometric properties (Quan et al., 2011) with moderate to good internal consistency (Cronbach Alpha Range =.74-.95) (de Groot et al., 2003).

Sleep Quality

The Pittsburgh Sleep Quality Index (PSQI) (PSQI; Buysse et al., 1989) is a 19-item self-reported questionnaire designed to assess sleep quality and disturbances over a 1-month time interval. The PSQI consists of seven components: subjective sleep quality, sleep latency, sleep duration, habitual sleep efficiency, sleep disturbances, use of sleep medication and daytime dysfunction. Each item is weighted on a 0-3 interval scale. The sum of component scores generates a single global score, which has a range of 0-21. A global score of five or greater is indicative of poor sleep quality. The PSQI has good psychometric properties (Buysse et al., 1989) and moderate to good internal consistency (Cronbach's Alpha Range =.70-.83) (Mollayeva et al., 2016).

Dementia Severity

The Frontotemporal Dementia Rating Scale (FRS; Mioshi et al., 2010) is a 30-item proxy-informant interview-based measure that assesses the severity of dementia. The FRS provides logit scores, which are subdivided into six stages of dementia severity: very mild, mild, moderate, severe, very severe and profound. In the current study, these stages were combined to create three groups of participants: mild (including very mild), moderate and severe (including very severe and profound). The FRS has good psychometric properties with good internal consistency (Cronbach Alpha =.95) (Mioshi et al., 2010).

Neuropsychiatric Symptoms

The Mild Behavioural Impairment Checklist (MBI-C; Ismail et al., 2017) is a 38-item proxy-informant interview-based questionnaire measuring the neuropsychiatric symptoms within five domains: apathy/drive/motivation; mood/affect; impulse control/agitation; social appropriateness; and thoughts/perception. The MBI-C is a comprehensive measurement and is considered to detect behavioural changes that are also common in non-Alzheimer’s dementia (Ismail et al., 2017). The total score ranges from 0 to 102, with higher scores indicating higher levels of neuropsychiatric symptoms. The MBI-C has good psychometric properties with good internal consistency (Cronbach Alpha =.94) (Liew, 2020).

Statistical Analysis

A descriptive analysis was conducted to categorise the sample using demographic information. Two separate regression analyses were conducted to address two research questions. Analyses were performed using SPSS statistical software (Version 25).

To address the first research question, a single regression analysis was conducted for each potential independent variable with carer anxiety as a dependent variable first. These independent variables included five carer-related factors (age, gender, hours of caring per week, comorbidities, sleep quality) and two patient-related factors (dementia severity, neuropsychiatric symptoms of dementia). The independent variables that demonstrated a significant standardised coefficient beta (β) in this single regression, were then included in the final multiple regression model to identify factors affecting carer anxiety.

To address the second research question, a single regression analysis was conducted for cohabitation status and each subscale of the PSQI (subjective sleep quality, sleep latency, sleep duration, habitual sleep efficiency, sleep disturbances, use of sleep medication and daytime dysfunction) with carer anxiety as a dependent variable. The significant independent variables and the control variable (i.e., cohabitation status) were then included in the final multiple regression model simultaneously to identify different aspects of sleep quality affecting carer anxiety.

Before conducting the regression analyses for the final models, visual examination of the normal probability plot (P–P) of the regression standardised residuals and residuals scatterplots were conducted to test the assumption of normality, linearity and homoscedasticity between predicted dependent variables and errors of prediction. To indicate any problems with multicollinearity within this sample, collinearity statistics with the variance inflation factor (VIF) was used. In the final regression models, the F-test and the model's adjusted R^2 were used to determine the overall model fit (Pallant, 2003). The standardised coefficients beta (β) was used to assess which of the variables has the strongest predictive value on anxiety symptoms.

The percentage of missing values across the seven variables varied between 0 and 2.2%. In total the records of three participants out of 91 were incomplete. This resulted in missing data for three independent variables (i.e., PSQI, MBI-C, cohabitation status). Listwise deletion was used to handle these missing data points. Therefore, in each final regression analysis, a dataset of 89 family carers was used.

Results

Participants

The demographic information and means and standard deviations of measurements are shown in Table 2.1. Descriptive statistics demonstrated that the majority of participants were female spouses, who lived in the same household as the care recipient. Participants' age ranged from 26 to 95 with 67% of participants being older than 65 years. Nearly half of the care recipients were diagnosed with Alzheimer's disease (44%) and the majority were in the severe stages of dementia (64%). Seventy-five percent of participants scored five or greater on the PSQI, suggesting that most participants presented poor sleep quality. Fifty-seven percent of participants showed minimal symptoms of anxiety, while 21% demonstrated mild symptoms and 10% and 12% of participants demonstrated moderate and severe symptoms, respectively.

Carer demographic variable	Percentage or M *(SD)*
Age	69.13 *(12.49)*
Female	67%
Type of relationship	
Wife	40%
Husband	28%
Daughter	26%
Son	5%
Sister	1%
Cohabitation status	
Living with person with dementia	69%
Living separate from person with dementia	30%
Not specified	1%
Hours of caring per week	
0-2h	4%
3-10h	17%
11-20h	10%
21-40h	17%
41-80h	15%
81+h	37%
Anxiety symptoms (GAD-7), score range 0-21	6.06 *(5.66)*
No. of participants on antidepressants	14%
No. of participants undergoing psychotherapy	1%
Sleep quality (PSQI), score range 0-21	8.11 *(3.85)*
Comorbidities (CCI), score range 0-24	1.26 *(1.90)*

Care recipient demographic variables	Percentage or M *(SD)*
Dementia Type	
Alzheimer's	44%
Mixed	19%
Vascular	15%
Frontotemporal	8%
Lewy Bodies	6%
Unknown	8%
Dementia Severity (FRS)	
Mild	6%
Moderate	30%
Severe	64%
Neuropsychiatric symptoms (MBI-C), score range 0-102	30.06 *(18.01)*

Note: CCI, Charlson Comorbidity Index; FRS, Frontotemporal Dementia Rating Scale; GAD-7, Generalised Anxiety Disorder Scale; MBI-C, Mild Behavioural Impairment Checklist; PSQI, Pittsburgh Sleep Quality Index.

Table 2.1. Demographic variables (N=89)

Carer- and patient- factors affecting carer anxiety

The results of each single regression analysis are shown in Table 2.2. Among seven potential independent variables, six demonstrated a significant *β*-value. Thus, carer age, gender, sleep quality, hours of caring per week, dementia severity and neuropsychiatric symptoms were included in the final regression model.

Potential independent variables	*β*	*P* value
Carer age	-.25	.02*
Carer gender	-.32	<.01*
Hours of caring per week	.28	.01*
Sleep quality	.36	<.01*
Comorbidities	-.14	.18
Dementia severity	.27	.01*
Neuropsychiatric symptoms	.26	.02*

Note: * represents significance at the 5% level

Table 2.2. Single regression analysis – carer and patient factors

In the final regression model, the VIF was greater than 10 for dementia severity (i.e., FRS), suggesting an issue of multicollinearity due to a high correlation between the FRS and the MBI-C. Therefore, dementia severity was deleted from the model, resulting in five independent variables. The results of the normal P-P Plot and the scatterplot of the standard residuals showed that the assumption of normality, linearity and homoscedasticity of residuals was met.

The adjusted R^2 value was 0.24 (R^2=.29, ΔR^2=.24, F(5,83)=6.64, p<.001), suggesting that the proposed model explains 24% of the variance in anxiety symptoms. The standardised coefficients beta were statistically significant only for hours of caring per week (β=.24) and sleep quality (β=.28) (see Table 2.3). The effect size for this regression model (Cohen's f^2) was 0.40, suggesting a large effect size.

Independent variables	β	t	*P* value
Carer age	-.19	-1.77	*n.s.*
Carer gender	-.19	-1.83	*n.s.*
Hours of caring per week	.24	2.37	<.05
Sleep quality	.28	2.86	<.01
Neuropsychiatric symptoms	.05	.47	*n.s.*

R^2 = 0.29, F (5, 83) = 6.64, p < .001

Note: n.s., not significant.

Table 2.3. Multiple regression analysis – carer and patient factors (N=89)

Aspects of sleep quality affecting carer anxiety

The results of each single regression analysis are presented in Table 2.4. Among seven potential independent variables, five demonstrated a significant *β*-value. Thus, subjective sleep quality, sleep latency, sleep disturbance, daytime dysfunction and cohabitation status were included in the final regression model.

Potential independent variables	*β*	*P* value
Subjective sleep quality	.46	<.01*
Sleep latency	.26	.01*
Sleep duration	.18	.10
Sleep efficiency	.07	.53
Sleep disturbance	.37	<.01*
Sleep medication	.06	.58
Daytime dysfunction	.28	.01*
Cohabitation status	-.24	.02*

Note: * represents significance at the 5% level

Table 2.4. Single regression analysis – different aspects of sleep quality

In this final regression model, the VIF value was below 1.59 for all independent variables, suggesting multicollinearity was not present. The results of the normal P-P Plot and the scatterplot of the standard residuals showed that the assumption of normality, linearity and homoscedasticity of residuals was met.

The adjusted R^2 value was 0.24 ($R^2=.29$, $\Delta R^2=.24$, $F(5,83)=6.68$, $p<.001$), suggesting that the proposed model explains 24% of the variance in anxiety symptoms. The standardised coefficients beta were statistically significant only for subjective sleep quality (i.e., subjective perception of overall sleep quality during the past month; $\beta=.33$) and sleep disturbance (i.e., experiences of trouble sleeping due to interruptions, such as difficulty in breathing during the past month; $\beta=.22$) after controlling for cohabitation status (see Table 2.5). This regression model showed a large effect size of 0.40 (Cohen’s f^2).

Independent variables	*β*	t	*P* value
Subjective sleep quality	.33	2.82	<.01
Sleep latency	.02	.19	*n.s.*
Sleep disturbance	.22	2.21	<.05
Daytime dysfunction	.05	.43	*n.s.*
Cohabitation status	-.14	-1.47	*n.s.*

$R^2 = 0.29$, $F(5, 83) = 6.68$, $p < .001$

Note: n.s., not significant.

Table 2.5. Multiple regression analysis – different aspects of sleep quality (N=89)

Discussion

The findings suggested that providing more hours of caring per week and having worse sleep quality may predict higher levels of anxiety symptoms in family carers of people with dementia. Furthermore, the individual's feelings on sleep quality (i.e., subjective sleep quality and sleep disturbances) seem to predict higher levels of anxiety symptoms than the subjective perception of sleep parameters (e.g., sleep latency, sleep duration), after controlling for the cohabitation status of the carer.

It is well known that the increased number of hours of caring leads to higher levels of depression in family carers of people with dementia (Schoenmakers et al., 2010). This study demonstrated that this common factor was also significantly associated with anxiety symptoms among this population. However, other well-known carer stressors, such as neuropsychiatric symptoms of dementia were not associated with anxiety symptoms, suggesting that more tailored interventions are needed to target carer anxiety. There are community services, which can help reduce caregiving demands, such as respite care (Alzheimer's Society, 2019). Current evidence suggests that the use of respite care alone may not be related to improvements in the psychological wellbeing of family carers of people with dementia (Cheng & Zhang, 2020; Maayan et al., 2014), but respite care may support carers to better manage their sleep or maintain hobbies and interests, which in turn may result in improved psychological health (Parkinson et al., 2016). Moreover, carers often report various barriers to access these community services (e.g., respite care, daycare centres), such as the lack of information about available services and their possible benefits (Boots et al., 2015; Qiu et al., 2019; Southby, 2017; Stephan et al., 2018). Furthermore, studies suggest that family carers may not use these services due to feelings of guilt and worry even when the services are available to them (Southby, 2017; Stephan et al., 2018). It is recommended that future research explores whether the combination of promotion of uptake of respite care and sleep management or the intervention to increase pleasure activities leads to reduced anxiety symptoms in this population.

This study provided evidence on different aspects of sleep quality associated with carer anxiety. Previous studies on sleep quality have used unstandardised measures, such as one single question (Li et al., 2021) or short instruments with one to four questions (Ali et al., 2020) to assess the whole concept of sleep quality in the adult population, including family carers. This study used a comprehensive measure of sleep quality, which has been standardised (i.e., PSQI), and this allowed us to explore the relationships between different aspects of sleep quality and carer anxiety. The relationship between sleep quality and anxiety symptoms requires further attention as some studies have reported that sleep quality may be bidirectionally related to anxiety (Alvaro et al., 2013; Neckelmann et al., 2007; Vedaa et al., 2016). Previous studies have shown that family carer of people with dementia experience both greater overall anxiety symptoms (Kaddour & Kishita, 2020) and poorer subjective sleep quality as well as greater sleep disturbance than non-carers (Cupidi et al., 2013; Gao et al., 2019). A previous study conducted with family carers of people with dementia suggested that the nature and duration of caregiving and the progression of dementia of the care recipient may be associated greater sleep disturbance and hence worse mental health (Johnson et al., 2006). Successful treatment of subjective sleep quality and sleep disturbances may thus prevent exacerbation of anxiety symptoms and vice versa. Future research should further investigate the impact of the sleep quality using a longitudinal design.

Currently, nonpharmacological interventions including cognitive behavioural therapy (CBT) (Murawski et al., 2018; Passarella & Duong, 2008; Patel et al., 2018), exercise-based interventions (Miyazaki et al., 2021) and mindfulness-based interventions (Golshani & Pirnia, 2019; Salari et al., 2020) are recommended as the first-line treatments for sleep problems. A recent systematic review of sleep interventions for informal carers of people with dementia (Pignatiello et al., 2021) showed mindfulness-based interventions and prescribed physical exercises have the potential to improve the subjective sleep quality among this population. However, it remains unclear whether these positive effects on subjective sleep quality diminish in the long term (Golshani & Pirnia, 2019; Salari et al., 2020). This long-term impact is particularly important given the established relationship between carers' quality of sleep and dementia severity. Carers' quality of sleep is known to diminish as dementia progresses due to the increased care challenges (Chiu et al., 2014; McCurry et al., 2009; Smyth et al., 2020). Randomised controlled trials are required to investigate the short-term and long-term effects of these interventions on the subjective sleep quality and anxiety symptoms in family carers of people with dementia. There are diverse causes of sleep disturbances such as sleep apnoea and physical pain (Patel et al., 2018). Sleep disturbances among dementia carers can involve a complex interaction between disturbances caused by the person with dementia, carer burden and psychological and physical wellbeing of the carer (Gibson et al., 2014; McCurry et al., 2007). Existing interventions such as CBT for Insomnia (CBT-I) are shown to be effective in managing sleep disturbances across multiple populations (Murawski et al., 2018; Shaffer et al., 2019). CBT is also considered to be effective in improving sleep quality in people with dementia (Jin et al., 2021). Future research is recommended to evaluate the effectiveness of dyadic sleep interventions on sleep disturbances and explore mechanisms of change in anxiety symptoms among family carers of people with dementia.

There are some methodological limitations, which should be considered. The adjusted R^2 value was 0.24 for both multiple regression models in the current study, which focused on the impact of demographic variables and carer stressors. Therefore, there may be other types of variables that affect carer anxiety. Future studies should investigate the impact of moderating variables, such as individual coping skills and support resources (van Ryn et al., 2011). Considering the high level of comorbidity between depression and anxiety in family carers of people with dementia (Mineka et al., 2014), future studies may benefit from controlling for depression when examining factors associated with anxiety symptoms in this population. In addition, the sample size required for a regression model in order to achieve a power level of 0.80, a significance level of 0.05 and a medium effect size (0.15) is 92 when five independent variables are included in the model. This study had a sample size of 89 in the multiple regression models, which is slightly smaller than required. However, the effect size for both regression models was large in this study. Hours of caring per week was measured using categorical data with a relatively wide range of time for each category (e.g., 21–40 h). The highest response option (i.e., 81+ hours) was selected by most of the participants. This may have caused the ceiling effect and decreased the sensibility of the assessment.

Furthermore, this study employed the PSQI to assess the sleep quality of family carers of people with dementia. Since the PSQI relies on self-report and recall of experiences during the past month, the PSQI scores may have been biased. In addition, although the PSQI has been widely used in research as a standardised measure of sleep quality, some studies examining the unidimensionality of the PSQI have however raised concerns over the factor structure of the instrument (Grandner et al., 2006; Mollayeva et al., 2016). Due to the observed poor internal consistency for some of the component scores of the PSQI (Grandner et al., 2006; Mollayeva et al., 2016), using this questionnaire in multivariate statistics might impose a limitation for this study. Therefore, future research is recommended to further investigate the impact of sleep quality using both standardised subjective measurements (e.g., PSQI) as well as objective measures of sleep quality (e.g., actigraphy or polysomnography).This study did not collect information on the ethnicity of participants. However, participant recruitment took place in counties in the East of England, where more than 90% of the population is White British. The ethnic diversity of the sample was thus limited. In addition, participants were mainly female, and half of the participants experienced minimal to mild anxiety symptoms. Future studies should investigate a wider population, including male family carers, those from different ethnic backgrounds and a clinical population (i.e., participants with more severe anxiety symptoms) to provide further evidence on the generalisability of findings. Finally, given the cross-sectional nature of the study, it is important to note that a conclusion cannot be drawn about causal assumptions.

Conclusion

Despite limitations, this study provided evidence that the hours of caring per week, subjective sleep quality and sleep disturbances are associated with anxiety symptoms in family carers of people with dementia. It is recommended that future research investigates the impact of tailored interventions for managing carer anxiety, such as exploring whether promotion of uptake of respite care combined with evidence-based sleep interventions (e.g., exercise, mindfulness-based interventions, dyadic CBT-I) improves anxiety symptoms in family carers of people with dementia.

CHAPTER 3:

DOES AVOIDING DISTRESSING THOUGHTS AND FEELINGS INFLUENCE THE RELATIONSHIP BETWEEN CARER SUBJECTIVE BURDEN AND ANXIETY SYMPTOMS IN FAMILY CARERS OF PEOPLE WITH DEMENTIA?

Published manuscript

Introduction

It is estimated that one in three people will care for a person with dementia in their lifetime (National Collaborating Centre for Mental Health, 2018). Due to an increase in life expectancy and prevalence of dementia, these numbers are likely to increase in the next decade (Alzheimer's Society, 2014). Supporting someone with dementia is known to have a significant negative impact on the wellbeing of family carers (Ali & Bokharey, 2016). Particularly, the prevalence of anxiety is considered to be high among this population with approximately one-third of family carers presenting clinical levels of anxiety symptoms (Kaddour & Kishita, 2020). This prevalence rate is greater than that of family carers of people with other conditions, such as cancer (Friðriksdóttir et al., 2011) and stroke (Loh et al., 2017). Nevertheless, the current dementia literature mainly focuses on carer depression as an outcome and carer anxiety is somewhat neglected. In addition, existing carer interventions, such as Cognitive Behavioural Therapy (CBT), are considered to be not as effective for anxiety as for depression in family carers of people with dementia (Kishita et al., 2018). Therefore, understanding factors that can moderate the relationship between carer stressors and anxiety symptoms is critical to inform future interventions aimed at improving the wellbeing of family carers of people with dementia.

Carer subjective burden refers to personal appraisals of burden including the physical, psychological, social and emotional impact their caring role has on their life (Liu et al., 2020). A recent meta-analysis, which reviewed 74 studies on informal carers including 24 studies targeting informal carers of people with dementia, demonstrated that carer subjective burden is a key determinant of anxiety symptoms (Del-Pino-Casado et al., 2021). Identifying individual factors that may moderate the association between carer subjective burden and anxiety symptoms could help find a way to prevent family carers experiencing high levels of burden from developing clinically significant anxiety. Experiential avoidance is the attempt to alter the form, frequency or intensity of private experiences such as thoughts or feelings, even when doing so is costly, ineffective or unnecessary (Hayes et al., 2013). Recently, studies have shown that experiential avoidance is significantly associated with psychological wellbeing among family carers of people with dementia (Cookson et al., 2020; Kishita et al., 2020). In addition, there is considerable evidence suggesting that experiential avoidance moderates the relationship between stressors and mental health outcomes in non-carer populations and higher experiential avoidance has been associated with worse mental health at greater stressor levels (Cookson et al., 2020; Trindade et al., 2020). Therefore, this study aims to investigate the moderating role of experiential avoidance in the relationship between a well-known stressor (carer subjective burden) and anxiety symptoms in family carers of people with dementia.

The most widely used measure of experiential avoidance in research is the Acceptance and Action Questionnaire-II (AAQ-II). The AAQ-II is considered a generic measure of experiential avoidance and has been validated across various populations (Bond et al., 2011; Fledderus et al., 2012). The AAQ-II is a brief measure containing only seven items and thus can be easily administrated in clinical and research settings. However, it has been argued that the AAQ-II may not be sensitive enough for detecting experiential avoidance in particular populations as the items are generic, not targeting domain-specific thoughts and feelings (Hayes et al., 2004). To overcome the limitation of the AAQ-II, researchers have developed several variations of instruments assessing experiential avoidance that are more specific to certain populations (Ong et al., 2019). These domain-specific measures have the advantage of assessing experiential avoidance directly related to a specific context and may perform better than a generic measure of experiential avoidance, allowing to predict changes in specific behaviour more accurately (Schmalz & Murrell, 2010). In this regard, a domain-specific measure of experiential avoidance has been developed for the carer population, the Experiential Avoidance in Caregiving Questionnaire (EACQ; Losada et al., 2014). This study aims to explore the moderating role of experiential avoidance in the relationship between carer subjective burden and anxiety symptoms using both, a generic and a domain-specific measure of experiential avoidance. The findings may inform directions of future research on experiential avoidance in dementia caregiving and provide important clinical implications in terms of assessment and intervention.

Considering the well-established moderating effect of experiential avoidance in non-carer populations between stressors and mental health outcomes, we hypothesise that both generic experiential avoidance and experiential avoidance in caregiving would moderate the relationship between carer subjective burden and anxiety symptoms in family carers of people with dementia. That is, higher levels of experiential avoidance would associate with greater anxiety symptomatology at higher levels of carer subjective burden. Carers who thus report high levels of carer subjective burden and present with high levels of experiential avoidance, are likely to report higher levels of anxiety symptomatology than carers with high levels of carer burden but low levels of experiential avoidance. Considering the possible differences in the moderating effects of general and domain-specific measures of experiential avoidance, we hypothesise that the domain-specific measure of experiential avoidance (EACQ) would account for more variance in anxiety symptoms than the generic measurement of experiential avoidance (AAQ-II).

Materials and Methods

Study design and sampling

This is a secondary analysis of data from an intervention study assessing the feasibility and acceptability of an online self-help Acceptance and Commitment Therapy (ACT) programme (Kishita et al., 2021). Screening data collected before the intervention phase were used for this study. The recruitment took place between August 2020 and January 2021 in England. Participants were included if they (1) were primary carers; (2) provided regular care to their family member with dementia (i.e., participants were asked whether they had regular contact with the care recipient providing support) and (3) were interested in engaging with an online self-help ACT programme. No criteria were set for frequency of care provide (e.g., hours of caring per week) as the psychological impact of caring is related to multiple factors such as the relationship they have with the person with dementia. We collected background and demographic data such as frequency of care they provide and their relationship to the care recipient instead. Seventy-nine eligible carers were recruited through clinician referrals from three national health services (NHS) through referrals from other ethically approved dementia studies led by the same research team, through self-referral from the community via advertisements in local newspapers, or a national recruitment website (i.e., Join Dementia Research). All participants provided written consent, via post or electronically, before attending the screening session. Full ethical approval was received from the NHS London-Queen Square Research Ethics Committee (20/LO/0025).

Procedure

Potential participants were contacted by the research team via telephone or email to check their eligibility. Participants meeting the eligibility criteria received an invitation letter and information sheet. Those who provided written consent were then invited to the screening session. Due to the COVID-19 pandemic, an appointment for the screening session was made remotely via video call or telephone. During this screening session, participants were asked to complete self-reported questionnaires using an online survey platform or hardcopies, which were sent home and returned via post, in the remote presence of a researcher.

Measures

Demographic information

Demographic information including carer age, gender, relationship to the care recipient and the length of care in months were collected to characterise the sample.

Carer Anxiety

The severity of anxiety symptoms was measured using the Generalised Anxiety Disorder Scale (GAD-7; Spitzer et al., 2006). The GAD-7 is a 7-item self-report questionnaire, which assesses how often an individual has experienced anxiety symptoms during the past two weeks (e.g., “Over the last two weeks, how often have you been bothered by not being able to stop or control worrying?”). Each item is scored on a 4-point scale ranging from 0 (*not at all*) to 3 (*nearly every day*). The total score indicates anxiety severity of minimal (0-4), mild (5-9), moderate (10-14) or severe (15-21). The GAD-7 has good psychometric properties with good internal consistency (Cronbach Alpha = .89) (Spitzer et al., 2006). The Cronbach’s alpha for the current study was .92.

Carer subjective burden

The 12-item version of the Zarit Burden Interview (ZBI-12; Bédard et al., 2001) was used to assess carer burden. The ZBI-12 assesses two domains of carer subjective burden: personal strain (e.g., “Do you feel you have lost control of your life since your relative’s illness?”) and role strain (e.g., “Do you feel you should be doing more for your relative?”). Each item is scored on a 5-point scale from 0 (*never*) to 4 (*almost always*). The total score ranges from 0 to 48, with higher scores representing higher levels of carer subjective burden. The ZBI-12 has good psychometric properties with good internal consistency (Cronbach Alpha = .88) (Bédard et al., 2001). The Cronbach’s alpha for the current study was .88.

Generic Experiential avoidance

The Acceptance and Action Questionnaire (AAQ-II; Bond et al., 2011) is the most widely used unidimensional measure of experiential avoidance. The AAQ-II is not specifically designed for certain groups or conditions but has been validated across various populations, including non-clinical samples (Bond et al., 2011) and people with mental health problems (Fledderus et al., 2012; Spinhoven et al., 2014). The AAQ-II consists of 7 items rated on a seven-point scale from 1 (*never true*) to 7 (*always true*). The items of the AAQ-II include statements such as “My painful experiences and memories make it difficult for me to live a life that I would value.”. The total score ranges from 7 to 49, with higher scores indicating greater levels of experiential avoidance. The AAQ-II has good psychometric properties with good internal consistency

(Cronbach Alpha = .88) (Bond et al., 2011). The Cronbach's alpha for the current study was .93.

Experiential avoidance in caregiving

The Experiential Avoidance Caregiving Questionnaire (EACQ; Losada et al., 2014) is a 15-item self-reported measure specifically designed to assess experiential avoidance in the caregiving context (the tendency to control, avoid or suppress distressing thoughts and feelings related to caregiving). The EACQ consists of items related to active avoidant behaviours (e.g., "I tend to 'ignore' the negative thoughts that come to me about my relative"), intolerance of negative thoughts and emotions towards the relative (e.g., "I cannot bear it when I get angry with my relative"), and apprehension concerning negative internal experiences related to caregiving (e.g., "It is normal for a carer to have negative thoughts about the person they are caring for"). The original version of the EACQ was developed in Spanish. The English-translated version of the EACQ presented in the original validation study (Losada et al., 2014) has also been used in previous research (George & Ferreira, 2020; K. J. Smith et al., 2018). The EACQ is rated on a 5-point scale ranging from 1 (*not at all*) to 5 (*a lot*). The total score ranges from 15 to 75, with higher scores indicating higher levels of experiential avoidance in caregiving. The EACQ has good psychometric properties with acceptable internal consistency (Cronbach Alpha = .70) (Losada et al., 2014). The Cronbach's alpha for the current study was .73.

Statistical analysis

All analyses were performed using IBM SPSS statistical software (Version 28). Data were examined for accuracy with no extreme outliers detected and most variables approximating normality. The percentage of missing data across the eight variables varied between 1.3% and 2.5%. Of the 79 participants, one respondent did not complete the Experiential Avoidance Caregiving Questionnaire (EACQ) while another respondent did not complete both the Zarit Burden Interview (ZBI-12) and the Experiential Avoidance Caregiving Questionnaire (EACQ). This resulted in a dataset of 77 family carers in the moderation model of EACQ and a dataset of 78 family carers in the moderation model of AAQ-II. To ensure consistency among both models, the participant that didn't complete the EACQ was removed from the final moderation model of AAQ-II. Removing this participant did not result in any difference of significance.

A descriptive analysis of demographic data was performed to categorise the sample. To examine the associations between all variables and account for possible issues of multicollinearity, Pearson's *r* correlations were conducted between control variables (carer age, gender, relationship to care recipient and length of care) and independent and moderator variables (ZBI, AAQ-II and EACQ), and the dependent variable (anxiety symptoms). Correlations of $r < .30$ were considered small, $r \geq .30$–.49 medium or moderate, and $r \geq .50$ were considered strong (Kraemer et al., 2003). Control, independent and moderator variables that demonstrated significant correlations with anxiety symptoms at $p < .05$ level were included in the moderation analyses. When a correlation coefficient of > .70 among two or more variables is identified, there may be a presence of multicollinearity (Shrestha, 2020). If multicollinearity was identified, the least significant of the multicollinear variables was removed from the models.

A separate moderation analysis was performed for each potential moderator (AAQ-II and EACQ) using the PROCESS computation macro (Model 1; Hayes, 2013) to examine their reverse buffering effect on the link between carer subjective burden (X) and anxiety symptoms (Y). Demographic variables significantly correlated with anxiety symptoms were entered into the model as covariates to control for their potential confounding effects. All continuous variables that defined the result were mean centred as literature suggests this can have important implications for the interpretability of regression coefficients and multicollinearity within the context of interaction modelling (Shieh, 2011). In addition, a 95% bootstrap resampling procedure (with 5000 samples) was used. Standardised coefficients were calculated (McCabe et al., 2018) and statistical significance was established when the 95% confidence intervals (CIs) did not include zero (Hayes, 2013). In addition, a simple slope analysis was performed using non-standardised coefficients of the continuous variables. Simple slope graphs were plotted for each moderator (AAQ-II and EACQ) with different levels of the moderator (i.e., low, average and high levels of experiential avoidance) to visualise the reverse buffering effects of different types of experiential avoidance. Given that there are no theoretical cut points for both the AAQ-II and the EACQ, this simple slope analysis considered the following cut-point values: one *SD* above the mean, the mean, and one *SD* below the mean (Cohen et al., 2003).

Results

Participants

Descriptive statistics demonstrated that the majority of participants were female spouses, who lived with the care recipient in the same household. On average, participants were taking care of their care recipient for 53 months and nearly half of the care recipients were diagnosed with Alzheimer's disease (43%). Participants' age ranged from 32 to 85 with 43% of participants being older than 65 years. Forty-two per cent of participants showed minimal symptoms of anxiety, while 39% demonstrated mild symptoms and 8% and 12% of participants demonstrated moderate and severe symptoms, respectively. Other demographic information and means and standard deviations of measurements are shown in Table 3.1.

Carer demographic variable	Percentage or M *(SD)*
Age	63.47 *(10.64)*
Female	73%
Type of relationship with care recipient	
Spousal relationship	52%
Non-spousal relationship	48%
Living with the person with dementia	
Yes	62%
No	38%
Hours of caring per week	
0-2h	4%
3-10h	21%
11-20h	10%
21-40h	7%
41-80h	14%
81+h	44%
Length of care (in months)	53.39 *(41.77)*
Anxiety symptoms (GAD-7), score range 0-21	6.45 *(5.27)*
Experiential Avoidance (AAQ-II), score range	20.43 *(9.85)*
Experiential Avoidance in Caregiving (EACQ), score range	41.42 *(8.95)*
Care recipient demographic variables	**Percentage or M *(SD)***
Dementia Type	
Alzheimer's	43%
of which early onset Alzheimer's	1%
Mixed	29%
Vascular	12%
Frontotemporal	3%
Lewy Bodies	4%
Unknown	9%

Note: AAQ-II, Action and Acceptance Questionnaire; EACQ, Experiential Avoidance in Caregiving Questionnaire; GAD-7, Generalised Anxiety Disorder Scale.

Table 3.1. Demographic variables (N=77)

Correlations

A series of Pearson's *r* correlations were conducted (see Table 3.2). Carer age was negatively associated with anxiety symptoms, meaning being younger of age was associated with greater anxiety symptoms, and carer gender was positively correlated with anxiety symptoms, meaning female carers were more likely to report anxiety symptoms. Therefore, age and gender were controlled in both moderation analyses. No correlation between the control, independent and moderator variables exceeded the recommended threshold of .70. Issues of multicollinearity were therefore not identified.

Variables	1	2	3	4	5	6	7	8	9	10
1. Carer age	1.00									
2. Carer gender	-.38**	1.00								
3. Spousal Relationship	-.68**	.30**	1.00							
4. Length of care	.15	-.12	.00	1.00						
5. Living with the person with dementia	.39**	-.36**	-.00	.04	1.00					
6. Hours of caring per week	.10	-.06	-.36**	.11	.64**	1.00				
7. Experiential avoidance	-.24*	.30**	.07	-.11	-.17	.02	1.00			
8. Experiential avoidance in caregiving	-.01	-.07	-.15	-.13	.04	.14	.36**	1.00		
9. Carer subjective burden	-.18	.14	-.10	-.01	.09	.26*	.67**	.31**	1.00	
10. Carer anxiety	-.32**	.29**	-.01	-.17	-.02	.16	.76**	.36**	.63**	1.00

**. Correlation is significant at the 0.01 level (2-tailed).

*. Correlation is significant at the 0.05 level (2-tailed).

Table 3.2. Pearson's r correlations (N=77)

Moderation effects

Generic experiential avoidance (AAQ-II)

The unstandardised coefficients (*b*) and standard errors (SE) of the variables (independent variables [carer subjective burden]; moderator [experiential avoidance]; interaction [carer subjective burden X experiential avoidance]; and the two control variables [age and gender]) and the model summary are presented in Table 3.3.

	β	Estimate (B)	SE	*t*	LLCI	ULCI	*p*
Intercept		9.20	3.30	2.78	2.61	15.79	**.007**
ZBI_centered (*X*)	.27	.16	.06	2.82	.05	.27	**.006**
AAQ-II_centered (*W*)	.44	.24	.06	4.09	.12	.35	**<.001**
ZBI x AAQ-II (*X* x *W*)	.21	.01	.00	2.65	.00	.02	**.010**
Age (C_1)	-.14	-.07	.04	-1.82	-.14	.01	.521
Gender (C_2)	.05	.59	.92	0.65	-1.23	2.42	.073
					R^2 = .66, *MSE* = 10.22 *F*(5,71) = 27.15, p < .001		

Note: ZBI, Zarit Burden Interview [assessment of carer subjective burden]; AAQ, Action and Acceptance Questionnaire [broad assessment of experiential avoidance]; LLCI, Lower level of 95% confidence interval for Estimate (B); ULCI, Upper level of 95% confidence interval for Estimate (B).

Table 3.3. Moderation analysis – generic experiential avoidance (AAQ-II)

The conditional effect of carer subjective burden on anxiety symptoms was significant (*β* = .27, 95% CI [.05, .27], *p* = .006), as well as the conditional effect of experiential avoidance on anxiety symptoms (*β* = .44, 95% CI [.12, .35], *p* <.001). The interaction term (*β* = .21, 95% CI [.00, .02], *p* = .010) incrementally accounted for 3.4% of the variance in anxiety symptoms (ΔR^2 = .03). The total model explained 66% of the variance of anxiety symptomatology (R^2 = .66, *F*(5,71) = 27.15, *p* <.001). The effect size for this regression model (Cohen's f2) was 1.91, suggesting a large effect size. These results confirmed that generic experiential avoidance measured by the AAQ-II is a significant moderator of the relationship between carer subjective burden and anxiety symptoms.

In addition, the standardised slope for carer subjective burden regressed on anxiety symptoms was significant for individuals one *SD* above the mean level of the AAQ-II (High; B = .26, SE = .07, 95% CI [.11, .40], *p* = .001) and at the mean level of the AAQ-II (Average; B = .16, SE = .06, 95% CI [.05, .27], *p* = .006). However, the slope at one *SD* below the mean was not significant (Low; B = .05, SE = .06, 95% CI [-.07, .18], *p* = .389) (see Figure 3.1). When participants were presenting the same level of carer subjective burden, those who reported less experiential avoidance demonstrated fewer anxiety symptoms. This reverse buffering effect of experiential avoidance was stronger when individuals presented higher levels of carer subjective burden.

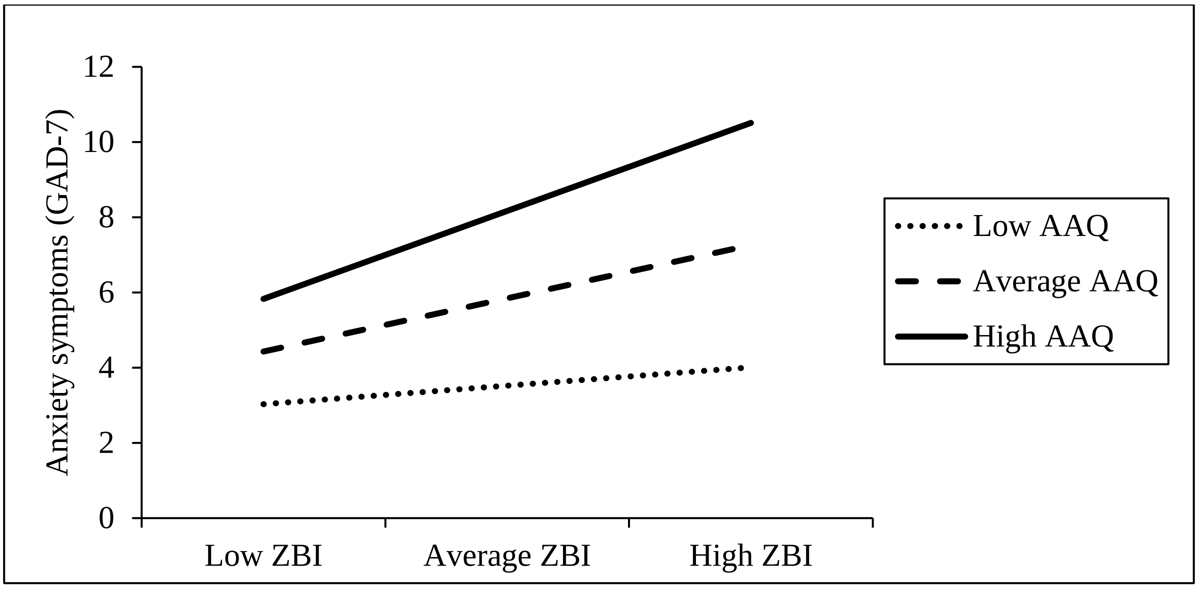


Figure 3.1. The interaction effect (carer subjective burden [ZBI] by experiential avoidance [AAQ]) in relation to anxiety symptoms.

Experiential avoidance in caregiving (EACQ)

The results of the moderation analysis are shown in Table 3.4 with the unstandardised coefficients (*b*) and standard errors (SE) of the variables (independent variables [carer subjective burden]; moderator [experiential avoidance in caregiving]; interaction [carer subjective burden X experiential avoidance in caregiving]; and the two control variables [age and gender]).

	β	Estimate (B)	SE	*t*	LLCI	ULCI	*p*
Intercept		7.01	3.88	1.81	-.73	14.74	.075
ZBI_centered (X)	.51	.30	.05	5.74	.19	.40	**<.001**
EACQ_centered (M)	.19	.12	.05	2.24	.01	.22	**.028**
ZBI x EACQ (X x M)	.17	.01	.01	2.05	.00	.02	**.045**
Age (C_1)	-.14	-.07	.04	-1.54	-.16	.02	.128
Gender (C_2)	.17	2.04	1.05	1.95	-.04	4.13	.055

$R^2 = .53$, *MSE* = 14.06

F(5,71) = 15.87, p < .001

Note: ZBI, Zarit Burden Interview [assessment of carer subjective burden]; EACQ, Experiential Avoidance Caregiving Questionnaire [assessment of experiential avoidance related to caregiving]; LLCI, Lower level of 95% confidence interval for Estimate (B); ULCI, Upper level of 95% confidence interval for Estimate (B).

Table 3.4. Moderation analysis – experiential avoidance in caregiving (EACQ)

The conditional effects of both carer subjective burden (*β* = .51, 95% CI [.19, .40], *p* < .001) and experiential avoidance in caregiving (*β* = .19, 95% CI [.01, .22], *p* = .028) on anxiety symptoms were significant. The total model explained 53% of the variance of anxiety symptoms ($R^2 = .53$, $F(5,71) = 15.87$, *p* <.001). This regression model showed a large effect size of 1.12 (Cohen's f^2). The addition of the interaction (*β* = .17, 95% CI [.00, .02], *p* = .045) did indicate a significant change beyond the main effect, incrementally accounting for 2.8% of the variance in anxiety symptomatology ($\Delta R^2 = .03$). These results confirmed that experiential avoidance in caregiving assessed by the EACQ is a significant moderator of the relationship between carer subjective burden and anxiety symptoms.

The standardised slope for carer subjective burden regressed on anxiety symptoms was significant for individuals one *SD* above the mean level of the EACQ (High; B = .38, SE = .07, 95% CI [.25, .52], *p* < .001), at the mean level of the EACQ (Average; B = .30, SE = .05, 95% CI [.19, .40], *p* < .001), and at one *SD* below the mean (Low; B = .21, SE =.07, 95% CI [.07, .34], *p* = .004) (see Figure 3.2). When participants were presenting the same level of carer subjective burden, those who demonstrated less experiential avoidance in caregiving reported fewer anxiety symptoms. The strength of this reverse buffering effect increased when participants presented higher levels of carer subjective burden.

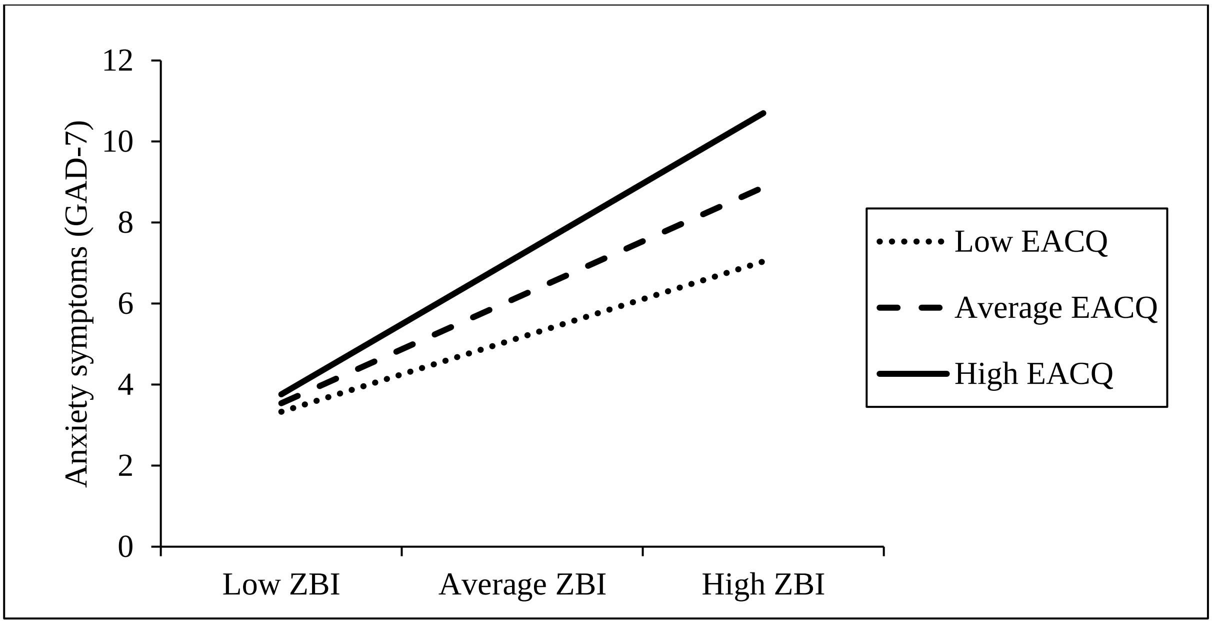


Figure 3.2. The interaction effect (carer subjective burden [ZBI] by experiential avoidance in caregiving [EACQ]) in relation to anxiety symptoms.

Discussion

Our results confirmed that both, generic experiential avoidance (measured by the AAQ-II) and experiential avoidance in caregiving (measured by the EACQ) were significantly moderating the relationship between carer subjective burden and anxiety symptoms. The strength of this reverse buffering effect increased when participants presented higher levels of carer subjective burden, suggesting that experiential avoidance could worsen the impact carer subjective burden has on anxiety symptoms, particularly among family carers experiencing higher levels of subjective burden.

Percentages of variance accounting beyond the main effects of experiential avoidance and carer subjective burden alone were significant in both models, with the interaction term of the AAQ-II and the EACQ accounting for 3.4% and 2.8% of the variance in anxiety symptoms respectively. The interaction terms of the AAQ-II had a standardised coefficient of .208, whereas the standardised coefficient of the interaction term of the EACQ was .169. Although both interaction terms were statistically significant, there is potential that generic experiential avoidance may have a better moderating effect, which contradicts our hypothesis. This is also supported by visual inspection of slopes, which suggests that all slopes are steeper regardless of levels of the EACQ (Figure 3.2) compared to slopes for all levels of the AAQ-II (Figure 3.1).

Unlike the AAQ-II, which is the generic measure of experiential avoidance, the EACQ assesses experiential avoidance towards thoughts and feelings related to the person with dementia and the care provided to them (e.g., ‘I am scared of emotions and thoughts I have about my relative -with dementia-)’ (Losada et al., 2014). Family carers are often faced with multiple stressors beyond their caregiving responsibilities such as their own physical health problems, financial difficulties, and lack of leisure time (Abdi et al., 2019; Lai, 2012). Therefore, family carers could be experiencing various unwanted internal experiences (e.g., worries about future disease progression or finances) and not simply distressing thoughts and feelings related to the person with dementia, or the care provided to them. This could be specifically true for younger carers, who are more likely to deal with competing needs such as work demands (H. Y. Liu et al., 2017). In these circumstances, the EACQ may be too narrow in their scope in capturing experiential avoidance presented by family carers.

The findings of this study provide important clinical implications in terms of assessment of experiential avoidance and interventions for preventing increased anxiety symptoms in family carers of people with dementia. Recent studies examining the association between carer subjective burden and Alzheimer’s disease severity and disease progression concluded that, as dementia progresses, carers are more likely to experience significant subjective burden (Froelich et al., 2021). This suggests that carers taking care of a person in the later stage of the disease may be more prone to higher levels of carer subjective burden. Since experiential avoidance moderates the relationship between carer subjective burden and anxiety symptoms; and this reverse buffering effect is likely to become more apparent as levels of burden increase (i.e., later stage of the disease), the development of early interventions for family carers of people with dementia are much needed. Recent studies found that acceptance and commitment therapy is effective for improving mental health problems among family carers of people with dementia (Fauth et al., 2022; Kishita et al., 2021). These interventions aim to reduce experiential avoidance by helping carers learn to step back from restricting thoughts and approach or allow painful emotions, while identifying personal values (what is most important to them) and engaging in such value-based activities (Hayes et al., 2013). Given the predictive difference of the measurements used in this study, monitoring the outcome of such interventions using the AAQ-II as the disease progresses is recommended.

While this study successfully examined the moderation effects of generic experiential avoidance and experiential avoidance in caregiving, there are some limitations that need consideration. First, this study employed the AAQ-II as a general measure of experiential avoidance. Although AAQ-II has been widely used in research, recent studies raised some concerns about its convergent and discriminant validity (Gámez et al., 2011; Vaughan-Johnston et al., 2017), highlighting that the concept measured by the AAQ-II may overlap with the underlying concept of the measures of psychological distress (Tyndall et al., 2019). Further studies may wish to consider using different measures of experiential avoidance such as the Multidimensional Experiential Avoidance Questionnaire (MEAQ; Gámez et al., 2011) to assess generic experiential avoidance in family carers of people with dementia and examine whether differences in findings can be found.

Considering the explained variances (66% for the AAQ-II and 53% for the EACQ), there may be other factors affecting the proposed moderation models. For example, a recent study examining the moderating role of experiential avoidance and cognitive fusion in a non-clinical sample concluded that experiential avoidance indirectly contributed to depression and anxiety through cognitive fusion rather than experiential avoidance directly affecting depression and anxiety (Cookson et al., 2020). Cognitive fusion refers to our tendency to become entangled with thoughts and inability to step back from such restricting beliefs (Hayes et al., 2013). Future studies could explore such combined moderating effect of experiential avoidance and cognitive fusion on the relationship between stressors and mental health outcomes in family carers of people with dementia.

The current study collected data during the COVID-19 pandemic, therefore results may be affected by the additional stress the pandemic brought to carers (Rising et al., 2022). In addition, this study did not collect information on the ethnicity of participants. Participants in this study were recruited in counties in the east of England where more than 90% of the population is White British, potentially resulting in a non-diverse sample. In addition, participants were mainly female, and half of the participants experienced minimal to mild anxiety symptoms, which may limit the generalizability of the findings. Future studies should therefore investigate a wider population and include male family carers, those from different ethnic backgrounds and a clinical population (i.e., participants with more severe anxiety symptoms).

Finally, the sample size required for a regression model to achieve a power level of 0.80, a significance level of 0.05 and a medium effect size (0.15) is 92 when five independent variables are used. This study had a sample size of 77, which is smaller than required, although the effect size for both regression models was large in this study. The cross-sectional nature of this study also does not allow for any causal assumptions to be made, and thus, the findings need to be interpreted with caution. In conclusion, it is recommended that future studies replicate this study in family carers of people with dementia with higher levels of anxiety, using different measures of generic experiential avoidance (e.g., MEAQ) alongside the AAQ-II and in a longitudinal design.

Conclusion

Despite limitations, this study provided evidence supporting that experiential avoidance may enhance the negative effect of carer subjective burden on anxiety symptoms in family carers of people with dementia. The strength of this reverse buffering effect seems to increase when carers present higher levels of subjective burden. The development of early interventions aimed at undermining experiential avoidance and monitoring the outcomes using the AAQ-II as the disease progresses may be beneficial for preventing increased anxiety symptoms among this population.

CHAPTER 4:

THE ROLE OF EXPERIENTIAL AVOIDANCE AND COGNITIVE FUSION IN THE DEVELOPMENT OF ANXIETY SYMPTOMS AMONG FAMILY CARERS OF PEOPLE WITH DEMENTIA

Published manuscript

Introduction

It is estimated that in the UK 700,000 unpaid carers take care of their loved one with dementia, saving the government an estimated £11 billion each year (Alzheimer's Society, 2014). These numbers are expected to continue to increase as the number of people diagnosed with dementia continues to rise (Alzheimer's Society, 2014; Carers UK, 2022). Taking care of a person with dementia is known to impact a carer’s wellbeing (George & Ferreira, 2020; Lindeza et al., 2020) and the prevalence of anxiety symptoms among this population is considered to be high (Kaddour & Kishita, 2020), with some studies suggesting that the prevalence is even greater than that of depressive symptoms (Cooper, Balamurali, & Livingston, 2007; Sallim et al., 2015). Nevertheless, current literature lacks insight into the underlying factors affecting anxiety symptoms among family carers of people with dementia (Puga et al., 2022). In addition, previous studies suggest that the existing carer interventions, such as Cognitive Behavioural Therapy, are not as effective for anxiety as for depression (Kishita et al., 2018). Therefore, understanding how different stressors and psychological processes influence anxiety symptoms among family carers of people with dementia is critical to inform future interventions.

The revised sociocultural stress and coping model adapted to the caregiving context highlights the importance of different caregiving stressors in their effects on poor health outcomes (Knight & Sayegh, 2010). One of the well-known stressors in this population is carer subjective burden (Burns, 2000). Carer subjective burden refers to personal appraisals of burden including the physical, psychological, social and emotional impact their caring role has on their life (Liu et al., 2020). A recent meta-analysis reviewing 74 studies on informal carers, of which 24 targeted carers of people with dementia, concluded that carer subjective burden is an important risk factor for anxiety symptoms among informal carers (Del-Pino-Casado et al., 2021). Given the established association between carer subjective burden and anxiety symptoms, understanding the underlying psychological processes in which such stressor affects the mental health outcome could provide important clinical implications.

Recent research has highlighted the importance of a currently under-researched psychological dimension that may have an impact on anxiety symptoms among family carers of people with dementia: experiential avoidance (Barrera-Caballero et al., 2021; Cookson et al., 2020; Kishita et al., 2020; Van Hout et al., 2023). Experiential avoidance is the attempt to alter the form, frequency or intensity of private experiences such as thoughts or feelings, even when doing so is costly, ineffective or unnecessary (Hayes et al., 2013). However, there are also some studies reporting weak correlations between experiential avoidance and anxiety symptoms among family carers of people with dementia (Cabrera et al., 2022; Lappalainen, Keinonen, et al., 2021; Losada et al., 2014), suggesting a lack of predictive effect of experiential avoidance alone on anxiety symptoms.

Furthermore, recent studies conducted with non-carer populations demonstrated that the combined effects of experiential avoidance and cognitive fusion are more predictive of depression, anxiety and posttraumatic stress than experiential avoidance alone (Bardeen & Fergus, 2016; Xiong et al., 2021). Cognitive fusion is the tendency to become entangled with thoughts and the inability to step back from such restricting beliefs (Hayes et al., 2013). Cognitive fusion is known to mediate the relationship between experiential avoidance and depressive symptoms in family carers of people with dementia (Kishita et al., 2022). Whether this is the case with anxiety symptoms remains unclear. In addition, previous studies within dementia caregiving have investigated mediating or moderating role of experiential avoidance or cognitive fusion separately in the association between caregiving stressors and mental health outcomes (Barrera-Caballero et al., 2021; Mausbach et al., 2012; Romero-Moreno et al., 2016). However, the combined effects of experiential avoidance and cognitive fusion within this population is currently underexplored.

Therefore, this study examines the indirect effect of carer subjective burden on anxiety symptoms through experiential avoidance and cognitive fusion. This study aimed to examine these combined effects of carer subjective burden, experiential avoidance and cognitive fusion on anxiety symptoms in family carers of people with dementia. We hypothesise that carer subjective burden will be indirectly associated with anxiety symptoms through its association with experiential avoidance in caregiving and cognitive fusion. That is, when family carers demonstrate high levels of burden, they are more likely to try controlling or getting rid of distressing thoughts and feelings related to caregiving (experiential avoidance in caregiving). In such situations, their behaviour is more likely to be overly regulated and influenced by cognitive fusion, which in turn leads to higher anxiety symptoms.

Materials and Methods

Study design and sampling

Screening (baseline) data from an interventional study assessing the feasibility and acceptability of an online self-help Acceptance and Commitment Therapy (ACT) programme with family carers of people with dementia (Kishita et al., 2021) was used in this study. The original study took place between August 2020 and January 2021 in England. Inclusion criteria were met if participants (1) were primary carers; (2) provided regular care to their family member with dementia (i.e., having a regular contact with the care recipient) and (3) were interested in engaging with online self-help ACT. In total, seventy-nine eligible carers were recruited through clinician referrals from three participating sites (healthcare services), through referrals from other ethically approved dementia studies or through self-referrals from the community via advertisements in local newspapers or a national recruitment website (i.e., Join Dementia Research).

Procedure

Eligibility criteria were checked by the research team via telephone or email. After eligibility criteria were met, participants received an invitation letter and information sheet. Written consent was obtained, via post or electronically, from all participants. Full ethical approval was received from the NHS London-Queen Square Research Ethics Committee (20/LO/0025). The screening session was conducted remotely via video call or telephone, in line with governmental rules during the COVID-19 pandemic. During the screening session, participants completed all self-reported questionnaires via post or an online survey in the presence of a researcher.

Measures

Demographic information

Demographic information including carer’s age, gender and relationship to the care recipient were collected to characterise the sample. Carers’ gender was coded as: 1=male and 2=female. The relationship to the care recipient was coded as: 1=spousal relationship and 2=non-spousal relationship.

Anxiety symptoms

The severity of anxiety symptoms was measured using the Generalised Anxiety Disorder Scale (GAD-7; Spitzer et al., 2006). The GAD-7 is a 7-item self-report questionnaire, which assesses how often during the last two weeks participants experienced anxiety symptoms. Each item is scored on a four-point scale ranging from 0 (not at all) to 3 (nearly every day).

Total scores categorise the severity of anxiety symptoms as minimal (0-4), mild (5-9), moderate (10-14) or severe (15-21). The GAD-7 has good psychometric properties with good internal consistency (Cronbach Alpha =.89) (Spitzer et al., 2006). The Cronbach's alpha for the current study was .92.

Carer subjective burden

The short version of the Zarit Burden Index (ZBI-12; Bédard et al., 2001) was used to assess carer subjective burden. The ZBI-12 consists of 12 items in two domains: personal strain (e.g., "Do you feel you have lost control of your life since your relative's illness?") and role strain (e.g., "Do you feel you should be doing more for your relative?"). Each item is scored on a five-point scale from 0 (never) to 4 (almost always). Total scores range from 0 to 48 with higher scores indicating higher subjective burden. Previous studies with community-dwelling older carers (Gratão et al., 2019) and carers of individuals with dementia (Higginson et al., 2010) have shown that the 12-version to be equally reliable and valid to the original 22-item version (Zarit et al., 1985) for detecting clinically significant levels of subjective burden. The ZBI-12 has good psychometric properties with good internal consistency (Cronbach Alpha = .88) (Bédard et al., 2001). The Cronbach's alpha for the current study was .88.

Cognitive Fusion

Cognitive Fusion Questionnaire (CFQ; Gillanders et al., 2014) is a general measure of cognitive fusion and is not specifically designed for specific populations or conditions. The CFQ assesses the degree of attachment to distressing thoughts (the tendency for behaviour to be overly influenced by such thoughts) in general and consists of 7 items. Each item is scored on a seven-point scale from 1 (never true) to 7 (always true). Total scores range from 7 to 49, with higher scores indicating higher levels of cognitive fusion. The CFQ has good psychometric properties with good internal consistency (Cronbach Alpha = .88) (Gillanders et al., 2014). The Cronbach's alpha for the current study was .94.

Experiential avoidance in caregiving

The Experiential Avoidance Caregiving Questionnaire (EACQ; Losada et al., 2014) is a 15-item self-report measure specifically designed for family carers of people with dementia to assess experiential avoidance in the caregiving context. That is, this measure assesses the tendency to control, avoid or suppress distressing thoughts and feelings related to caregiving. The original version of the EACQ was developed in Spanish, however, an English translated version of the EACQ has also been used in research (George & Ferreira, 2020; Kishita et al., 2022; K. J. Smith et al., 2018). The EACQ asks participants to score each question on a five-point scale ranging from 1 (not at all) to 5 (a lot). Total scores vary between 15 and 75 with higher scores indicating higher levels of experiential avoidance in caregiving. The EACQ has good psychometric properties with acceptable internal consistency (=.70) (Losada et al., 2014). The Cronbach's alpha for the current study was .73.

Statistical analysis

All analyses were performed using IBM SPSS statistical software (Version 28) and AMOS 28. Data were examined for accuracy with no extreme outliers detected. All variables followed a normal distribution although a tendency towards leptokurtosis was observed for the GAD-7. However, when appropriate transformations were performed (*i.e.,* a logarithmic transformation of the GAD-7), analyses yielded identical results. Therefore, only non-transformed analyses are reported. The percentage of missing data across the eight variables varied between 1.27% and 2.53%. Little's MCAR tests were conducted for all variables, which suggested that data were missing at random. Of the 79 datasets, data for the EACQ was missing for two participants. One participant did not have the EACQ data due to a technical error and another participant did not wish to complete the measure. AMOS 28 does not allow conducting certain analyses (i.e., calculation of modifications indices) when there are missing values, and thus participants with missing data were removed from the dataset rather than imputing them. This resulted in a dataset of 77 family carers.

A descriptive analysis was performed to categorise the sample using demographic information. To examine the associations between all variables and account for possible problems with multicollinearity, bivariate correlations were conducted between the demographic (i.e., carers' age, carers' gender and relationship to care recipient) and care-related variables (i.e., carer subjective burden (ZBI-12), cognitive fusion (CFQ) and experiential avoidance in caregiving (EACQ)), and the outcome variable (i.e., anxiety symptoms (GAD-7)). All variables significantly correlated with anxiety symptoms on a .05 level were included in the final path model.

Path analysis was conducted to test the proposed model of an indirect effect of carer subjective burden on anxiety symptoms through experiential avoidance in caregiving and cognitive fusion. The multiple mediation analysis used 1,000 bootstrap samples and 95% bias-corrected confidence intervals (CI) around the standardised estimate of the effect as recommend by Preacher and Hayes (2004). Fitness of the final model was assessed using chi-square ($\chi 2$) statistic. In addition, the root mean square error of approximation (RMSEA), the comparative fit index (CFI) and goodness-of-fit index (GFI) were also assessed. An excellent fit of the data to the model was considered at values under .06 for RMSEA and over .95 for CFI and GFI as indicated by Hu and Bentler (1998). Standardised root-mean-square residual (SRMR) was evaluated with a cutoff value close to .08 (Hu & Bentler, 1998). The

Hoelter index was also used to test the adequacy of the sample size. By convention, Hoelter's N > 200 suggests the sample size is acceptable. Hoelter's N under 75 is considered unacceptably low to accept a model by chi-square (Hoelter, 1983).

Results

Sample characteristics

Sample characteristics are presented in Table 4.1. The study sample (N=77) had a mean age of 63.47 years (SD = 10.64) and included mostly women (73%). Participants' age ranged from 32 to 85 with 43% of participants being older than 65 years. Most participants cared for a spouse (52%) with Alzheimer Disease (44%). On average, participants have been providing care for 53.39 months (SD = 41.77), with 44% of them devoting 81 or more hours to caregiving each week.

Carer demographic variable (N=77)	Percentage or M *(SD)*
Age	63.47 *(10.64)*
Age Range	32-85
Female	73%
Type of relationship with care recipient	
Spousal relationship	52%
Non-spousal relationship	48%
Hours of caring per week	
0-2h	4%
3-10h	21%
11-20h	10%
21-40h	7%
41-80h	14%
81+h	44%
Length of care (in months)	53.39 *(41.77)*
Anxiety symptoms (GAD-7), score range 0-21	6.45 *(5.27)*
Carer subjective burden (ZBI-12), score range 0-48	24.87 *(9.03)*
Experiential Avoidance in Caregiving (EACQ), score range 15-75	41.42 *(8.95)*
Cognitive Fusion Questionnaire (CFQ), score range 7-49	24.25 *(9.96)*

Care recipient demographic variables	Percentage or M *(SD)*
Dementia Type	
Alzheimer's	44%
Mixed	29%
Vascular	12%
Frontotemporal	3%
Lewy Bodies	4%
Unknown	9%

Note: CFQ, Cognitive Fusion Questionnaire; EACQ, Experiential Avoidance in Caregiving Questionnaire; GAD-7, Generalised Anxiety Disorder Scale; ZBI-12, Zarit Burden Interview.

Table 4.1. Demographic variables (N=77)

Correlations of main variables

The result of the correlation analysis is presented in Table 4.2. Significant correlations were identified between anxiety symptoms and the carer's age and gender, meaning younger female carers were more likely to experience anxiety symptoms. The relationship to the care recipient was not associated with anxiety symptoms. In addition, correlation analysis indicated a significant association between experiential avoidance in caregiving, cognitive fusion and anxiety symptoms. These results demonstrated that greater experiential avoidance in caregiving was associated with greater cognitive fusion and anxiety symptoms, and greater cognitive fusion was associated with greater anxiety symptoms.

Variables	1	2	3	4	5	6	7
1. Carer age	1.000						
2. Carer gender	-.379**	1.000					
3. Spousal Relationship	-.680**	.297**	1.000				
4. Carer subjective burden	-.184	.137	-.099	1.000			
5. Experiential avoidance in caregiving	-.006	-.070	-.150	.309**	1.000		
6. Cognitive Fusion	-.271*	.163	.023	.765**	.394**	1.000	
7. Anxiety symptoms	-.317**	.292**	.011	.632**	.356**	.701**	1.000

**. Correlation is significant at the 0.01 level (2-tailed).

*. Correlation is significant at the 0.05 level (2-tailed).

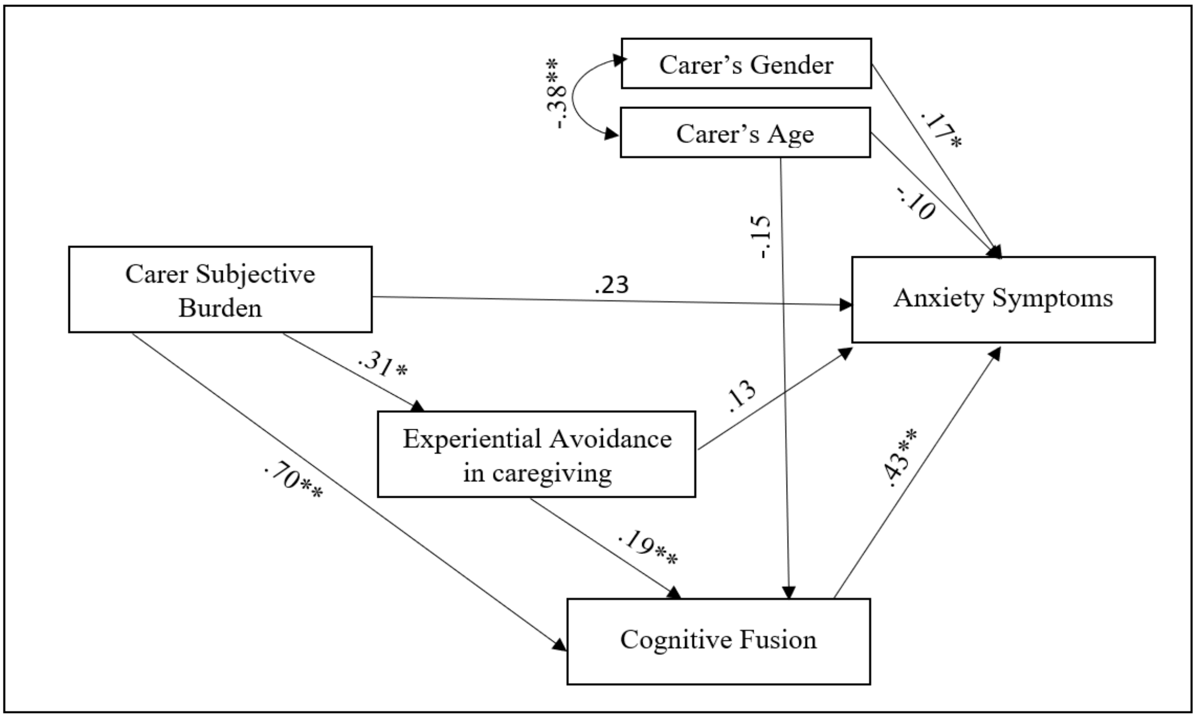
Table 4.2. Pearson's r correlations (N=77)

Path analysis of a proposed model

Path analysis was conducted as presented in Figure 4.1. The final model showed a relatively good fit to the data (χ^2 (5, N = 77) = 4.315, p = .505; CFI = 1.00; GFI = .982; RMSEA = .000; SRMR = .0685; Hoelter's N = 195). The examined variables accounted for 54% of the variance in anxiety symptoms.

As shown in Figure 4.1, the standardised direct effect of carer subjective burden on anxiety symptoms was .23 (p = .074, 95% CI = -.02-.47), which was not significant. The indirect effect of carer subjective burden on anxiety symptoms through its effect on experiential avoidance in caregiving was .02 (p = .095, 95% CI = -.00-.08). This indirect effect was also not significant due to the lack of association between experiential avoidance in caregiving and anxiety symptoms. The indirect effect of carer subjective burden on anxiety symptoms through its effect on cognitive fusion was .17 (p = .002, 95% CI = .06-.31). This significant indirect path indicates that higher carer subjective burden is likely to lead to higher cognitive fusion, in turn leading to higher anxiety symptoms.

The indirect effect of carer subjective burden on anxiety symptoms through its effect on experiential avoidance in caregiving and cognitive fusion was .01 (p = .008, 95% CI = .00-.05). This significant indirect path indicates that higher carer subjective burden is likely to lead to higher experiential avoidance in caregiving, in turn leading to higher cognitive fusion, which then leads to higher anxiety symptoms. In addition, female gender was associated with higher anxiety symptoms. However, carer's age was not associated with anxiety symptoms or cognitive fusion in the final model.



Note: $^{**}P < .01$ and $^{*}P < .05$, significant levels of standardised coefficients. The examined variables accounted for 54% of the variance of anxiety symptoms. The errors have been omitted for ease of presentation.

Figure 4.1. Conceptual overall path analysis model with standardised coefficients

Discussion

This cross-sectional study examined the indirect effect of carer subjective burden on anxiety symptoms through experiential avoidance in caregiving and cognitive fusion. Overall, the proposed model explained 54% of the variance in anxiety symptoms in family carers of people with dementia. Consistent with recent studies examining the role of experiential avoidance and cognitive fusion in predicting mental health outcomes (Cookson et al., 2020; Kishita et al., 2022), the relationship between carer subjective burden and anxiety symptoms was significantly mediated by experiential avoidance in caregiving and cognitive fusion. However, the indirect effect of carer subjective burden on anxiety symptoms through its effects on experiential avoidance in caregiving was not significant in the model, suggesting that addressing experiential avoidance in caregiving alone might not be sufficient to eliminate the aggravation of anxiety symptomatology. This is in contrast with significant mediating paths of experiential avoidance found in the relationship between caregiving stressors and depressive symptomatology in family carers of people with dementia (Mausbach et al., 2012). Considering the high level of comorbidity between depression and anxiety in family carers of people with dementia (Mineka & Zinbarg, 2006), this lack of relationship between experiential avoidance and anxiety symptoms is surprising. However, this may be explained by the weak correlation found between experiential avoidance in caregiving questionnaire and anxiety symptoms, which is consistent with the findings of previous studies conducted with family carers (Cabrera et al., 2022; Lappalainen, Keinonen, et al., 2021; Márquez-González et al., 2018). Noteworthy, the model demonstrated a significant path from carer subjective burden to anxiety symptoms through its effect on cognitive fusion alone. This indirect effect of cognitive fusion alone demonstrated a higher explanatory value than the combined indirect effect of experiential avoidance in caregiving and cognitive fusion.

Previous studies within dementia caregiving have separately investigated mediating roles of experiential avoidance or cognitive fusion in the association between caregiving stressors and mental health outcomes (Barrera-Caballero et al., 2021; Mausbach et al., 2012; Van Hout et al., 2023). To the best of our knowledge, this is the first study to investigate the combined mediating roles of experiential avoidance in caregiving and cognitive fusion on the relationship in family carers of people with dementia. Findings support the importance of experiential avoidance and cognitive fusion as relevant variables for understanding anxiety symptoms among this population. Given the higher explanatory value demonstrated for the indirect effect of cognitive fusion alone, results suggest that cognitive fusion might independently mediate the association between carer subjective burden and anxiety symptoms in this population. This study therefore highlights that undermining cognitive fusion through psychological interventions may be critical for preventing clinically significant levels of anxiety symptoms. This may be particularly the case among those carers experiencing high levels of carer subjective burden.

Nevertheless, family carers with higher experiential avoidance may be prone to cognitive fusion, which in turn could lead to a higher risk of developing anxiety symptoms. The progression of dementia is often associated with a significant increase in carer subjective burden (Froelich et al., 2021), which has been linked to augmented levels of experiential avoidance in previous literature (Van Hout et al., 2023). Findings of Bardeen and Fergus (2016) reported how the relationship between cognitive fusion, depression, anxiety and stress symptomatology became significantly stronger as levels of experiential avoidance increased. Therefore, interventions targeting early-stage experiential avoidance may prove beneficial in alleviating the risk of cognitive fusion and anxiety symptom development during the advanced caregiving phases. Nevertheless, our current dataset does not strongly support this hypothesis. While our findings revealed a statistically significant point estimate of .01 in the experiential avoidance-cognitive fusion pathway, the inclusion of a 95% confidence interval containing 0 underscores the presence of ambiguity in the observed association. Nonetheless, the enduring significance of the experiential avoidance-cognitive fusion connection warrants additional investigation to address this study limitation.

Psychological interventions, such as Acceptance and Commitment Therapy (ACT), which aims to reduce experiential avoidance and cognitive fusion and increase value-based meaningful activities, have been found to be effective in improving mental health problems among family carers of people with dementia (Fauth et al., 2022; Han et al., 2022). ACT is considered to be particularly effective for family carers of people with dementia presenting high levels of cognitive fusion (Barrera-Caballero et al., 2022; Kishita et al., 2021). Our findings thus provide additional support to the use of interventions, which can directly target cognitive fusion, for reducing anxiety symptoms among family carers of people with dementia.

While this study successfully examined the roles of cognitive fusion and experiential avoidance in anxiety symptoms among family carers of people with dementia, there are some limitations that need consideration. Firstly, the cross-sectional nature of this study does not allow for any causal assumptions to be made. Secondly, half of the participants in this study experienced minimal to mild anxiety symptoms. In addition, this study did not collect information on the ethnicity of participants. Given the location, i.e., counties in the east of England where more than 90% of the population is White British, the sample was not diverse. This limits the generalizability of the findings to the general dementia carer population. Future studies should therefore investigate a wider population and include those from different ethnic backgrounds and a clinical population (i.e., participants with more severe anxiety symptoms). Furthermore, the well-established model for explaining carer distress, the sociocultural stress and coping model, suggest potential other mediating variables that could potentially affect how carers respond to caregiving stressors and distress from these stressors: social support and cultural values (Knight & Sayegh, 2010). Further investigations on the role of social support and cultural values may provide a more comprehensive understanding of anxiety symptomatology in family carers of people with dementia. Finally, this study had a sample size of 77 in the path analysis, which is smaller than required according to the Hoelter’s Index. Since Hoelter’s N was still above 75, this model can still be considered acceptable by chi-square, with a good fit to the data. However, replication of these findings in a larger more diverse sample is recommended.

Conclusion

Despite limitations, this study adds to the currently limited body of evidence of the pathways involving anxiety symptoms among family carers of people with dementia. Targeting cognitive fusion using psychological interventions, such as ACT, may be particularly useful among family carers experiencing high levels of subjective burden. In addition, the provision of interventions in the early stages of dementia caregiving that can target experiential avoidance may help decrease the likelihood of increased cognitive fusion and anxiety symptoms among family carers of people with dementia.

CHAPTER 5:

UNDERSTANDING THE IMPACT OF DEMENTIA ON SPOUSAL RELATIONSHIPS: A QUALITATIVE STUDY WITH FEMALE SPOUSAL CARERS OF PEOPLE LIVING WITH DEMENTIA

Submitted manuscript

Introduction

In the UK, approximately 920,000 people are living with dementia and this prevalence rate is expected to rise even further in the future (Alzheimer's Society, 2019). By 2050, it is expected that more than 131 million people will have dementia worldwide (Xiong et al., 2020). Most people with dementia in the UK live at home and 80% of these people are supported by unpaid family carers, with the majority being older women (Alzheimer's Society, 2019). Given the complex situation of caregiving, often both negative and positive feelings emerge when carers are asked about their experiences. Positive aspects of experiences include an increase in carers' self-esteem, a stronger bond with the care recipient, and an increase in meaning in life (Frias et al., 2020). However, being a carer for a person living with dementia is a complex situation which may also negatively impact the carer's mental, physical, and social functioning (Stall et al., 2019).

According to McGovern (2011), dementia does not merely affect individuals but rather has a profound impact on relationships. The act of caregiving occurs within the context of a relationship, and this relationship plays a crucial role in both, the formation and continuation of caregiving. For example, a qualitative study exploring how motivation and relationship dynamics influence carers' subjective experience of dementia caregiving, found that carers' capacity to find meaning in their role and relationship with the care recipient appears to affect the motivation to continue providing good care (Quinn et al., 2015).

Many theories within the dementia caregiving context, such as the grief-stress model of caregiving (Noyes et al., 2010), highlight the importance of considering interpersonal (i.e., relationship adjustment, communication engagement, and emotional connection between two individuals) and intrapersonal dynamics (i.e., loss of self within the context of relationship) when exploring the healthy relationship (Knobloch et al., 2019; Lyons & Lee, 2018; Rippon et al., 2020). Nevertheless, these dynamics are still underexplored empirically in the current dementia literature compared to other factors that can affect carer experiences (e.g., coping skills) since such dynamics are often challenging to capture quantitatively (Knobloch et al., 2019).

Interpersonal dynamics in spousal caregiving

The presence of successful *relationship adjustment* is considered to be one of the critical components of the healthy interpersonal dynamics between the carer and the care-recipient and positively associated with the wellbeing of carers (Hawken et al., 2018). In general, relationship adjustment is described as a combination of a good balance within their relationship experience and positive evaluations or attitudes toward this relationship and the partner (Fincham & Rogge, 2010). Equity theory suggests that couples generally strive to maintain a good balance of give and take in carer-partner relationships (Hatfield & Rapson, 2012). However, when a couple is faced with a serious illness, imbalance (inequity) can occur leading to negative attitudes and increased distress among both carer and the care recipient (Rippon et al., 2020; Shim et al., 2012).

Communication engagement also plays an important role in maintaining the heathy interpersonal dynamics. Communication engagement refers to how actively and explicitly people communicate with a partner (Knobloch et al., 2019). It is not simply about reaching an agreement but the presence of joint collaborative effort. This effort made by both carer and care recipient to engage and empathise, even when content is not understood, is critical for positive experiences of communication (Alsawy et al., 2020). Communication engagement is essential for sustaining valued relationships and the absence of engagement can lead to social isolation, loneliness, depression and anxiety (Wawrziczny et al., 2016).

A third critical component of the healthy interpersonal dynamics is the *emotional connection* carers and care recipients experience. Emotional connection refers to the feelings of bonding and being valued and understood by each other, which often involves the process of sharing various subjective feelings (Baumeister & Vohs, 2007). The presence of emotional connection or perceived closeness between two people is an important component of relationship quality or satisfaction (Enright et al., 2020). This connection tends to decrease in the carer-care recipient relationship after a dementia diagnosis, leaving the carer feeling isolated and potentially resulting in increased mental health difficulties (Alsawy et al., 2020; Enright et al., 2020).

Intrapersonal dynamics in spousal caregiving

Carers often experience a role transition from partner/spouse to carer (Lee et al., 2019). Such transformed relationship is known to contribute to a loss of couple identity (Hernandez et al., 2017), potentially leading to a loss of identity in the carer themselves (Tuomola et al., 2016). *Loss of self* refers to perceived changes in “the individual’s characteristic ideas about who they are and what they are like” (Baumeister & Vohs, 2007). The loss of self is related to negative outcomes in carers of people living with dementia, including poorer wellbeing and mental health (Enright et al., 2020).

Investigating the subjective experiences of spousal carers of people living with dementia with regard to these interpersonal and intrapersonal dynamics will allow for a deeper understanding of the meaning derived from these dynamics and how carers adapt to changes in such dynamics. Therefore, this study aims to gain a deeper understanding of these interpersonal and intrapersonal dynamics using a qualitative approach and explore these different dynamics in terms of meaning given to them by family carers of people living with dementia. A meta-analysis of studies comparing carer spouses, adult children, and children-in-law, concluded that spousal carers report greater burden, lower levels of psychological wellbeing, and greater strain on their relationship (Pinquart & Sörensen, 2011). Given that the majority of carers are women and spousal carers are more likely to be affected by the relationship strain, this study will focus on gaining insight into the meaning given to relationship dynamics among female spousal dementia carers. The findings of this study will inform which inter- and intrapersonal dynamics should be targeted in future interventions to facilitate the effective spousal relationship and promote the wellbeing of carers.

Methods

Study design

This study used an interpretative phenomenological approach, following the guidelines of Smith and colleagues (2022). The interpretative phenomenological approach focuses on understanding how people make sense of their lived experiences and allows for a more in-depth exploration of how individuals personally construct meaning from their experiences, which was deemed essential for the aim of the study. Qualitative data were obtained through semi-structured interviews. This study was approved by the Faculty of Medicine and Health Sciences Research Ethics Subcommittee (FMH S-REC) of the University of East Anglia (ETH2122-0759). This study followed the Standards for Reporting Qualitative Research (SRQR) (O'Brien et al., 2014).

Participant selection

Purposive sampling was used to recruit family carers who had the capacity to consent for themselves, were female, were an unpaid carer with a partner/spousal relationship, were caring for a community-dwelling person living with dementia and were supporting activities of daily living of the care recipient on a day-to-day basis (i.e., more than seven hours per week). Participants with an insufficient understanding of English to complete interviews were excluded. An invitation to the study was sent to potential participants who took part in other ethically approved dementia carer studies led by the authors and had consented to be further contacted about participation in other studies. Potential eligible participants were contacted by the researcher via telephone or email, depending on the carer's preference, to check if they were happy to receive information about this study and to double check eligibility. Recruitment took place between March and July 2022. In total, nine family carers agreed to take part in the interview session.

Data collection

After obtaining written informed consent, family carers were asked to complete a demographic questionnaire to characterise the sample. The interview session was conducted face-to-face in the participant's own home or remotely via telephone or video call (Microsoft Teams). The semi-structured interviews lasted about one hour and were conducted by one researcher (EVH), a nurse with MSc in Human Sexuality Studies and experienced in qualitative research. The interview guide containing a list of questions and prompts was piloted with a family carer and revised until consensus between researchers was reached. The interview guide for the study is presented in supplementary file 5.1. A state of not knowing and a blended approach were applied during the interview, which consists of passive interviewing (allowing the participant space and time to share their narrative) and more active approaches by using questions and prompts listed in the interview guide. Audiotaped interviews were transcript verbatim. The data collected were anonymised and checked for accuracy. Data collection continued until data saturation was attained, meaning that conducting additional interviews no longer provided new insights.

Analysis

The questionnaire data was analysed descriptively to characterise the sample. The interview data were analysed using the interpretative phenomenological approach. The interpretative phenomenological analysis includes, but is not limited to, familiarisation with the data, identification and formulations of meanings described by the participants, clustering these meanings into themes, and development of inclusive descriptions of the dynamics (Howitt & Cramer, 2011). To ensure the validity and reliability of the data analysis, two researchers (EVH and MC) reviewed the transcripts independently. In addition, formulations of meanings and associated themes were generated by both coders. Any disagreement was settled through discussion between EVH (Female Nurse, MSc) and MC (Female psychologist, PhD), with close supervision of NK (Female psychologist, PhD). Analysis of all the individual transcripts was finalised before moving to the group-level analysis. A summary list of themes was compiled and related themes were clustered together at the group level. After creating a summary list, the themes were then coded onto all the transcripts using NVivo, providing the opportunity to check the accuracy of the themes. The retraction of those themes and corresponding quotes formed the basis for the account presented here.

Results

Nine participants were interviewed between March and July 2022. Characteristics of participants are summarised in Table 5.1. Findings from the data analysis are summarised by describing the impact of dementia caregiving on these four interpersonal and intrapersonal dynamics (i.e., relationship adjustment, emotional connection, communication engagement, sense of self) and how participants overcame difficulties associated with such changes.

Demographic characteristics	Carer	Partner living with dementia
Age (in years)		
Mean (SD)	69.56 (7.54)	75.44 (7.78)
Range	60-80	61-86
Gender		
Female (n, %)	9 (100%)	0
Male (n, %)	0	9 (100%)
Carer relationship to person with dementia		
Spouses	9 (100%)	
Length of care (in months)		
Mean (SD)	77.33 (39.04)	
Range	48-168	
Time since diagnosis (in years)		
Mean (SD)		7.11 (2.57)
Range		3-12
Dementia Diagnosis		
Alzheimer's disease		3 (33.33%)
Mixed dementia		3 (33.33%)
Vascular dementia		1 (11.11%)
Lewy Body dementia		1 (11.11%)
Early onset dementia		1 (11.11%)

Table 5.1. Demographic characteristics

Relationship adjustment

Impact of dementia on the relationship

Many participants expressed that they experienced gradual changes in the relationship between them and the person they were caring for. They particularly experienced those changes as losses, which became more evident when participants reflected on their own past relationship or when they compared themselves to other couples. All participants mentioned that their caring responsibilities were increasing while their husbands' independence decreased. They described these increased responsibilities as "*being on call 24/7*" (Participant 9) and "*never having any downtime*" (Participant 10). The decreasing husband's independence also involved a reduction in initiative and decision-making. Therefore, participants became the metaphorical driver of all decisions in their husbands' lives.

"He is sort of more dependent on me, maybe, then otherwise. And he never… he does not really do anything, I guess, without me sort of organising it." (Participant 1)

These changes in the husband's independence due to the dementia symptoms also changed the roles within the relationship. Most participants expressed that they felt more like a carer rather than a companion towards their husband. To a great degree, participants were associating the caregiving skills they use with the parental skills of mothers when describing them. For example, participants were using metaphors to explain their husband's behaviour referring to them as if they were raising a child during interviews.

"I talked to him like he is a child. I said, "why don't you wear these and that would be really good for us" and then just put them on. He went, "oh, that's great". So now this is completely not romantic, it is fully carer." (Participant 10)

When asked about how this carer role was perceived within their relationship, two perceptions were mentioned. Some participants perceived their carer role as a marital duty, while others saw it as an act of love.

"This is about sort of 'for better or worse'. It could have been the boot on the other foot. For some reason it is so. So I guess there is a kind of duty element here." (Participant 5)

"When you have been with somebody most of their life, because I was young when I got married, that person is part of you in a way. […] They are literally the expression 'your other half'. That is what he is. He is my other half" (Participant 4)

Adjusting to the changes in the relationship

The ability to adjust the relationship according to the "*good*' and the "*bad*' days (Participant 6) was highlighted as a critical element to overcome the relationship challenges. Participants described how certain methods worked one day, but on other days, those same methods would not work. This taught them to seize the good days whenever they occurred. In addition, participants highlighted the benefits of learning to step back when the behaviour of their husbands was challenging. They learnt that not all arguments and/or discussions with their husbands are worth pursuing, particularly when the behaviour displayed was repetitive.

"I knew [Husband] was, by lack of a better word, pushing my buttons this morning. So, I am not fighting you. So, I just literally turned my back on him and got on with something" (Participant 2)

Emotional connection

Impact of dementia on emotional connection

Participants described how dementia led to changes in the emotional connection with their husband. They expressed how their husband changed their expression of love or compassion towards them. Some participants expressed how their husbands were more emotionally dependent on them than before. Other participants described how their husbands were less attentive towards them. Most participants reported that they had to grieve for the husband and the future they lost.

"I fell the other day because I was rushing around in the kitchen. I slipped and he did not realise that I had fallen and since then he has not asked me if I am okay or anything. He does not ask me if I am alright, whereas he would have done that before." (Participant 6)

Some participants also described the ambivalent feeling of anticipatory grief (i.e., grieving the different losses associated with changes that occur before the death of a significant person) and happiness about still being able to have their husband with them.

"It is a double-edged sword, because I keep saying I am happy looking after [Husband], but I know he is dying. So I am not happy, I am probably in, I mean, permanent grief. All the time I am talking to you, I am nearly crying, because… But I am like that all the time, not just when I am talking to somebody. So, I am permanently in grief at the same time as I am really happy that I still have him with me." (Participant 10)

Facilitating emotional connection in the relationship

Different strategies to facilitate the emotional connection were highlighted during interviews. Some participants mentioned that the emotional connection to their husband increased when there were moments of recognition. Meaning, the husband would recognise the carer or the memories they have created together. This connection through previously shared moments was generated by looking through pictures of their families or holidays and revisiting activities or places they have been in the past.

“I could see that he was not even sure who I was, and he had no idea who the grandchildren were… About half an hour into the drive home, suddenly he grabbed my arm, “you are [Carer’s name], you are my [Carer’s name]”, and there you go. That is the connection.” (Participant 10)

Participants also described how they became more observant of their husbands’ new ways of showing affection. This ranged from noticing their husbands physical touch (e.g., putting their hand on the carer’s back) to realising that their husbands are giving them space (e.g., going to a different room when carer is about to get angry). Compassion for their husbands’ struggles was also expressed by the participants. They were trying to become more empathetic and more sensitive towards their needs.

“He is always sort of… very close and he always wants to hold my hand. We still sleep together, and we still share the same bed. He still cuddles up to me and that type of thing, you know. He wants to know that I am there.” (Participant 6)

Communication Engagement

Impact of dementia on the communication engagement

All participants expressed a loss of meaningful communication with their husband. Their conversations felt unproductive, and the content of the conversation was often not fully understood. This meant that participants were constantly feeling that their messages to their husbands did not fully get through, and that the comments made by their husbands were often hard to grasp for the participants, as they were not related to the context of the conversation. A few participants expressed how this led to them sharing less with their husband.

“He understands. But I do not tell him that much because it is not… well he does not really get everything. So, no, I do not really share everything with him like I used [to].” (Participant 6)

In addition, participants reported a loss of a two-way interaction when asked about their current communication engagement. Some participants described a rather silent life with a limited amount of small talk, while other participants described talking continuously without necessarily getting a response from their husband.

“There is barely no engagement from him. I am literally at no point even asking him a question. Let us say, “do you want a cup of tea?”. I just put the tea there and say, “There is the tea you wanted darling” and then he is so happy.” (Participant 10)

Dealing with the loss of communication engagement

Many participants expressed that knowing their husbands for a long time helped them to overcome the difficulties they were experiencing in terms of communication. Their understanding of their husbands helped the participants to deduce the content of the conversation even from a few words and recognise the complex feelings poorly expressed by their husbands.

“If you know the man you are married to, you do learn very quickly how to… when to stop or what to say and what matter you say it.” (Participant 9)

Moreover, participants expressed that they watched their husband more closely and tried to learn their ways of communicating and read their signs. These strategies helped them to understand what their husband would need from them by reading signs unique to their husband, which are difficult to explain to others. Participants acknowledged that they became their husbands’ “*translator*” when speaking to others.

“You do learn things. For instance, I have learned to read the signs… particularly I can notice like if he wants to go to the toilet. I can notice that, and I have learned… I have learned to read that sign. So, you learn, and you cannot explain it to anyone else.” (Participant 2)

“If I am with him, they sort of look at me and say, “can you help me I don’t know what he’s doing or saying?”. And I think [Husband] relies on me to explain what his… he would feel very lost if he was trying to talk and I was not there.” (Participant 2)

Sense of self

Impact of caregiving on the sense of self

When asked about how caregiving had affected their sense of self, participants expressed both positive and negative consequences. Some participants felt that caregiving made them more aware of other people’s circumstances, and consequently, allowed them to empathise more with others and have a better understanding of what they are going through. Other participants expressed that they had to become more tolerant and patient towards the repetition demonstrated by the person living with dementia and saw this as a positive change in the way they perceived themselves. Nevertheless, most participants mentioned feeling a loss of self and being “*trapped*” (Participant 5). They expressed a loss of activities and leisure time that defined themselves, due to an increase in responsibilities and caregiving duties, led to an increased sense of loss of self. There was limited room for their own lives, with participants describing a necessity to put their husbands' needs before their own.

"It has taken away things from me. It has taken away some of my personality. It has taken away my thinking." (Participant 9)

Participants also voiced how the loneliness of caring made it harder for them. They felt misunderstood by people in their surroundings and healthcare professionals. In addition, participants expressed that their circle of friends and family decreased. This, in combination with limited free time, created a feeling of isolation and loss of self for the participants.

"I find those who should support you, do not support you. And be that, with your friends you lose along the way because you know, they cannot handle it. So, those that were not handling it, choose to ignore you. The authorities who… All of that is… "Well, we are very busy"." (Participant 2)

Strategies to avoid loss of self

Some participants mentioned that the active search for support and understanding from others helped them to overcome the feeling of isolation and loss of self. Talking with other people facing similar situations and being able to "*unload*" (Participant 2) feelings was seen as beneficial for most participants. Some participants also mentioned that they found it particularly helpful to talk about something completely different. These participants felt relieved to not talk about their caregiving situation and the dementia progress.

"It is about being able to just unload and saying, "you know what, at the moment, I'm feeling really shit". But that is a hard thing to say to people, unless they actually asked you." (Participant 2)

Furthermore, participants described techniques which helped them to be more kind to themselves. This was mainly achieved by focusing on the present task at hand (e.g., doing crossword) or by changing their mindset (e.g., not being too self-demanding or self-critical). Most participants also expressed the need for time for themselves. Participants mentioned that they were aware of non-negotiables (i.e., things and activities that are important to them) in their life that needed to be maintained, and that prioritising these, when possible, consequently allowed them to keep some of their own identity. However, half of those participants also mentioned feelings of guilt to leave their husband behind to prioritise their own needs.

"I do try to go out quite a lot. I hope I do. I am quite active because that keeps me going. But then I feel a bit guilty if I am leaving him." (Participant 1)

Discussion

This study examined the subjective experiences of female spousal carers of people living with dementia, investigating both interpersonal (relationship adjustment, emotional connection, communication engagement) and intrapersonal (sense of self) dynamics, and carers' strategies for adapting to the changes in such dynamics.

In the first theme 'Relationship adjustment', female spouses highlighted a critical change in their relationship, a decrease in initiative and decision-making demonstrated by their partner whereby carers became the metaphorical driver in their relationship. This is consistent with a systematic review highlighting the imbalance of the spousal relationship as dementia progresses (Pozzebon et al., 2016). Equity theory suggests that when the imbalance of the spousal relationship occurs in the context of non-dementia caregiving couples tend to strive to maintain a good balance of give and take in carer-partner relationships (Hatfield & Rapson, 2012; McPherson et al., 2011). However, strategies to maintain such balance was not evident in our sample potentially due to the severity of dementia. Instead, carers were acknowledging notable role changes, with the carer taking a more parental role although this caused a decrease in emotional connection. Carers were adjusting to these changes in the relationship by learning to step back when difficult moments arose, such as repetitive behaviour from their partner, and to be more present in the moment.

Regarding the second theme 'Emotional connection', carers in this study expressed that they experienced significant losses in their relationships (i.e., anticipatory grief) and how their partner living with dementia changed their expression of love and compassion towards them affected emotional connection between them. This is consistent with a recent study examining the meaning of dementia for emotional connection (Eskola et al., 2022), which highlighted how the lack of reciprocity of affection in couples weakened the physical and emotional intimacy. The findings of the current study demonstrated that carers were coping with such emotional challenges by reminiscing on their shared history. This reminiscing helped carers to feel connected with their partner and consequently maintaining a sense of shared identity as a couple.

The lack of reciprocity was also seen in the third theme 'Communication engagement'. A loss of meaningful communication and loss of a two-way interaction was expressed by all carers in this study. This loss of two-way interaction and disturbed communication has been described in other literature as the greatest challenge in spousal dementia caregiving (Pozzebon et al., 2016). The findings of the current study demonstrated that carers were overcoming a lack of verbal communication engagement by watching their partner more closely and relying more on non-verbal ways of communicating, such as reading signs unique to their partner. Furthermore, carers appeared to recognize the necessity of embracing one-way communication.

In the last theme 'Sense of self', female spousal carers reported that they experienced a loss of self and isolation, stemming from a reduction in participating in activities and leisure time. This, combined with diminished external support, led to a feeling of loneliness. This phenomenon resonates with previous research, which highlights the tension resulting from greater partner dependency and diminishing carers' inability to pursue their own activities, affecting carers' sense of self (Tuomola et al., 2016). Interestingly, the carers in this study demonstrated a proactive stance in seeking support from various sources, including healthcare professionals, to overcome these challenges. This contradicts findings from prior research where family carers were often hesitant to ask for support due to fear of misunderstanding and sense of duty (Messina et al., 2022). In addition to seeking formal support, the findings of the current study demonstrated the importance of the carers' ability to be self-compassionate towards oneself in maintaining their sense of self. This consists with a recent study which demonstrated that individuals who exhibit self-compassion while caring for people living with dementia are more inclined to exhibit improved psychological wellbeing (Lloyd et al., 2019).

Clinical implications

There is an increasing interest in the significant effect dementia symptoms have on spousal relationships and the carers' wellbeing (Hawken et al., 2018). However, to the best of our knowledge, this study is the first study to explore such impacts and highlight strategies that are potentially effective in overcoming relationship challenges using a qualitative approach. These findings revealed some effective strategies carers use to adjust to the changes in their relationship. These included acknowledging the role changes while stepping back when difficult moments arose, focusing on the present, reminiscing on their shared history, learning new ways of communicating (e.g., watching their partner more closely and relying more on non-verbal ways of communicating), and increasing self-compassionate attitudes towards themselves.

A recent scoping review of psychosocial interventions to enhance the relationship of couples living with dementia concluded that there was a limited body of evidence. This was partly due to the fact that studies included in the review did not provide a detailed account of the processes whereby the intervention was expected to benefit the relationship (Gilbert et al., 2023). Currently, single-component interventions such as cognitive behavioural therapy (CBT) are often used to improve psychological wellbeing, carer burden and relationship problems within family carers of people with dementia (Population Health et al., 2022). Our findings demonstrated that multifaceted interventions (i.e., interventions that include two or more components) may be beneficial for female spousal carers in improving their relationship with their partner living with dementia. Such multifaceted interventions could be a combination of existing interventions that may be able to target several key factors identified in this study.

For example, narrative therapy (i.e., couples life story approach or reminiscence therapy) may be particularly beneficial for increasing emotional connection between the carer and their partner living with dementia (Gilbert et al., 2023). The 'couple's life story approach' enables couples to reminisce about their shared experiences and shows to be an effective method for enhancing the quality of a couple’s relationship (Colloby et al., 2022). The process of reminiscing not only fosters the emergence of fresh insights concerning their partnership but also enhances comprehension of their caregiving responsibilities, even in situations where the dynamics of their relationship were imbalanced prior to the onset of dementia (Ryan et al., 2020). Nevertheless, while reminiscing can foster deeper emotional connection, it can also serve as a reminder for carers of the losses they have endured due to their partner's dementia progression (Scherrer et al., 2014).

The use of interactive communication interventions with a focus on non-verbal ways of communicating may also be beneficial for improving communication engagement and these interventions are shown to have some preliminary effects on the communication and behavioural management skills of carers in their interactions with people living with dementia (Nguyen et al., 2019). A recent systematic review highlights the impact of communication partner training on facilitating relationships among family members of people living with dementia (Folder et al., 2023), with one feasibility study showing improvements in spousal relationship quality (Berwig et al., 2020).

In addition, compassion-focused therapies, which promotes individuals to be compassionate toward themselves and other people (Gilbert, 2009), may be helpful to aid the relationship adjustment of carers and their partner with dementia. Compassion-focused therapy has shown to have positive effects on quality of life of couples living with dementia (Collins et al., 2018), and higher levels of self-compassion have been associated with more positive relationship behaviours as opposed to those with lower self-compassion (Neff and Beretvas (2013). However, to date, no research has directly looked at the effectiveness of compassion-focused therapies on relationship related outcomes. Future studies are thus needed to develop these multifaceted interventions and evaluating their effectiveness on the quality of relationship of couples living with dementia.

Limitations

This study conducted only semi-structured interviews with the female spousal carer, thus limiting understanding of the role gender may play in long-term intimate relationship. Furthermore, studies suggest ethnicity and culture may affect psychological wellbeing and their proactive stance in seeking support (Duran-Kiraç et al., 2022). The views of carers from minority ethnic groups on the relationship and the associated changes may thus be different. Participants in this study were recruited in counties in the east of England where more than 90% of the population is White British, questions about ethnicity were not directly asked during the recruitment and interview process. Future studies should therefore aim to investigate a more diverse sample by including male spousal carers and spousal carers from minority ethnic groups.

Conclusion

This study provided valuable insights to the growing body of knowledge on dementia caregiving relationships and demonstrated a deeper understanding of the meaning derived from interpersonal and intrapersonal dynamics and how carers adapt to changes in such dynamics. The findings highlighted the need for multifaceted interventions for female spousal carers in maintaining and improving their relationship with their partner living with dementia. Such interventions could include a couple's life story approach to enable couples to reminisce about their shared experiences, interactive communication training to enhance meaningful engagements, and a psychological approach such as compassion focused therapy to overcome emotional challenges and improve self-compassion. Future research should focus on developing and evaluating these interventions and explore whether different components can enhance the relationships of couples living with dementia, ultimately improve carers' wellbeing.

CHAPTER 6:

A QUALITATIVE COMPARATIVE ANALYSIS OF INTERPERSONAL AND INTRAPERSONAL DYNAMICS AFFECTING ANXIETY SYMPTOMS AMONG FEMALE SPOUSAL CARERS OF PEOPLE LIVING WITH DEMENTIA

Introduction

Dementia presents a pressing challenge in the UK, with approximately 920,000 individuals currently living with dementia, and this prevalence is projected to escalate in the future (Alzheimer's Association, 2019). Globally, the dementia population is expected to exceed 131 million by 2050 (Xiong et al., 2020). A significant proportion of those living with dementia in the UK reside at home, and 80% of these individuals are cared for by unpaid family carers, most of whom are older women (Alzheimer's Society, 2019).

Caring for a person with dementia is recognised to significantly impact the wellbeing of the carer (George & Ferreira, 2020; Lindeza et al., 2020). Notably, anxiety symptoms are prevalent among this population, with some studies suggesting a higher prevalence compared to depressive symptoms (Cooper, Balamurali, & Livingston, 2007; Kaddour & Kishita, 2020; Sallim et al., 2015). Surprisingly, the current literature lacks in-depth understanding of the underlying factors contributing to anxiety symptoms among family carers of people with dementia (Puga et al., 2022). Moreover, existing interventions, such as Cognitive Behavioural Therapy (CBT), seem less effective for anxiety than for depression (Kishita et al., 2018). Therefore, investigating how various stressors and psychological processes influence anxiety symptoms among family carers of people with dementia is crucial to inform future interventions.

As highlighted by McGovern (2011), dementia not only affects individuals, but also profoundly impacts relationships. Caregiving is embedded within the context of a relationship, a factor pivotal in both its formation and continuation. For instance, a qualitative study examining the influence of motivation and relationship dynamics on carers' subjective experience of dementia caregiving found that the carer's ability to find meaning in their role and relationship significantly influences the motivation to sustain high-quality care (Quinn et al., 2015).

Numerous theories within the dementia caregiving context, such as the grief-stress model of caregiving (Noyes et al., 2010), underscore the significance of considering both interpersonal (e.g., communication engagement and emotional connection) and intrapersonal dynamics (e.g., sense of self within the context of the relationship) when exploring healthy relationships (Knobloch et al., 2019; Lyons & Lee, 2018; Rippon et al., 2020). There is some literature, although limited and scarce, that explored the impact of these dynamics on mental health outcomes such as depression (Enright et al., 2020). However, there is an even larger gap in empirical exploration regarding their potential effect on anxiety symptoms, primarily due to the inherent difficulty in quantifying these dynamics (Knobloch et al., 2019).

Interpersonal dynamics in spousal caregiving

Communication engagement plays an important role in maintaining heathy interpersonal dynamics. It involves active and explicit communication between the carer and care recipient, reflecting a joint collaborative effort (Knobloch et al., 2019). This engagement goes beyond mere agreement, emphasizing the importance of empathetic communication, even when content is not fully understood (Alsawy et al., 2020). Carers of people living with dementia often experience a loss of meaningful communication and a shift to a one-way interaction in their relationship, demonstrating a lack of reciprocity (Van Hout et al., Submitted). The absence of positive communication engagement has been associated with social isolation, loneliness, depression, and anxiety among family carers (Wawrziczny et al., 2016).

Another crucial element of healthy interpersonal dynamics is *emotional connection,* encompassing feelings of bonding, being valued, and mutual understanding between carers and care recipients (Baumeister & Vohs, 2007). This emotional connection is integral to relationship quality and satisfaction (Enright et al., 2020). However, research indicates that this connection tends to diminish in the carer-care recipient relationship following a dementia diagnosis. The altered expressions of love and compassion from partners living with dementia may influence the emotional connection (Eskola et al., 2022; Van Hout et al., Submitted), leaving the carer feeling isolated and vulnerable to increased mental health difficulties (Alsawy et al., 2020; Enright et al., 2020).

Intrapersonal dynamics in spousal caregiving

Carers often experience a role transition from partner/spouse to carer (Lee et al., 2019). Such transformed relationship is known to contribute to a loss of couple identity (Hernandez et al., 2017), potentially leading to a loss of identity in the carer themselves (Tuomola et al., 2016). *Sense of self*, defined as “the individual’s characteristic ideas about who they are and what they are like”, may be affected (Baumeister & Vohs, 2007). Spousal dementia carers may experience a loss of self and isolation, stemming from a reduction in participating in activities and leisure time (Van Hout et al., Submitted). The loss of a sense of self is correlated with negative outcomes in carers of people living with dementia, including poorer wellbeing and mental health (Enright et al., 2020).

The aim of this study is to examine how these inter- and intrapersonal dynamics influence carers' anxiety using a Qualitative Comparative Analysis (QCA). QCA is a case-based approach, which allows us to systematically analyse the complex combinations of conditions (i.e., the absence or presence of communication engagement, emotional connection and/or sense of self) contributing to anxiety symptoms, capturing the intricate interplay that traditional quantitative methods might oversimplify. This approach enables the identification of specific combinations of conditions leading to anxiety outcomes, making QCA particularly well-suited to unveil the multifaceted nature of anxiety symptoms within dementia caregiving and providing valuable insights for targeted interventions tailored to the needs of carers.

Materials and Methods

Study Design

A qualitative case-oriented retrospective approach was chosen to obtain a deep understanding of how inter- and intrapersonal dynamics (i.e., the absence or presence of communication engagement, emotional connection and/or sense of self) influence carer anxiety. Qualitative data was obtained through semi-structured interviews. This study was approved by the Faculty of Medicine and Health Sciences Research Ethics Subcommittee of the University of East Anglia (ETH2122-0759).

Participant selection

Purposive sampling was used to recruit family carers who were fluent enough in English to complete the interview, had the capacity to consent for themselves, were female, were an unpaid carer with a partner/spousal relationship to a community-dwelling person living with dementia, and were supporting activities of daily living of the care recipient on a day-to-day basis (i.e., more than seven hours per week). In total, seventeen eligible carers were recruited through referrals from local carer groups or from other ethically approved dementia studies or through self-referrals from the community via advertisements in local newspapers or a national recruitment website (i.e., Join Dementia Research). Potential eligible participants were contacted by the researcher via telephone or email, depending on carers’ preference, to check if they would like to receive information about this study and to double check eligibility. Recruitment took place between March 2022 and June 2023.

To identify how inter- and intrapersonal dynamics (i.e., the absence or presence of communication engagement, emotional connection and/or sense of self) influence carer anxiety using QCA (further described in the Analysis section), this study recruited participants with presence and absence of anxiety symptoms. The presence and absence of anxiety symptoms was determined by the participants' score on the Generalized Anxiety Disorder-7 (GAD-7; Spitzer et al., 2006). To optimise sensitivity without compromising specificity, participants scoring 8 or above (i.e., in the clinical range) on the GAD-7 were categorised as having anxiety symptoms (i.e., group above threshold). Participants that scored 7 or lower on the GAD-7 were categorised as having no anxiety symptoms (i.e., group below threshold). Of the 17 participants recruited seven presented anxiety symptoms based on this definition.

Data collection

After obtaining their written informed consent, participating family carers were asked to complete a demographic questionnaire and questionnaires assessing anxiety (i.e., the GAD-7; Spitzer et al., 2006) and depressive symptoms (i.e., the Patient Health Questionnaire-9; Kroenke et al., 2001) to characterise the sample. The interview session was conducted face-to-face in the participant's own home (*n* = 6) or remotely via telephone or Microsoft Teams (*n* = 11), depending on carers' preference. The semi-structured interviews lasted about one hour and were conducted by one researcher (EVH), a nurse with a MSc degree in Human Sexuality Studies and 3rd year PhD student. Before conducting the interviews for this study, a pilot interview was conducted with a family carer currently support a person living with dementia who did not take part in this study to improve the interview questions and to refine the researcher's interview techniques. A state of not knowing and a blended approach was applied during the interview, which consists of passive interviewing (allowing the participant space and time to share their narrative) and more active approaches by using questions and prompts listed in the interview guide. Audiotaped interviews were transcribed verbatim. The data collected were anonymised and checked for accuracy.

Measures

Anxiety symptoms

The severity of anxiety symptoms was measured using the Generalised Anxiety Disorder Scale (GAD-7; Spitzer et al., 2006). The GAD-7 is a 7-item self-report questionnaire, which assesses how often during the last two weeks participants have experienced anxiety symptoms. Each item is scored on a four-point scale ranging from 0 (not at all) to 3 (nearly every day). Total scores range from 0 to 21, with higher scores indicating greater severity of anxiety symptoms. The GAD-7 has good psychometric properties with good internal consistency (Cronbach's Alpha =.89) (Spitzer et al., 2006).

Depressive symptoms

The severity of depressive symptoms was assessed using the Patient Health Questionnaire-9 (PHQ-9; Kroenke et al., 2001). The PHQ-9 is a 9-item self-report questionnaire designed to measure the frequency of various depressive symptoms experienced by participants over the past two weeks. Respondents rate each item on a scale from 0 (not at all) to 3 (nearly every day). The total scores on the PHQ-9 range from 0 to 27, with higher scores indicating greater severity of depressive symptoms. The PHQ-9 has demonstrated robust psychometric properties, including good internal consistency (Cronbach's Alpha = .88) (Kroenke et al., 2001).

Analysis

A Qualitative Comparative Analysis (QCA) was used to examine how inter- and intrapersonal dynamics (the absence or presence of communication engagement, emotional connection and sense of self) affect carers' anxiety. QCA was employed as a case-based, qualitative, comparative research approach, which allows to examine the relationship between so called conditions (i.e., communication engagement, emotional connection, and sense of self) and outcome (i.e., presence or absence of anxiety symptoms).

Initially, theoretical and case-based definitions of interpersonal and intrapersonal dynamics (i.e., communication engagement, emotional connection, and sense of self) were generated using pre-existing theoretical concepts (Van Hout et al., Submitted). Subsequently, a clear definition was established to discern the presence of each condition, such as the definition of the presence of communication engagement. For example, when an interview transcript contained a carer's comment describing their partner's preserved ability to communicate (e.g., how their partner can communicate as they did before) and efforts made by their partner to engage in communications (e.g., initiating conversation) it was considered that communication engagement was present, while a loss of a two-way interaction with no alternative communication strategies was regarded as an absence of communication engagement. To ensure consistency, coding rules were formulated to ascertain the presence of each condition (see Table 6.1). These coding rules underwent consensus agreement among three independent coders (EVH, MC, MR), with MR possessing an MSc in Rehabilitation Psychology and MC holding an MSc in Psychology with a PhD in dementia care.

Label (Overall theme)	Description of occurrence (codes)	Definition
Presence of emotional connection	Being loved and valued by partner	Participants describe being loved and valued by partner
	Being able to share feelings	Participants can share subjective feelings with partner
	Reminiscing on shared history	Participants describe moments of recognition, where husband would recognise carer or the memories they created together
	Sharing physical affection with partner	Participants describe sharing physical affection with their husband and how they became more observant of their partners' new ways of showing affection
	Compassion/love/respect for husband	Participants describe the compassion and love they have for their husband. They describe supporting him and being kind and sensitive towards his needs.
	Operating as a team and feeling united against adversities	Participants describe feeling part of a team with their husband, working towards shared goals
	Satisfaction within the relationship	Participants describe feeling satisfied and happy with the relationship they have with their husband
Presence of communication engagement	Efforts in engagement	Participants describe efforts made by the partner to engage in terms of their husband initiating conversation (even if efforts are out of context/repetitive/confabulations)
	Few words are enough	Participants describe filling in the blanks - being able to deduce content of conversation from a few words of their partner
	New way of communicating	Participants describe reading signs unique to their partner to understand context and content, including picking up non-verbal cues. They describe using different strategies to aid communication
	Having the ability to discuss multiple topics/sharing events	Participants describe being able to talk to their husband about many things, including concerns, shared interests, and family situations
	Ability to have open and honest conversations	Participants describe being able to have open, honest conversations with their husband

	Preserved ability to communicate	Participants describe how their husband can communicate as he did before and that they talk about the same topics as they used to
Presence of a sense of self	Positive aspects of self	Participants describe positive traits of themselves or how they have become better version of themselves through caring
	Self-compassion	Participants describe strategies with regards to self-compassion, including taking time for self-care
	Activities and leisure time	Participants describe participating in activities and leisure time that defines oneself
	Self-understanding	Participants describe understanding themselves, including realising their own worth
	Maintaining an individual identity	Participants describe maintaining their own identity outside of being a carer

Table 6.1. Code manual

Following this initial step, a deductive approach to thematic analysis was employed to allow coders to familiarise themselves with the data collected in the semi-structured interviews. Three coders (EVH, MC, MR) independently identified excerpts that aligned with the coding rules for each condition (see Table 6.1). Selected excerpts were compared between coders, and in cases of disagreement, further revisions to the definitions or coding rules were made until consensus was reached. Subsequently, a truth table, facilitating systematic comparison of combinations of conditions across different cases differing on the outcome variable (i.e., participants with and without anxiety symptoms), was generated. A crisp-set QCA was applied in the table, utilizing ternary data based on a condition being either present ('1') or absent ('0') (see Table 6.2 for examples). In a truth table for crisp-set QCA, each row represents a combination of conditions, and the columns indicate the presence or absence of these conditions for each case (i.e., participant).

QCA aims to identify configurations of conditions that may cause the presence or absence of the outcome (i.e., anxiety symptoms). These are described in terms of necessary conditions and sufficient conditions. A necessary condition refers to a condition (i.e., communication engagement, emotional connection, or sense of self alone) that must exist for a specific outcome (i.e., anxiety) to be present, while sufficient conditions refer to combinations of conditions (i.e., the absence or presence of communication engagement, emotional connection and/or sense of self) that collectively lead to the presence of the outcome (i.e., anxiety symptoms).

Consistency and coverage are two essential parameters of QCA that aid in interpreting the analysis. Consistency measures how well observed cases align with the conditions needed to produce a particular outcome (i.e., the absence or presence of anxiety symptoms). High consistency means that the conditions consistently lead to the outcome, boosting confidence in the results (Ragin & Sean, 2022). In this exploratory analysis with a small number of cases, we opted for a consistency threshold of 0.8 to allow for flexibility in identifying potential configurations associated with anxiety symptoms (Greckhamer et al., 2018). Given the limited sample size and the exploratory nature of the study, this lower threshold enables us to capture meaningful patterns in the data and generate hypotheses for further investigation, without overly strict criteria that might exclude potentially relevant configurations. In addition, Coverage refers to the extent to which the outcome is accounted for by the identified configurations. Coverage is generally set above 0.8 for the pathway to be considered a significant outcome predictor (Ragin & Sean, 2022). However, a coverage of for instance 0.6 does not imply lower relevance to the pathway, where configurations with a low coverage could still be considered for the interpretation.

Both Rstudio software, using the QCA package (Ragin & Sean, 2022), and crisp-set QCA of the TOSMANA software (Cronqvist, 2019), designed for handling small N-studies in social science research, were used for calibrations and truth table analyses. Boolean minimalization, which allows to simplify complex combinations of conditions by eliminating conditions that are likely to be irrelevant (e.g., if conditions A and B are always present when the outcome is present, regardless of condition C, C is less likely to be relevant), was used. This approach enables to identify critical conditions when contradictions are present (i.e., a configuration of conditions leading to the present of anxiety in some observed cases, but to the absence in other observed cases).

Two-value crisp-set	Description of crisp-set	Definition	An example case for communication engagement
1	Fully in	Condition is present within data with one or more occurrences	Carer expresses how she tries to understand his confusion and describes conversations with husband as playing a game to find out what he means. Carer expresses how they laugh their way through it with having specific attention to non-verbal signs like humming.
0	Fully out	Condition is absent within data with no occurrences	Carer expresses how partner can go nearly all day without saying anything and how he is not interested in discussing topics with carer

Table 6.2. Set membership coding example for communication engagement

Results

Characteristics of cases

The characteristics of the cases (i.e., participants) are presented in Table 6.3. The study sample (N=17) had a mean age of 77.24 years (SD = 7.24) and most participants cared for a spouse or partner with Alzheimer's Disease (47%). On average, participants had been providing care for 68.24 months (SD = 40.91).

Demographic characteristics	Carer	Partner living with dementia
Age (in years)		
Mean (SD)	72.24 (7.25)	77.88 (7.92)
Range	60-85	61-90
Gender		
Female (n, %)	17 (100%)	0 (0%)
Male (n, %)	0 (0%)	17 (100%)
Carer relationship to person with dementia		
Spouses	17 (100%)	
Length of care (in months)		
Mean (SD)	68.24 (40.91)	
Range	14-168	
Group below threshold		
Anxiety symptoms (GAD-7; mean, SD)	3.6 (2.76)	
Depressive symptoms (PHQ-9; mean, SD)	4.9 (4.23)	
Group above threshold		
Anxiety symptoms (GAD-7; mean, SD)	13.29 (4.07)	
Depressive symptoms (PHQ-9; mean, SD)	10.86 (6.39)	
Time since diagnosis (in years)		
Mean (SD)		7.11 (2.57)
Range		3-12
Dementia Diagnosis		
Alzheimer's disease		8 (47%)
Mixed dementia		4 (23%)
Vascular dementia		3 (18%)
Lewy Body dementia		1 (6%)
Early onset dementia		1 (6%)

Table 6.3. Demographic characteristics

Qualitative comparative analysis

The analysis examined the relationships among the conditions (i.e., communication engagement, emotional connection and sense of self) and anxiety symptoms. All possible configurations are included in the so-called truth table (Table 6.4). A systematic analysis of the relationship between the conditions and the outcome, based on the truth table, is discussed below. Following the completion of the truth table, a crisp-set QCA was conducted, leading to the creation of a Venn diagram (see supplementary file 6.1). This diagram provides a visual representation of the interplay among various conditions, in this case communication engagement, emotional connection, and sense of self, in relation to anxiety symptoms.

Communication engagement	Emotional connection	Sense of self	Outcome (Anxiety)	N	Participant IDs with and without anxiety
0	0	0	C	2	P02(1), P06(0)
0	0	1	0	2	P03(0), P07(0)
0	1	0	C	2	P05(1), P14(0)
0	1	1	C	3	P09(0), P12(0), P17(1)
1	0	1	0	1	P16(1)
1	1	0	1	1	P11(1)
1	1	1	C	6	P01(1), P04(1), P08(0), P10(0), P13(1), P15(1)

Note. 1 = Presence; 0 = Absence; C = Contradictions (i.e., a configuration of conditions leading to the present of anxiety in some observed cases, but to the absence in other observed cases).

Table 6.4.Truth table

The results of the crisp set QCA revealed limited consistency in the truth table, indicating that the identified configurations only partially explained the presence of anxiety symptoms. Several configurations demonstrated consistency in their association with the outcome, yet a significant portion of the truth table exhibited contradictions (i.e., a configuration of conditions leading to the presence of anxiety in some observed cases, but to the absence in other observed cases). This suggests that additional factors not included in the analysis may play a role in influencing the outcome.

Presence of anxiety symptoms

The crisp set QCA with Boolean minimalization using TOSMANA software (Cronqvist, 2019) explaining the presence of anxiety (1), while accounting for the absence (0) and contradictions (C) in the truth table, yielded only one configuration solution. This indicated that the presence of emotional connection is necessary for the occurrence of anxiety symptoms within our sample. Necessary analysis using RStudio (Ragin & Sean, 2022) also identified similar results with the presence of emotional connection being associated with the occurrence of anxiety symptoms with a consistency of 0.86 (Table 6.5). This highlights a potential contributing role of emotional connection to anxiety symptoms among family carers of people with dementia.

Condition	Consistency	Coverage
Presence of communication engagement	0.57	0.50
Absence of communication engagement	0.43	0.33
Presence of emotional connection	0.86	0.50
Absence of emotional connection	0.14	0.20
Presence of sense of self	0.57	0.33
Absence sense of self	0.43	0.60

Table 6.5. Necessary analysis: Presence of anxiety symptoms (1)

Absence of anxiety symptoms

In addition to configurations leading to the presence of anxiety symptoms, some configurations were found to be associated with the absence or negation of anxiety symptoms. The presence of negated outcomes in the analysis underscores the importance of considering not only what factors contribute to the occurrence of the outcome, but also what factors may prevent or inhibit it.

The crisp-set QCA with Boolean minimalization using TOSMANA software (Cronqvist, 2019) explaining the absence of anxiety (0), while accounting for the presence (1) and contradictions (C) in the truth table, yielded only one configuration solution. This indicated that the presence of sense of self is necessary for the absence of anxiety symptoms within our sample. Necessary analysis using Rstudio (Ragin & Sean, 2022) yielded similar results with the presence of sense of self being associated with the absence of anxiety symptoms with a consistency of 0.80 (Table 6.6). This highlights a potential protective role of sense of self.

Condition	Consistency	Coverage
Presence of communication engagement	0.40	0.50
Absence of communication engagement	0.60	0.67
Presence of emotional connection	0.60	0.50
Absence of emotional connection	0.40	0.80
Presence of sense of self	0.80	0.67
Absence sense of self	0.20	0.40

Table 6.6. Necessary analysis: Absence of anxiety symptoms (0)

In summary, the presence of emotional connection was necessary for the occurrence of anxiety symptoms, while the presence of sense of self was necessary for the absence of anxiety symptoms in our sample. Sufficient conditions (i.e., combinations of conditions that collectively lead to the presence of the outcome) were not identified due to contradictions.

Discussion

Our results indicated that the presence of emotional connection is associated with the presence of anxiety symptoms, while the presence of a sense of self is associated with the absence of anxiety symptoms among female spousal carers of people with dementia. The results also indicated that communication engagement is not associated with anxiety symptoms in female spousal carers.

The finding that the presence of emotional connection (the reciprocal feeling of love and the existence of shared feelings) may be linked to anxiety symptoms contrasts with our original hypothesis. This result may suggest that the dynamics of emotional connection within caregiving relationships could be more complex. Existing research has highlighted the multifaceted nature of emotional connection, acknowledging both its positive and negative effects (Conway et al., 2018; Quinn et al., 2009; Stedje et al., 2023). For instance, a longitudinal study by Fauth and colleagues (2012) found that while higher levels of closeness initially predicted beneficial outcomes for dementia family carers, increased emotional closeness in the long term was associated with worse mental health ratings. This suggests that while emotional closeness may offer short-term benefits, prolonged exposure to intense emotional bonds could lead to adverse mental outcomes in dementia family carers over time. Future research could explore factors that may moderate the relationship between emotional connection and carer anxiety, such as a lack of boundaries or fear of loss of intimacy, to gain a better understanding of the complex nature of the dynamics of emotional connection linked to carer anxiety among this population.

The finding that a stronger sense of self (acknowledging positive aspects of oneself and being compassionate towards oneself) may be associated with lower levels of anxiety symptoms aligns with our original hypothesis. This finding is consistent with previous research on self-compassion, which suggests that individuals who possess a secure sense of self and are kind and understanding toward themselves are less prone to experiencing anxiety and distress (Lloyd et al., 2019). In the context of caregiving for individuals with dementia, maintaining a stable sense of self despite the challenges and stressors associated with caregiving may serve as a protective factor against the development of anxiety symptoms (Conway et al., 2018).

The lack of significant association between communication engagement and anxiety symptoms was not consistent with our original hypothesis. However, it's essential to consider that communication engagement was already limited within the sample, potentially due to difficulties in communication arising from the progression of dementia (Banovic et al., 2018). While the severity of communication difficulties was not explicitly assessed in the current study, it could have influenced the results. Future research could delve deeper into understanding how specific aspects of communication, such as the effectiveness of communication strategies or the level of understanding between carers and the person with dementia, impact anxiety levels among dementia family carers.

Clinical Implications

In this study, emotional connection was defined as the reciprocal feeling of love and compassion between carers and their partners, fostering a sense of unity against adversities. This emotional connection emerged as a risk factor for anxiety symptoms among dementia family carers. Hence, early assessment of emotional connection and its potential impact on anxiety symptoms is crucial for planning carer support among this population. Interventions targeting boundary setting may be warranted in cases where emotional connection contributes to carer's distress as without clear boundaries, individuals may become entangled in the lives of others, leading to a loss of individual identity. A recent systematic review of emotional detachment interventions in work settings suggests that strategies such as mindfulness, boundary management and emotion regulation can positively affect employees' mood (Karabinski et al., 2021). Similar results have been found within cancer caregiving, where detachment from caregiving duties (i.e., lives of others) during non-caregiving time has demonstrated a positive impact on reducing carer burden (Hou et al., 2016). Currently, these interventions targeting emotional boundaries have not been fully investigated with dementia family carers and future studies could explore the potential impact of such approaches.

Furthermore, a strong sense of self, characterized by self-compassion, self-understanding, and participation in activities that define oneself, emerged as a protective factor against anxiety symptoms. There are several existing interventions that could facilitate these aspects of a sense of self. For example, self-compassion involves showing oneself kindness in times of difficulty, recognizing shared human experiences, and maintaining mindful awareness of thoughts and emotions (Neff, 2003). A scoping review for mindfulness- and compassion-based interventions, which directly target these skill sets, suggested that these interventions have some potential utility in improving mental health outcomes in family carers of older adults, particularly among dementia family carers (Murfield et al., 2021). Behavioural activation, a critical element in CBT for depression, focuses on increasing pleasurable activities that are rewarding and lead to a sense of achievement (Fenn & Byrne, 2013). This approach may also contribute to facilitating one's sense of self. A systematic review of Xu and colleagues (2020) concluded that behavioural activation has the potential to improve psychological and cardiovascular health in family carers of people with dementia. While some studies have explored the effectiveness of compassion-based intervention and behaviour activation on the psychological health of dementia family carers, their impact on sense of self has not been thoroughly investigated. Future research could explore the potential benefit of these approaches to enhance a sense of self in this population.

Limitations

This study serves as an exploratory research study, laying some groundwork for more focused investigations into interpersonal and intrapersonal dynamics within dementia caregiving. Given that a significant portion of the truth table exhibited contradictions in our results, there may be other factors influencing carer anxiety beyond emotional connection and sense of self. A recent systematic review on influential factors of spousal relationship quality in carers and the person living with dementia highlighted how attitudes about the different losses experienced, humour and social behaviours might be potential factors influencing the relationship and, as a result, their coping strategies (Stedje et al., 2023). The impact of these unexplored relational factors on carer anxiety could be explored in further research.

This study solely focused on the experiences and perspectives of carers and the reciprocal nature of the relationship was not assessed. Future studies could employ an observational approach, which could capture such reciprocal aspects of the relationships, accounting for the perspective of the person living with dementia. Recent developments in research methodology offer promising avenues for assessing the quality of dyadic relationships within couples affected by dementia. A pilot validation study on the Tavistock Relationships Observational Scale (TROS) for the assessment of the quality of dyadic relationships in couples affected by dementia suggests that the TROS may serve as a valuable tool for standardized assessment in research settings (Polek et al., 2021). Incorporating the TROS into future studies could enhance our understanding of the spousal relationship dynamics within dementia caregiving.

Methodologically, the sample size limitation may have influenced the contradictions observed in the findings. Therefore, future studies should consider larger sample sizes to enhance the robustness of results. Specifically, this study could not investigate communication engagement in family carers supporting individuals with varying levels of dementia severity. To achieve this, a standardised measure that can systematically assess levels of communication engagement that can be implemented to a larger sample is required. For example, Jones and colleagues recently developed and validated a new Couples Communication Satisfaction Scale (CCSS) (Jones et al., 2018), which presents a promising tool for such assessments. This scale enables the assessment of participants’ perspectives on both their own and their partner’s communication experiences. Participants are asked to rate not only their satisfaction with communication processes but also behaviours such as interest and initiation. Standardised measures such as this could be tested in future studies to determine the association between emotional engagement and carer’s anxiety symptoms in family carers supporting individuals with varying levels of dementia severity.

Finally, while it may serve as a strength to focus on female carers, considering the predominance of female carers in the population, further studies should explore the impact of relationships on carer anxiety in male family carers. A systematic review of male family carers of people living with dementia (Robinson et al., 2014) demonstrated that few studies to date have examined gender-related differences in carers’ perceptions of intimacy and relational wellbeing. While evidence is scarce, this review highlighted that some literature suggests that male carers may be more concerned about the anticipated loss of their relationship with their partner, possibly due to having a smaller social network. Exploring male carers’ perspectives can offer valuable insights into gender-specific caregiving experiences and coping mechanisms. Furthermore, this study exclusively involved heterosexual couples. Future research should examine whether similar inter- and intrapersonal dynamics are observed in couples of diverse sexual orientations, or if their experiences vary.

Conclusion

This study identified significant associations between emotional connection, sense of self, and anxiety symptoms among female spousal carers of people with dementia. The presence of emotional connection was associated with the presence of anxiety symptoms. Additionally, a stronger sense of self was associated with the presence of anxiety symptoms. Clinically, early assessment of emotional connection and sense of self is crucial for planning support for dementia family carers. To reduce the risk of heightened levels of anxiety symptoms, interventions targeting boundary setting may be beneficial, along with other approaches focusing on enhancing self-compassion and increasing pleasurable activities that lead to a sense of achievement. Moving forward, further research should explore other factors that may influence the quality of spousal relationships, including dementia severity, humour, social behaviour and gender.

CHAPTER 7:

GENERAL DISCUSSION

Summary of the key results

The first three studies used a quantitative approach to explore factors associated with anxiety symptoms in family carers of people living with dementia. The first study (Chapter 2) revealed that increased caregiving hours and poorer sleep quality are linked to elevated anxiety symptoms. Notably, individual’s feelings on sleep quality (i.e., subjective sleep quality and sleep disturbances) seem to predict higher levels of anxiety symptoms than the perception of sleep parameters, such as sleep latency and sleep duration. The second study (Chapter 3) indicated that experiential avoidance moderates the relationship between carer subjective burden and anxiety symptoms. The effect of experiential avoidance was particularly pronounced in instances of higher subjective burden, suggesting that experiential avoidance exacerbated the impact of subjective burden on anxiety symptoms. The third study (Chapter 4) found significant indirect effects of carer subjective burden on anxiety through its influence on cognitive fusion alone. Also, it showed a combined effect of experiential avoidance in caregiving and cognitive fusion on carer anxiety symptoms.

The fourth and fifth studies used a qualitative approach to explore the impact of relationships (interpersonal and intrapersonal dynamics) on anxiety symptoms in family carers of people living with dementia. The fourth study (Chapter 5) explored the meaning female carers give to interpersonal and intrapersonal dynamics within their relationship, which informed the development of the definition of different relationship aspects in the caregiving context, including communication engagement, emotional connection and a sense of self. The fifth study (Chapter 6) then investigated their potential link to anxiety symptoms. The findings suggested that communication engagement (i.e., the level of active participation and meaningful interaction between the female spousal carer and their partner with dementia) is not associated with anxiety symptoms in female spousal carers. Emotional connection (i.e., the depth and quality of emotional bonding between the female spousal carer and their partner with dementia) seems to be associated with the presence of anxiety symptoms among female carers of people living with dementia. Finally, a stronger sense of self (i.e., the individual's perception and understanding of their own identity, autonomy, and purpose within the context of caregiving for a partner with dementia) is associated with lower levels of anxiety symptoms.

Overall clinical implications

The sociocultural stress and coping model adapted to caregiving (Knight & Sayegh, 2010) provides a comprehensive framework for understanding the multifaceted impact of caregiving on individual wellbeing. According to this model, carer stressors often arise from contextual factors, such as those found in the current project (i.e., caregiving hours and sleep quality), and they are considered to directly influence carer distress. However, this model also emphasises the importance of individual factors that may moderate such relationships. This project particularly identified the key reverse buffering effects of experiential avoidance and cognitive fusion, suggesting that undermining these psychological processes may prevent family carers experiencing high levels of carer burden from developing clinically significant anxiety. This model traditionally emphasizes the importance of coping strategies as individual factors; relational aspects of caregiving, such as emotional connection and sense of self, have not been fully integrated into the model. The findings from this project suggested that these relational factors significantly contribute to carer anxiety symptoms, underscoring the importance of incorporating them into the sociocultural stress and coping framework.

Assessments

This project has highlighted specific factors that require careful consideration when providing support to family carers of people living with dementia. For example, regular monitoring of carers' subjective sleep quality is essential, as it tends to reduce as dementia progresses (Smyth et al., 2020), potentially having a greater impact on anxiety symptoms. Furthermore, early assessment of experiential avoidance and cognitive fusion is recommended due to their moderating and mediating effect on the relationship between carer subjective burden and anxiety symptoms. Monitoring these factors may be particularly important in later stages of dementia progression, as this is when the impact of carer burden could be more significant (Bardeen & Fergus, 2016; Froelich et al., 2021). When assessing relational factors, early assessment of emotional connection between carers and individuals with dementia is crucial, as it emerged as a risk factor for anxiety symptoms. Assessing the sense of self among family carers is also warranted, as it emerged as a protective factor against anxiety symptoms. Determining the most effective methods for assessing these relational factors falls outside the scope of this project. In addition, unlike some other factors that can be quantitatively assessed, these relational factors may not lend themselves to simple measurement. In future research, it is important to investigate various methods for evaluating relational factors. This should include an observational approach, which has the potential to capture the reciprocal dynamics of relationships, while also considering the perspective of the individual living with dementia.

Interventions

Multi-component interventions are consistently acknowledged as effective approaches for sustaining carer health (He et al., 2022). However, the optimal combination of individual components for practical implementation remains uncertain. The findings of this thesis underscore the potential use of multi-component interventions incorporating acceptance, mindfulness and self-compassion-based approaches to effectively address various factors contributing to carer anxiety symptoms, including sleep quality, cognitive fusion, experiential avoidance and sense of self. A scoping review for mindfulness- and compassion-based interventions suggested that these interventions have some potential utility in improving mental health outcomes in family carers of older adults, particularly among dementia family carers (Murfield et al., 2021).

Currently, acceptance and mindfulness-based interventions are recommended as treatment for key factors identified in this project, including sleep problems, cognitive fusion and experiential avoidance (Han et al., 2020; Salari et al., 2020). Acceptance- and mindfulness-based therapies are therapeutic approaches that emphasize embracing difficult thoughts and emotions and focusing on the present, connecting with what is happening in the moment, rather than trying to control or get rid of them (Fuchs et al., 2013). Examples of such therapies include Acceptance and Commitment Therapy (ACT; Hayes et al., 2012) and Mindfulness-Based Stress Reduction (MBSR; Kabat-Zinn, 2013). A recent systematic review of sleep interventions for informal carers of people with dementia showed mindfulness-based interventions have the potential to improve the subjective sleep quality among this population (Pignatiello et al., 2021). In addition, a meta-analysis investigating acceptance-based interventions among family carers of people with dementia highlighted the effectiveness of those interventions in reducing cognitive fusion and experiential avoidance (Han et al., 2020). While the recommended duration of these types of interventions are normally 8 weeks (Fjorback et al., 2011; Zhu et al., 2024), evidence has shown that shorter interventions can still yield positive outcomes. For example, research has demonstrated the effectiveness of mindfulness-based interventions in improving mental health with durations as short as 4 sessions (Demarzo et al., 2017). If beneficial, such shorter interventions can be useful for a multi-component intervention that requires the integration of other components.

Another key element identified in this project is sense of self, which involves understanding their own identity and worth, being compassionate towards oneself and allowing to prioritise own needs as per Study 4 (Chapter 5) and Study 5 (Chapter 6). This may be most effectively targeted by compassion-based approaches. Self-compassion-based approaches are therapeutic interventions that involve learning to treat oneself with kindness, recognize one's shared humanity, and be mindful of one's own suffering (Neff, 2003). These interventions have shown to increase self-compassion in clinical populations other than dementia carers across multiple randomised control trials (Ferrari et al., 2019; Millard et al., 2023). In addition, a meta-analysis investigating the effect of self-compassion interventions on reducing anxiety among individuals with psychological distress symptoms in non-dementia carer populations has shown some preliminary evidence of a positive effect of such approach on cognitive fusion (Han & Kim, 2023).

A recent systematic review on web-based compassion interventions for family carers, including family carers of individuals living with Alzheimer’s disease, demonstrated emerging evidence on the effectiveness of those interventions in enhancing family carers’ self-compassion and mindfulness (Zhu et al., 2024). Of eight studies included in this systematic review, seven used a guided or unguided self-help approach, suggesting that these types of interventions can be brief and delivered with minimal input from healthcare professionals, which may be suitable for a multi-component intervention requiring the integration of various elements. Furthermore, online delivery of interventions may provide accessibility and convenience, allowing carers to engage with the intervention from the comfort of their homes and at times that suit their schedules. This flexibility is particularly beneficial for family carers, who often have limited time due to their caregiving responsibilities (Liu et al., 2020). Additionally, internet-based interventions can reach a broader audience, including those in remote areas who may have limited access to traditional healthcare services (Andersson & Titov, 2014). By eliminating geographical barriers, online delivery ensures that all carers, regardless of their location, can benefit from the intervention (Lappalainen, Pakkala, et al., 2021).

To target one of the key relational factors identified in this project, emotional connection, incorporating boundary-setting techniques may be beneficial. Boundary-setting involves establishing clear limits on caregiving responsibilities, asserting personal needs, and prioritising self-care activities (Hou et al., 2016; Karabinski et al., 2021). A recent systematic review examining interventions aimed at emotional detachment in workplace settings indicates that such techniques as boundary-setting and emotion regulation may contribute to improved employee mood (Karabinski et al., 2021). Comparable findings have been observed in the context of cancer caregiving, where distancing oneself from caregiving responsibilities during non-caregiving periods has shown promise in alleviating carer burden (Hou et al., 2016). Complementary to this intervention, respite care services could also offer carers temporary relief from their caregiving responsibilities (Parkinson et al., 2016), potentially reducing burden and facilitating the implementation of those boundary-setting skills.

Future research should explore whether each proposed component can directly target the factors contributing to anxiety symptoms identified in this project, including sleep quality, cognitive fusion, experiential avoidance and sense of self among family carers of people living with dementia. Future research also should explore how best to incorporate these different types of interventions as a multi-component carer intervention including the format of delivery, appropriate dose and the required degree of input from healthcare professionals. Assessing the feasibility and acceptability of such intervention may provide insights into the suitability of the intervention and identify potential barriers and facilitators to the successful delivery of a definitive trial and could be a crucial next step before the clinical and cost effectiveness of the intervention can be evaluated.

Overall limitations and future directions of research

Limitations across the entire thesis include the predominantly cross-sectional nature of the quantitative studies, which restricts the ability to establish causal relationships and understand changes over time. Furthermore, it is critical to highlight that both Study 2 and 3 (i.e., Chapter 3 and 4) collected data during the COVID-19 pandemic, therefore results may be affected by the additional stress the pandemic brought to carers (Rising et al., 2022). Considering the high level of comorbidity between depression and anxiety in family carers of people with dementia (Mineka & Zinbarg, 2006), future studies may also benefit from controlling for depression when examining factors associated with anxiety symptoms in this population.

Additionally, the sample size and characteristics of the sample may have limited the generalizability of these findings, particularly regarding ethnic diversity and levels of anxiety symptoms. Firstly, the studies did not collect information on the ethnicity of participants. Participants were recruited in counties in the East of England where more than 90% of the population is White British, potentially resulting in a non-diverse sample. Secondly, in the quantitative samples, half of the participants experienced minimal to mild anxiety symptoms. To address these limitations, future quantitative research could benefit from larger and more ethnically diverse samples, including a clinical population (i.e., participants with more severe anxiety symptoms). This would allow for a more comprehensive understanding of carer experiences across different caregiving and cultural contexts. Moreover, longitudinal designs could provide valuable insights into the trajectories of carer anxiety and the long-term effects of caregiving on this outcome.

Semi-structured interviews were conducted with female spousal carers for the qualitative studies for this thesis, providing valuable insights into their experiences within caregiving relationships. However, similarly, this focus may have limited our understanding of the potential role of gender dynamics in shaping long-term intimate relationships in the context of caregiving. Previous research suggests that male carers may have distinct worries regarding the anticipated loss of their relationship with their partner, potentially influenced by factors such as their social network size (Robinson et al., 2014). In addition, this thesis solely focused on the experiences and perspectives of carers and the reciprocal nature of the relationship was not assessed. Therefore, future qualitative research should strive to incorporate a more diverse range of participants, including male spousal carers and individuals from minority ethnic groups. Furthermore, employing observational methods alongside interviews could offer a more holistic understanding of the relationship dynamics at play, capturing their reciprocal nature while considering the perspective of the person living with dementia.

In revisiting the sociocultural stress and coping model adapted to caregiving (Knight & Sayegh, 2010), it is essential to highlight factors that were not addressed in this project. This may include factors such as cultural beliefs and practices, social support networks, and access to resources and services. One important dimension of cultural beliefs is familism, characterized by a deep sense of identification and attachment individuals have with their families as well as strong sentiments of loyalty, reciprocity, and solidarity among family members (Losada et al., 2020). Within the caregiving context, familism is known to have both positive and negative effects on family carers and it particularly can have a negative impact when caregiving is seen as familial obligation (Losada et al., 2010). A recent meta-analysis highlighted the significant positive relationships between familism and anxiety among dementia carers (Tian et al., 2022). Furthermore, a meta-analysis investigating the correlation between social support and anxiety among informal carers, including carers for people living with dementia, determined that higher levels of perceived social support were significantly linked to lower carer anxiety symptoms (Priego-Cubero et al., 2023). By incorporating these additional factors, future research can provide a more nuanced understanding of the complexities of caregiving and inform the development of more tailored interventions.

Conclusion

In conclusion, the findings of this project shed light on various factors influencing anxiety symptoms among family carers of people living with dementia. The quantitative studies highlighted the significance of caregiving hours, sleep quality, experiential avoidance, and cognitive fusion in contributing to carer anxiety symptoms. The qualitative studies deepened the understanding of interpersonal and intrapersonal dynamics within caregiving relationships, emphasizing the importance of emotional connection and sense of self in their association with anxiety symptoms. Multi-component interventions incorporating acceptance, mindfulness and self-compassion-based approaches, boundary-setting techniques and respite care services, which could potential directly target factors identified in this project, may be beneficial for family carers experiencing anxiety symptoms. Despite the methodological limitations, overall, this project contributed to our understanding of the complex interplay of factors influencing anxiety symptoms in the context of dementia family caregiving. By addressing the identified limitations and incorporating these insights into future research and intervention development, we can better support the psychological health and wellbeing of family carers, ultimately improving the quality of care provided to people living with dementia.

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GLOSSARY

Acceptance and Commitment Therapy (ACT)	This intervention aims to reduce cognitive fusion and experiential avoidance by helping carers learn to step back from restricting thoughts and approach or allow painful emotions, while identifying personal values (what is most important to them) and engaging in such value-based activities.
Anxiety symptoms	A combination of different symptoms with the main symptoms being feelings of worry and fear, muscular tension, fatigue and insomnia.
Carer burden	The physical and psychological strain experienced by individuals providing care to someone.
Carer subjective burden	Personal appraisals of burden including the physical, psychological, social and emotional impact their caring role has on their life.
Cognitive Behavioural Therapy (CBT)	An intervention in which negative patterns of thought are challenged in order to alter unwanted behaviour patterns or treat mood disorders such as depression.
Cognitive fusion	The tendency to become entangled with thoughts and the inability to step back from such restricting beliefs.
Communication engagement	It involves active and explicit communication between the carer and care recipient, reflecting a joint collaborative effort.
Compassion-focused therapy	This intervention promotes individuals to be compassionate toward themselves and other people.
Couple's life story approach	This intervention enables couples to reminisce about their shared experiences and shows to be an effective method for enhancing the quality of a couple’s relationship.
Dementia	A progressive chronic illness, categorised by disruptions in behaviour and a decrease in cognitive abilities, which can lead to a gradual decrease in a person’s independence.
Emotional connection	This is defined as the reciprocal feeling of love and compassion between carers and their partners, fostering a sense of unity against adversities.

Experiential avoidance	The attempt to alter the form, frequency or intensity of private experiences such as thoughts and feelings, even when doing so is costly, ineffective or unnecessary.
Sense of self	This is defined as the individual's characteristic ideas about who they are and what they are like. It is characterized by self-compassion, self-understanding, and participation in activities that define oneself.
Sleep disturbance	Experiences of trouble sleeping due to interruptions, such as difficulty in breathing.
Subjective sleep quality	A person's perception on how well they sleep without any disturbances.
The 12-version of the Zarit Burden Interview (ZBI-12)	A 12-item measure assessing two domains of carer subjective burden: personal strain (e.g., “Do you feel you have lost control of your life since your relative's illness?”) and role strain (e.g., “Do you feel you should be doing more for your relative?”).
The Acceptance and Action Questionnaire (AAQ-II)	The most widely used unidimensional measure of experiential avoidance.
The Charlson Comorbidity Index (CCI)	A measure that assesses comorbidities based on the presence or absence of certain medical conditions.
The Experiential Avoidance Caregiving Questionnaire (EACQ)	A 15-item self-reported measure specifically designed to assess experiential avoidance in the caregiving context (the tendency to control, avoid or suppress distressing thoughts and feelings related to caregiving).
The Frontotemporal Dementia Rating Scale (FRS)	A 30-item proxy-informant interview-based measure that assesses the severity of dementia.
The Generalised Anxiety Disorder Scale (GAD-7)	A 7-item self-report questionnaire that measures the severity of anxiety symptoms.
The Mild Behavioural Impairment Checklist (MBI-C)	A 38-item proxy-informant interview-based questionnaire measuring the neuropsychiatric symptoms within five domains: apathy/drive/motivation; mood/affect; impulse control/agitation; social appropriateness; and thoughts/perception.
The Pittsburgh Sleep Quality Index (PSQI)	A 19-item self-reported questionnaire designed to assess sleep quality and disturbances over a 1-month time interval.

APPENDICES

Supplementary file Chapter 5

Supplementary file 5.1. Participant interview guide

To start, could you briefly explain to me your own situation and that of your partners? I understand you are a carer for your partner, what does this entail for you?

Q1: Could you tell me what your role as a carer means within your relationship with your partner?
Possible prompt: Could you describe to me how this feels for you?

Q2: To what extent do you feel your relationship has adjusted to the dementia diagnosis?
Possible prompts: How do you notice this? Could you give me some examples?; Could you describe to me how you can see your relationship has adjusted/changed? How important do you feel this relationship adjustment was for you in your relationship with your partner?

Q3: How does the current caregiving situation affect your feelings towards the relationship?
Possible prompts: How do you currently view your relationship?

Q4: Do you currently feel connected to your partner?
Possible prompts: How do you experience this connection to your partner?; Are there things that have complicated this connection throughout the disease process or the care for your partner? Could you explain to me the situations where this happened?; How important do you feel this connection is in your relationship with your partner with dementia?; Could you describe a situation where you felt connected with your partner? Could you describe the reason why you felt connected at that point?

Q5: How do you feel the communication between you and your partner currently transpires?
Possible prompts: Can you describe to me how this makes you feel?; To what extent do you experience difficulties in communicating with your partner?; How do you overcome these challenges?

Thank you for answering all these questions already. We've talked about how you experience the relationship to your partner; the last question is a bit more specific about yourself and your identity as a carer.

Q6: To what extent do you feel the dementia disease and the caregiving situation has an influence on who you are?
Possible prompts: How do you perceive yourself?; Do you feel you as a person have changed throughout this process? In which way (positive/negative)?; To what extent do you think this has an influence on how you currently feel?

This is the end of the interview. Before I stop the recording…

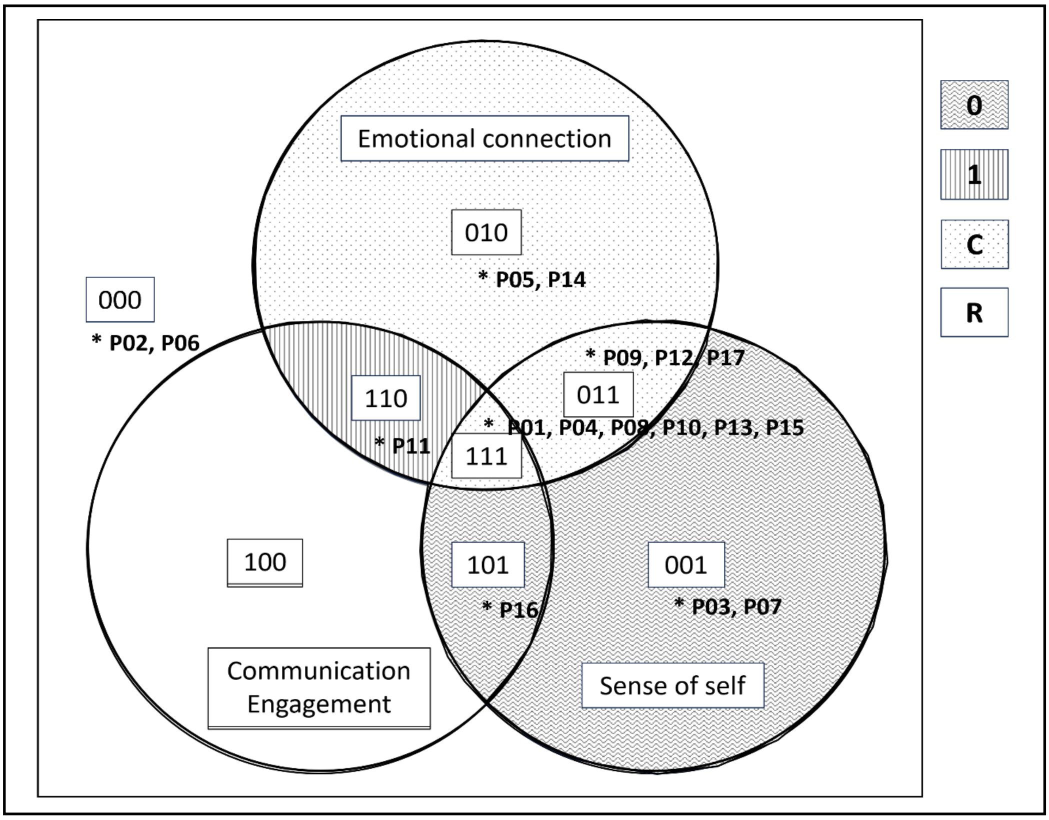
Q7: Do you have any other thoughts on the topics we have discussed that you would like to share with me?

Q8: Do you have any questions you would like to ask me?

I would like to say thank you again for giving up your time to speak with me today. [DEBRIEF]

Supplementary file Chapter 6

Supplementary file 6.1. Venn Diagram



Supplementary file 6.1. Venn Diagram explaining presence of anxiety symptoms (1), absence of anxiety symptoms (0) and contradictions (C) among cases.

1

0	Cases with the absence of anxiety symptoms
1	Cases with the presence of anxiety symptoms
C	Contradictions (cases with the absence and the presence of anxiety symptoms co-exist)
R	No confirmed cases

Note. P with two digits (e.g., P01) presents the case number. Three digits (e.g., 000) in a small box present different pattern of conditions. Each digit only takes zero (0) or one (1) as a value. 0 presents the absence and 1 presents the presence of a condition. The first digit of three refers to communication engagement. The second and the third digits refer to emotional connection and sense of self respectively. As an example,101 means the presence of communication engagement and sense of self but the absence of emotional connection. There is only one case in this area (P16) in the diagram. This area is coloured with fine wavy lines, which indicates the absence of anxiety symptoms. P16 demonstrated the presence of communication engagement and sense of self but the absence of emotional connection. P16 did not show clinical levels of anxiety symptoms.

Participant information sheet and consent form Chapter 5 and 6

PARTICIPANT INFORMATION SHEET

Exploring the effect of interpersonal and intrapersonal dynamics on carer anxiety in female dementia carers: A qualitative investigation

(1) What is this study about?

We are interested in finding out how you relate, interact and communicate with the person you are caring for and whether these different aspects of the relationship have affected your wellbeing in any way. We would like to learn from your experiences through an individual interview. You have been invited to participate in this study because you are currently supporting your partner/spouse with dementia and may be eligible to take part in this study.

Participating in this study is however up to you. You do not have to take part if you don't want to. This Participant Information Sheet tells you what will happen if you decide to take part. Please read this information sheet carefully and feel free to ask questions about anything that you don’t understand or want to know more about.

Participation in this research study is voluntary. By giving consent to take part in this study you are telling us that you:

- ✓ Understand what you have read.
- ✓ Agree to take part in the research study as outlined below.
- ✓ Agree to the use of your personal information as described.
- ✓ You have received a copy of this Participant Information Sheet to keep.

(2) Who is running the study?

The study is being carried out by the following researcher(s): Miss Elien Van Hout.
This will take place under the supervision of Dr Naoko Kishita ([INSERT PRIMARY SUPERVISOR'S EMAIL ADDRESS], [INSERT PRIMARY SUPERVISOR'S TELEPHONE NUMBER]).

(3) What will the study involve for me?

Once you have read this information sheet, we will give you a phone call. In this phone call, you can ask as many questions as you wish before deciding to take part in the study. If you decide to take part, we will ask you to provide written consent. You can do this online using an online consent form or via post using a hard copy of the consent form.

Once we have received your written consent, you will be invited to attend an individual interview, which is expected to last about one hour. The interview can take place on the date and time that suit you best. The interview can be conducted face-to-face in your own home or remotely via telephone or Microsoft Teams video call, depending on your preference. We will follow the UK government's COVID guidelines all the time. Home interviews will only happen if the guidelines permit face-to-face interactions. To minimise the risk, the researcher will get regular rapid lateral flow tests, maintain social distancing and wear a facemask when interviewing you at your home.

During the interview session, you will be asked to complete some questionnaires about yourself and your wellbeing first. You can complete these online using an online survey form or via post using hard copies. Upon the completion of the questionnaires, you will be invited to take part in an individual interview. We will ask your views and thoughts on the relationship you have with your partner/spouse living with dementia and your own wellbeing. The interview will be audio recorded to make sure that we don't miss anything that you say and to help us summarise the results of the interviews.

After the completion of the interview, no further involvement from your side would be required. You will have the opportunity to review information generated about you prior to publication if you wish.

(4) How much of my time will the study take?

The time taken for the individual interview and filling out the questionnaires will vary but is likely to take around one hour.

(5) Do I have to be in the study? Can I withdraw from the study once I have started?

Being in this study is completely voluntary and you do not have to take part. Your decision whether to participate will not affect your current or future relationship with the researchers or anyone else at the University of East Anglia now or in the future.

If you decide to take part in the study, you can withdraw your consent up to the point that your data is fully anonymised. You can do this by contacting the research team. You can withdraw from the study without explaining why.

(6) What are the consequences if I withdraw from the study?

You are free to stop the interview at any time. Unless you say that you want us to keep them, any recordings will be erased and the information you have provided will not be included in the study results. You may also refuse to answer any questions that you do not wish to answer during the interview. If you decide at a later time to withdraw from the study, your information will be removed from our records and will not be included in any results, up to the point we have analysed and published the results.

(7) Are there any risks or costs associated with being in the study?

There are no known risks and no anticipated discomfort from taking part in this study. However, some people may find it upsetting to talk about the person they are caring for or their experiences of caregiving. You can refuse to answer any questions which you feel uncomfortable with, or you can stop the interview anytime.

(8) Are there any benefits associated with being in the study?

We can’t guarantee that the study will be of direct benefit to you, although you may experience some indirect positive effects, such as knowing that you are helping researchers learn more about experiences of caregiving, which may improve the wellbeing of others, now or in the future.

The findings of this project will provide important information on how family carers relate, interact and communicate with the person they are caring for and how different aspects of the relationship affect their wellbeing. We will use this information to inform the development of future interventions aimed at supporting family carers of people with dementia.

(9) What will happen to information provided by me and data collected during the study?

The information you provide during this study and some personal background data will be used in the analysis of this study. In order to protect your anonymity, individual data will be anonymised and indexed by a code number, which is kept separately from other data, retained only by the study team. Physical de-identified data will be stored within locked filing cabinets accessible only to the study team, within an office that requires security key-card access. This de-identified data will also be electronically stored on University servers on an encrypted database requiring a password retained by only the research team.

Digital audio data recorded on voice recorders or through the recording function on Microsoft Teams will be transferred and stored on the University East Anglia's password-protected secure electronic network. All data will be deleted from voice recorders after the data has been transferred. Following the interview session, a transcription of your interview will be completed and anonymised as best as possilble by removing identifiable data such as names, companies, birth dates, addresses, educational institutions and locations. Once the accuracy of this transcript is checked, the digital audio data of your interview will be deleted. If you have any concerns regarding the anonymity of your interview transcript, please let us know. We can send a copy for your review.

The individual results will remain anonymous, as your name will not be attached to your results, and the hardcopy results will be identified only by a numerical code. Once the study has been completed, we will publish the results in a scientific journal in an anonymous way. The anonymised findings will also be presented at international and national conferences and seminars.

Your personal data and information will only be used as outlined in this Participant Information Sheet, unless you consent otherwise. Data management will follow the Data Protection Act 2018 (DPA 2018) and UK General Data Protection Regulation (UK GDPR), and the University of East Anglia's Research Data Management Policy.

The information you provide will be stored securely and your identity will be kept strictly confidential, except as required by law. Study findings may be published, but you will not be identified in these publications if you decide to participate in this study.

Study data may also be deposited with a repository to allow it to be made available for scholarly and educational purposes. The data will be kept for at least 10 years beyond the last date the data were accessed. The deposited data will not include your name or any identifiable information about you.

The only circumstance in which we may need to break confidentiality is if you tell us anything which may put yourself, the person you care for, or others at risk of harm. If this happens, we will explain why we will need to break confidentiality and who we will inform.

(10) What if I would like further information about the study?

When you have read this information sheet, Miss Elien Van Hout (E.Van-Hout@uea.ac.uk, 07547 099925) will be available to discuss it with you further and answer any questions you may have.

(11) Will I be told the results of the study?

You have a right to receive feedback about the overall results of this study.
You can tell us that you wish to receive feedback by ticking the relevant box on the consent form. If you would like to know more about this, please do not hesitate to get in contact and ask the research team.
This feedback will be in the form of a one page lay summary
This feedback will be given to you at the end of this study

(12) What if I have a complaint or any concerns about the study?

If there is a problem, please let us know. You can contact me or the primary supervisor at the following address:

Miss Elien Van Hout
School of Health Sciences
University of East Anglia
NORWICH NR4 7TJ
E.Van-Hout@uea.ac.uk
+44 (0)7417 377359

Dr Naoko Kishita
School of Health Sciences
University of East Anglia
NORWICH NR4 7TJ
N.Kishita@uea.ac.uk
+44 (0)1603 593891

If you are concerned about the way this study is being conducted or you wish to make a complaint to someone independent from the study, please contact the Head of School of Health Sciences [*INSERT NAME OF HEAD OF SCHOOL/DEPARTMENT AND EMAIL AND TELEPHONE NUMBER]*.**(13) How do I know that this study has been approved to take place?**

To protect your safety, rights, wellbeing and dignity, all research in the University of East Anglia is reviewed by a Research Ethics Body. This research was approved by the FMH S-REC (Faculty of Medicine and Health Sciences Research Ethics Subcommittee).

(14) What is the general data protection information I need to be informed about?

According to data protection legislation, we are required to inform you that the legal basis for processing your data as listed in Article 6(1) of the UK GDPR is because this allows us to process personal data when it is necessary to perform our public tasks as a University.

In addition to the specific information provided above about why your personal data is required and how it will be used, there is also some general information, which needs to be provided for you:

- The data controller is the University of East Anglia.
- For further information, you can contact the University's Data Protection Officer at dataprotection@uea.ac.uk
- You can also find out more about your data protection rights at the Information Commissioner's Office (ICO).
- If you are unhappy with how your personal data has been used, please contact the University's Data Protection Officer at dataprotection@uea.ac.uk in the first instance.

(15) OK, I want to take part – what do I do next?

When you have read this information sheet, we will give you a phone call to discuss further and answer any questions you may have. We will then ask you if you would like to take part in the study and will clearly explain the next steps to you.

(16) Further information

This information was last updated on 15 December 2021.

If there are changes to the information provided, you will be notified by the research team using your preferred method of contact.

This information sheet is for you to keep

PARTICIPANT CONSENT FORM (First Copy to Researcher)

I, ... [PRINT NAME], **am** willing to participate in this research study.

In giving my consent I state that:

- I understand the purpose of the study, what I will be asked to do, and any risks/benefits involved.
- I have read the Participant Information Sheet, which I may keep, for my records, and have been able to discuss my involvement in the study with the researchers if I wished to do so.
- The researchers have answered any questions that I had about the study and I am happy with the answers.
- I understand that being in this study is completely voluntary and I do not have to take part. My decision whether to be in the study will not affect my relationship with the researchers or anyone else at the University of East Anglia now or in the future.
- I understand that I may stop the interview at any time if I do not wish to continue, and that unless I indicate otherwise any recordings will then be erased and the information provided will not be included in the study results. I also understand that I may refuse to answer any questions I don’t wish to answer.
- I understand that the results of this study may be published but that any publications will not contain my name or any identifiable information about me.
- I understand that personal information about me that is collected over the course of this project will be stored securely and will only be used for purposes that I have agreed to. I understand that information about me will only be told to others with my permission, except as required by law.

Completing a questionnaire YES ☐ NO ☐

Audio-recording YES ☐ NO ☐

Reviewing transcripts YES ☐ NO ☐

Would you like to receive feedback about the overall results of this study?

YES ☐ NO ☐

If you answered **YES,** please indicate your preferred form of feedback and address:

☐ Postal: ____

____

☐ Email: ____

....

Signature

....

PRINT name

....

Date

PARTICIPANT CONSENT FORM (Second Copy to Participant)

I, ... [PRINT NAME], **am** willing to participate in this research study.

In giving my consent I state that:

- I understand the purpose of the study, what I will be asked to do, and any risks/benefits involved.
- I have read the Participant Information Sheet, which I may keep, for my records, and have been able to discuss my involvement in the study with the researchers if I wished to do so.
- The researchers have answered any questions that I had about the study and I am happy with the answers.
- I understand that being in this study is completely voluntary and I do not have to take part. My decision whether to be in the study will not affect my relationship with the researchers or anyone else at the University of East Anglia now or in the future.
- I understand that I may stop the interview at any time if I do not wish to continue, and that unless I indicate otherwise any recordings will then be erased and the information provided will not be included in the study results. I also understand that I may refuse to answer any questions I don't wish to answer.
- I understand that the results of this study may be published but that any publications will not contain my name or any identifiable information about me.
- I understand that personal information about me that is collected over the course of this project will be stored securely and will only be used for purposes that I have agreed to. I understand that information about me will only be told to others with my permission, except as required by law.

Completing a questionnaire YES ☐ NO ☐

Audio-recording YES ☐ NO ☐

Reviewing transcripts YES ☐ NO ☐

Would you like to receive feedback about the overall results of this study?

YES ☐ NO ☐

If you answered **YES** on the last question, please indicate your preferred form of feedback and address:

☐ Postal: ____

____

☐ Email: ____

....

Signature

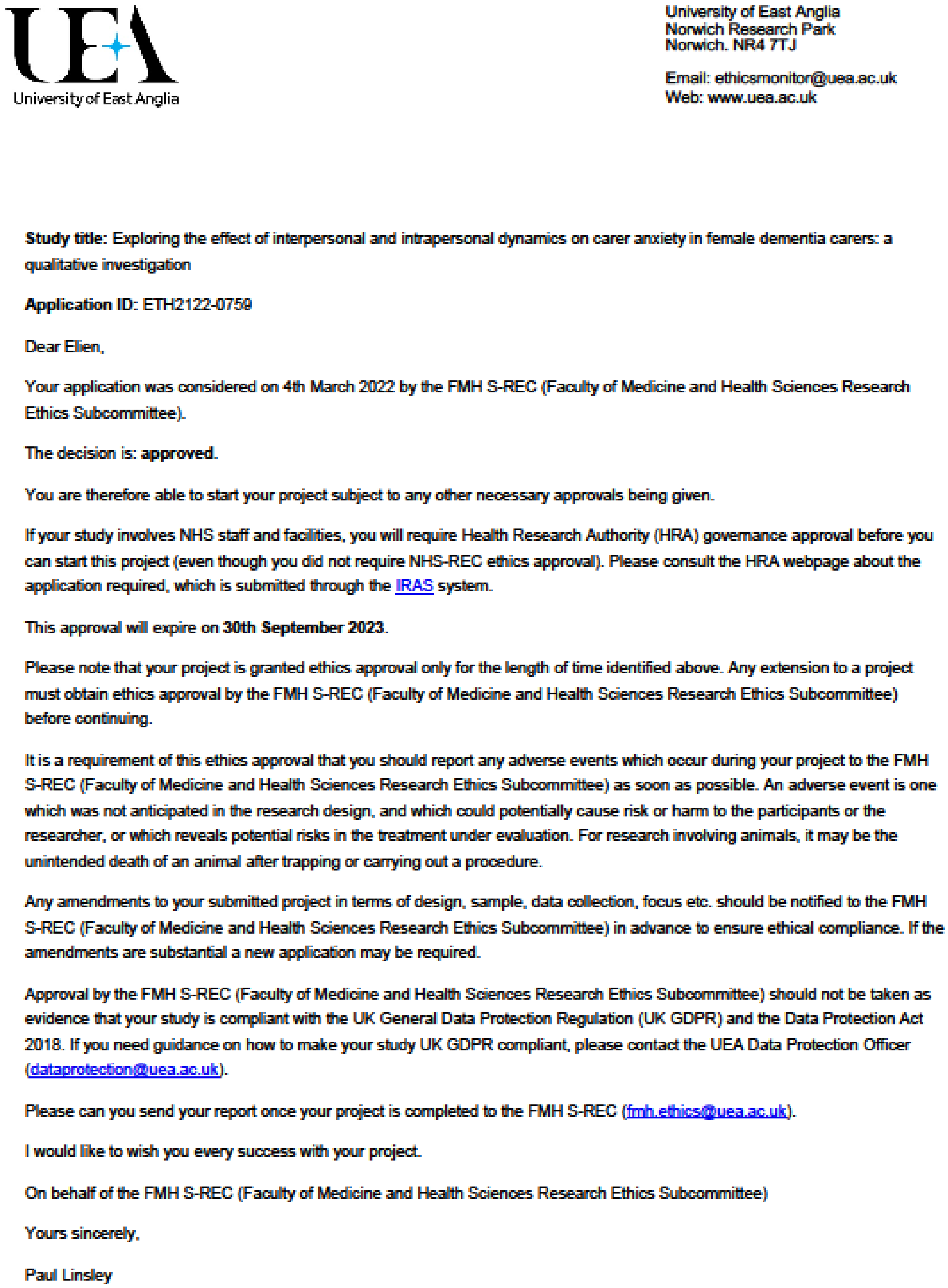
....

PRINT name

....

Date

Ethical approval Chapter 5 and 6



University of East Anglia
Norwich Research Park
Norwich. NR4 7TJ

Email: ethicsmonitor@uea.ac.uk
Web: www.uea.ac.uk

Study title: Exploring the effect of interpersonal and intrapersonal dynamics on carer anxiety in female dementia carers: a qualitative investigation

Application ID: ETH2122-0759

Dear Elien,

Your application was considered on 4th March 2022 by the FMH S-REC (Faculty of Medicine and Health Sciences Research Ethics Subcommittee).

The decision is: **approved**.

You are therefore able to start your project subject to any other necessary approvals being given.

If your study involves NHS staff and facilities, you will require Health Research Authority (HRA) governance approval before you can start this project (even though you did not require NHS-REC ethics approval). Please consult the HRA webpage about the application required, which is submitted through the IRAS system.

This approval will expire on **30th September 2023**.

Please note that your project is granted ethics approval only for the length of time identified above. Any extension to a project must obtain ethics approval by the FMH S-REC (Faculty of Medicine and Health Sciences Research Ethics Subcommittee) before continuing.

It is a requirement of this ethics approval that you should report any adverse events which occur during your project to the FMH S-REC (Faculty of Medicine and Health Sciences Research Ethics Subcommittee) as soon as possible. An adverse event is one which was not anticipated in the research design, and which could potentially cause risk or harm to the participants or the researcher, or which reveals potential risks in the treatment under evaluation. For research involving animals, it may be the unintended death of an animal after trapping or carrying out a procedure.

Any amendments to your submitted project in terms of design, sample, data collection, focus etc. should be notified to the FMH S-REC (Faculty of Medicine and Health Sciences Research Ethics Subcommittee) in advance to ensure ethical compliance. If the amendments are substantial a new application may be required.

Approval by the FMH S-REC (Faculty of Medicine and Health Sciences Research Ethics Subcommittee) should not be taken as evidence that your study is compliant with the UK General Data Protection Regulation (UK GDPR) and the Data Protection Act 2018. If you need guidance on how to make your study UK GDPR compliant, please contact the UEA Data Protection Officer (dataprotection@uea.ac.uk).

Please can you send your report once your project is completed to the FMH S-REC (fmh.ethics@uea.ac.uk).

I would like to wish you every success with your project.

On behalf of the FMH S-REC (Faculty of Medicine and Health Sciences Research Ethics Subcommittee)

Yours sincerely,

Paul Linsley