Risk and protective factors affecting the quality of life of family carers of people with dementia: the role of psychological flexibility

Milena Lucía Contreras

Thesis submitted for the degree of Doctor of Philosophy

School of Health Sciences

Faculty of Medicine and Health Sciences

University of East Anglia

May 2021

Abstract

Caring for someone with dementia can be physically and emotionally demanding, which leads to family carers of people with dementia having a low quality of life (QoL). Currently, the effects of existing interventions on the QoL of family carers of people with dementia is limited. Thus, this thesis focused on identifying key factors that affect the QoL in this population to inform future interventions. First, a meta-analysis was conducted to update the current knowledge about factors associated with carer QoL. The findings demonstrated that previous studies exclusively relied on the use of generic QoL measures not designed for dementia carers and focused on exploring the impact of contextual factors such as the care recipient's neuropsychiatric symptoms on QoL. To overcome the gap in the literature, it was decided to use a QoL measure suitable for the carer population, which defines QoL in terms of an individual's capability to do certain things that are important in life (e.g. doing things that make an individual feel valued) for this thesis. The impact of various risk and protective factors, which were not fully investigated in the previous literature, on carer QoL were explored in the subsequent three cross-sectional studies. The findings suggested that carer anxiety and sleep quality seem to have a significant impact on carer QoL. However, individuals with high levels of psychological flexibility, the ability to choose to do what matters most even in the presence of painful internal struggles, seem to be able to maintain a better QoL, despite the impact of such risk factors. The final study focused on exploring the educational and support needs of family carers of people in the early stages of Alzheimer's disease using qualitative methods. The factors that may need to be targeted in future interventions aimed at improving carers QoL are discussed.

Access Condition and Agreement

Each deposit in UEA Digital Repository is protected by copyright and other intellectual property rights, and duplication or sale of all or part of any of the Data Collections is not permitted, except that material may be duplicated by you for your research use or for educational purposes in electronic or print form. You must obtain permission from the copyright holder, usually the author, for any other use. Exceptions only apply where a deposit may be explicitly provided under a stated licence, such as a Creative Commons licence or Open Government licence.

Electronic or print copies may not be offered, whether for sale or otherwise to anyone, unless explicitly stated under a Creative Commons or Open Government license. Unauthorised reproduction, editing or reformatting for resale purposes is explicitly prohibited (except where approved by the copyright holder themselves) and UEA reserves the right to take immediate 'take down' action on behalf of the copyright and/or rights holder if this Access condition of the UEA Digital Repository is breached. Any material in this database has been supplied on the understanding that it is copyright material and that no quotation from the material may be published without proper acknowledgement.

List of contents

List of tables

List of figures

List of Abbreviations

AAQ-II	Acceptance and Action Questionnaire-II
ACT	Acceptance and Commitment Therapy
AD	Alzheimer’s disease
ADL	Activities of daily living
CBT	Cognitive Behavioural Therapy
CCI	Charlson Comorbidity Index
DKAS	Dementia Knowledge Assessment Scale
ES	Early stages
ESAD	Early stages of Alzheimer’s disease
EQ-5D	EuroQol-5D
FRS	Frontotemporal Dementia Rating Scale
GAD	General anxiety disorder
GAD-7	Generalised Anxiety Disorder Scale
HDI	Human Development Index
HRQoL	Health-Related Quality of Life
ICECAP-O	Index of Capability for Older People
MBI-C	Mild Behavioral Impairment Checklist
MC	Milena Contreras (first author)
NICE	National Institute for Health and Care Excellence
NHS	National Health System
NK	Naoko Kishita (third author)
NR	Not reported
PHQ-9	Patient Health Questionnaire
PSQI	Pittsburgh Sleep Quality Index
PRISMA	Preferred Reporting Items for Systematic Reviews and Meta-Analyses
PwD	People with Dementia
QoL	Quality of Life
QALYs	Quality-adjusted life years
SCS-SF	Self-compassion Scale short form
SF-36	36-Item Short Form Survey
UK	United Kingdom
WHO	World Health Organization

Acknowledgements

As I finish writing up my thesis I cannot stop thinking about how grateful I am for all the people that have supported me during my PhD.

I would like to thank to all the participants that took part in the quantitative and qualitative studies, I am truly grateful for your time, for opening me your doors, the cups of teas you shared with me during the cold days and the lifts to the bus and train stations on those rainy days. I have learned so much from all of you and helping you has been my great motivation throughout my PhD.

To my supervisors Naoko Kishita and Eneida Mioshi, thank you so much for your support, you have made the whole PhD experience so enjoyable and I really appreciate your kindness and encouragement during these last years. I particularly would like to thank you Nao for your dedication and for always being there for me, you have been a great inspiration and I will be forever grateful for everything you have taught me.

To the NIHR ARC East of England, the Norfolk and Suffolk Primary and Community Care Research Office and the Faculty of Medicine and Health Sciences, University of East Anglia, thank you for funding my PhD and for the incredible opportunity you have given me. Thank you Juni West from the Norfolk and Suffolk NHS Foundation Trust for your help with the recruitment and data collection, it has been a pleasure working with you. I also would like to thank Luke Emrich-Mills, Natali Sofroniou, Jasmin Plan, Amanda Wheeler and Elien Van Hout for their time and assistance in different moments during my research.

Thanks to all the members of the Neurodegeneration Network. In particular, I would like to thank Julieta Camino for being my partner in crime since day one, having shared this PhD journey with you has been the best. Thanks to Polly Trucco as well, I will always treasure our talks while walking to campus or around the neighbourhood and, above all, your kindness. You two have been my Argentinian family at UEA and I am so grateful for your friendship and support.

To team QB for our tea breaks and the support. I particularly would like to thank my Berlin babes Allie Welsh and Bryony Porter. I will always be grateful for your friendship, and for having created the best memories during my time in Norwich. Thanks for your support, particularly during lockdown and during the last months.

To Marcos Cupani, who has motivated me and inspired me to pursue a career in research. I got this amazing opportunity because of what you have taught me.

To Carol, Mark and Eddie, thank you for welcoming me into the Robinson family. Having you close made me feel less homesick and I am very grateful for all the love, support and encouragement (and meals) you gave me since I moved to the UK. I feel very happy to be part of your family.

To all my friends from Argentina, I feel so lucky so have you all and I am grateful for your continuous support and love despite the distance. Thank you Guada for always having my back, and for our weekly Pilates classes over zoom when I was really stressed, *lo tenemos!* Special thanks to Eve and Anni for accompanying me while writing my thesis through our virtual coworking, you can't imagine how much you have helped me! Thank you Juli, Mica and Nachi for all the talks, the laughs and your infinite friendship.

To all my family in Argentina whom I miss every day, *if I could bottle up the ocean, we could share a glass or two*. To my aunt Elda for being like another mum, you have always been there to encourage me and I cannot wait to celebrate this with you. To Pablo and Facu for the brotherly love, in particular to Facu, who always has inspired me and for giving me the greatest happiness during my PhD. To my nice Pauli, thanks for all the games and laughs by video call, your smile has been my booster throughout my PhD and seeing your photo on my desktop every day has motivated me to work hard to show you that women can achieve anything we put our mind to. To my dad for your wise and loving words, for always supporting my decisions and for encouraging me to carry on. To my mum for setting a great example of female empowerment that has inspired me my whole life, for looking after me despite the distance, for all the love and support and for always reminding me that life is beautiful and colourful.

To my amazing partner Tom, thank you for being my number one supporter. I cannot thank you enough for everything you have done for me and for the patience during these last years. I am truly grateful for having you in my life and for all the love you give me every day.

Finally, I would like to dedicate this thesis to my aunt Beba who passed away a year ago. You have been the grandma I never had, and our relationship has inspired me to dedicate my career to working with older adults. I will be forever grateful for all the love and the inspiration.

Oral presentations arising from this thesis

The role of psychological flexibility in improving the quality of life, depression and anxiety in family carers of people with dementia. 10th International Congress of Cognitive Psychotherapy. [Oral Presentation accepted as part of the Symposium: "Advances in the conceptualization and treatment of dysfunctional cognition in the context of dementia family caregiving stress: The Acceptance and Commitment Therapy approach"]. May 2021.

Risk and protective factors affecting the quality of life of family carers of people with dementia: the role psychological flexibility. NIHR ARC East of England Early Career Researcher Event. February 2021.

Introduction to research in contextual behavioural science. Association for Contextual Behavioral Science (ACBS) Argentina Chapter. [90 minutes workshop in Spanish]. November 2020.

The impact of psychological flexibility on depression, anxiety and quality of life in family caregivers of people with dementia. ACBS Argentina Chapter Conference. [Oral presentation in Spanish]. September 2020.

What factors affect the quality of life of Family Carers of People with Dementia? Dementia Open Forum. UEA Dementia Research Collaborative & Alzheimer's Research UK. [Public lecture]. February 2020.

Predictive Factors of Quality of Life in Family Carers of People with Dementia. The Second Tohoku Conference on Global Japanese Studies: Aging and Maturing of Japan and the World. Tohoku, Japan. December 2019.

Towards integrated care: Understanding the needs of families supporting a person with dementia (iCARE). Norfolk and Suffolk NHS Foundation Trust Older People's Open Forum. Norfolk and Suffolk NHS Foundation Trust. October 2019.

Poster presentations arising from this thesis

Protective factors predicting quality of life in family carers of people with dementia: the role of psychological flexibility. Association for Contextual Behavioral Science (ACBS) World Conference 2021. June 2021.

Risk and protective factors affecting the quality of life of family carers of people with dementia. Alzheimer's Association International Online Conference. July 2020

Factors Affecting the Quality of Life in Family Carers of People with Dementia: a meta-analysis. 29th Alzheimer Europe Conference: making valuable connections. The Hague, Netherlands. October 2019.

Predictive Factors of Depression, Anxiety and Quality of Life in Family Carers of People with Dementia: the role of psychological flexibility. ACBS World Conference 17. Dublin, Ireland. June 2019.

Factors Affecting the Quality of Life in Family Carers of People with Dementia: a meta-analysis. CLAHRC East of England Celebration and ARC Planning Event. NIHR Collaboration for Leadership in Applied Health Research & Care East of England. February 2019.

Publications arising from this thesis

Contreras, M., Mioshi, E. & Kishita, N. (2020). Factors related to the quality of life in family carers of people with dementia: a meta-analysis. *Journal of Geriatric Psychiatry and Neurology*. https://doi.org/10.1177/0891988720924713

Kishita, N, **Contreras, M.,** West, J. & M. L., Mioshi, E. (2020). Exploring the impact of carer stressors and psychological inflexibility on depression and anxiety in family carers of people with dementia. *Journal of Contextual Behavioral Science, 17 119-125.* https://doi.org/10.1016/j.jcbs.2020.07.005

Contreras, M., Mioshi, E. & Kishita, N. (2021). What are the educational and support needs of families looking after someone in the early stages of Alzheimer's disease? A qualitative retrospective approach. *Health & Social Care in the Community* [In press].

Contreras, M., Khondoker, M., Mioshi, E. & Kishita, N. (2021). Factors affecting the quality of life of family carers of people with dementia: The role of carer anxiety. [Under review].

Contreras, M., Mioshi, E. & Kishita, N. (2021). Protective factors predicting quality of life in family carers of people with dementia: the role of psychological flexibility. [Under review].

Contreras, M., Mioshi, E. & Kishita, N. (2021). The impact of physical health, sleep quality and psychological flexibility on the quality of life of family carers of people with dementia. [Submitted for publication].

Chapter 1

General Introduction

Dementia

General Overview

The term ‘Dementia’ does not refer to a specific disease but is used to describe a set of symptoms that can include loss of memory and cognitive functioning. Some of the most common symptoms may include difficulties with thinking, planning, problem-solving, time and place disorientation, or language and, sometimes, changes in perception, mood or behaviour. Dementia is not a normal part of ageing but is caused by physical changes and damages in the brain due to neurodegenerative diseases (Alzheimer's Society, 2013).

According to the World Alzheimer Report, in 2015, there were 46.8 million people worldwide living with dementia and it is estimated that there will be 74.7 million by 2030 and 131.5 million by 2050. This means that the numbers will almost double every 20 years (Prince et al., 2015). In the United Kingdom (UK), it is believed that currently 885,000 people are living with dementia and these numbers will rise to over 1.6 million by 2040 (Wittenberg et al., 2019).

Dementia affects not only the patient but also the whole family. Independently of the type of dementia, individuals start losing their independence and needing some support in carrying out the essential aspects of daily living at some point. Family members are often a primary resource for this type of care (Brodaty & Donkin, 2009; Ferrara et al., 2008). It is estimated that over 60 per cent of people with dementia are living in the community in the UK and around 87% of them receive help from their family members in their daily life (Alzheimer's Society, 2017; Prince et al., 2014). This means that family carers have a crucial role in dementia care.

Dementia Costs

Dementia is one of the most expensive health conditions. The total estimated worldwide cost of dementia was one trillion dollars in 2018 (Prince et al., 2014). In the UK, the current estimated annual cost of supporting people with dementia is approximately £34.7 billion. It is estimated that health care accounts for 14% of this annual cost in the UK, social care (public and privately funded) for 45% and unpaid care account for 40%. Crucially, around 60% of the overall social care costs are currently shouldered by people with dementia and their families, saving the UK economy billions each year (Wittenberg et al., 2019). For this reason, it is critical to ensure that carers are well supported and their own needs are assessed and responded to throughout the journey of their caring role (Lewis et al., 2014; Prince et al., 2014).

Informal care: the impact of caregiving on QoL

There are several positive aspects of caregiving that have been explored in the dementia literature. A previous systematic review including 41 quantitative and qualitative studies, identified a sense of personal accomplishment and gratification, feelings of mutuality in the dyadic relationship, an increase of family cohesion and functionality, and a sense of personal growth and purpose in life to be rewarding aspects of caregiving (Yu et al., 2018).

Despite the presence of these positive aspects of caregiving, most of the existing research is focused on exploring the negative consequences. It is well known that dementia carers have high levels of physical burden and psychological distress and these levels are higher than in carers of people with other conditions, such as cancer and frailty (Harding et al., 2015; Kim & Schulz, 2008; National Alliance for Caregiving in partnership with the Alzheimer's Association, 2017). Previous meta-analyses have found that the prevalence of mental health problems, such as depression, anxiety and burden, is substantial in family carers of people with dementia (Collins & Kishita, 2020; Kaddour & Kishita, 2019).

Furthermore, the stress of providing dementia care increases carers' susceptibility to disease and physical health complications (Fonareva & Oken, 2014) which also upsurges the utilisation of healthcare services significantly when compared to non-carers (Rahman et al., 2019). Moreover, being a carer can also have a significant impact on social life. Family members often still have the perception that dementia is a part of ageing, rather than a disease, and sometimes this perception appears to be used to justify family disengagement (Bamford et al., 2014). As a consequence, primary, sole family carers are required to take the greatest responsibility for the daily care, making it difficult to find time for themselves. In the UK, it is estimated that 8 in 10 carers (81 per cent of the total sample) feel lonely or socially isolated as a result of their caring responsibilities and only a third of them have as much social contact as they would like (NHS Digital, 2017). Dementia caregiving also has long-term economic impacts. It is estimated that people with dementia and their carers typically spend £100,000 on the care the patient needs, but for many people, the costs can be much higher (Alzheimer's Society, 2018).

To summarise, caring for someone with dementia can be physically and emotionally demanding and it can seriously affect the psychological, physical and social wellbeing of the carer and their economic conditions (Ferrara et al., 2008; Richardson et al., 2013). Although the positive aspects of caregiving can coexist with the negative consequences (Andrén & Elmståhl, 2005; Narayan et al., 2001), family carers tend to have a lower quality of life (QoL) as every aspect of their life is significantly affected, and their QoL tends to be lower than non-dementia carers and non-carers (Karg et al., 2018; Pierre Moïse et al., 2004; Scholzel-Dorenbos et al., 2009).

The current evidence for the efficacy of carer interventions on QoL

The UK Government's action plan - 'Carers Strategy: Second National Action Plan 2014 - 2016' (2014) and the 'Prime Minister's Challenge on Dementia 2020 Implementation Plan' (Department of Health UK, 2016) emphasise the importance of supporting carers to remain mentally and physically well and the need of focusing on prevention and early interventions for carers to improve their QoL. Poor carer QoL is also likely to be associated with poorer outcomes for the person with dementia, and with higher economic costs (Prince et al., 2014), and QoL is now seen as a key measure of efficacy and cost-effectiveness of interventions in health and social care research (NICE, 2013).

Different types of non-pharmacological interventions have been developed for dementia carers and have been tested in the research context. Several systematic reviews and meta-analyses have summarised the benefits and limitations of these interventions. Most of the reviews remark the relevance of educational interventions, counselling/psychotherapeutic interventions and multicomponent interventions for this population in particular (Cheng & Zhang, 2020; Cheng et al., 2020; Kishita et al., 2018).

Despite the increased awareness of the importance of improving QoL, many studies included in these previous reviews demonstrated that the efficacy of interventions on subjective wellbeing outcomes, such as QoL, was smaller when comparing to that of other carer outcomes (e.g. depression and burden) (Cheng et al., 2020). A recent comprehensive meta-review, which included sixty systematic reviews and meta-analyses, also supported this key finding, suggesting that there might be a potential for psychoeducational interventions to enhance carer QoL, but there is not enough evidence on the efficacy of other types of interventions on this important outcome (Cheng & Zhang, 2020). Therefore, it is fundamental to identify the modifiable factors that may affect the family carers' wellbeing to fill the gaps in the literature and to guide the formulation and delivery of policy, treatment, care, and support to improve their QoL (Farina et al., 2017).

How best to assess QoL in family carers of people with dementia

General Quality of Life and Health-Related Quality of Life

QoL is a term frequently used in the literature, but to date, there is no consensus about how to define it (Dow et al., 2018; Langenhoff et al., 2001). The World Health Organization (1995) considers the general QoL as a broader, multidimensional and subjective concept. They define it as the individual's perception of their position in life in relation to their goals, expectations, standards and concerns, according to the culture and value systems in which they live. General QoL can include several aspects such as psychological state, physical health, level of independence, personal beliefs and spirituality, social relationships and environment (WHO, 1995).

Another important concept that is present in the QoL literature is the Health-Related Quality of Life (HRQoL). This can be considered as the objective QoL and refers to the components of QoL that are directly and indirectly affected by health, disease, disorder, and injury and, therefore, it overlaps with the concept of health status (Dijkers, 1997; Post, 2014).

To date, several self-rated QoL measures have been developed to assess the concept as a whole (general QoL), or as health-related or disease-specific QoL (HRQoL). Evaluating general QoL is useful when evaluating conditions or interventions that affect the individual as a whole, as well as their ability to function in multiple roles within their family, workplace and community. On the other hand, HRQoL measures have a substantial emphasis on physical and mental functioning, and they focus only on the areas of life that are directly affected by their health or the condition or disease, and its treatment. Nevertheless, whether measuring general QoL or HRQoL, instruments can be generic, disease or symptom-specific (Bowling et al., 2015; Dow et al., 2018).

The critical problem with the existing literature on carers of people with dementia, including interventional studies, is the types of QoL measures used. The most commonly used measures are generic measures of QoL, such as the 36-Item Short Form Survey (SF-36) (Ware & Sherbourne, 1992), EuroQol-5D (EQ-5D) (The EuroQol Group, 1990) and WHOQOL-BREF (WHO, 1995) (Farina et al., 2017; Jones et al., 2012). This is problematic as generic measures of QoL or instruments that have not been validated in dementia carers may not capture caring-specific components that can affect QoL and might not be sensitive enough for detecting changes in the progression of dementia (Farina et al., 2017; Hounsome et al., 2011; Kishita et al., 2018; Reed et al., 2017).

QoL measures designed for the carer population

Previous reviews have identified that some care-specific and dementia-specific instruments have been used in the carer literature, but the number is very limited, and there is no consensus between these reviews in terms of the best instrument to measure QoL among dementia carers (Bowling et al., 2015; Dow et al., 2018; Jones et al., 2012, 2014; Manthrope & Bowling, 2016; Page et al., 2017). To overcome these challenges, a few new instruments have been developed in recent years (Kishita et al., 2018).

The Dementia Quality of Life Scale for Older Family Carers (DQoLOC) is a 22-item scale for measuring QoL in older family carers of people with dementia (de Oliveira et al., 2018). Even though some of the psychometric properties reported are good, the scale is relatively new and has some limitations, such as the small sample size used in the data analysis and the fact that the study did not present evidence of discriminant validity against differing psychological constructs (e.g. burden or depression). Thus, more validation and replication studies with larger samples are needed before sound psychometric properties can be established (de Oliveira et al., 2018; Hubbard, 2016; Morgado et al., 2017).

The C-DEMQOL is a 30-item questionnaire that was also specially developed for family carers of people with dementia (Brown et al., 2019). Although this recently developed scale seems a promising measure to assess QoL, it is still considered experimental and more studies are needed to evaluate its psychometric properties, to examine its responsiveness, to replicate the model, as well as some validation studies (Brown et al., 2019; Hubbard, 2016; Morgado et al., 2017).

Finally, the Scales measuring the Impact of DEmentia on CARers (SIDECAR) (Horton et al., 2021) comprise of three independent scales: a primary scale evaluating the direct impact of caring on carer QOL (SIDECAR-D; 18 items), and two secondary scales measuring the indirect impact of caring (SIDECAR-I; 10 items) and support and information (SIDECAR-S; 11 items). These needs-based scales may be used independently, or together, to provide a profile of QoL across the three domains. The development of the SIDECAR overcame some of the limitations of the aforementioned questionnaires by using a larger sample, conducting a Rash analysis and including a study of responsiveness. However, the scales are still new and replication studies are needed before the scales can be used with confidence (Horton et al., 2021; Hubbard, 2016).

The development of these three QoL measures represents an important step in the dementia caregiving literature. However, some other limitations are shared across the measures. Firstly, they are quite long and time-consuming instruments which could be problematic if other questionnaires measuring different constructs are being applied at the same time. Secondly, the studies developing and validating these three carer-specific scales were conducted in the UK, which may imply that the instruments are not culturally sensitive. Thirdly, none of the measures can be used in economic evaluations yet, which is a disadvantage when choosing an instrument to inform the impact of interventions on carers QoL.

ICEpop CAPability measure for Older people (ICECAP-O) Measuring QoL

In this thesis, the ICEpop CAPability measure for Older people (ICECAP-O) (Grewal et al., 2006) has been used across three studies (Study 2, Study 3 and Study 4). There are several advantages of using the ICECAP-O. First of all, it has good psychometric properties with decent evidence about its reliability, validity and responsiveness, while over twenty studies have explored its psychometric properties in different demographic and clinical groups from different countries (Proud et al., 2019). Furthermore, this instrument has been validated in a sample of informal carers of people with dementia. Even though this measure is sensitive to changes related to age and was originally developed to assess QoL in individuals aged 65 and over, this validation study demonstrated that the scale is also appropriate for younger carers who may also be living with uncontrollable life circumstances (Perry-Duxbury et al., 2020). Another advantage of this measure is that it only has 5 items (i.e., short and concise measure of carer QoL). This would offer greater flexibility to researchers and clinicians as they often need to conduct these assessments alongside several other scales.

The previous literature has shown that QoL does not decrease due to specific factors such as poorer health, but instead QoL decreases because of limitations in what the person can do as a result of poor health (Grewal et al., 2006). In other words, it is critical to assess the levels of capabilities and fundamental conditions required for individuals to pursue activities that they value (e.g. sense of independence) rather than functioning (e.g. the level of disabilities) or a reduction in their ability as a result of the uncontrollable life circumstances such as health conditions (Coast et al., 2008).

In this context, HRQoL measures such as the EQ-5D (e.g., the assessment of mobility and self-care such as dressing) may not be the most suitable tool to detect key areas of needs in the older population and particularly in carers. The ICECAP-O assesses QoL defined in a broader sense, rather than health, such as the ability to do things that make them feel valued and their sense of independence. Given that many family carers are likely to be older adults themselves, the capability approach and this measure, in particular, seem appropriate to use with the target sample.

Furthermore, unlike other recently developed carer-specific QoL measures, the ICECAP-O is a tool that can be used to assess the cost-effectiveness of new interventions using years of full capability equivalent. Standard methods of health economic evaluations mainly report the effectiveness of interventions and treatments in quality-adjusted life years (QALYs), which is calculated using preference-based utility measures, such as the EQ-5D (Jones et al., 2012). While this approach is widely used in the economic evaluation literature, it only identifies outcomes based on a quite narrow definition of health (e.g. physical health). Instead, years of full capability equivalent allows estimating the effectiveness of many interventions, particularly in the areas of mental health and health and social care, where the impacts of interventions go beyond this narrow view of health (Helter et al., 2020).

Potential factors affecting QoL in family carers

This thesis aimed to identify modifiable factors that can predict QoL in family carers of people with dementia to understand the complex needs of family carers and identify critical components that need to be considered in the development of future interventions aiming at improving carer QoL using the QoL assessment tool suitable for this population (i.e. the ICECAP-O). To achieve this key objective, five different studies were conducted.

In the first study (Chapter 2), a meta-analysis review was conducted to update the existing systematic reviews and quantitatively synthesise the findings from the previous studies to identify carer- and patient-level factors that were associated with the QoL of family carers of people with dementia. Furthermore, the type of instruments used to measure QoL and the moderating factors that could influence the strength of the relationship between such potential predictive factors and QoL were explored.

The factors that were found to have a significant association with QoL in family carers of people with dementia, according to this meta-analysis (i.e. carer depression, burden, and people with dementia's neuropsychiatric symptoms), were considered as potential predictors of QoL as assessed by the ICECAP-O in the second study (Chapter 3). Moreover, considering how prevalent anxiety is in this population and how neglected this construct is in the carer literature, anxiety was also included as one of the potential predictors in the regression analysis.

While the second study (Chapter 3) was solely focused on risk factors, the third study (Chapter 4) explored the impact of potential protective factors (i.e., knowledge about dementia, psychological flexibility, self-compassion and hours of support from other family members) that could lead to improvements in QoL. After identifying that psychological flexibility was the only protective factor predicting QoL in the third study, the fourth study (Chapter 5) explored if this protective factor could still predict QoL despite the presence of common health problems among dementia carers, such as comorbidities and low quality of sleep.

Finally, the fifth study (Chapter 6) explored the educational and support needs of family carers of people with dementia in the early stages, the subgroup of carers often neglected in the carer literature, by employing a qualitative approach with retrospective semi-structured interviews with family carers of people in the later stages of Alzheimer's disease. This study found other key components to be considered for future inventions that would not have been identified using only quantitative methods.

The context in which the PhD project was situated

Some parts of the current PhD project (chapters 3, 4 and 5) were derived from a larger research study: ‘Towards Integrated support: The role of carer- and patient-level characteristics on family CARER quality of life at different stages of dementia (iCARE)’. The study protocol was developed by the primary and secondary supervisors, who selected the measures to be included in the assessment package, and the project received ethical approval from the NHS Research Ethics Committee and Health Research Authority (17/LO/0564).

The iCARE study started in 2017 without any funding, but its delivery and data collection were supported by the Norfolk and Suffolk NHS Foundation Trust during this initial stage. In 2018, the primary and secondary supervisors received funding to employ a doctoral student to take responsibility for the iCARE study and, from April 2018, the PhD candidate led the iCARE study. The tasks carried out by the PhD candidate included leading the recruitment of participants, data collection, managing all research-related documentation, designing the research questions and study aims of the three cross-sectional studies presented in chapters 3, 4 and 5, analysing the data, writing up the manuscripts for publication and disseminating the findings to the public.

Moreover, the meta-analysis (chapter 2) and qualitative study (chapter 6) were not included in the iCARE study protocol but were developed by the PhD candidate independently to fill the gap in the literature and provide a better understanding of the QoL of dementia family carers. In the meta-analysis, the PhD candidate designed the research question and study aims, conducted the search, led the data analysis and wrote the manuscript for publication. In the qualitative study, the PhD candidate was responsible for designing the research questions and study aims, obtaining the ethical approval, recruiting participants, conducting the interviews, leading the data analysis and writing up the manuscript.

Chapter 2

Factors related to the quality of life in family carers of people with dementia: a meta-analysis

Published manuscript

Introduction

The number of people living with dementia worldwide is currently estimated at 35.6 million and this number is expected to double by 2030 and more than triple by 2050 (Wortmann, 2012). Dementia is one of the most expensive health conditions and the current annual worldwide cost of dementia is estimated to be US$ 818 billion (Wimo et al., 2018). As such, dementia is considered as one of the greatest health challenges we face today.

Dementia is a progressive condition and while some individuals maintain their independence for many years, many require progressively more support with daily activities, particularly in the later stage of the condition (Alzheimer's Society, 2013). Family members are considered as a primary resource for this type of care in many countries. For example, in the UK, people affected by dementia and their relatives are currently shouldering two-thirds of all dementia care costs, saving the UK economy billions each year (Alzheimer's Society, 2018). In Latin-American countries, such as Brazil, there are fewer healthcare services specialised in dementia, which reinforces the belief that families should be responsible for the person with dementia (Santos et al., 2013). The lack of provision of dementia services within the public healthcare system is also common in Asian countries such as China, and as a consequence, families take over the significant caring role (J. Wang et al., 2014).

These suggest that unpaid family carers are an essential taskforce in caring for people with dementia worldwide. Therefore, this review focused on unpaid family carers (i.e. informal carers) who are characteristically different from formal carers (i.e., healthcare professionals) paid to provide essential care.

Caring for someone with dementia can be physically and emotionally demanding and it can seriously affect the social, psychological and physical wellbeing of the family carer (Ferrara et al., 2008; Richardson et al., 2013). The previous literature demonstrates that poor carer quality of life (QoL) is likely to be associated with poorer QoL for the person with dementia (Bruvik et al., 2012) and with higher economic costs (Prince et al., 2015).

QoL is a term frequently used in the literature but, to date, there is no consensus about how to best define and assess QoL in family carers of people with dementia (Dow et al., 2018; Langenhoff et al., 2001). The World Health Organization (WHO) defines it as the individual's perception of their position in life in relation to their goals, expectations, standards and concerns, according to the culture and value systems in which they live. General QoL includes several aspects such as psychological state, physical health, level of independence, personal beliefs and spirituality, social relationships and environment (WHO, 1995). There is another important concept of QoL often used in the literature that is the Health-Related Quality of Life (HRQoL). HRQoL refers to the components of QoL that are directly and indirectly affected by health, disease, disorder, and injury and therefore, HRQoL often overlaps with the concept of health status (Dijkers, 1997; Post, 2014).

In the past ten years, there have been emerging studies, which have developed more specific instruments to measure carer QoL (Al-Janabi et al., 2008; Dow et al., 2018; Quirk et al., 2012). Early carer studies predominately used general QoL and HRQoL measures. The use of general QoL and HRQoL instruments with older carers can be problematic as some aspects of these types of QoL (e.g., level of independence) could be affected by their age-related factors such as changes in physical conditions (Grewal et al., 2006). In this regard, these types of instruments have been criticised for lacking validity and not being sensitive enough to measure the psychological consequences and positive aspects of caring (Al-Janabi et al., 2011; Dow et al., 2018). In this meta-analysis, we defined the QoL of carers in a broader sense and included all types of QoL measures to provide a wider understanding of the potential impacts of different factors on carer QoL.

The national guidelines and policies such as the UK Government's action plan (2010) emphasise the need for focusing on early interventions for carers to support them in maintaining their QoL. For this reason, it is fundamental to identify the modifiable factors that may affect the family carers' QoL in order to guide the formulation and delivery of policy, treatment, care, and support to improve this crucial outcome (Farina et al., 2017).

Previously, there have been three review studies that have examined factors associated with the QoL of family carers of people with dementia. The first systematic review conducted by de Oliveira, Vass & Aubeeluck, which solely focused on examining the association of carers' advanced age with their QoL, demonstrated that carer's advanced age to be associated with low levels of their QoL (de Oliveira et al., 2015).

The second study, an integrative review conducted by Pereira & Soares and published in Portuguese, found that both factors related to carers themselves (e.g., having depression, poor sleep quality, pre-existing health problems, social support received, leisure activities, having received interventions or training for carers) and people with dementia (e.g., dementia type, neuropsychiatric symptoms) can influence the QoL of family carers (Pereira & Soares, 2015).

The most recent systematic review conducted by Farina et al. found that having better physical and mental health was the factor most strongly associated with having a better QoL. They also found that greater carer independence (e.g. activities and time not spent on caring duties) was positively associated with better QoL and that carers who lived with the care recipient had poorer QoL than those who did not. The health status of the people with dementia and their behavioural and psychological symptoms also seem to be detrimental to carer QoL (Farina et al., 2017).

These three reviews highlighted that both carer- and patient-characteristics could be potential predictors of carer QoL. However, these reviews have some methodological limitations. First, all reviews only included studies written in English, which might have induced a bias in the findings. One of the reviews (de Oliveira et al., 2015) only included studies that targeted carers aged 60 years or older and all included studies were carried out in developed countries and thus, the generalisability of the findings may be limited due to selection bias. When comparing the distribution of the total costs of dementia worldwide, 87% is currently spent in high-income countries despite the fact that the contribution of informal carers is expected to be greatest in developing countries (Wimo et al., 2018). It is, therefore, important to explore the impact of dementia across countries with different economic development status. Another limitation is that the second review by Pereira & Soares did not employ a systematic approach, but it was rather an integrative review using purposive sampling. Therefore, the findings could be prone to researcher bias (Pereira & Soares, 2015).

Large heterogeneity in the study designs was also evident across all three reviews. The authors combined correlational and regression studies (de Oliveira et al., 2015; Farina et al., 2017; Pereira & Soares, 2015) and included interventional and cross-sectional studies (Pereira & Soares, 2015) or quantitative and qualitative studies (Farina et al., 2017) in their single purposive sampling review. As a result, the included studies were completely heterogeneous, making it difficult to draw a robust conclusion.

Moreover, although the most recent review by Farina et al. was published in 2017, the literature search was conducted in November 2015. Taking into consideration that in recent years, there has been an increasing interest in dementia care research (Manthrope & Bowling, 2016), it is expected to find a larger number of articles over the last few years. As such, an updated review could address previous limitations and enhance our understanding of factors associated with carer QoL.

To overcome the aforementioned limitations and clarify the current state of the evidence base, an updated review using a meta-analytic approach was conducted with the following objectives:

1) To quantify the point estimate of effect size between carer QoL and different types of independent variables including those related to carers themselves (e.g., carer depression) and people with dementia (e.g., neuropsychiatric symptoms); and

2) To explore factors that may moderate the strength of such relationship including the development status of the country and types of tools used to assess the constructs of interest.

Methods

This meta-analysis adhered to the Preferred Reporting Items for Systematic Reviews and Meta-Analyses guidelines (PRISMA; Moher et al., 2009). The PRISMA checklist is included as a supplementary file (see Supplementary Table 2.1).

Eligibility Criteria

The review included quantitative articles published in peer-reviewed journals or academic reports (e.g. PhD thesis). Only cross-sectional and longitudinal studies were eligible for the review.

In order to be eligible for the current review, the study had to (a) recruit unpaid family carers of people with dementia; (b) use a validated measure of generic, health-related or care-related QoL to assess QoL in family carers as a dependent variable; (c) be published in English, Spanish, Portuguese or Japanese; and (d) report a Pearson correlation between the dependent variable (i.e., carer QoL) and independent variables. Any types of independent variables were eligible for the review including variables related to carers themselves (e.g., carer depression) and people with dementia (e.g., neuropsychiatric symptoms).

Information Sources

The databases of PubMed, PsycINFO and Scopus were searched to identify relevant published articles. ProQuest was used to search unpublished doctoral thesis and Lilacs and Scielo were used to search for studies from Spain and Latin America.

Search

The search was conducted by the first author (MC) using the keywords and search strategies outlined in Supplementary Table 2.2 Manual searches in the reference lists of relevant systematic reviews and articles were also completed to identify any potential missing articles. No date restriction was applied to the search for studies.

Study Selection

Search results were merged using EndNote software and duplicate articles were removed. All the titles and abstracts were screened for eligibility by the first author (MC), whereby clearly irrelevant articles were excluded. Following the initial screening, full-text articles were reviewed by two authors (MC and NK) independently using a structured checklist. The Kappa coefficient for the inter-rater agreement was .84, indicating almost perfect agreement(Cohen, 1960). Disagreements between two coders were resolved through discussions.

Data Collection Process

The first author (MC) developed an electronic data extraction sheet, which was pilot tested on a randomly selected study by two authors (MC and NK). Following this, the electronic form was refined accordingly. To minimize bias, data extraction was conducted on the first five selected studies by two authors (MC and NK) independently. No discrepancies were identified during this pilot phase. Following this, the first author (MC) and a research assistant independently extracted data from the remaining studies. The agreement rate between the two coders was 90.3%, indicating almost perfect agreement.

Data Items

For each included study, information was recorded on (a) study characteristics (the country where the study was conducted and study design); (b) sample characteristics (number of participants, age, gender, relationship with the person with dementia, the average length being a carer); (c) dementia type of the carer recipient; (d) measures used to assess carer QoL; (e) measures used to assess independent variables; and (f) correlation coefficient between carer QoL and the independent variables. If relevant information was not provided in the selected studies, it was considered as “not reported” and the authors did not contact researchers for further clarification.

Risk of Bias in Individual Studies

The Appraisal of Cross-sectional Studies (Downes et al., 2016) was used to assess the risk of bias in each included study. This tool consists of 20 items, which assess different aspects of the methodological quality and reporting quality such as appropriateness of study design and target population, measurement validity and reliability, appropriateness of interpretation of results and justification of conclusion. The Appraisal of Cross-sectional Studies does not include a numerical scale that can be used to produce a quality assessment score; instead, it aims to measure the individual characteristics of a study cumulatively (Wong et al., 2018). The first author and a research assistant assessed the risk of bias independently and disagreements were discussed. The Kappa coefficient for the inter-rater agreement was 0.56 indicating moderate agreement between the raters (Cohen, 1960).

Summary of Measures and Synthesis of Results

The entire analysis was conducted using Comprehensive Meta-Analysis software version 3 (Borenstein et al., 2005). There are no simple criteria in terms of how many studies are needed to calculate the meaningful pooled effect size. However, the combination of very few studies with very different characteristics makes any kind of synthesis untenable in most cases (Valentine et al., 2010). In this study, the meta-analysis was conducted only when the correlation coefficient between carer QoL and the targeted independent variable was available from more than three studies (i.e., if only two studies reported the correlation coefficient between carer QoL and the targeted independent variable and then quantitative synthesis was not performed).

The correlation coefficient from included studies was transformed to corresponding Fisher's scores to estimate a pooled effect size and its 95% confidence intervals (CI) for each independent variable. A fixed-effect model was used to provide a pooled estimated effect for each independent variable and a test for heterogeneity was performed using the Q-statistic and the I^2 statistic. Where there was evidence of heterogeneity a random-effects model was used. Estimated effect sizes of <0.09 were considered negligible, 0.10–0.29 small, 0.30–0.49 moderate and >0.50 large (Cohen, 1988).

If the correlation coefficient for the same independent variable was reported from two or more independent samples within a single study, they were treated as separate studies for the purpose of analyses. For example, the correlation coefficient for the same independent variable was reported separately for female and male samples in one study (Thompson et al., 2004) and for carers of people with mild, moderate and severe dementia in another study (Novelli & Caramelli, 2010). When the correlation coefficient for the same independent variable was reported for each subscale of the QoL measure rather than the total QoL score within a single study (Moreno et al., 2015), correlation coefficients were combined by calculating the mean of effect sizes across subscales to produce a single effect size (Borenstein et al., 2009). The "total QoL score" was used when possible (Amorim et al., 2017).

Risk of Bias Across Studies

To assess publication bias, the trim and fill method (Duval & Tweedie, 2000) was used to estimate how many studies could be missing from each meta-analysis and calculate adjusted effect-size estimates. Rosenthal's Fail-Safe N (Rosenthal, 1979) was used to calculate the number of missing studies needed to be included in the analysis to reduce the overall effect size to a non-significant level. If only a few studies are required to nullify the observed effect, the observed overall effect may not be robust (Borenstein et al., 2009).

Additional Analyses

For those independent variables, which demonstrated significant heterogeneity, a series of subgroup analyses were planned to examine the possible sources of variance. Initially, a series of subgroup analysis using the following moderators were planned: (a) the development status of the country as defined by the Human Development Index (HDI) category (low, medium, high, very high), which is a summary measure of a country's overall achievement in its social and economic dimensions (i.e., health, education and standard living) (UNDP, 2018); (b) types of measures used to assess carer QoL; (c) types of measures used to assess the independent variable; (d) the relationship with the person with dementia; (e) dementia type of the care recipient; (f) carer's gender; and (g) average length being a carer. However, the latter four moderators (i.e., relationship, dementia type, gender, length as a carer) were not reported consistently in many of the included studies or seemed to be similar across the included studies that did report. Therefore, it was not possible to conduct the subgroup analyses using these four moderators.

Results

Study Selection

The search was conducted on 30th May 2018 and a total of 2458 articles were found. After deleting 1124 duplicated articles, 1334 titles and abstracts were examined by the first author (MC). One hundred and two studies were identified as relevant for the meta-analysis and the full text were reviewed by the two coders (MC and NK) independently. From the 102 full-text reviewed, 33 fulfilled the inclusion criteria and data was extracted from each study. However, only 27 were included in the final meta-analysis (See Figure 1.1). The remaining five studies did report correlations between QoL and some independent variables, but data for the same independent variable was not available from more than three studies. Thus, these five studies were not included in the quantitative synthesis.

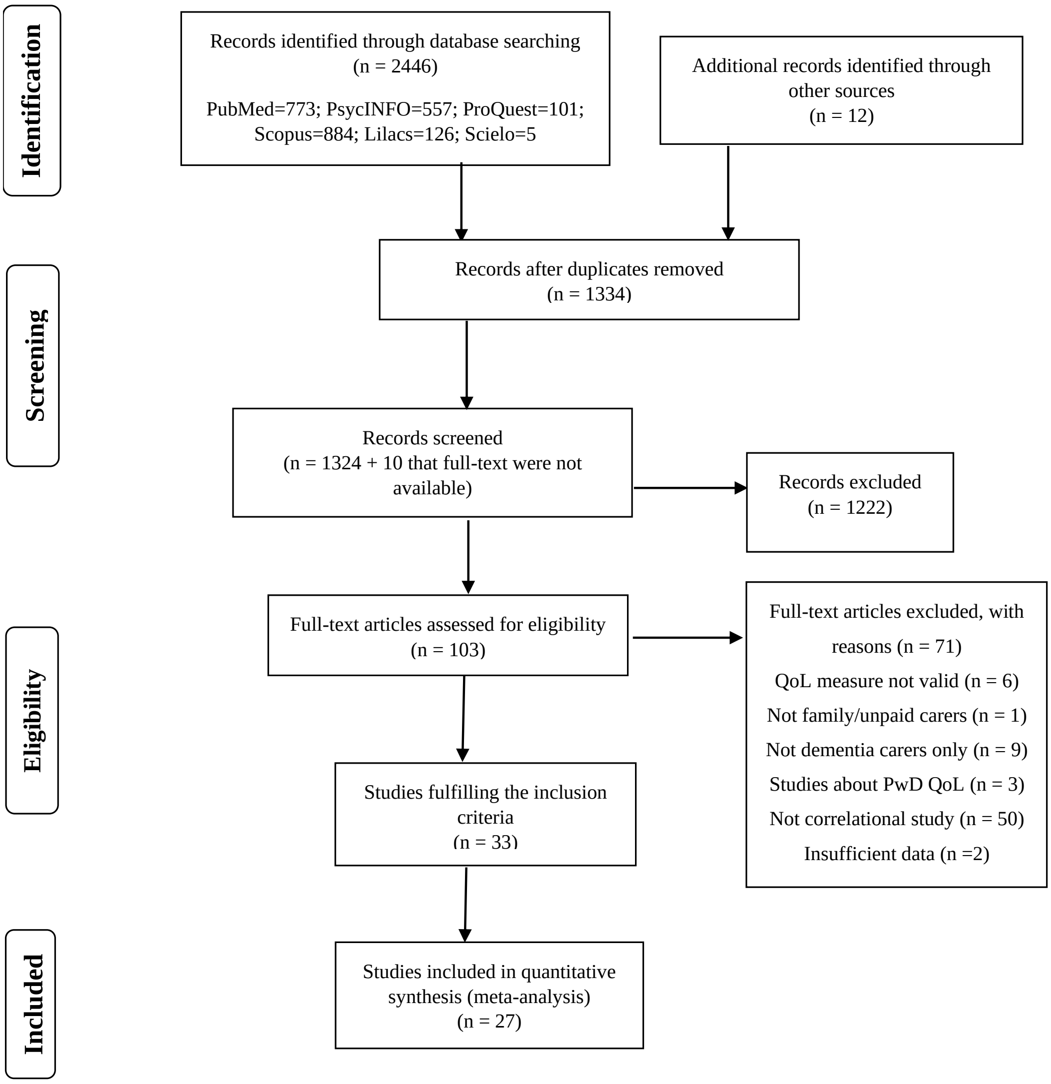


Figure 1.1 PRISMA flowchart of the selection of studies. QoL: quality of life; PwD: people with dementia.

Study Characteristics

Participants. The characteristics of included studies are presented in Table 2.1. The total number of carers was 6177. The majority of studies recruited carers from Europe (study *n*=12), North America (*n*=8) and South America (*n*=8). There were fewer studies which recruited carers from Asia (*n*=4) and Oceania (*n*=1). More than 65% of carers were females in the majority (over 70%) of the studies included (*n*=24). Over 75% of the studies (*n*=26) recruited people over 55 years old and 78% of studies only recruited carers with Alzheimer's disease (*n*=26). This diagnosis was the most prevalent in the remaining studies. Eight studies did not report the type of dementia of the care recipient. These results suggest that carers recruited in the identified studies were predominantly females over 55 years old looking after a family member with Alzheimer's disease.

QoL measures. The most commonly used measure of carer QoL were Quality of Life in Alzheimer's disease for carers (Logsdon et al., 1999) (QoL-AD; *n*=7), 36-Item Short Form Survey (Ware & Sherbourne, 1992) (SF-36; *n*=6) and WHO-QOL-BREF(WHO, 1995) (*n*=6). Over 60% of the included studies (*n*=20) used a general QoL measure (e.g., QoL-AD, WHO-QOL-BREF) and the rest used a health-related QoL measure (e.g., SF-36, EuroQol-5D (The EuroQol Group, 1990).

Independent variables. Most of the included studies reported correlations between carer QoL and carer subjective burden (*n*=11), carer depression (*n*=10), people with dementia's neuropsychiatric symptoms (*n*=11) and their level of independence in activities of daily living (ADL) (*n*=10). The majority of the studies used the Zarit Burden Interview (ZBI) (Zarit et al., 1985) to measure subjective burden (*n*=10), the Beck Depression Inventory (BDI) (Beck et al., 1988) to measure depression (*n*=5), the Neuropsychiatric Inventory (NPI) (Cummings et al., 1994) to measure neuropsychiatric symptoms (*n*=6) and the Katz Index of Activities of Daily Living (Katz et al., 1963) (*n*=3) to measure ADL.

Independent variables that were not included in the meta-analysis due to the number of studies identified were carer anxiety, satisfaction with life, coping strategies, social skills, frequency of nocturnal disruptions, relationship quality with the person with dementia, interpersonal support, some personality traits such as extraversion and neuroticism, physical health, number of hours providing care weekly, duration of caregiving in years (see Table 2.1).

Risk of bias within studies

The assessment of study quality and bias using the Appraisal of Cross-sectional Studies tool is presented in Table 2.2. All of the included studies clearly specified the aim of the study, used the appropriate study design, clearly defined the target population, measured carer QoL appropriately, used validated questionnaires, fully described the methods, and presented the results of all the analyses described in the methods. Overall, the methodological quality was adequate across the included studies. However, the majority of the included studies (*n*=25) did not justify the sample size and almost no studies reported information about non-responders.

Synthesis of results

Twenty-seven studies included in the meta-analysis demonstrated associations between carer QoL and different types of carer-related independent variables (subjective burden, depression, age, income, and distress) and people with dementia-related independent variables (neuropsychiatric symptoms, ADL, cognitive functioning and self-/proxy-rated QoL). A random model was used for carer depression and subjective burden, people with dementia's proxy-rated QoL, their neuropsychiatric symptoms and ADL due to significant heterogeneity.

Independent variables with a significant effect size (Figure 2.2)

Carer's depression (number of studies included in the analysis n=10). Ten studies reported the correlation coefficient between carer QoL and depression. The effect sizes varied from -0.30 to -0.82. Overall, the point estimate of effect size between carer QoL and depression was -0.58 (95% CI = -0.66 - -0.48, p < 0.00) suggesting a significant large effect. There was statistically significant high heterogeneity between study effect sizes (I^2 = 80.77%, *Q* = 57.29).

Carer's subjective burden (n=11). The effect sizes varied from -0.03 to -0.66. The point estimate of effect size between carer QoL and subjective burden was -0.47 (95% CI = -0.51 - -0.21, *p* < 0.00), suggesting a significant moderate effect. The heterogeneity between study effect sizes was significantly high (I^2 = 87.95%, *Q* = 82.98).

Table 2.1. Characteristics of included studies.

Authors	Country	Sample	Relationship to patient (%)	Average length being carer in years	Care Recipient Characteristics (Diagnosis, severity %)	Carer QoL measures	Variables correlated with QoL
1. Andreakou et al. (2016)	Greece	155 carers Female %: NR Mean age (SD): 58.1 (13.4)	Spouse: 38.00 Daughter/son: 48.40 Siblings: 2.60 Other: 11.60	4.6	Alzheimer's: 100.0 Mild: 22.6 Moderate: 54.8 Severe: 22.6	SF-36 (mental and physical components)	**Depression (ZDRS)**
2. Amorim et al. (2017)	Brazil	41 carers Female %: 87.8 Mean age (SD): 61.09 (13.4)	Spouse: 34.10 Daughter/son: 56.09 Other: 9.81	4.8	Alzheimer's:100.0 Severity: NR	WHOQOL-BREF	**Social Skills**
3. Borghi et al. (2011)	Brazil	50 carers Female %: 82.0 Mean age (SD): 53.83 (14.52)	Spouse: 16.00 Daughter: 60.0 Other: 24.00	4.63	Alzheimer's:100.0 Severity: NR	QoL-AD	**Carer-rated PwD QoL (QoL-AD)**
4. Coen et al. (1999)	Ireland	50 carers Female %: 72.0 Mean age: 56.5	Spouse: 46.00 Daughter/son: 44.00 Siblings: 2.00 Other: 8.00	2 (Median)	Alzheimer's: 100.0 Mild: 66.0 Moderate: 22.0 Severe: 12.0	Evaluation of Individual Quality of Life – Direct Weighting (SEIQoL-DW)	**Perceived Burden (ZBI); Well-being;** Social support; Behaviour disturbance (DBD); Cognitive functioning; Functional status; Carer-rated patient QoL (QoL-AD)
5. Conde-Sala et al. (2010)	Spain	251 carers Female %: 66.1 Mean age (SD): Spouse: 73.6(7.4); Child: 49.3(7.2)	Spouse: 44.60 Daughter/son: 55.30	NR	Alzheimer's: 100.0 Mild: 10.36 Moderate: 68.92 Severe: 20.72	SF-12 (mental component)	**Daughter-rated patient QoL (QoL-AD)**; Wives-rated patient QoL (QoL-AD); Husbands-rated patient QoL (QoL-AD); Son-rated patient QoL (QoL-AD)
6. Creese et al. (2008)	Canada	60 carers Female %: 68 Mean age (SD): 73.65 (9.26)	Spouse: 100	4.61	Alzheimer's: 100.0 Severity: NR	SF-36 (mental and physical components)	Current sleep quality; Change in sleep quality; Frequency of nocturnal disruptions; Current sleep quality; Change in sleep quality; **Frequency of nocturnal disruptions**
7. Crellin (2015)	UK	289 carers Female %: 68.2 Mean age (SD): 66.7 (12.3)	Spouse: 63.3 Adult child/other family: 34.9 Other: 1.7	4.4	Alzheimer's: 51.0 Vascular: 18.6 Others: 30.4 Mild: 63.0 Moderate: 27.0 Severe: 10.0	SF-12 (mental and physical components)	**Positive impact; QoL physical component score (SF-12); Self-efficacy for obtaining respite; Self-efficacy for responding to disruptive behaviours; Self-efficacy for controlling upsetting thoughts; Self-efficacy for managing neuropsychiatric symptoms; Quality of support,** Emotion-focused coping**; Problem focused coping; Dysfunctional coping; PwD neuropsychiatric symptoms (NPI);** PwD Cognitive functioning**; PwD activities of daily living**

Note: NR= Not reported; QoL= quality of life; PwD= people with dementia, AD= Alzheimer's Disease. SF= Short form; ZDRS= Zung Depression Rating Scale; ZBI= Zarit Burden Interview; DBD= Dementia Behaviour Disturbance. Variables in bold are those ones that presented statistically significant correlations with carer QoL.

Table 2.1 (continued)

Authors	**Country**	**Sample**	**Relationship to patient (%)**	**Average length being carer in years**	**Care Recipient Characteristics (Diagnosis, severity %)**	**Carer QoL measures**	**Variables correlated with QoL**
8. Feast et al. (2017)	UK	157 carers Female %: 70.96 Mean age: 66.34	Spouse: 53.55	NR	Diagnosis: NR Severity: NR	EQ-5D	BPSD-related distress; Frequency of BPSD; **Relationship quality**; Carer competence; **Carer guilt;** Carer-rated patient QoL (EQ-5D); **Burden (The relative stress scale)**; Reactivity to BPSD
9. Häusler et al. (2016)	Germany	82 carers Female %: 60.97 Mean age (SD): 73.02 (6.68)	Spouse: 100	NR	Alzheimer's: 78.05 Vascular: 18.6 Lewy bodies: Others: 30.4 Severity: NR	WHOQOL-BREF	**Perceived Stress**
10. Jackson et al. (2009)	UK	132 carers Female %: 72.0 Mean age (SD): 62 (13.4)	Spouse: 36.00 Offspring (or son or daughter in law) : 44.00 Siblings: 4.00 Other: 16.00	NR	Alzheimer's: 100.0 Severity: NR	WHOQOL-BREF Physical Psychological Social Environmental	Activities of Daily Living; **Memory and Behaviour Problems (MBPC-1990R)**
11. Kaufman et al. (2010)	United States	141 carers Female %: 85.1 Mean age: 52	Spouse: 9.9 Daughter/son: 58.9 Other: 31.2	NR	Diagnosis: NR Severity: NR	Quality of Life Inventory (QOLI)	**Interpersonal Support tangible component; Interpersonal Support appraisal component; Interpersonal Support belonging component; Interpersonal Support self-esteem component**
12. Kim et al. (2016)	South Korea	476 carers Female %: 67.7 Mean age (SD): 57.4 (13.1)	Spouse: 67.7 Daughter/son: 37.9 Other: 42.5	4.3 +/- 4.6	Diagnosis: NR Severity: NR	SF-36 (mental and physical components)	**QoL Mental component & Physical component (SF-36); Depression (BDI); Burden (ZBI) Extraversion;** Agreeableness; Conscientiousness; **Neuroticism**, Openness
13. Kramer (1993)	United States	72 carers Female %: 100.0 Mean age: 70.0	Spouse: 100	4.75	Alzheimer's: 100.0 Severity: NR	The Quality of Life Index	PwD functional status ADL; PwD functional status instrumental ADL; **PwD Memory and behavior problems (MBPC)**; Caregiver age; Duration of caregiving; **Quality of prior relationship**; **Physical health**; Family income; **Social involvement satisfaction**; Appraisal of the stressfulness of ADL; **Appraisal of the stressfulness of IADL**; **Appraisal of the stressfulness of MBP**
14. Markowitz et al. (2003)	United States	2477 carers Female %: 77.7 Mean age (SD): 58.8 (10.1)	Spouse: 67.7 Daughter/son: 37.9 Other: 42.5	NR	Alzheimer's: 100.0 Severity: NR	SF-12 (mental and physical components)	**PwD disruptive behaviour (MBPC-R); PwD feelings of depression (MBPC-R); PwD Memory (MBPC-R);** PwD instrumental functioning; PwD personal functioning; **No hours per week providing care**; Caregiver's age

Note: NR= Not reported; QoL= quality of life; PwD= people with dementia. BPSD= Behavioural and psychological symptoms of dementia; MBPC= Memory and Behaviour Problems Checklist; SF= Short form; BDI= Bender Depression Inventory; ZBI= Zarit Burden Interview; ADL= Activities of daily living; IADL= Instrumental activities of daily living; MBPC-R= Memory and Behaviour Problems Checklist-revised. Variables in bold are those ones that presented statistically significant correlations with carer QoL.

Table 2.1 (continued)

Authors	Country	Sample	Relationship to patient (%)	Average length being carer in years	Care Recipient Characteristics (Diagnosis, severity %)	Carer QoL measures	Variables correlated with QoL
15. McConaghy and Caltabiano (2005)	Australia	42 carers Female %: 76.2 Mean age (SD): 62 (13.2)	Spouse: 54.76 Daughter/son: 34.8 Other: 9.5	5.45	Diagnosis: NR Mild: 40.9 Moderate: 18.18 Severe: 40.9	SF-12 v2 Physical component	Coping; Burden (ZBI); Satisfaction with life
16. McLennon et al. (2011)	United States	84 carers Female %: 59.5 Mean age (SD): 73.3 (10.5)	Spouse: 100	4.6	Diagnosis: NR Severity: NR	SF-36 v2 (mental and physical components)	**Income; Duration of caregiving; Burden (ZBI); Finding meaning;** Education;
17. Moreno et al. (2015)	Colombia	102 carers Female %: 81.4 Mean age (SD): 58.4 (13.3)	NR	3.9	Diagnosis: NR Severity: NR	36 Physical functioning, Role-Physical, Vitality, Social functioning, Bodily pain and General Health components	**Satisfaction with life; Depression (PHQ-9); Burden (ZBI)**
18. (Nogueira et al., 2015)	Brazil	54 carers Female %: 66.7 Mean age (SD): Males: 72 (13.6); Females:67.6 (8.2)	Spouse: 100	NR	Alzheimer's: 100.0 Moderate: 62.96 Severe: 37.04	QoL-AD	**PwD QoL (QoL-AD); Burden (ZBI); PWD functional status; PwD awareness of disease**
19. Novelli and Caramelli (2010)	Brazil	60 carers Female %: 73.3 Mean age (SD): Mild dementia: 59.5 (15.4) Moderate: 60.1(14.5)	Spouse: 41.67 Daughter/son: 41.67 Siblings: 13.33 Other: 3.3	NR	Alzheimer's: 100.0 Mild: 50.0 Moderate: 50.0	QoL-AD (mild dementia and moderate dementia)	PwD cognitive function; PwD depression/mood; **PwD Instrumental ADL; PwD ADL; PwD behavioral disturbances (NPI); Carer depression/mood (GDS); PwD QoL self-reported; Carer-rated PwD QoL (QoL-AD)**
20. (Papastavrou et al., 2014)	Cyprus	76 carers Female %: 75.0 Age%: <50: 18.0; 51-60: 25.0; 61-70: 29.0; >71: 21.0	Spouse: 53.0 Other:47.0	1-2: 33.3 3-4: 28 >5: 38.7	Diagnosis: NR Severity: NR	QoL-AD	**Burden (ZBI); Depression (CES-D);** ADL
21. Perrin et al. (2014)	Colombia	90 carers Female %: 64.4 Mean age (SD): 54.1 (11.5)	Spouse: 17.8 Daughter/son: 22.2 Siblings: 60.0	3.7	Alzheimer's: 91.11 Vascular: 4.44 Mixed: 2.22 Others: 2.22	SF-36 (Values not available to conduct meta-analysis)	**Satisfaction with life;** Depression (PHQ-9)**; Burden (ZBI)**

Note: NR= Not reported; QoL= quality of life; PwD= people with dementia; AD= Alzheimer's Disease. SF= Short form; ZBI= Zarit Burden Interview; PHQ-9= Patient health questionnaire; ADL= Activities of daily living; IADL= Instrumental activities of daily living; CES-D= Center for Epidemiologic Studies Depression Scale. Variables in bold are those ones that presented statistically significant correlations with carer QoL.

Table 2.1 (continued)

Authors	**Country**	**Sample**	**Relationship to patient (%)**	**Average length being carer in years**	**Care Recipient Characteristics (Diagnosis, severity %)**	**Carer QoL measures**	**Variables correlated with QoL**
22. Santos et al. (2014)	Brazil	88 carers Female %: 76.1 Mean age (SD): 59.22 (13.8)	Spouse: 31.8 Daughter/son: 48.9 Other: 19.3	4.4	Alzheimer's: 100.0 Mild: 48.9 Moderate: 51.1	QoL-AD	Carer's gender; Carer's age; Carer's schooling; **Burden (ZBI); Mood (BDI); Anxiety;** PwD gender; PwD age; PwD schooling; PwD marital status; **PwD age of onset; PwD duration of disease; PwD self-rated QoL (QoL-AD); PwD carer-rated (QoL-AD); PwD cognition; PwD depression; PwD functional activities; PwD Neuropsychiatric symptoms (NPI)**
23. Schiffczyk et al. (2013)	Germany	194 carers Female %: 72.2 Mean age (SD): 69 (7.7)	NR	NR	Alzheimer's (most of them) Severity: NR	QoL-AD	PwD cognitive symptoms; **Non-cognitive symptoms of the PwD (Behave-AD)**
24. Scholzel-Dorenbos et al. (2009)	The Netherlands	87 carers Female %: 47.0 Mean age (SD): 72.2 (7.3)	NR	NR	Alzheimer's: 100.0 Severity: NR	SEIQoL	**PwD cognitive symptoms; Burden (ZBI)**
25. Shin et al. (2005)	United States	62 carers Female %: NR Mean age (SD):NR	Spouse: 51.6 Daughter/son: 33.9 Other: 14.5	NR	Diagnosis: Alzheimer's Severity: NR	QoL-AD	**PwD Neuropsychiatric symptoms (NPI); Caregiver distress**
26. Takahashi et al. (2005)	Japan	23 carers Female %: 78.27 Mean age (SD): 61.1 (13.0)	Spouse: 78.3 Daughter/son: 60.9 Other: 17.4	3	Alzheimer's: 73.9 Vascular: 4.3 Lewy bodies: 8.7 Frontotemporal: 8.7 Others: 4.4 Mild: 30.4 Moderate: 30.4 Severe: 3.1	WHO-QOL26	**Depression**
27. Takai et al. (2011)	Japan	118 carers Female %: 59.3 Mean age (SD): 60.9 (14.0)	Spouse: 55.1 Daughter/son: 37.3 Other: 7.6	NR	Alzheimer's: 77.9 Vascular: 11.0 Lewy bodies: 2.5 Frontotemporal: 4.2 Mixed: 4.2 Severity: NR	WHO-QOL26	PwD Cognitive function; PwD Cognitive and functional performance; **PwD Neuropsychiatric symptoms (NPI); Burnout; Depression (BDI-II)**

Note: NR= Not reported; QoL= quality of life; PwD= people with dementia AD= Alzheimer's Disease; ZBI= Zarit Burden Interview; BDI= Bender Depression Inventory; NPI= Neuropsychiatric Inventory. Variables in bold are those ones that presented statistically significant correlations with carer QoL.

Table 2.1 (continued)

Authors	**Country**	**Sample**	**Relationship to patient (%)**	**Average length being carer in years**	**Care Recipient Characteristics (Diagnosis, severity %)**	**Carer QoL measures**	**Variables correlated with QoL**
28. Tay et al. (2014)	Singapore	84 carers Female %: 69.0 Mean age (SD): 50.89 (10.6)	Spouse: 7.1 Daughter/son: 83.3 Other: 9.6	NR	Alzheimer's: 36.9 Vascular: 27.4 Mixed: 35.7 Mild: 59.5 Moderate: 40.5	WHOQoL-BREF	**Family burden (FBIS); Coping strategies Total; General perceived** self-efficacy**; Caregiver's age; Patient's age; Income**
29. Thompson et al. (2004)	United States	61 carers Female %: 73.80 Mean age: Female: 69.7 Male: 71.4	Spouse: 100	5.3	Alzheimer's: 100.0 Severity: NR	SF-36 (Mental component)	**Natural killer cell number; Male Sense of coherence; Male Depression (CES-D); Male Stress; Female Sense of coherence; Female Depression (CES-D); Female Stress**
30. Välimäki et al. (2009)	Finland	170 carers Female %: 62.9 Mean age (SD): 71.6 (7.2)	Spouse: 100	NR	Alzheimer's: 100.0 Severity: Only Mild	15D + 15D VAS	**PwD Cognitive function; PwD Neuropsychiatric symptoms (NPI);** PwD Cognitive function; Caregiver's age; PwD age; **HRQoL VAS; Sense of Coherence; Distress; Depression (BDI);** Income**; Total amount of medication;** Years of education
31. Vargas Escobar and Afanador (2010)	Colombia	192 carers Gender: most of them women Age: 36-59 years old	Daughter/son: most of them	NR, between 10-36 months	Alzheimer's: 100.0 Mild: 25.5 Moderate: 45.8 Severe: 28.6	QOL (Betty Ferrell)	PwD functional dependency
32. Weisman de Mamani et al. (2017)	United States	106 carers Female %: 81.1 Mean age (SD): 50.73 (12.7)	Spouse: 14.2 Daughter/son: 51.9 Siblings: 1.9 Other: 32.1	NR	Alzheimer's: 100.0 Severity: NR	Quality of Life Inventory (QOLI)	**Expressed Emotion (EE) total; EE Emotional Overinvolvement; EE Criticism**
33. Zawadzki et al. (2011)	France	51 carers Female %: 66.67 Mean age (SD) Female: 64.3(10.2) Male: 74.5(14.7)	Spouse: 57.0 Daughter/son: 37.0 Siblings: 2.0 Other: 10.0	3.5	Alzheimer's: 100.0 Severity: NR	PIXEL Study	**Authoritarianism; Benevolence; Social restrictiveness; Community mental health ideology; Emotional Reaction Rejection; Emotional Reaction Anxiety; Emotional Reaction Aggressiveness;** Emotional Reaction Prosocial Reactions; Perceived overall incompetence; Perceived susceptibility of having AD during one day

Note: NR= Not reported; QoL= quality of life; PwD= people with dementia AD= Alzheimer's Disease; FBIS= Family Burden Interview Schedule; CES-D= Center for Epidemiologic Studies Depression Scale; NPI= Neuropsychiatric Inventory; HRQoL VAS= Visual analogue rating scale of health-related quality of life BDI= Bender Depression Inventory; Variables in bold are those ones that presented statistically significant correlations with carer QoL.

Table 2.2 Assessment of study quality using the Appraisal of Cross-sectional Studies tool.

	Study number according to table 2.1																															
Introduction	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	23	24	25	26	27	28	29	30	31	32	33
Were the aims/objectives of the study clear?	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Was the study design appropriate for the stated aim(s)?	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Was the sample size justified?	Y	N	N	N	N	N	Y	N	N	Y	Y	Y	N	N	N	Y	N	N	N	N	Y	N	N	N	N	N	N	Y	N	N	N	N	N
Was the target/reference population clearly defined? (Is it clear who the research was about?)	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Was the sample frame taken from an appropriate population base so that it closely represented the target/ reference population under investigation?	Y	Y	N	Y	Y	N	Y	Y	Y	Y	Y	Y	Y	N	N	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	N	N	Y	Y	Y	Y	Y	N
Was the selection process likely to select subjects/participants that were representative of the target/reference population under investigation?	Y	Y	N	N	N	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	N	N	N	Y	N	N	N	Y	Y	N	Y	N	Y	Y	N	Y	Y
Were measures undertaken to address and categorise non-responders?	Y	N	N	Y	Y	N	Y	N	Y	Y	N	N	N	Y	Y	Y	N	N	N	Y	Y	N	Y	Y	N	N	Y	N	N	N	N	N	N
Were the risk factor and outcome variables measured appropriate to the aims of the study?	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Were the risk factor and outcome variables measured correctly using instruments/ measurements that had been trialled, piloted or published previously?	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Is it clear what was used to determine statistical significance and/or precision estimates? (e.g. p-values, confidence intervals)	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Were the methods (including statistical methods) sufficiently described to enable them to be repeated	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y

Note: Y= Yes, (the study clearly demonstrated the information regarding the question); N= No, (no clear information was provided in the study to record the item as yes).

Table 2.2 (continued)

	Study number according to table 2.1																																
Results	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	23	24	25	26	27	28	29	30	31	32	33
Were the basic data adequately described?	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	N	Y	N	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	N	Y	Y
Does the response rate raise concerns about non-response bias?	Y	N	N	Y	Y	N	Y	N	Y	N	N	N	N	Y	Y	Y	N	N	N	Y	N	N	Y	Y	N	N	Y	N	N	N	N	N	N
If appropriate, was information about non-responders described?	N	N	N	N	N	N	Y	N	N	N	N	N	N	N	N	N	N	N	N	N	N	N	N	N	N	N	N	N	N	N	N	N	N
Were the results internally consistent?	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	N	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Were the results presented for all the analyses described in the methods?	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Discussions																																	
Were the authors' discussions and conclusions justified by the results?	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	N	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Were the limitations of the study discussed?	Y	N	Y	Y	Y	Y	Y	N	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	N	Y	Y	N	Y	Y	N	N	N	Y	Y
Other																																	
Were there any funding sources or conflicts of interest that may affect the authors' interpretation of the results?	Y	N	N	Y	N	Y	Y	Y	Y	Y	N	Y	N	N	N	N	N	Y	Y	Y	Y	N	Y	N	Y	N	Y	Y	N	Y	Y	N	Y
Was ethical approval or consent of participants attained?	Y	Y	Y	N	Y	Y	Y	Y	Y	Y	N	Y	N	N	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	N
Total number of items rated as yes	**19**	**14**	**13**	**16**	**16**	**15**	**20**	**15**	**18**	**18**	**15**	**15**	**14**	**14**	**16**	**18**	**14**	**15**	**15**	**18**	**17**	**14**	**15**	**17**	**16**	**12**	**17**	**16**	**14**	**15**	**13**	**15**	**14**

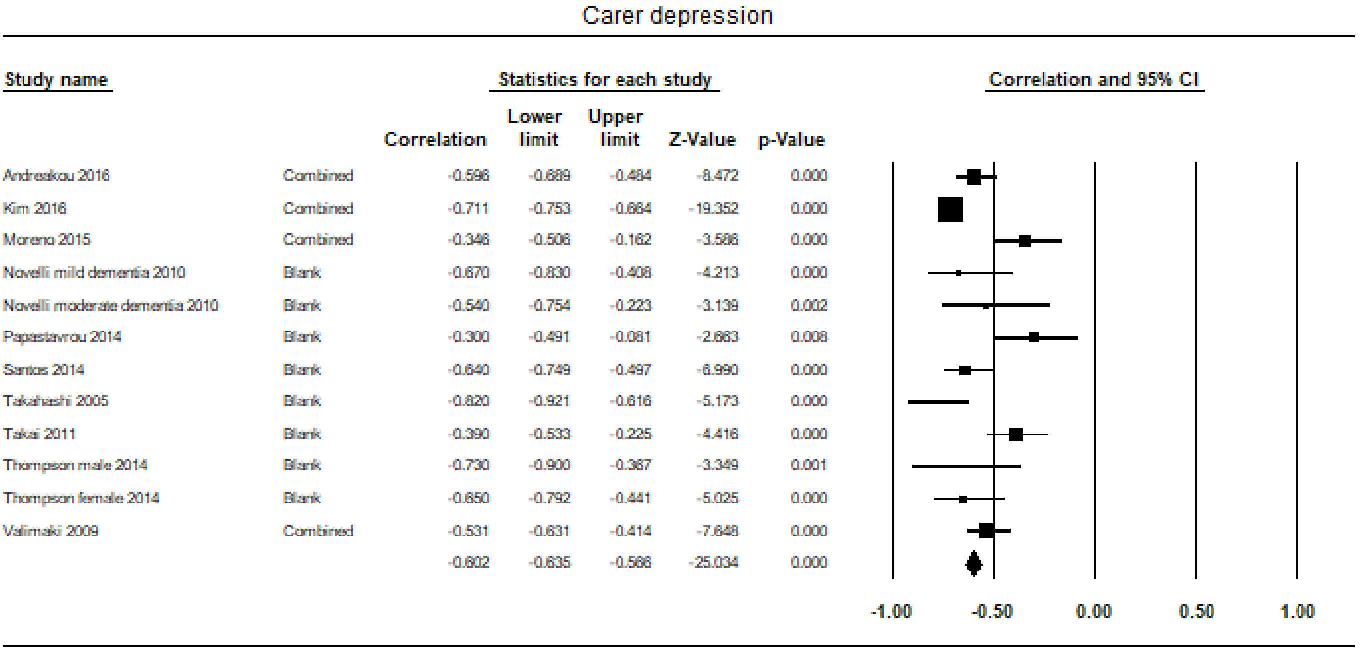
Note: Y= Yes, (the study clearly demonstrated the information regarding the question); N= No, (no clear information was provided in the study to record the item as yes

Carer’s distress (n=3). The effect sizes varied from -0.15 to -0.34. The point estimate of effect size between carer QoL and care’s distress was small -0.22 (95% CI = -0.33 - -0.11, $p < 0.00$). The heterogeneity between study effect sizes was not significant ($I^2 = 0.00\%$, Q = 1.94). However, this could be due to the limited number of studies included.

People with dementia’s self-rated QoL (n=3). The effect sizes varied from 0.25 to 0.55. The point estimate of effect size between carer QoL and self-rated QoL was 0.37 (95% CI = 0.24 - 0.49, $p < 0.00$) suggesting a significant moderate effect. The heterogeneity between study effect sizes was not statistically significant ($I^2 = 41.07\%$, $Q = 5.09$).

People with dementias proxy-rated QoL (n=5). The effect sizes varied from -0.15 to 0.44. The point estimate of effect size between carer QoL and proxy-rated QoL was 0.27 (95% CI = -0.00 - 0.51, $p < 0.05$) suggesting a significant small effect. The heterogeneity between study effect sizes was significantly high ($I^2 = 89.69\%$, Q =38.79).

People with dementia’s neuropsychiatric symptoms (n=11). The effect sizes varied from -0.11 to -0.44. The point estimate of effect size between carer QoL and neuropsychiatric symptoms was -0.24 (95% CI = -0.31 - -0.17, $p < 0.00$) suggesting a significant small effect. There was statistically significant moderate heterogeneity between study effect sizes ($I^2 = 61.77\%$, $Q = 28.73$).

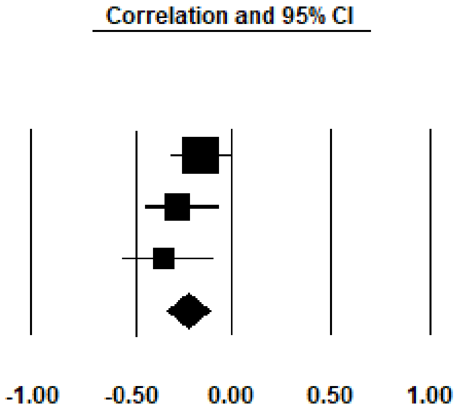

Carer depression

Study name		Statistics for each study				
		Correlation	Lower limit	Upper limit	Z-Value	p-Value
Andreakou 2016	Combined	-0.596	-0.689	-0.484	-8.472	0.000
Kim 2016	Combined	-0.711	-0.753	-0.664	-19.352	0.000
Moreno 2015	Combined	-0.346	-0.506	-0.162	-3.586	0.000
Novelli mild dementia 2010	Blank	-0.670	-0.830	-0.408	-4.213	0.000
Novelli moderate dementia 2010	Blank	-0.540	-0.754	-0.223	-3.139	0.002
Papastavrou 2014	Blank	-0.300	-0.491	-0.081	-2.663	0.008
Santos 2014	Blank	-0.640	-0.749	-0.497	-6.990	0.000
Takahashi 2005	Blank	-0.820	-0.921	-0.616	-5.173	0.000
Takai 2011	Blank	-0.390	-0.533	-0.225	-4.416	0.000
Thompson male 2014	Blank	-0.730	-0.900	-0.367	-3.349	0.001
Thompson female 2014	Blank	-0.650	-0.792	-0.441	-5.025	0.000
Valimaki 2009	Combined	-0.531	-0.631	-0.414	-7.648	0.000
		-0.602	-0.635	-0.566	-25.034	0.000

Figure 2.2 Forest plot for independent variables with a significant effect.

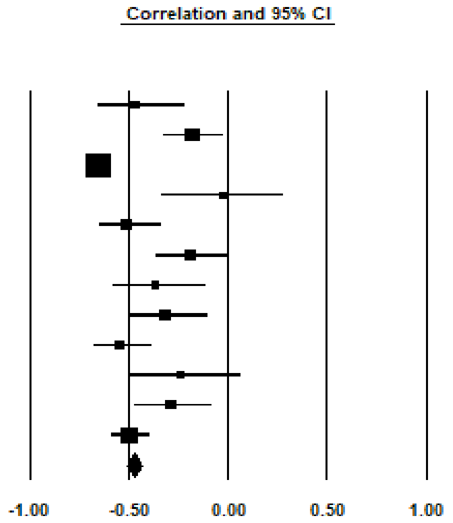
Carer distress

Study name	Correlation	Lower limit	Upper limit	Z-Value	p-Value
Feast 2017	-0.150	-0.301	0.008	-1.863	0.062
Hausler 2016	-0.270	-0.460	-0.056	-2.461	0.014
Shin 2005	-0.340	-0.552	-0.087	-2.602	0.009
	-0.221	-0.328	-0.108	-3.789	0.000



Carer subjective burden

Study name		Correlation	Lower limit	Upper limit	Z-Value	p-Value
Coen 1999	Blank	-0.470	-0.662	-0.220	-3.497	0.000
Feast 2017	Blank	-0.180	-0.328	-0.023	-2.244	0.025
Kim 2016	Combined	-0.659	-0.707	-0.604	-17.185	0.000
McConaghy 2005	Blank	-0.030	-0.335	0.280	-0.185	0.853
McLennon 2011	Combined	-0.512	-0.655	-0.335	-5.092	0.000
Moreno 2015	Combined	-0.193	-0.373	0.002	-1.942	0.052
Nogueira 2015	Blank	-0.370	-0.580	-0.113	-2.774	0.006
Papastavrou 2014	Blank	-0.320	-0.508	-0.103	-2.853	0.004
Santos 2014	Blank	-0.550	-0.681	-0.385	-5.701	0.000
Scholzel-Dorenbos 2009	Blank	-0.240	-0.498	0.058	-1.586	0.113
Tay 2016	Blank	-0.290	-0.475	-0.081	-2.687	0.007
bib	mental	-0.500	-0.593	-0.394	-8.110	0.000
		-0.474	-0.513	-0.433	-19.568	0.000



PwD self-rated QoL

Study name		Correlation	Lower limit	Upper limit	Z-Value	p-Value
Nogueira 2015	Blank	0.550	0.331	0.713	4.416	0.000
Novelli 2010	mild	0.260	-0.111	0.567	1.383	0.167
Novelli 2010	moderate	0.480	0.145	0.716	2.718	0.007
Santos 2014	Blank	0.250	0.043	0.437	2.355	0.019
		0.373	0.245	0.489	5.409	0.000

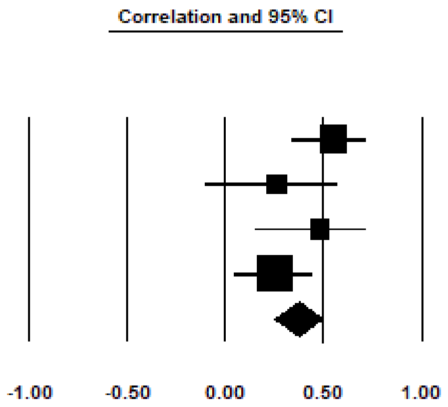
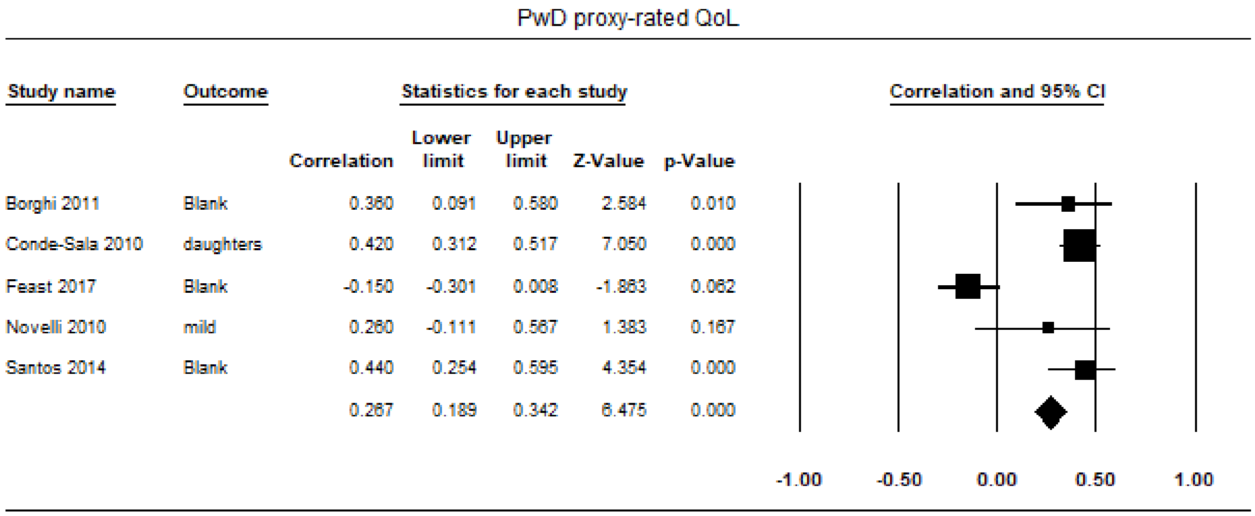
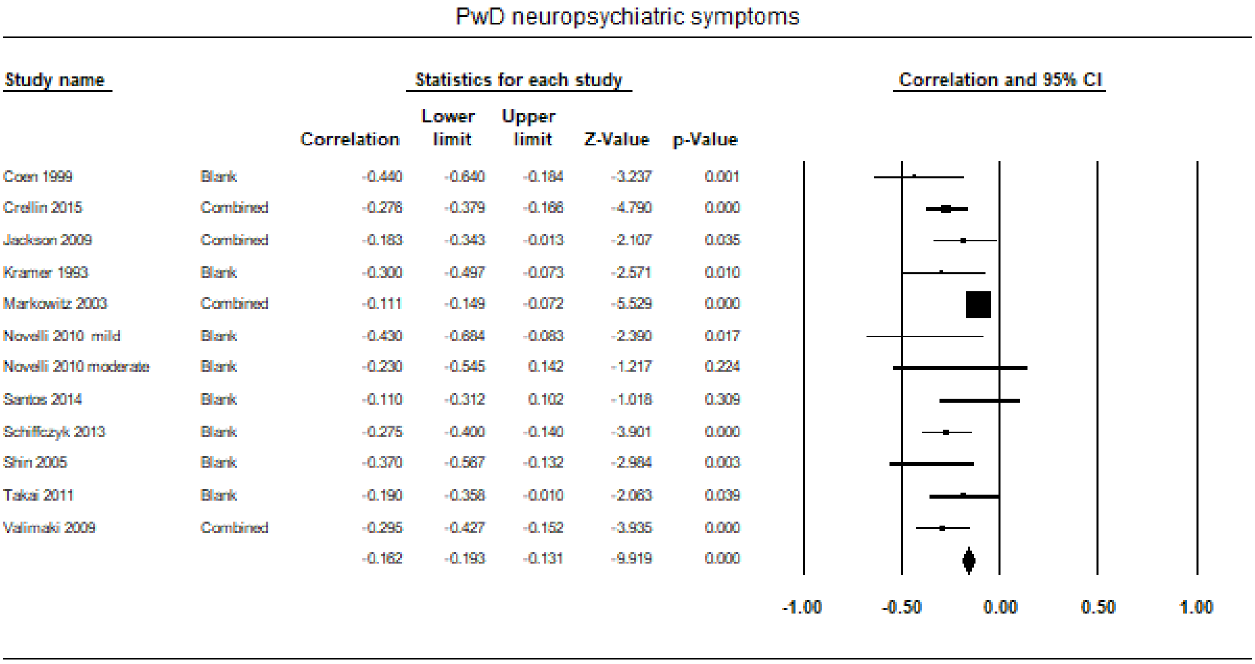


Figure 2.2 (continued)



Study name	Outcome	Correlation	Lower limit	Upper limit	Z-Value	p-Value
Borghi 2011	Blank	0.360	0.091	0.580	2.584	0.010
Conde-Sala 2010	daughters	0.420	0.312	0.517	7.050	0.000
Feast 2017	Blank	-0.150	-0.301	0.008	-1.863	0.062
Novelli 2010	mild	0.260	-0.111	0.567	1.383	0.167
Santos 2014	Blank	0.440	0.254	0.595	4.354	0.000
		0.267	0.189	0.342	6.475	0.000



Study name		Correlation	Lower limit	Upper limit	Z-Value	p-Value
Coen 1999	Blank	-0.440	-0.640	-0.184	-3.237	0.001
Crellin 2015	Combined	-0.276	-0.379	-0.166	-4.790	0.000
Jackson 2009	Combined	-0.183	-0.343	-0.013	-2.107	0.035
Kramer 1993	Blank	-0.300	-0.497	-0.073	-2.571	0.010
Markowitz 2003	Combined	-0.111	-0.149	-0.072	-5.529	0.000
Novelli 2010 mild	Blank	-0.430	-0.684	-0.083	-2.390	0.017
Novelli 2010 moderate	Blank	-0.230	-0.545	0.142	-1.217	0.224
Santos 2014	Blank	-0.110	-0.312	0.102	-1.018	0.309
Schiffczyk 2013	Blank	-0.275	-0.400	-0.140	-3.901	0.000
Shin 2005	Blank	-0.370	-0.567	-0.132	-2.984	0.003
Takai 2011	Blank	-0.190	-0.358	-0.010	-2.063	0.039
Valimaki 2009	Combined	-0.295	-0.427	-0.152	-3.935	0.000
		-0.162	-0.193	-0.131	-9.919	0.000

Figure 2.2 (continued)

Independent variables with no significant effect size (Supplementary Figure 2.1)

Carer's income (n=4).

The effect sizes varied from -0.06 to 0.30. The point estimate of effect size between carer QoL and care's income was 0.13 (95% CI = -0.00 - 0.26, p =0.06). Both the overall effect size and the heterogeneity between study effect sizes were not statistically significant (I^2 = 42.23%, Q = 5.19).

Carer's age (n=10).

The effect sizes varied from -0.10 to 0.10. Overall, the point estimate of effect size between carer QoL and carer's age was -0.03 (95% CI = -0.05 - 0.0, p = 0.13). Both the overall effect size and the heterogeneity between study effect sizes were not statistically significant (I^2 = 0.00%, Q = 2.58).

People with dementia's cognitive functioning (n=8). The effect sizes varied from -0.15 to 0.29. The point estimate of effect size between carer QoL and cognitive functioning was -0.04 (95% CI = -0.05 - 0.13, p = 0.40). Both the overall effect size and the heterogeneity between study effect sizes were not statistically significant (I^2 = 44.83%, Q = 14.50).

People with dementia's ADL (n=10). The effect sizes varied from -0.33 to 0.17. The point estimate of effect size between carer QoL and ADL was -0.01 (95% CI = -0.07 - 0.8, p = 0.79). Both the overall effect size and the heterogeneity between study effect sizes were not statistically significant (I^2 = 53.20%, Q = 21.37).

Risk of Bias Across Studies

The Duval & Tweedie trim-and-fill approach suggested that potentially no studies are missing for carer's depression, distress, income and age as well as people with dementia's neuropsychiatric symptoms and ADL. The results demonstrated that six studies are potentially missing for carer's subjective burden and three for people with dementia's cognitive functioning. If these missing studies were imputed, the point of estimate would decrease to -0.58 (95% CI = -0.69, -0.44) and -0.01 (95% CI = -0.07, 0.05) respectively. The results demonstrated that one study is potentially missing for people with dementia's self-rated and proxy-rated QoL. If these studies are imputed, the point of estimate would decrease to 0.30 (95% CI = 0.18, 0.41) and 0.23 (95% CI = -0.01, 0.44) respectively.

Rosenthal's Fail-safe N analysis suggested that more than 100 studies are required for the combined two-tailed p-value to exceed .05 for depression, subjective burden and people with dementia's neuropsychiatric symptoms, suggesting that the observed point of estimates are likely to be robust for these independent variables. Rosenthal's Fail-safe N analysis suggested that less than 50 studies are required for carer's distress people with dementia's self-rated QoL and proxy-rated QoL suggesting that the observed point of estimates are less likely to be robust for these two variables.

Subgroup Analyses

Subgroup analyses were conducted with independent variables, which demonstrated a significant heterogeneity (i.e., people with dementia's neuropsychiatric symptoms, their proxy-rated QoL, carer's depression and carer's subjective burden). The possible sources of variance were tested using three moderators (i.e., the development status of the country, types of measures used to assess carer QoL and types of measures used to assess the independent variable).

People with dementia's neuropsychiatric symptoms. Subgroup analyses demonstrated that the point of estimate for neuropsychiatric symptoms differed according to the type of measure used to assess neuropsychiatric symptoms (*p*<0.01), but not according to the development status of the country (*p*=0.79) or the type of measures used to assess carer QoL (*p*=0.47). The subgroup of studies that used Revised Memory and Behaviour Problems Checklist (RMBPC)(Teri et al., 1992) reported the lowest effect estimate while the study that used the Baumgarten Dementia Behaviour Disturbance questionnaire (DBD)(Baumgarten et al., 1990) reported the highest estimate of effect.

People with dementia's proxy-rated QoL. Subgroup analyses demonstrated that the point of estimate for people with dementia's proxy-rated QoL differed according to the type of measure used to assess their QoL (*p*<.01) and the types of measures used to assess carer QoL (*p*<0.01) but not according to the development status of the country (*p*=0.48). The subgroup of studies that used EQ-5D to assess proxy-rated QoL as an independent variable reported the lowest effect estimate while the studies that used proxy-rated QoL-AD reported the highest estimate of effect. The subgroup of studies that used EQ-5D to assess carer QoL as a dependent variable reported the lowest effect estimate while the studies that used SF-12 reported the highest estimate of effect.

Carer's depression. The test for subgroup differences indicated that the point of estimate for carer's depression did not differ according to any of the moderators (measures used to assess depression *p*=0.72; measures used to assess carer QoL *p*=0.94; development status of the country p=0.69).

Carer's subjective burden. Subgroup analyses demonstrated that the point of estimate for carer's subjective burden did not differ according to any of the moderators (measures used to assess subjective burden *p*=0.68; measures used to assess carer QoL *p*=4.00; development status of the country *p*=0.48).

Discussion

The current meta-analysis had two purposes, mainly to quantify the point estimate of effect size between carer QoL and different types of independent variables related to carers themselves and people with dementia. Secondly, it aimed to explore factors that may moderate the strength of such relationships, including the development status of the country and the types of tools used to assess the measures of interest. To our knowledge, this was the first meta-analysis to quantitatively synthesise the factors associated with carer QoL. Thirty-three cross-sectional studies providing data from 6177 family carers were included, however, only 27 studies were included in the final meta-analysis.

The current meta-analysis found that the pooled correlations with carer QoL (i.e., effect size) were significantly large for depression and significantly moderate for carer subjective burden, while the effect size for people with dementia's neuropsychiatric symptoms was significant but small. These results were indicated to be robust in the context of publication bias. The effect size for people with dementia's self-rated QoL was also significantly moderate. Furthermore, the effect size was significantly small for people with dementia's proxy-rated QoL and carer's distress. However, these results were less likely to be robust in the context of publication bias, therefore, the findings need to be interpreted with caution.

The results of this meta-analysis support evidence from the previous review (Farina et al., 2017) that suggested that carer's mental health and people with dementia's behavioural and psychological symptoms were strongly associated with carer QoL. On the other hand, the findings differed from those of de Oliveira, Vass & Aubeeluck, which included only studies that targeted carers aged 60 and over (de Oliveira et al., 2015). While the previous review suggested that carer's increased age was associated with lower levels of QoL, the results of the current meta-analysis without any age restriction did not support this association. This could be due to the differences in methodological approaches. De Oliveira, Vass & Aubeeluck included both regression and correlational studies in the systematic review and did not conduct a quantitative synthesis (de Oliveira et al., 2015). The current study also included four studies that were not considered in the review conducted by de Oliveira, Vass & Aubeeluck and the findings of the current study were similar to those from a more recent review conducted by Farina et al., which concluded that the associations between carer QOL and carer age to be less clear (Farina et al., 2017).

The results of subgroup analyses demonstrated the moderating effect of the country development status (i.e., high versus very high developed countries) was not significant for any of the independent variables. The results of subgroup analyses suggest that independent variables which are considered to be a critical predictor of carer QoL (i.e., carer depression, carer subjective burden and neuropsychiatric symptoms) may be important variables for intervention regardless of the opportunities offered for better health, education and living conditions across different high and very high developed countries.

This finding is particularly important as, in the recent years, there has been an increase in the number of interventions developed for family carers of people with dementia, but the majority of well-established interventions have only been tested in the most economically developed countries (Jones et al., 2011; Nickel et al., 2018). Interventions that can be accessed globally and can support carers worldwide are urgently needed considering that a greater number of people with dementia are currently living in low and middle-income countries and this trend is expected to be more profound in the future (Pot et al., 2019).

The well-established multi-component interventions that can tackle some of the critical predictors such as START (Livingston et al., 2013) could be beneficial for carers from countries with the lower development status if the intervention materials could be translated into multiple languages. However, there are other factors that should be considered apart from the language translation such as differences in culture, health and social care systems and the availability of resources including skilled therapists. To address such challenges, the 10/66 Dementia Research Group developed a programme called Helping Carers to Care, which is a psychoeducational intervention especially designed for use in low and middle-income countries and this programme has already been tested in India, Peru and Russia (Prina et al., 2019).

The results of subgroup analyses also demonstrated that the type of measure used to assess independent variables such as neuropsychiatric symptoms and people with dementia’s proxy-rated QoL may moderate the relationship between these variables and carer QoL. It is not possible to make direct recommendations on which measures to be used to assess these types of variables based on the current review due to a large variability across included studies. Future studies are required to carefully make a choice of measures guided by several considerations such as the setting in which the assessment will occur and their reliability and validity. For example, previous studies have found that the Neuropsychiatric Inventory (NPI) seems to be one of the most efficient measures of people with dementia’s neuropsychiatric symptoms, as it includes multiple behavioural domains at a general level as well as targets specific behaviours within domains and can be used in multiple clinical settings (Gitlin et al., 2014). A recent systematic review, which identified 16 different types of QoL measures specifically designed for people with dementia, concluded that many measures still have limited evidence supporting their reliability and validity and thus more research is needed to have complete confidence in their utility (Bowling et al., 2015).

Limitations

This meta-analysis has some methodological limitations. Firstly, although we made every effort to minimise missing studies, all the identified studies were from high or very high developed countries as indicated by the HDI category. Regardless of the inclusion of non-English articles, the current meta-analysis was not able to identify any studies from low developed countries (e.g., countries from Africa, Central America, Caribbean islands and some areas of Asia). However, it is worth mentioning that the current meta-analysis included seven studies conducted in countries that are defined as high developed countries by the HDI (e.g., Colombia and Brazil), but are also considered middle-income countries according to the World Bank classification by income per capita (The World Bank, 2020). Thus, the results of the subgroup analysis by the HDI category still provide an important implication. Although, it is recommended future cross-sectional studies focus on researching the impact of caring on carer QoL in low developed countries as a great number of people with dementia are expected to be living in these countries (Prince et al., 2004).

Secondly, due to a large variation in the existing assessment tools, it was not possible to have enough studies in each subcategory when conducting subgroup analyses for some independent variables such as people with dementia's proxy-rated QoL and their neuropsychiatric symptoms. For example, 11 studies with four different types of measures were included in the analysis of neuropsychiatric symptoms. Of these 11 studies, there was only one study that used the DBD. Consequently, these results could potentially change if more studies are included.

Furthermore, subgroup analyses were also challenging, as characteristics of the sample (e.g., relationship with the person with dementia, hours of caring per day) were not fully reported across the included studies. Therefore, only three moderating factors were explored in the current study. In order to conduct a robust moderation analysis, we encourage future cross-sectional studies to fully report data on sample characteristics for both carers and people with dementia.

Thirdly, similarly to previous reviews (de Oliveira et al., 2015; Farina et al., 2017; Pereira & Soares, 2015), all included studies employed generic QoL or HRQoL measures to assess carer QoL and no studies used care-related QoL measures. This is problematic as generic measures of QoL may not capture caring-specific components that can affect QoL and might not be sensitive enough for detecting changes in the progression of dementia (Farina et al., 2017; Kishita et al., 2018; Reed et al., 2017). Therefore, it is recommended that future studies use carer-related QoL instruments.

Fourthly, some independent variables that reported a statistically significant correlation with carer QoL were not included in the meta-analysis due to the small number of studies identified (i.e., fewer than three studies). These independent variables included carer anxiety, satisfaction with life, coping strategies, social skills, frequency of nocturnal disruptions, relationship quality with the person with dementia, interpersonal support, some personality traits such as extraversion and neuroticism, physical health, number of hours providing care weekly, and duration of caregiving in years. Future studies should continue exploring the association of carer QoL with these variables in order to be included in future meta-analyses, especially with anxiety as the correlation was reported to be strong in two studies (Santos et al., 2014; Zawadzki et al., 2011). A recent systematic review also highlighted that although anxiety is a prevalent psychological difficulty experienced by family carers of people with dementia, it is somewhat neglected compared to other carer outcomes (e.g., care burden, depression) in the current literature and therefore requires more attention (Kaddour & Kishita, 2019).

Previous studies also have demonstrated that carer's race and ethnicity can have an impact on carer outcomes such as depression and burden (Connell & Gibson, 1997; Janevic & Connell, 2001; Sun et al., 2012). Ethnicity was not included in the current meta-analysis as in most of the included studies the data was collected mainly from white carers and there was a lack of diversity in the study samples. Future cross-sectional studies should look at other ethnicities and races to understand how it might affect the caring experience.

Finally, the current meta-analysis was based on correlational studies, and thus the causality in the relationship between independent and dependent variables may not be entirely one-way. It is possible that poorer carer QoL could lead to higher depression or worse neuropsychiatric symptoms. Future longitudinal studies should explore how these variables change over time as dementia progresses.

Conclusion and Implications

In summary, this meta-analysis revealed that carer depression, carer subjective burden and people with dementia's neuropsychiatric symptoms are critical predictors of carer QoL.

Therefore, carer interventions that can target multiple outcomes, such as these three variables, seem important for improving carer QoL. Most of the included participants were female, over fifty-five years old and from developed countries, thus the findings may not be able to generalise to the groups of carers who do not fall into this category.

It is highly recommended for future studies to target a wider population, including those from low or moderately developed countries, to use instruments specifically designed for carers to measure carer QoL and to explore the relationship between carer QoL and those independent variables that seem to have a strong correlation with carer QoL but have been less studied such as carer anxiety.

Chapter 3

Risk factors affecting the quality of life of family carers of people with dementia: the role of carer anxiety

Submitted manuscript

Introduction

Dementia is one of the major causes of disability and dependency among older people and it affects roughly 50 million people worldwide (WHO, 2017). Due to the great responsibility for care delivery, which family members shoulder, their life is often broadly affected psychologically, physically, and socially (Brodaty & Donkin, 2009). As such, the literature suggests that the quality of life (QoL) of family members is significantly lower than that of non-dementia carers and non-carers (Karg et al., 2018; Scholzel-Dorenbos et al., 2009). Therefore, policies such as the UK's Carers Action Plan (Department of Health & Social Care, 2018) emphasise the need for understanding how the QoL of family carers is affected to inform interventions that aim to improve carer QoL.

In recent years, there has been an increasing interest in understanding factors affecting carer QoL but, the lack of validated carer-specific QoL measures has led to greater use of generic QoL and health-related QoL instruments. These measures are often criticised for not being sensitive enough for this population (Manthrope & Bowling, 2016; Perry-Duxbury et al., 2020), and several issues need to be considered when measuring QoL in family carers of people with dementia and determining how best to assess this variable.

Firstly, more than one-third of family carers of people with dementia are aged 65 or older across the world, while in some countries, such as Australia, this number can be even greater (i.e., more than half of carers are aged 65+) (Glasby & Thomas, 2019). The use of generic or health-related QoL with older carers can be problematic as their QoL is often affected by age-related factors, such as changes in physical conditions and levels of independence or loss of social network (Grewal et al., 2006). Indeed, a recent comprehensive systematic review demonstrated that existing carer interventions seem to be more beneficial for younger carers in terms of enhancing QoL compared with older carers (Cheng et al., 2020).

Secondly, family carers are often faced with changed circumstances where they may have limited control (e.g., reduced free time). Finding ways to maintain valued roles and goals in light of losses (e.g., having short calls frequently rather than planning a family holiday to connect with other family members) may be particularly important for this population (Han et al., 2020).

That said, the key aspect of well-being in older people and family carers is meeting needs rather than how they are met, and function (e.g., physical mobility, size of social network) per se may become less important if the need can be met in another way (Grewal et al., 2006). Therefore, in the current study, we defined carer QoL in terms of an individual's capability to do certain things that are important to them in life (e.g., doing things that make an individual feel valued) rather than functionality (e.g., physical health) in order to understand factors affecting QoL in family carers of people with dementia.

A recent comprehensive meta-analysis that explored the relationship between various carer- and patient-related factors and QoL demonstrated that carer depression, carer burden, and people with dementia's neuropsychiatric symptoms were the only factors that had a significant association with QoL in family carers (Contreras et al., 2020a). All studies included in this meta-analysis had used generic or health-related QoL measures as their dependent variable. Therefore, whether these well-established predictors equally affect QoL when carer QoL is defined as an individual's capability to do things that are important in life is still uncertain.

Moreover, this recent meta-analysis only identified a small number of studies that explored the relationship between carer anxiety and carer QoL, and thus it was not possible to calculate a meaningful effect size. However, considering anxiety is as highly prevalent as depression is in this population (Kaddour & Kishita, 2019), providing further evidence on the predictive effect of carer anxiety on carer QoL, in addition to common factors known to have an impact, seems crucial.

Based on the current evidence, this exploratory study will examine predictive effects of potentially modifiable factors, which are considered to have an impact (i.e., carer depression, anxiety and burden, and people with dementia's neuropsychiatric symptoms) on QoL, an individual's capability to do things that are important in life, in family carers of people with dementia.

Methods

Participants

This cross-sectional study collected data from family carers looking after a relative with a clinical diagnosis of dementia that were in a first-degree relationship with the person with dementia (i.e., parent, spouse/partner, sibling, or adult child) and were aged 18 years or older. The dementia diagnosis was based on the self-report of participants. Recruitment took place between July 2017 and February 2020.

A total of 91 participants were recruited from carer support groups; an NHS mental health trust; and from Join Dementia Research, a UK-based online recruitment tool that allows people with dementia and their carers to register their interest in taking part in research studies. Participants were also recruited through referrals from other ethically approved dementia studies conducted by collaborators. Two participants were excluded from the analyses for having missing data in one of the questionnaires, resulting in 89 participants for the analysis. All questionnaires for data collection were administrated at participants' own homes, the university, or local NHS premises depending on their preference. Full ethical approval was obtained from the NHS Health Research Authority and Research Ethics Committee. Written informed consent was obtained from all participants.

Sample Size Calculation

Prior to the study, the required sample size was calculated using G*Power. This calculation estimated that, based on a linear regression model with four independent variables included in the model, 85 participants would detect a medium effect size (f^2=0.15) at a 5 per cent level of significance with 80 per cent power.

Measures

Anxiety.
The Generalised Anxiety Disorder Scale (GAD-7) (Spitzer et al., 2006) was used to measure the severity of anxiety symptoms in family carers. Each item is rated on a 4-point scale: not at all (0), several days (1), more than half the days (2), and nearly every day (3). The sum of scores can indicate anxiety severity of mild (5-9), moderate (10-14), and severe (15-21).

Depression.
The Patient Health Questionnaire (PHQ-9) (Kroenke et al., 2001) was used to measure the severity of depressive and anxiety symptoms in family carers. Each item is rated on a 4-point scale: not at all (0), several days (1), more than half the days (2), and

nearly every day (3). The sum of scores can indicate depression severity of none (<4), mild (5-9), moderate (10-14), moderately severe (15-19) and severe (20-27).

Burden. Family carer's burden was assessed by the number of hours devoted to caregiving each week. The following response options were used: 0-2 hours, 3-10 hours, 11-20 hours, 21-40 hours, 41-80 hours, and 81 or more hours.

Neuropsychiatric Symptoms. The Mild Behavioral Impairment Checklist (MBI-C) (Ismail et al., 2017) is a 34-item proxy-informant interview-based measure that assesses the severity of neuropsychiatric symptoms within five domains: motivation, emotional regulation, impulse control, social cognition, and abnormal thoughts/perception. For each item, severity is assessed using a four-point scale: no symptom (0), mild (1), moderate (2), and severe (3). The total score ranges from 0 to 102, with higher scores indicating higher levels of neuropsychiatric symptoms.

Dementia severity. The Frontotemporal Dementia Rating Scale (FRS) (Mioshi et al., 2010) was used to assess dementia severity. The FRS is a 30-item proxy-informant interview-based measure validated in various forms of dementia including Alzheimer's disease. This measure provides logit scores, which are subdivided into six stages of dementia severity: very mild, mild, moderate, severe, very severe, and profound.

Demographics. Information collected included carer age and their level of education, type of relationship with the person with dementia, whether family carers report ongoing health conditions, and if they currently live in the same household as the person with dementia. The type of dementia diagnosed and average years since diagnosis were also recorded.

Carer QoL. The key outcome of this study (i.e., carer QoL) was assessed using the 5-item ICEpop CAPability measure for Older people (ICECAP-O) (Grewal et al., 2006). This instrument defines QoL in a broader sense, rather than only health, and was specifically designed to assess QoL among older people. Even though this measure is sensitive to changes related to age, it has also been validated in a sample of informal carers of people with dementia that included younger carers (Perry-Duxbury et al., 2020). The scale comprises five attributes: attachment (love and friendship), security (thinking about the future without concern), role (doing things that make you feel valued), enjoyment (enjoyment and pleasure), and control (independence). Each attribute can be scored on four levels (1-4) that range from "not any", "a little", "a lot" to "all" with higher values indicating greater QoL. The ICECAP-

O has good psychometric properties with decent evidence about its reliability and validity (Proud et al., 2019).

Statistical Analyses

Descriptive analyses of demographics were performed to characterise the sample. A multiple regression analysis was conducted to examine to what extent different carer- and patient-related risk factors predicted carer QoL. Neuropsychiatric symptoms of the person with dementia, carer depression, anxiety, and burden were entered into the model as independent variables. The overall model fit was assessed using the F-test and the model's R^2. The standardized coefficients beta (β) were used to assess which of the variables had the strongest impact on the dependent variable (i.e., carer QoL). All statistical analyses were conducted using SPSS version 25 and p-values smaller than 0.05 were considered to be statistically significant.

The Tolerance value and VIF were estimated to check multicollinearity and the Mahalanobis distance to check the presence of outliers. The visualisation of residuals against predicted values scatterplot was used to check normality, linearity, and homoscedasticity of residuals.

Results

Sample Characteristics

The demographic characteristics of participants are presented in Table 3.1. The majority of family carers were female (67.4 per cent), over 65 years old (68.5 per cent), who had at least completed secondary school (94.3 per cent), and 58.4 per cent reported having ongoing health conditions (e.g., cardiovascular problems, diabetes, arthritis). The majority were looking after a spouse (68.5 per cent) with Alzheimer's disease (44.9 per cent) in the severe stage (46.1 per cent) and 73.1 per cent were living in the same household with the person with dementia. Pearson's correlations and means and standard deviations for all variables are presented in Table 3.2.

Model-checking

The Tolerance value was higher than 0.33 and the VIF value was below 3.02 for all independent variables in the multiple regression analysis, suggesting that the presence of multicollinearity is less likely to be a concern.

Table 3.1 Demographic characteristics of the sample (N=89).

Family carer characteristics		
Age (in years)	69.1	(± 12.5)
Gender (Female %)	67.4	
Educational Level %		
Unfinished Primary School	1.1	
Primary school	4.5	
Secondary school	40.4	
Vocational diploma	27.0	
Bachelor’s degree	20.2	
Master’s degree	5.6	
PhD	1.1	
Type of relationship %		
Wife	40.4	
Husband	28.1	
Daughter	25.8	
Son	4.5	
Sister	1.1	
Living with the care recipient (yes %)	73.0	
Ongoing health conditions reported (yes %)	58.4	
Characteristics of people with dementia		
Dementia type		
Alzheimer's %	44.9	
Mixed %	18.0	
Vascular %	14.6	
Frontotemporal %	7.9	
Lewy bodies %	5.6	
Unknown %	6.7	
Other %	2.2	
Years since diagnosis	3.6	(± 2.4)
Dementia Severity %		
Mild	5.6	
Moderate	30.3	
Severe	46.1	
Very severe	18.0	

The visualisation of the scatterplot of the standard residuals demonstrated that the residuals were distributed with most of the scores plotted on the centre and with a spread pattern. These results suggest that the assumption of normality, linearity, and homoscedasticity of residuals was not violated. The Mahalanobis distance maximum value of 12.73 indicated that there were no extreme outliers present.

Table 3.2 Pearson’s correlations among independent and dependent variables and means and standard deviations (N=89).

Variables	1	2	3	4	*M* (SD)
1 Quality of life (ICECAP-O: 0-1)	-				0.73 (0.16)
2 Carer Depression (PHQ-9: 0-27)	-0.53*	-			7.22 (6.31)
3 Carer Anxiety (GAD-7: 0-21)	-0.55*	0.81*	-		6.10 (5.66)
4 Carer Burden (1-6)	-0.19	0.35*	0.28*		4.31 (1.66)
5 Neuropsychiatric symptoms (MBI-C: 0-102)	-0.22*	0.25*	0.26*	0.26*	30.06 (18.00)

*$P < 0.05$. ICECAP-O high scores denote a better QoL; PHQ-9 high scores denote more symptoms of depression; GAD-7 high scores denote more symptoms of anxiety; Burden high scores denote more hours devoted to caregiving; MBI-C high scores denote more neuropsychiatric symptoms.

Factors affecting family carer QoL

Results of the regression analysis showed that the model with neuropsychiatric symptoms of the person with dementia, carer depression, anxiety, and burden accounted for approximately 33 per cent of the variance in QoL. Carer anxiety was the only variable significantly predicting carer QoL (β = -0.34, p =0.03, 95%CI: –0.64 to -0.04) (See Table 3.3). These findings suggest that having more symptoms of anxiety can lead to worsening QoL in family carers.

Table 3.3 Results of multiple regression analysis (N=89).

Predictors	Carer QoL			95% CI	
	β	t	P	Lower	Upper
Neuropsychiatric symptoms	-0.08	-0.8	0.43	-0.26	0.11
Carer' depression	-0.25	-1.59	0.12	-0.55	0.06
Carer's objective burden	0.01	0.08	0.93	-0.18	0.20
Carer's anxiety	-0.34	-2.22	0.03	-0.64	-0.04
F	10.45				
d.f.	4				
R^2	0.33				

Discussion

This study aimed to explore the impact of carer depression, anxiety, burden and people with dementia’s neuropsychiatric symptoms on carer QoL as defined in terms of an individual’s capability to do certain things that are important in life. The results demonstrated that carer anxiety was the only significant predictor of QoL.

There is robust evidence that carer depression and burden and neuropsychiatric symptoms of dementia have a negative impact on carer QoL when carer QoL is assessed by generic or health-related QoL instruments (Contreras et al., 2020a; Markowitz et al., 2003; Papastavrou et al., 2014). This study suggested that when these well-established predictive factors are included in the same model along with anxiety, they may no longer explain carer QoL, particularly when QoL is focused on an individual's capability rather than functionality. These findings suggest that improving carer's anxiety may be particularly important in promoting their QoL and future interventions should target this key variable to achieve the desired result of improving carer QoL.

To our knowledge, this is the first study to assess the impact of common factors affecting carer QoL, using a measure of QoL that prioritises capability rather than functionality. The literature has shown that QoL does not decrease due to specific factors such as poorer health, but instead QoL decreases because of limitations in what the person can do as a result of poor health (Grewal et al., 2006). In this regard, the ICECAP-O assesses QoL defined in a broader sense, rather than physical health such as the ability to do things that make them feel valued and their subjective sense of independence. This is particularly important for family carers as they often experience high levels of strain and deterioration in subjective well-being, which tend to be the main focus of interventions rather than their physical health outcomes (Perry-Duxbury et al., 2020). The ICECAP-O has been validated in informal carers of people with dementia, which is also a strength of this measure (Perry-Duxbury et al., 2020).

Another strength of this study is that carer anxiety was included as one of the potential predictors of carer QoL. Currently, anxiety is fairly neglected compared to depression or burden in the carer literature and older people in general (Contreras et al., 2020a; Kaddour & Kishita, 2019). In fact, current national guidelines such as the National Institute for Health and Care Excellence (NICE) guideline for dementia care in the UK emphasises that carers of people with dementia are at an increased risk of depression (NICE, 2018). However, the guideline does not refer to the heightened risk of anxiety in this population. Since anxiety is as prevalent as depression in this population (Kaddour & Kishita, 2019), exploring the effect of anxiety on carer QoL seems critical.

Anxiety disorders such as general anxiety disorder (GAD) in family carers of people with dementia, and older people in general, are considered to be hard to treat since a condition such as GAD does not spontaneously remit (Lenze et al., 2005). Current evidence suggests that a conventional psychological approach (e.g. cognitive behaviour therapy) for GAD may be less effective for older adults compared to adults of working age (Kishita & Laidlaw, 2017). The findings of the current study further support the fact that anxiety can have a significant impact on carers' capability to do things that are important to them, and the development of interventions, which can directly target anxiety throughout the dementia journey, is critical.

This study also has several limitations that should be taken into account. This study used a measure of objective burden (the number of hours devoted to caring) rather than subjective burden (e.g., the Zarit Burden Interview), which is a commonly used measure in family carers (Chiao et al., 2015). This may have resulted in the contradicting findings between the current study and previous studies that used other types of QoL measures. However, previous literature has shown that the number of hours devoted to caring on a day-to-day basis is one of the most consistent predictors of subjective burden in family carers of people with dementia (Park et al., 2015). This means that, unless objective burden is reduced, subjective burden will not improve and, therefore, objective burden is highly important and modifiable as a target of treatment.

All the independent variables included in this study were selected based on evidence of their association with carer QoL. All these variables are considered to be risk factors, characteristics at the patient, or carer level which could lead to lower levels of QoL. The impact of protective factors was not considered in the current study. A recent systematic review on factors associated with carer QoL suggests that studies that explore the impact of protective factors such as coping strategies, social skills, and interpersonal support are limited (Contreras et al., 2020a). Future studies should equally focus on the effect of protective factors that might improve carer QoL to inform future interventions aimed at improving carer QoL.

The use of the ICECAP-O with the carer population has several advantages. However, it is important to acknowledge the existence of other recently developed measures for this population. For example, the C-DEMQOL (Brown et al., 2019) and the Dementia Quality of Life Scale for Older Family Carers (DQoLOC) (de Oliveira et al., 2018) were specially developed for family carers of people with dementia. Although these scales seem to be promising measures to assess QoL, more studies are needed to evaluate their psychometric properties.

The generalisation of the findings may be limited by participants' characteristics. Most of the participants included in this study were female, aged 65 or older, and were looking after a spouse with moderate to severe Alzheimer’s disease in a developed country. Future research should replicate the findings of the current study with other types of carers, including those from different races and ethnicities.

Finally, it is important to highlight that this was an observational study and thus the results regarding the causality between the variables should be interpreted with caution. Future studies using a longitudinal design are needed to draw conclusions about the direction of effects.

Conclusion

This study found that carer anxiety was the only risk factor affecting carer QoL as assessed by a QoL measure for older adults. Future interventions aiming to improve carer QoL could benefit from targeting anxiety symptoms. It is recommended that future studies continue exploring the underestimated role of anxiety in QoL, especially in carers of less common types of dementia, in the early stages, as well as from other countries, races and ethnicities.

Chapter 4

Protective factors predicting quality of life in family carers of people with dementia: the role of psychological flexibility

Submitted manuscript

Introduction

Caring for someone with dementia can be physically and emotionally challenging and it can have a negative impact on the social, psychological and physical wellbeing of the carer (Ferrara et al., 2008; Richardson et al., 2013). This results in family carers of people with dementia having a lower quality of life (QoL) than non-dementia carers and non-carers (Karg et al., 2018; Pierre Moïse et al., 2004; Scholzel-Dorenbos et al., 2009). Poor carer QoL is also likely to be associated with poorer outcomes for the person with dementia and with higher economic costs (Banerjee et al., 2003; Prince et al., 2014).

For this reason, it is fundamental to identify the modifiable factors that may affect family carers' QoL in order to provide them with appropriate support and to improve the care they provide to the person with dementia. In fact, the existing carer interventions, such as psychoeducation interventions and cognitive behaviour therapy are considered to be effective for reducing negative psychological outcomes, such as carer burden and depression in family carers of people with dementia. However, the level of evidence for such interventions in improving carers' overall QoL is still questionable (Amador-Marín & Guerra-Martín, 2017; Huis In Het Veld et al., 2015; Kishita et al., 2018).

Previous systematic reviews looking at factors associated with the QoL of family carers of people with dementia (Contreras et al., 2020a; Farina et al., 2017; Pereira & Soares, 2015) highlight that the majority of existing studies are focused on variables that are considered to be contextual factors (i.e., characteristics unique to a particular group, such as the level of cognitive impairment). Indeed, in one of the most recent reviews (Contreras et al., 2020a), one-third of the included studies were focused on exploring the impact of neuropsychiatric symptoms of dementia on carer QoL.

The sociocultural stress and coping model for carers (Knight & Sayegh, 2010) suggests that the impact of such contextual factors (so-called stressors) on carers' wellbeing may not always be direct. This model proposes that other individual factors, such as coping styles also contribute to explaining how carers are affected differently by such stressors. Therefore, exploring individual factors that can prevent family carers from having lower QoL (i.e., protective factors) seems highly practical as it can provide important clinical implications, and this is the key aim of this study.

Several potential individual factors will be explored in this study. Firstly, this study will explore the impact of carers' knowledge about dementia on carer QoL. Previous studies suggest that a lack of knowledge could lead to specific types of dysfunctional thoughts such as the misinterpretation of symptoms of dementia (Losada et al., 2006; Mittelman et al., 2014). For example, carers may see a behavioural symptom (e.g., lack of impulse control) as aggression due to their lack of knowledge, which in turn could lead to increased distress among family members. Previous studies suggest that both carer's dysfunctional thoughts and misattribution are often associated with depression and with other negative emotional outcomes (Losada et al., 2006; McNaughton et al., 1995). The impact of such dysfunctional thoughts on positive carer outcomes such as carer QoL has been less studied and the available evidence is currently somewhat limited (Graham et al., 1997; Proctor et al., 2002). Thus, it seems highly practical to understand the potential impact of carers' knowledge about dementia on carer QoL.

Existing research also recognises the critical role played by psychological flexibility in explaining the impact of caregiving on family carers of people with dementia. Psychological flexibility refers to the ability to fully contact the present moment, being mindful of own psychological reactions (e.g., distress and anger) and persist or change own behaviour in situations according to the individual's chosen values (Fletcher & Hayes, 2005; Hayes, 2004). Psychological flexibility is a multi-faceted construct that includes six interrelated processes: acceptance, defusion, contact with the present moment, self as context, values and committed action. Each of these processes is conceptualised as a positive psychological ability and not just a method of avoiding psychopathology. When an individual presents high levels of psychological inflexibility, they tend to avoid uncomfortable private events, even when doing so causes behavioural harm, which is known as experimental avoidance (Hayes et al., 2006). The current evidence suggests that lower psychological flexibility (i.e. higher levels of experimental avoidance) leads to higher levels of negative emotional outcomes, such as depression and anxiety among family carers of people with dementia (Kishita et al., 2020; Romero-Moreno et al., 2016; Spira et al., 2007). However, its impact on family carers' QoL is still unclear and further investigation on whether this variable can equally improve positive carer outcomes could provide further insights.

Furthermore, previous literature suggests that it is very common for family carers to engage in dysfunctional coping strategies, such as self-criticism (e.g., telling oneself “I should be more patient”) (Li et al., 2012). While this approach works in the short term to motivate oneself to do better, it usually does not work in the long term. Instead, being warm and understanding toward ourselves when we suffer (i.e., being self-compassionate) is considered to be more effective in the face of challenges (Lloyd et al., 2019; Neff, 2003). A previous study demonstrates that carers of people with dementia with higher levels of self-compassion report lower levels of negative psychological outcomes, such as carer depression and burden (Lloyd et al., 2019). Another study including carers of people with various neurological conditions (including dementia) found that carers that report higher levels of self-compassion have lower symptoms of depression and a better QoL (Hlabangana & Hearn, 2020). Having said that, whether self-compassion can predict QoL in dementia carers is still unclear.

In summary, this exploratory study aims to explore the predictive effect of variables known to have an impact on negative emotional outcomes (i.e., knowledge about dementia, psychological flexibility and self-compassion) on QoL in family carers of people with dementia. All of these potential individual factors will be considered simultaneously in a multiple regression model. The relevant demographic characteristic, the support received from other relatives (i.e., the number of hours of care provided by other relatives each week), will also be included in the proposed regression model, as previous studies suggest that having support from other people may lead to better QoL and lower depression (Losada et al., 2006; Rapp et al., 1998)

Methods

Participants

This cross-sectional study collected data from participants that: a) were currently looking after a relative with a clinical diagnosis of dementia and would identify themselves as the primary or co-carer, b) were in a first-degree relationship with the person with dementia (i.e., parent, spouse/partner, sibling, or adult child), and c) were aged 18 years or older. Care recipients were not assessed or present during the assessment sessions. The dementia diagnosis was based on the self-report of participants (i.e. carers). Recruitment took place between July 2017 and February 2020.

Ninety-one participants were recruited from carer support groups, an NHS mental health trust and from Join Dementia Research, a UK-based online recruitment tool that allows people with dementia and their carers to register their interest in taking part in research studies. Participants were also recruited through referrals from other ethically approved dementia studies conducted by collaborators. All questionnaires and interviews were administrated at the participants' own home, the university, or local NHS premises depending on their preference by researchers trained to administer all the questionnaire-based and interview-based tools. Ethical approval was obtained from the NHS Health Research Authority and Research Ethics Committee. Written informed consent was obtained from all participants.

Sample size calculation

Prior to the study, the required sample size was calculated using G*Power. This calculation estimated that, based on a linear regression model with four independent variables included in the model, 85 participants would detect a medium effect size (f^2=0.15) at a 5% level of significance with 80% power.

Measures

Knowledge about dementia.

The Dementia Knowledge Assessment Scale (DKAS) (Annear et al., 2017; Annear et al., 2015) is a self-report measure that assesses dementia knowledge across a range of domains including causes and characteristics, communication and engagement, care needs, risk factors, and health promotion. The DKAS originally had 27 items (Annear et al., 2015) but a later confirmatory factor analysis demonstrated that removing two items improved the construct validity (Annear et al., 2017). Therefore, data for those two items were removed and the revised 25-item version was used for the current study. Each item is rated on a 5-point true/false scale: False, Probably False, Probably True, True, and I don't know. Higher scores indicate greater knowledge about dementia.

Psychological flexibility/inflexibility.

The Acceptance and Action Questionnaire-II (AAQ-II) (Bond et al., 2011) assesses the degree of psychological flexibility/inflexibility. Each item is rated on a 7-point scale that ranges from never true (1) to always true (7). The total score ranges from 7 to 49, with higher scores indicating greater levels of psychological inflexibility and lower scores indicating higher levels of psychological flexibility.

Self-compassion. Self-compassion Scale short form (SCS-SF)(Raes et al., 2011)) is a 12-item self-report questionnaire that measures the six components of self-compassion: Self-Kindness, Self-Judgment, Common Humanity, Isolation, Mindfulness and Over-Identification. Each item is rated on a 5-point scale ranging from *almost never* (1) to *almost always* (5) with higher scores indicating greater self-compassion. A total self-compassion score is calculated by reversing the negative items and then computing a total mean.

Support from other family members. Support from other family members was assessed by the number of hours devoted to caregiving each week from other relatives. The following response options were used: no support, 0-2 hours, 3-10 hours, 11-20 hours, 21-40 hours, 41-80 hours, and 81 or more hours.

Dementia severity. The Frontotemporal Dementia Rating Scale (FRS) (Mioshi et al., 2010) was used to assess dementia severity. The FRS is a 30-item proxy-informant interview-based measure validated in various forms of dementia including Alzheimer's disease (Lima-Silva et al., 2013). This measure provides logit scores, which are subdivided into six stages of dementia severity: very mild, mild, moderate, severe, very severe and profound.

Demographics. Information collected included carer age and their level of education, type of relationship with the person with dementia, if they currently live with the person with dementia in the same household and if they are members of a carer support group. The type of dementia diagnosed and average years since diagnosis were also recorded.

Carer QoL. The key outcome of this study (i.e., carer QoL) was assessed using the 5-item ICEpop CAPability measure for Older people (ICECAP-O) (Grewal et al., 2006). This instrument defines QoL in a broader sense, rather than health, and was specifically designed to assess QoL among older people. Even though this measure is sensitive to changes related to age, it has also been validated in a sample of informal carers of people with dementia that included younger carers (Perry-Duxbury et al., 2020). The scale comprises five attributes: attachment (love and friendship), security (thinking about the future without concern), role (doing things that make you feel valued), enjoyment (enjoyment and pleasure), and control (independence). Each attribute can be scored on four levels (1-4) that range from "not any", "a little", "a lot" to "all", with higher values indicating greater QoL. The ICECAP-O rescaled values range from 0 to 1, distinguishing 1024 possible "capability states". The tariffs assign 0, the lowest value, to the state of having no capability on all the attributes (11111), the state of having a little capability on all attributes (22222) has value 0.556, the state of having a lot of capability on all of the attributes (33333) has a value of 0.866, and 1, the highest value, is assigned when having full capability on all the attributes (44444) (Coast et al., 2008; Perry-Duxbury et al., 2020). The ICECAP-O has good psychometric properties with decent evidence about its reliability and validity (Proud et al., 2019).

Statistical analyses

Descriptive analyses of demographics were performed to characterise the sample. A multiple regression analysis was conducted to examine to what extent different carer-related protective factors predicted carer QoL. Knowledge about dementia, psychological flexibility, self-compassion and the hours of support from other family members were entered into the model as independent variables. The overall model fit was assessed using the F-test and the model's R^2. The standardised coefficients beta (β) were used to assess which of the variables had the strongest impact on the dependent variable (i.e., carer QoL). All statistical analyses were conducted using SPSS version 25 and p-values smaller than 0.05 were considered to be statistically significant.

The Tolerance value and VIF were estimated to check multicollinearity and the Mahalanobis distance to check the presence of outliers. The visual examination of the Normal Probability Plot (P-P) of the regression standardised residuals and residuals scatterplot were used to check normality, linearity and homoscedasticity of residuals.

Results

Sample characteristics

The demographic characteristics of participants are presented in Table 4.1. The majority of family carers were female (67.0 %), over 65 years old (69.2%), who had at least completed secondary school (93.4%). The majority were looking after a spouse (69.2%) with Alzheimer's disease (44.0%) in the severe stage (45.1%) and 73.6% were living in the same household with the person with dementia. A small percentage of the participants were members of a carer support group (25.3%) and most of the participants (67%) reported receiving no or up to 2 hours of support from other family members weekly. Pearson's correlations and means and standard deviations for all dependent and independent variables are presented in Table 4.2. The distribution of the data of each included variable is presented in boxplots in figure 4.1.

Table 4.1 Demographic characteristics of the sample (N=91).

Family carer characteristics		
Age (in years)	69.5	(± 12.5)
Gender (Female %)	67.0	
Educational Level %		
Unfinished Primary School	1.1	
Primary school	5.5	
Secondary school	40.7	
Vocational diploma	26.4	
Bachelor’s degree	19.8	
Master’s degree	5.5	
PhD	1.1	
Type of relationship %		
Wife	40.7	
Husband	28.6	
Daughter	25.3	
Son	4.4	
Sister	1.1	
Hours of support from other family members %		
No support	52.7	
0-2 hours	14.3	
3-10 hours	16.5	
11-20 hours	3.3	
21-40 hours	6.6	
41-80 hours	1.1	
81 or more hours	5.5	
Living with the care recipient (yes %)	73.6	
Member of a carer support group (yes %)	25.3	
Characteristics of people with dementia		
Dementia type		
Alzheimer's %	44.0	
Mixed %	16.5	
Vascular %	15.4	
Frontotemporal %	7.7	
Lewy bodies %	5.5	
Unknown %	8.8	
Other %	2.2	
Years since diagnosis	3.7	(± 2.4)
Dementia Severity %		
Mild	5.5	
Moderate	30.8	
Severe	45.1	
Very severe	18.7	

Table 4.2 Pearson's correlations among independent and dependent variables and means and standard deviations (N=91).

Variables	1	2	3	4	*M* (SD)
1 Quality of life (ICECAP-O: 0-1)	-				0.73 (0.16)
2 Psychological flexibility (AAQ-II: 7-49)	-0.46*	-			19.70 (10.50)
3 Self-compassion (SCS-SF: 1-5)	-0.33*	-0.65*	-		3.28 (0.70)
4 knowledge about dementia (DKAS: 0-50)	-0.02	0.12	0.02		27.86 (8.59)
5 Support from other family members (1-6)	0.08	0.18	-0.11	0.09	1.22 (1.72)

Note: *p<0.05 (two-tailed).
ICECAP-O high scores denote a better QoL; AAQ-II high scores denote greater levels of psychological inflexibility and low scores indicate higher levels of psychological flexibility; SCS-SF high scores denotes greater self-compassion; DKAS high scores indicate greater knowledge about dementia; Support from other family members high scores denote more hours of support from other family members.

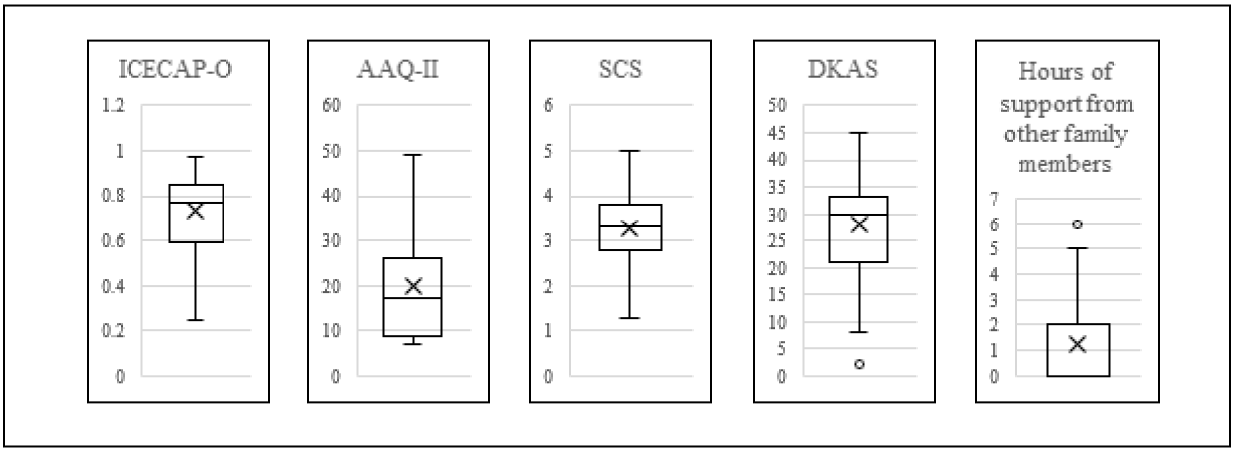


Figure 4.1 Boxplots showing the distribution of the data. ICECAP-O high scores denote a better QoL; AAQ-II high scores denote greater levels of psychological inflexibility and low scores indicate higher levels of psychological flexibility; SCS-SF high scores denotes greater self-compassion; DKAS high scores indicate greater knowledge about dementia; Support from other family members high scores denote more hours of support from other family members.

Model-checking

The Tolerance value was higher than 0.55 and the VIF value was below 1.83 for all independent variables in the multiple regression analysis, suggesting that the presence of multicollinearity is less likely to be a concern.

The Normal P-P Plot revealed that all points lied in a reasonably straight diagonal line from bottom left to top right, indicating no major deviations from normality. The visualisation of the scatterplot of the standard residuals demonstrated that the residuals were distributed with most of the scores plotted on the centre and with a spread pattern. These results suggest that the assumption of normality, linearity and homoscedasticity of residuals was not violated. The Mahalanobis distance maximum value of 15.36 indicated that there were no extreme outliers present.

Factors affecting family carer QoL

Results of the regression analysis showed that the model with psychological flexibility, self-compassion, knowledge about dementia and hours of support from other family members accounted for approximately 24% of the variance in carer QoL. Psychological flexibility/inflexibility was the only variable significantly predicting carer QoL (β = -0.46, p =0.00, 95%CI: -0.71 to -0.20) (See Table 4.3). These findings suggest that greater psychological flexibility can lead to improved QoL in family carers.

Table 4.3 Results of multiple regression analysis (N=91).

Predictors	Carer QoL			95% CI	
	β	t	P	Lower	Upper
Psychological flexibility	-0.46	3.58	0.00	-0.71	-0.20
Self-compassion	0.05	0.36	0.72	-0.20	0.29
knowledge about dementia	0.02	0.17	0.86	-0.17	0.21
Hours of support from other family members	0.16	1.68	0.10	-0.03	0.35
F	6.61				
d.f.	4				
R^2	0.24				

Discussion

This study aimed to explore the impact of carer knowledge about dementia, psychological flexibility, self-compassion and support from other family members on carer QoL. The results demonstrated that psychological flexibility was the only significant predictor of QoL. The findings suggest that improving carer's psychological flexibility may be particularly important in promoting their QoL. Previous studies have demonstrated that psychotherapeutic interventions that directly target psychological flexibility such as Acceptance and Commitment Therapy (ACT) are beneficial for treating depression and anxiety in family carers of people with dementia (Losada et al., 2015; Márquez-González et al., 2020). Currently, there is no clear evidence of whether ACT can also improve the overall QoL of carers, but this potential is worth investigating in future research.

Contrary to our hypotheses, carer knowledge about dementia, self-compassion and support from other family members did not predict carer QoL. There are several existing measures that are commonly used to assess knowledge about dementia. However, the majority of these measures only focus on information about Alzheimer's disease, particular stages of dementia or specific knowledge about biomedical domains, or they have been developed in small and narrowly defined populations (Annear et al., 2015; Carpenter et al., 2009; Gilleard & Groom, 1994; Kuhn et al., 2005; Toye et al., 2013). The DKAS, which was used to assess knowledge about dementia in the current study, was developed to overcome the limitations of existing measures. The DKAS assesses the knowledge in four different domains related to all types of dementia: causes and characteristics, communication and behaviour, care considerations, and risks and health promotion, while it has also been developed and validated in a larger and broader population (Annear et al., 2017; Annear et al., 2015). Even in spite of this, the variable still did not predict carer QoL in the current study.

Self-compassion and its relationship with psychological flexibility have been gaining more attention in recent years. Although these variables have different constructs, previous research has demonstrated that self-compassion and psychological flexibility have a medium to large significant correlation in diverse populations, which was consistent with our findings (Marshall & Brockman, 2016; McLean et al., 2018; Meyer et al., 2018; Pyszkowska, 2020). Nevertheless, when comparing both variables as predictors of emotional wellbeing, psychological flexibility seems to predict more variance than self-compassion, which is also consistent with our findings (Marshall & Brockman, 2016; Woodruff et al., 2014).

The current study also did not find a significant impact in the support from other family members on carer QoL. This is inconsistent with previous studies, in which receiving more support from other family members was associated with decreased depression and burden among family carers (Losada et al., 2006; Rapp et al., 1998). In the current study, 67 per cent of the participants had less than 2 hours a week or no support from other family members. Moreover, the support from other family members was measured by calculating the number of hours devoted to caregiving from other relatives. To estimate this, a categorical measure (e.g., 0-2 hours, 3-10 hours) was used rather than a continuous quantitative measure and thus this might have limited the ability to capture the wider variance. Furthermore, information about the use of respite services and the support received from non-family member carers (e.g. friends), community-based organisations or third parties (e.g. privately paid carers) was not included, which may have been confounding factors. For these reasons, great caution should be used in interpreting this result.

The findings of the current study have important clinical implications, potentially allowing us to optimise currently available evidence-based interventions. Previous reviews have demonstrated that most of the existing interventions developed for family carers of people with dementia are psychoeducational, which are aimed at increasing the carer's knowledge and teaching dementia- and caregiving-related skills (Cheng et al., 2020; Jensen et al., 2015; Kishita et al., 2018). Despite psychoeducational approaches being the most common type of interventions, these interventions have been proved to have a limited impact on family carer QoL (Amador-Marín & Guerra-Martín, 2017; Cheng et al., 2020; Kishita et al., 2018), which is consistent with the findings of the current study.

Previous studies have also highlighted that family carers often demonstrate a great need of receiving information about the disease, symptoms, prognosis, life expectancy and end-of-life care, particularly when they receive the diagnosis (Karnieli-Miller et al., 2012; Killen et al., 2016; Lee et al., 2019). It is critical that such educational needs of family carers are met, although may not be enough on their own to improve and maintain family carer QoL. Future research should explore the way to improve awareness of their own psychological needs and facilitate access to evidence-based psychological interventions among this population.

The generalisability of these results is subject to certain limitations, such as participants' characteristics. Most of the participants included in this study were female, aged 65 or older and were looking after a spouse with moderate to severe Alzheimer's disease in a developed country. Only a small percentage of the participants included in the study were caring for someone in the early stages of dementia.

Another limitation is that even the sociocultural stress and coping model for carers (Knight & Sayegh, 2010) refers to cultural aspects (e.g. familism) as an important factor, this was not considered in the current study, while information on the ethnicity of participants was not collected either. A systematic review exploring racial, ethnic and cultural differences in carers of people with dementia found that the caregiving experiences varied among different groups (Janevic & Connell, 2001). Future research should replicate the findings of the current study with other types of carers, including those from different ethnicities and races.

While the AAQ-II is one of the most used generic measures of psychological flexibility/inflexibility in the literature, there is a specific measure that targets psychological inflexibility in carers. The Experiential Avoidance in Caregiving Questionnaire (EACQ), which has been developed and validated in Spanish, shows acceptable psychometric properties. However, most of the measures of psychological flexibility to date are limited to global self-report questionnaires or more specific questions about unpleasant thoughts or the willingness to take actions in the direction of values in spite of the presence of unpleasant thoughts and feelings. In this regard, Kashdan & Rottenberg (2010) recommend that assessments of psychological flexibility should incorporate temporality and person–situation interactions in multiple contexts, which might be a more dynamic approach for such a dynamic construct.

Another potential methodological limitation is the R^2 value (i.e. 24%), which suggests that there may be other variables that need to be further considered in future research. For instance, this study assessed the knowledge about dementia but did not include any variables assessing whether carers have the ability to put said knowledge into practice (e.g. competencies in skills). The latter could be more directly relevant to minimising the negative impact of caregiving. Moreover, misattribution of symptoms was interpreted as a consequence of the lack of knowledge about dementia that some carers might have and thus the DKAS was used in this study. However, some previous studies have used other methods to assess dementia carers' attributions about neuropsychiatric symptoms, such as quantitative questionnaires and focus groups (Martin-Cook et al., 2003; Polenick et al., 2018). This study also did not include any stressor variables such as the care recipient's neuropsychiatric symptoms, which would have allowed to test the capacity of the proposed variables to predict carer QoL above and beyond the stressors.

Finally, it is important to emphasise that this was a cross-sectional study and thus the results regarding the causality between the variables may be limited. Future studies using a longitudinal design are needed to draw conclusions about the direction of effects.

Conclusion

This study found that psychological flexibility may serve as a protective factor for carer QoL as assessed by an old age-specific QoL measure. Future multicomponent interventions aiming to improve carer QoL could be optimised by incorporating an evidence-based treatment that targets psychological flexibility, such as ACT. It is recommended that future studies continue exploring the role of psychological flexibility and other protective factors for QoL, especially in carers of less common types of dementia, in the early stages, and from other countries, races and ethnicities.

Chapter 5

The impact of physical health, sleep quality and psychological flexibility on the quality of life of family carers of people with dementia

Submitted manuscript

Introduction

It is estimated that eighty-seven per cent of the people with dementia living in the community receive help from family members in their daily life and, thus, family carers play a crucial role in dementia care (Prince et al., 2014). Since dementia is a progressive condition, family carers tend to carry out this role for years and, in the UK, it is estimated that thirty per cent of them continue providing care for 5 to 10 years (NHS Digital, 2017).

Although there are some positive aspects of caring, looking after someone with dementia can have a negative impact on the social, psychological and physical wellbeing of the carer due to prolonged stress and the physical demands of caregiving (Alzheimer's Association, 2019; Ferrara et al., 2008; Richardson et al., 2013). As a consequence, family carers of people with dementia tend to have a lower quality of life (QoL) than non-dementia carers and non-carers (Karg et al., 2018; Pierre Moïse et al., 2004; Scholzel-Dorenbos et al., 2009). Poor carer QoL is also likely to be associated with poorer outcomes for the person with dementia, and with higher economic costs (Prince et al., 2014). Therefore, it is fundamental to support family carers to improve their QoL and, as such, identifying factors that may affect the family carer QoL seems critical.

There is accumulating evidence that chronic stress increases the vulnerability to physical disease (e.g. significant changes in biomarkers related to physical conditions such as hypertension, cardiovascular disease and metabolism) among family carers of people with dementia (Fonareva & Oken, 2014). It is estimated that 81.5 per cent of the carers have at least one chronic illness such as hypertension, arthritis or heart disease, and 60.5 per cent are likely to be experiencing multi-comorbidities (X. R. Wang et al., 2014). Furthermore, higher perceived caregiving strain is considered to be associated with higher mortality risk in this population (Perkins et al., 2013). This susceptibility to disease and health complications as a result of prolonged caregiving stress also increases the utilisation of healthcare services significantly when compared to non-carers (Rahman et al., 2019) and reduces their ability to provide optimal care for the person with dementia (Fonareva & Oken, 2014).

Despite the significant impact of caregiving stress on the physical health of the family carer, previous studies looking at factors associated with carer QoL are largely focused on the impact of contextual factors (e.g. neuropsychiatric symptoms of the person with dementia) or the carer's emotional wellbeing and mental health (e.g. depression and burden) (Contreras et al., 2020a; Farina et al., 2017). The impact of the physical health of the family carer on their QoL is somewhat neglected in the literature. Addressing this gap seems important given the increasing number of family carers, particularly in older adults, who are also at high risk of health complications (X. R. Wang et al., 2014).

In addition to the issue of multi-comorbidities, sleep problems are also highly frequent among dementia family carers and for many carers sleep disruptions usually occur as a result of care recipients' nocturnal awakenings and early morning awakening (McCurry et al., 1999; McCurry & Teri, 1995). Inadequate sleep can result in problems in the immune system and daily functioning and, therefore, physical health (Kryger et al., 2010; Peng & Chang, 2013). Previous research has demonstrated that worse sleep quality and greater sleep disturbances are associated with worse QoL in family carers of people with dementia (Creese et al., 2008; Cupidi et al., 2012; Lee, 2008; Peng & Chang, 2013).

It is also equally important to consider individual factors, which may contribute to improving QoL despite the impact of health complications. There is robust evidence that people from the non-carer population living with a physical health condition can still have better QoL and wellbeing when they are showing high levels of psychological flexibility (Densham et al., 2016; McAteer & Gillanders, 2019; McCracken & Velleman, 2010; Vowles & McCracken, 2010).

Psychological flexibility refers to the ability to fully connect with the present moment, being mindful of one's psychological reactions (e.g. distress and anger) and to persist or change one's behaviour in situations according to the individual's chosen values (Fletcher & Hayes, 2005; Hayes, 2004). This approach is highly practical for those living with a physical health condition as it focuses on what an individual can still do considering the available resources (e.g. seeking support to look after oneself, connecting with other family members and friends) rather than spending a lot of time fighting with their internal psychological struggles (e.g. thoughts and feelings related to their physical illness or loss of functioning).

In the dementia caregiving literature, some preliminary data demonstrates that present-moment awareness, one of the components of psychological flexibility, can moderate the impact of carer stressors on their physical health. This study found that present moment awareness may have a protective effect on blood pressure when carers face high levels of stress as a result of the high frequency of disruptive behaviours of the care recipient (Vara-García et al., 2019). Although these findings seem promising, the evidence that supports the protective effect of psychological flexibility on physical health among family carers of people with dementia is still limited and more studies are needed to draw a robust conclusion.

Considering the negative impact of physical health comorbidities and sleep quality and the potential protective effect of psychological flexibility on the daily life of family carers, this exploratory study aimed to explore the predictive effect of these three variables on QoL in family carers of people with dementia.

Methods

Participants

This cross-sectional study collected data from participants that: a) were currently looking after a relative with a clinical diagnosis of dementia and would identify themselves as the primary or co-carer, b) were in a first-degree relationship with the person with dementia (i.e., parent, spouse/partner, sibling, or adult child), and c) were aged 18 years or older. Care recipients were not assessed or present during the assessment sessions. The dementia diagnosis was based on the self-report of participants (i.e. carers). Recruitment took place between July 2017 and February 2020.

A total of 91 participants were recruited from carer support groups from Norfolk, an NHS mental health trust, and from Join Dementia Research, a UK-based online recruitment tool that allows people with dementia and their carers to register their interest in taking part in research studies. Participants were also recruited through referrals from other ethically approved dementia studies conducted by collaborators. All questionnaires and interviews for data collection were administrated at participants' own homes, the university, or local NHS premises depending on their preference by trained researchers. Full ethical approval was obtained from the NHS Health Research Authority and Research Ethics Committee. Written informed consent was obtained from all participants.

Sample size calculation

Prior to the study, the required sample size was calculated using G*Power. This calculation estimated that, based on a linear regression model with three independent variables included in the model, 77 participants would detect a medium effect size ($f^2=0.15$) at a 5% level of significance with 80% power.

Measures

Sleep quality.

The Pittsburgh Sleep Quality Index (PSQI) (Buysse et al., 1989) was used to assess sleep quality. The PSIQ is a 19-item self-report measure that assesses the quality and patterns of sleep during the past month. The items are combined to form seven ‘component’ scores: subjective sleep quality, sleep latency, sleep duration, habitual sleep efficacy, sleep disturbances, use of sleep medication, and daytime dysfunction. Each component score ranges from 0 to 3 and is added together to yield one global score. The global score ranges from 0 to 21, with lower scores indicating less difficulty and higher scores indicating more difficulties in all areas (Buysse et al., 1989).

Physical health.

The Charlson Comorbidity Index (CCI) (Charlson et al., 1994) is a weighted measure that assesses the number and severity of the following medical conditions: myocardial infarction, peripheral vascular disease, diabetes (complicated or not), congestive heart failure, liver disease (mild or severe), cerebrovascular disease, dementia, chronic obstructive pulmonary disease, connective tissue disease, long term kidney disease (moderate to severe), hemiplegia, peptic ulcer disease, metastatic solid tumour, and AIDS. Each condition is assigned a score (1, 2, 3 or 6) according to its weighted prognostic value. To create a combined age-comorbidity score, a weight of 1 score was assigned per decade of age over 40 years (e.g. 50-59 years, 1 point; 60-69 years, 2 points; 70-79 years, 3 points). These points for age are added to the CCI score to generate a final CCI score. A higher score indicates higher comorbidity, a higher risk of mortality, and, therefore, worse physical health (Charlson et al., 1994).

Psychological flexibility/inflexibility.

The Acceptance and Action Questionnaire-II (AAQ-II) (Bond et al., 2011) assesses the degree of psychological flexibility/inflexibility. Each item is rated on a 7-point scale that ranges from never true (1) to always true (7). The total score ranges from 7 to 49, with higher scores indicating greater levels of psychological inflexibility and lower scores indicating higher levels of psychological flexibility.

Dementia severity. The Frontotemporal Dementia Rating Scale (FRS) (Mioshi et al., 2010) was used to assess dementia severity. The FRS is a 30-item proxy-informant interview-based measure validated in various forms of dementia including Alzheimer's disease (Lima-Silva et al., 2013). Clinically, this measure categorizes people into six stages of dementia severity: very mild, mild, moderate, severe, very severe and profound. Logit scores are used for the analyses.

Demographics. Information collected included carer age and their level of education, type of relationship with the person with dementia, if they currently live with the person with dementia in the same household, and the number of hours devoted to caregiving. The type of dementia diagnosed and average years since diagnosis were also recorded. In addition, information about the use of primary (i.e. General Practitioner and Practice/Community Nurse) and secondary (i.e. Outpatient Department and Physiotherapist) healthcare services by the carers in the last three months prior to the assessment was collected.

Carer QoL. The key outcome of this study (i.e., carer QoL) was assessed using the 5-item ICEpop CAPability measure for Older people (ICECAP-O) (Grewal et al., 2006). This instrument defines QoL in a broader sense, rather than health, and was specifically designed to assess QoL among older people. Even though this measure is sensitive to changes related to age, it has also been validated in a sample of informal carers of people with dementia that included younger carers (Perry-Duxbury et al., 2020). The scale comprises five attributes: attachment (love and friendship), security (thinking about the future without concern), role (doing things that make you feel valued), enjoyment (enjoyment and pleasure), and control (independence). Each attribute can be scored on four levels (1-4) that range from "not any", "a little", "a lot" to "all", with higher values indicating greater QoL. The ICECAP-O rescaled values range from 0 to 1, distinguishing 1024 possible "capability states". The tariffs assign 0, the lowest value, to the state of having no capability on all the attributes (11111), the state of having a little capability on all attributes (22222) has value 0.556, the state of having a lot of capability on all of the attributes (33333) has a value of 0.866, and 1, the highest value, is assigned when having full capability on all the attributes (44444) (Coast et al., 2008; Perry-Duxbury et al., 2020). The ICECAP-O has good psychometric properties with decent evidence about its reliability and validity (Proud et al., 2019).

Statistical analyses

Descriptive analyses of demographics were performed to characterise the sample. A multiple regression analysis was conducted to examine to what extent different physical health-related factors predicted carer QoL. Physical health, sleep quality and psychological flexibility use were entered into the model as independent variables. The overall model fit was assessed using the F-test and the model's R^2. The standardised coefficients beta (β) were used to assess which of the variables had the strongest impact on the dependent variable (i.e. carer QoL). All statistical analyses were conducted using SPSS version 25 and p-values smaller than 0.05 were considered to be statistically significant.

The Tolerance value and VIF were estimated to check multicollinearity and the Mahalanobis distance to check the presence of outliers. Visual examination of the Normal Probability Plot (P-P) of the regression standardised residuals and residuals scatterplot was used to check normality, linearity and homoscedasticity of residuals.

Results

Sample characteristics

The demographic characteristics of participants are presented in Table 5.1. The majority of family carers were female (67.0 %), over 65 years old (69.2%), who had at least completed secondary school education (93.4%). The majority were looking after a spouse (69.2%) with Alzheimer's disease (44.0%) in the severe stage (45.1%) and 73.6% were living in the same household with the person with dementia. Over half of the participants (51.7%) reported spending 41 hours or more per week looking after the person with dementia, which is the equivalent of a full-time job. Table 5.2 shows the use of primary and secondary healthcare services and the average number of visits to these services in the last 3 months prior to the assessment. Pearson's correlations and means and standard deviations for all dependent and independent variables are presented in Table 5.3.

Model-checking

The Tolerance value was higher than 0.89 and the VIF value was below 1.12 for all independent variables in the multiple regression analysis, suggesting that the presence of multicollinearity is less likely to be a concern.

Table 5.1 Demographic characteristics of the sample (N=91).

Family carer characteristics		
Age (in years)	69.5	(± 12.5)
Gender (Female %)	67.0	
Educational Level %		
Unfinished Primary School	1.1	
Primary school	5.5	
Secondary school	40.7	
Vocational diploma	26.4	
Bachelor's degree	19.8	
Master's degree	5.5	
PhD	1.1	
Type of relationship %		
Wife	40.7	
Husband	28.6	
Daughter	25.3	
Son	4.4	
Sister	1.1	
Hours of support from other family members %		
No support	52.7	
0-2 hours	14.3	
3-10 hours	16.5	
11-20 hours	3.3	
21-40 hours	6.6	
41-80 hours	1.1	
81 or more hours	5.5	
Living with the care recipient (yes %)	73.6	
Characteristics of people with dementia		
Dementia type		
Alzheimer's %	44.0	
Mixed %	16.5	
Vascular %	15.4	
Frontotemporal %	7.7	
Lewy bodies %	5.5	
Unknown %	8.8	
Other %	2.2	
Years since diagnosis	3.7	(± 2.4)
Dementia Severity %		
Mild	5.5	
Moderate	30.8	
Severe	45.1	
Very severe	18.7	

The Normal P-P Plot revealed that all points lied in a reasonably straight diagonal line from bottom left to top right, indicating no major deviations from normality. The visualisation of the scatterplot of the standard residuals demonstrated that the residuals were distributed with most of the scores plotted on the centre and with a spread pattern. These results suggest that the assumption of normality, linearity and homoscedasticity of residuals was not violated. The Mahalanobis distance maximum value of 9.70 indicated that there was no extreme outlier present.

Table 5.2 Use of Primary and Secondary healthcare services in the last 3 months (N=87).

Use of healthcare services		
Primary healthcare services	53%	
Secondary healthcare services	28%	
Primary and Secondary healthcare services	23%	
None	29%	
Number of visits to healthcare services	**M**	**(SD)**
Primary healthcare services	1.59	(2.20)
Secondary healthcare services	0.71	(1.36)

Note. Four participants did not provide information about the use of healthcare services and thus only this analysis was conducted with 87 participants instead of 91.

Table 5.3 Pearson's correlations among independent and dependent variables and means and standard deviations (N=91).

Variables	1	2	3	*M* (SD)
1 Quality of life (ICECAP-O: 0-1)	-			0.73 (0.16)
2 Physical health (CCI: 0-37)	0.08	-		4.11 (2.73)
3 Sleep quality (PSQI: 0-21)	-0.39*	0.14	-	8.10 (3.81)
4 Psychological flexibility (AAQ-II: 7-49)	-0.46*	-0.23*	0.20	19.70 (10.50)

Note. ICECAP-O high scores denote a better QoL; CCI high scores denote worse physical health; PSQI high scores denote worse sleep quality; AAQ-II high scores denote greater levels of psychological inflexibility and low scores indicate higher levels of psychological flexibility.

Factors affecting family carer QoL

Results of the regression analysis showed that the model with physical health, sleep quality and psychological flexibility accounted for approximately 30% of the variance in carer QoL. Sleep quality (β = -0.32, p =0.00, 95%CI: -0.50 to -0.13) and psychological flexibility (β = -0.38, p =0.00, 95%CI: -0.57 to -0.20) were the only variables significantly predicting carer QoL (See Table 5.4). These findings suggest that having fewer sleep difficulties and higher psychological flexibility could lead to improved QoL in family carers.

Table 5.4 Results of multiple regression analysis (N=91).

Predictors	Carer QoL			95% CI	
	β	t	P	Lower	Upper
Carer Physical health	0.04	0.40	0.69	-0.15	0.23
Carer Sleep quality	-0.32	-3.41	0.00	-0.50	-0.13
Carer Psychological flexibility	-0.37	-4.04	0.10	-0.57	-0.20
F 12.53					
d.f. 4					
R^2 0.30					

Discussion

This observational study aimed to explore the impact of physical health, sleep quality and psychological flexibility on the QoL of family carers of people with dementia. The results demonstrated that sleep quality and psychological flexibility were the only significant predictors of QoL. The findings suggest that improving carer's sleep quality and psychological flexibility may be particularly important and that QoL can still be improved despite the impact of health complications. Our results are consistent with a previous study that highlighted the potential protective effect of psychological flexibility on carer QoL (Contreras et al., 2020b) and with those studies that demonstrated that worse sleep quality and greater sleep disturbances were associated with worse QoL in family carers of people with dementia (Creese et al., 2008; Cupidi et al., 2012; Lee, 2008; Peng & Chang, 2013).

Previous studies have demonstrated that psychotherapeutic interventions that directly target psychological flexibility, such as Acceptance and Commitment Therapy (ACT), are beneficial for treating negative outcomes in family carers of people with dementia such as depression and anxiety (Losada et al., 2015; Márquez-González et al., 2020). However, there is no clear evidence of whether ACT can also improve the overall QoL of carers and, therefore, future research should explore this possibility.

Furthermore, a recent systematic review demonstrated that ACT has a significant effect on primary and comorbid insomnia and sleep quality, and it can be used as an appropriate treatment method to control and improve sleep difficulties in different populations (Salari et al., 2020). Nevertheless, the effect of ACT on the sleep quality of dementia carers is still unknown. Future studies should investigate whether ACT alone would be enough to improve the sleep quality and consequentially QoL in dementia carers, or whether the development of multicomponent treatment such as combining ACT with existing sleep interventions for carers (e.g. sleep hygiene education, light chronotherapy treatments, or daytime exercise) (Gao et al., 2019) is required to target QoL among this population.

One unanticipated finding was that carer physical health did not predict carer QoL. This was contrary to the only previous study identified, which found that physical health predicted carer QoL (Kramer, 1993). This result may be explained by the fact that the participants included in the study were relatively healthy. Thirty-five per cent of the participants reported that they did not have any ongoing physical condition as assessed by the CCI. Thirty-three per cent of the participants reported that they had two or more ongoing physical conditions (i.e. multi-comorbidities), which is lower than reported in previous studies (X. R. Wang et al., 2014). Even though over seventy per cent of the participants used healthcare services in the last three months prior to the assessment date, the number of visits to the healthcare services in that period was also relatively low.

It is somewhat surprising that the participants included in the study were mostly healthy, considering that the existing literature has demonstrated that family carers of people with dementia have significantly lower levels of physical health than non-carers and non-dementia carers (Pinquart & Sörensen, 2003; Vitaliano et al., 2003). A prior meta-analysis on the correlates of physical health of informal carers demonstrated that carer depressive symptoms, lower socioeconomic status, and lower levels of informal support were significantly associated with poorer physical health (Pinquart & Sörensen, 2007). According to this data, it is possible to infer that family carers with multiple health conditions are more overwhelmed and more isolated than other healthier carers and, thus, they may be underrepresented in the literature. Future research needs to increase the representation of socially disadvantaged groups by involving its members in the planning and designing of the study and tailoring the procedure according to different subgroups of carers (Bonevski et al., 2014).

Furthermore, there is currently a lack of studies exploring how to best assess physical health conditions in family carers of people with dementia. Existing meta-analyses demonstrated that, unlike the current study which used the CCI, most of the previous studies used non-validated self-reported questionnaires retrieving information about the number of physician visits, medication use, number of physical symptoms, number of chronic illnesses, and/or hospitalisation to assess physical health conditions in carers (Pinquart & Sörensen, 2003; Vitaliano et al., 2003). Other studies have used physiological measures (e.g. cardiovascular measures, metabolic measures, functional immune measures), which are more objective and reliable than self-reported measures (Vitaliano et al., 2003). There is abundant room for further progress in determining the most appropriate way to measure physical health in family carers and, therefore, future studies on the current topic are recommended.

The generalisability of these results is subject to certain limitations, such as participants' characteristics. Most of the participants included in this study were female, aged 65 or older, and were looking after a spouse with moderate to severe Alzheimer’s disease in a developed country. Only a small percentage of the participants included in the study were caring for someone in the early stages of dementia. Future research should replicate the findings of the current study with other types of carers, including those from different ethnicities and races.

The current study used a QoL instrument that has been validated in family carers of people with dementia and that defines QoL in terms of an individual’s capability to do certain things that are important in life (i.e. the ICECAP-O). While the use of the ICECAP-O with the carer population has several advantages, it is important to acknowledge the existence of other recently developed measures for this population such as the C-DEMQOL and the Dementia Quality of Life Scale for Older Family Carers (DQoLOC) (Brown et al., 2019; de Oliveira et al., 2018). However, even though both scales seem to be promising instruments to measure carer QoL, it is important to highlight that they are relatively new, and more studies are needed to evaluate their psychometric properties.

Another potential methodological limitation is the R^2 value (i.e. 30%), which may suggest that there may be other variables that need to be further considered in future research. For instance, this study did not include any information about the sleep quality of the care recipients, which could be associated with disturbed sleep in carers (Gao et al., 2019).

Finally, it is necessary to emphasise that this was an observational study and thus the results regarding the causality between the variables may be limited. Future studies using a longitudinal design are needed to draw conclusions about the direction of effects.

Conclusion

This study found that psychological flexibility and sleep quality may contribute to improving carer QoL, as an individual’s capability to ‘do certain things that are important in life. Future interventions aiming to improve carer QoL could be enhanced by incorporating an evidence-based treatment that targets psychological flexibility, such as ACT, and by including components that directly target the sleep quality of the carer. It is recommended that future studies continue exploring the effect of psychological flexibility and sleep quality on carer QoL, especially in carers of less common types of dementia, in the early stages, and from other countries, races and ethnicities. Involving members of socially disadvantaged groups, such as those with severe health conditions, in planning the study is critically important in future research.

Chapter 6

What are the educational and support needs of family carers looking after someone in the early stages of Alzheimer's disease? A qualitative retrospective approach

Submitted manuscript

Introduction

Caring for someone with dementia can be physically and emotionally challenging and it can have a negative impact on the social, psychological and physical wellbeing of the carer (Ferrara et al., 2008; Richardson et al., 2013). This results in family carers of people with dementia often having high levels of physical burden and psychological distress (Collins & Kishita, 2020; Kaddour & Kishita, 2019). Therefore, exploring family carers' specific needs is critical as this information can lead to the successful planning and delivery of community services and care plans, to the referral of carers to appropriate support and resources and to designing research programmes design research programmes and interventions to improve carer outcomes (Novais et al., 2017).

A recent comprehensive systematic review on the needs of informal carers of people with different types of dementia demonstrated that the most explored topics of carers' needs in the literature were: information on the disease, support for the carers, coping with caring, community services related to patient care, financial issues and safety (Novais et al., 2017). In this review, the most commonly included studies used a quantitative approach although qualitative studies were also eligible. Using a quantitative approach to assess dementia carers' needs may allow the exploration of a larger number of topics simultaneously in a larger sample. However, qualitative research is also valuable as it can explore aspects of complex behaviours, attitudes, and in-depth specific needs and experiences from the standpoint of the participant, which may vary across family carers (Braun & Clarke, 2013; Pope & Mays, 1995).

Several limitations also exist for qualitative studies in this area. Existing qualitative studies on carers' needs are often focused on carers of people with moderate to severe dementia (Farran et al., 2004; Shanley et al., 2011) or do not differentiate the results by dementia stage, making it difficult to generalise those findings to carers of people with dementia in specific stages, such as the early stages (ES) (Peterson et al., 2016). The needs of family carers of people with dementia in the ES may be qualitatively different from those caring for people with moderate to severe dementia as physical support needs of the care recipient may be limited due to the level of independence at the ES.

There are a few qualitative studies that aimed to explore the in-depth experiences of family carers of people with dementia in the ES (Lee et al., 2019). However, these qualitative studies mainly focused on the experiences of the diagnostic process and the transition to the caregiving role, rather than directly asking about the educational or support needs of carers during these times. There is only one qualitative study, which used focus groups to directly explore the needs of family carers of people with dementia in the ES (Boots et al., 2015). Nevertheless, this study also included carers of patients with mild cognitive impairment and carers of people with different types of dementia. Furthermore, the sample was not large enough for such a heterogeneous population, making it difficult to draw a robust conclusion.

To overcome the limitations of previous research, the current study aimed to identify the needs of family carers of people with dementia in the ES by employing a qualitative approach with retrospective semi-structured interviews with family carers of people in the later stages of Alzheimer’s disease (AD). In order to reduce the heterogeneity of sample characteristics, AD was chosen as it is the most common cause of dementia (Alzheimer's Association, 2019). The data was collected from carers of people in the later stages of AD and explored the experiences of caregiving in the ES retrospectively, as previous studies suggested that family carers of people with dementia in the ES are hard to identify as they often do not see themselves as carers (Boots et al., 2015; Carduff et al., 2014) or they struggle to recognise their own needs due to difficulties in accepting the changed circumstances and fear of stigma (Boots et al., 2015; Peterson et al., 2016). The retrospective views of later-stage carers can provide valuable insights as they allow us to explore educational and support needs during the ES, which could have had an impact for a prolonged period of time (Boots et al., 2015; Jenkins & Feldman, 2018).

Methods

Study Design

A qualitative retrospective approach was employed to explore the experiences of caregiving in the early stages of Alzheimer’s Disease (ESAD) from the perspective of unpaid family carers. Semi-structured interviews were conducted with family carers of people with moderate to severe AD.

Ethics

The study received approval from the FMH Research Ethics Committee of the University of East Anglia (August 2021; project number 2019/20-150).

Setting

Due to the COVID-19 pandemic, the interviews were conducted via telephone or Microsoft Teams video call, depending on the carer's preference.

Participants and recruitment

Purposive sampling was used to ensure that the maximum variation of viewpoints was obtained. It is estimated that 60 to 70 per cent of the family carers are female in the UK (Glasby & Thomas, 2019). Therefore, the study aimed to maintain this proportion in the final sample. Previous studies also suggest that the experiences of spouses and children looking after someone with dementia can differ due to the relationship (Brodaty & Donkin, 2009; Glasby & Thomas, 2019; Jenkins & Feldman, 2018). Thus, the aim was to recruit female and male participants with different types of relationships with the care recipients to ensure that the sample was representative of the targeted population.

The participants included in the study had conversational English and the capacity to consent for themselves; were at least 18 years old; were an unpaid carer with a first-degree relationship (spouse/partner or adult child) with a person with AD, and were caring for a family member with moderate to severe AD, according to the Frontotemporal Rating Scale (Mioshi et al., 2010). The study aimed to achieve an approximate sample size of 12, informed by the concept of Information Power (Malterud et al., 2016). Participants were purposively sampled from other ethically approved large dementia studies led by the authors. These participants had already given consent to be contacted for future research.

Data collection

After obtaining informed consent via post or electronically, potential participants were asked to attend an initial screening assessment via telephone or Microsoft Teams video call. The screening assessment aimed to assess the participants' eligibility by checking the dementia severity of the care recipient using the Frontotemporal Dementia Rating Scale (FRS) (Mioshi et al., 2010). The FRS is a 30-item interview-based measure of patients' dementia severity. The scale is a well-established dementia staging tool used largely in research studies (Turró-Garriga et al., 2017). The scale has been validated in various types of dementia patients, including AD (Lima-Silva et al., 2013).

Eligible participants were invited to the semi-structured individual interview, which was also conducted via telephone or Microsoft Teams video call. A researcher experienced in working with family carers of people with dementia conducted all interviews (MC), which were audio-recorded with the participant's permission. At the beginning of the individual interview session, participants were asked to answer some demographic questions, including information about their age, gender, type of relationship with the care recipient, level of education, and work status at the time of diagnosis.

The interviews were conversational, using a blended approach of passive interviewing (allowing the participant space and time to share their narrative) and more active approaches, using questions listed in an interview guide that was developed from the literature and investigators consensus (see supplementary material 6.1). Participants were reminded that the interview was focused on their experiences during the ESAD throughout the interview to ensure that shared experiences were relevant to the research question. The participants were asked to reflect on (i) challenges experienced in the ESAD; (ii) the type of information and support received for themselves or the person in the ESAD; (iii) their own educational and support needs in the ESAD; and (iv) preferred sources and settings for learning and receiving such support.

Data processing and analysis

The audio-recorded interviews were transcribed, any identifiable information regarding participants was removed and the data was analysed following Braun and Clarke’s six-stage thematic analysis approach (Braun & Clarke, 2006). To ensure the validity and reliability of data analysis, the first coder (MC) and the second coder (NK) separately reviewed the initial five transcripts to familiarise themselves with the data and start generating initial codes. They then met to compare these initial codes to achieve consensus.

Following this, all transcripts were imported into NVivo 12 and (MC) used the initial set of codes as an aid to code all the transcripts consistently and generate additional codes as required. Once all the transcripts were coded, (MC) and (NK) independently identified potential themes that were then compared to illustrate broad themes and define further sub-themes. Discussions and consensus between (MC) and (NK) finalised the mapping and interpretation of key themes and sub-themes.

Findings

Twelve participants were interviewed between September 2020 and January 2021. The sociodemographic details of participants are shown in Table 6.1. Three overarching themes of the educational and support needs of family carers of people in the ESAD were identified: (1) *challenges in the ESAD*, (2) *limited support received after the diagnosis*, and (3) *I'll tell you what I want, what I really, really want.* An overview of the overarching themes and their categories is provided in Table 6.2.

Table 6.1 Demographic characteristics of the sample (N=12).

Family carer characteristics		
Age (in years)	Range	52 - 90
	Mean	69.17
Gender	Female	7
	Male	5
Type of relationship	Wife	4
	Husband	3
	Daughter	3
	Son	2
Educational Level	Secondary school	4
	Vocational diploma	1
	Bachelor’s degree	6
	PhD	1
Work status at the time of diagnosis	Part-time	1
	Full-time	5
	Retired	6
Characteristics of people with dementia		
Gender	Female	7
	Male	5
Dementia Severity	Moderate	3
	Severe	9
Number of years since receiving the diagnosis	Range	1.5 - 8
	Mean	2.79

Table 6.2 Overview of overarching themes and categories

Challenges in the early stages of AD	Limited support received after the diagnosis	I'll tell you what I want, what I really, really want
Feeling guilty for seeking support and information	Feelings of helplessness	1) Interpersonal support needed in the early stages
Family obligations – Barriers to seeking support	Support limited to self-help resources	2) Educational needs in the early stages
Significant worries about the future and own health		3) Self-care needs in the early stages

Challenges in the ESAD

Feeling guilty for seeking support and information

Carers' insights demonstrated complex emotional difficulties arising from the interpersonal dynamics between carer and their care recipient following the dementia diagnosis. Care recipients were often unable to accept the diagnosis, making it difficult for carers to directly ask for help in the ESAD. This had a significant emotional impact on the carers, experiencing feelings of guilt due to carers having to do certain things behind the care recipient's back, such as talking about the diagnosis with close friends to seek support or looking for more information about AD without making the care recipient aware:

> I mean, the other interesting thing, and I suspect this is fairly common, [care recipient] didn't want me to tell people… and that's quite hard and in fact, I did tell… well certainly our close friends and I didn't tell him that I told some because he didn't want, obviously he knew we told the family and, you know, gradually, I told him that I've told people because, you know, I need some support as well as him. But, you know, I think handling that whole business, you know, obviously, if you got Alzheimer's, your first worry is that everybody is gonna think that you're… you know, that you're some kind of sub-standard person and maybe avoid you or whatever, I don't know, but I mean… people don't do that. But… clearly [care recipient] was embarrassed by the fact of having it and didn't want to tell people. (Participant 011; wife).
>
> The other thing was, even at that stage I felt guilty about reading it in front of [care recipient] you know cos um, it was a very gradual letting go of, um feeling resentful about the um diagnosis of Alzheimer's for her. (Participant 02; husband).

Family obligations – Barriers to seeking support

Participants were often unable to see themselves as carers in the ESAD, which became another barrier to seeking support. Carers felt that looking after the person with AD was their family obligation. This difficulty to see themselves as carers beyond the familial bond impacted the way they perceived their own needs, which some of them only recognised once they had accepted that they were carers:

> I've went through a lot on my own before I sought any help with the care and I would pass the carer centre, often and I never thought it is a place that was for me, I didn't think that that was my place. So obviously, the people, you know, who are looking after their family just think, well, I'm doing as a daughter, as a sister, or... I don't know, as a relative, you're doing this job, because you're related to that person, and that's your duty, but you don't realise that you are a carer. (Participant 09; daughter).
>
> She [care recipient's sister] described me as mum's primary caregiver and up to that point, that hadn't actually occurred to me and somehow, that kind of made me think, that made me be more aware of my needs, not just mum's. (Participant 07; daughter).

Significant worries about the future and own health

There was overwhelming evidence in the interviews suggesting that carers experienced numerous worries in the ESAD. Carers often worried about the future, such as how quickly the disease would progress, how the caregiving tasks would impact their own physical and mental health, how they would cope in the more severe stages and the financial impact it may have (e.g. costs of care homes).

> Because the only thing, as I say, the thing once you have the diagnosis, is your worry the more you find out about how, not what's happening at the moment but how am I going to cope in a years time or two years time or whatever, when that person's situation deteriorates and you are suddenly finding yourself under a lot more pressure, so I was, was obviously worried about what I'd read about in terms of the potential for how he might deteriorate. (Participant 01; son).
>
> You do worry about what's gonna happen in the future, you sort of worry about the future a bit and, you know, I started to think about, you know, to think about finances, (…) I looked at the cost of care homes if it came to that, cost of, you know, having carers coming to the house, that sort of thing. (Participant 011; wife).

Limited support received after the diagnosis

Feelings of helplessness

After receiving the diagnosis, there was a recurrent feeling of helplessness among most of the carers. The carers felt that they received no or not enough information about AD to help prepare for the future, nor sufficient support to look after their own physical and mental health from healthcare professionals.

> No, they, they gave me no other information. When the mental health nurse, got [care recipient] medication settled, she then said ‘oh, now I’ll hand you over to the doctor’s surgery’ and I thought ‘oh, someone I’d been able to talk to and get information from’, suddenly wasn’t going to be doing anything for me, she was just going to hand me back to the doctor’s surgery [pause] and I thought ‘well, that is really tough’. (...)But really they didn’t answer the questions, they sent him off to have a brain scan and they sent him off to other things with no explanation, and I think they need to talk a lot more to the carers, so that we understand what is going on. (Participant 04; wife).
>
> They [healthcare professionals] don't really take into account the carer; they're just dealing with what are they diagnosing this person (…). But they don’t, it's not really about carers and how to care for yourself. And I think that would have been really good from the onset, because by the time you get any information about how to look after yourself, you're probably burnt out already. (Participant 09; daughter).

Support limited to self-help resources

Carers expressed that they only received printed or online resources for self-learning about AD in the ES. These materials were often provided by healthcare professionals once the diagnosis was confirmed or carers did their own online research to look for more information from relevant charities. Carers also received limited information about self-care. The only information carers received was often a list of contacts of charities for seeking support or very brief informal advice from their GP or consultant such as being encouraged to ask for help without further details.

> I’ve had a lot of information in books, or I had some pamphlets and all that sort of thing… I can’t recall anything apart from that. (Participant 08; husband).
>
> I think one of the leaflets said, obviously if you need support as a carer, here are some contacts that you could read or phone up, but the information was very basic and, and again consisted primarily of just places you could go. (Participant 01; son).

> He [GP] said to me '[participant's name] don't wait until you need help, get it now. (Participant 12; husband).

Carers also consistently expressed the disadvantages of such self-help resources. The information available on the internet was not practical for carers who do not use computers. Having to be proactive to look for information to seek support and to read a lot of written information following the diagnosis was somewhat overwhelming for carers in the ESAD. Non-personalised information, which is very common for self-help resources, did not address their concerns and worries, and carers felt that resources were insufficient when faced with such a difficult situation.

> And I think then you have, you know, someone who you care for and you love had that kind of diagnosis it's quite devastating. And I think just handing you a few leaflets, is quite, it's quite cold really, you know, I know, they don't mean to be, but I just don't think that it's appropriate. (Participant 09; daughter).

> Let's face it, unless you can be really bothered, you're not going to read, um because the reading, there is so much of it and you sort of think to yourself, 'oh I've got better things to read than this', you know, it's a bit pointless, well it is in my case, um I've got better things to do, then sit down and read a hundred pages of guff from people who probably are very good and know what they are doing but they don't answer the questions that you would like to put to a person, you know what I mean? (Participant 03; wife).

I'll tell you what I want, what I really, really want

Three key topics emerged from this overarching theme: 1) interpersonal support needed in the ESAD, 2) educational needs in the ESAD, and 3) self-care needs in the ESAD.

1) Interpersonal support needed in the ESAD

There was overwhelming evidence in the interviews suggesting that carers wanted to receive interpersonal support in the ESAD. Carers wanted to have the opportunity to ask questions to healthcare professionals directly after receiving the diagnosis. Carers suggested that this could take a group format (e.g. one-day workshop) with dementia specialists following the diagnosis or a one-to-one format, such as regular contact with their GP or a dementia specialist face-to-face or via telephone.

> I really feel that with Alzheimer's, when you get somebody who has been diagnosed, it would be really, really helpful to have a day where you are, you and your family, because obviously if you've got several family members,

> you know, it would be really helpful to have a proper um briefing day for you and the patient to really help you understand what the issues are. (Participant 01; son).
>
> (...) there should be someone who you could actually talk to who knows about dementia, in all its forms, that you can actually go to them and say, “am I doing the right thing?”, “Who do I go to next to get the information I need?” But there doesn’t seem to be anybody who covers that sort of area of dementia at all. (Participant 04; wife).

Carers also felt interpersonal support outside of the formal healthcare services could be helpful. Talking to other family carers going through a similar experience was something carers wanted to have in the ESAD. Carers suggested that this could include other carers that had just found out about the diagnosis, but also more experienced carers, face-to-face but also virtually.

> I think you can speak to people about how, you know, if somebody’s going through a similar situation, depending on the type of dementia, how they’ve dealt with that situation, if they found something tough. But you’ve also, you know, you got somebody that has been through it, they can probably help you, give you some support back and some ideas as well. (Participant 06; daughter).
>
> I mean, I guess if there was a group of carers that could get together, but that would be very difficult, because you can’t leave your partner or whatever, so that’s become more difficult, maybe that could be done virtually, you can do these things virtually these days. (Participant 11; wife).

2) Educational needs in the ESAD

Carers wanted to receive more information about dementia in the ESAD. They wanted a better understanding of expected progressions and how to manage the symptoms of dementia and to provide better care to the person with AD as the disease progresses from the start. Carers also wanted to receive practical advice such as information on financial and legal aspects and the use of assistive technology.

> I think it would be incredibly useful actually, I think that, you know, you do need to give people information, not to scare them too much but I think give them information about what to expect”. (...)I think, information about the sort of things you need to think about and the stage of which you need to think, I mean thinking about finances and how you’re gonna cope with any financial impact in the future is quite important. So, that sort of information would be helpful, if that sort of thing was in a leaflet… it would be helpful

> what's the cost of care, what's the cost of carers coming to your house. (Participant 011; wife).
>
> (...) it should be a holistic approach, that we are provided information about what is going on with this person, the diagnosis, how to look after, how they need to be looked after, what medications, what exercise, what diet, all the things, lifestyle changes everything that they need. (Participant 09; daughter).

3) Self-care needs in the ESAD

Finally, carers felt that their self-care needs were unmet in the ESAD. As identified earlier, carers struggled to see themselves as carers beyond the familial bond in the ESAD. Thus, carers wanted to receive education and support which could help to increase awareness of their own needs in the ESAD.

Carers also wanted to learn coping skills to build resilience in the ESAD so that they could be more prepared for future challenges. Some carers also expressed the need for receiving more intense mental health support from the ESAD as they considered that caring for someone with AD was stressful, burdensome and isolating.

> (...) actually helping them [carers in the ESAD] build resilience at a point when they are not having to deal with those issues but thinking about if things do get worse in a years time or whatever, you know how will you, what are your support mechanisms, who are the people you could turn to in your family or who you live with or your neighbours or whatever, so I think that is another important thing to make that more clear and make people really think carers, as much, well not as much but actually think about a plan of how they are going to cope down the line. (Participant 01; son).
>
> Well, I, I think you know, mental and physical health support would have been important because it, it can be quite stressful so the more you look after yourself the better able you are to withstand the stresses and learn techniques to deal with them (Participant 02; husband).

Discussion

This study aimed to identify the educational and support needs of family carers of people with dementia in the ESAD. Three overarching themes were identified in the retrospective semi-structured interviews with family carers in later stages. The first theme was the challenges in the ESAD. Family carers manifested feelings of guilt for seeking support, particularly when the care recipient had difficulties in accepting the diagnosis. Perceiving the caregiving tasks as a family obligation was another barrier to seeking support. The frequent and extensive worries about the future and their own physical and mental health were also evident.

The second theme revealed the limited support the carers received following the diagnosis. This led to a feeling of helplessness among most of the carers that expressed that they had not received enough information and support at that time. The minimal support received was often reduced to self-help resources which had several limitations such as non-tailored information not being helpful in addressing their concerns and worries.

The third theme identified what carers really wanted in the ESAD. This included more interpersonal support following the diagnosis with opportunities to ask questions to professionals, but also to talk with other carers going through similar experiences. Carers wanted to receive more practical advice (e.g. legal and financial advice) to look after their care recipient. Provision of support to increase awareness of their own needs and to learn coping skills to build resilience was also identified to be critical in the ESAD.

Previous studies have found that carers struggle to acknowledge their needs and to accept help in the ES of dementia (Boots et al., 2015). By exploring the retrospective views of experienced carers, this study not only identified the type of information and support that carers needed in the ES, but it also enabled to identify potential factors that may hinder acceptance of support, such as difficulties in accepting the diagnosis and feelings of the need to fulfil a family obligation. These led to significant emotional challenges such as worries and feelings of guilt in the ES.

Different types of interventions have been developed for dementia carers and have been tested in the research context. There is robust evidence that depression is modifiable across these different types of interventions (e.g. psychoeducation, counselling, psychotherapy, occupational therapy, multicomponent interventions) while the sense of competence and self-efficacy in their role may be improved through some specific types of interventions (e.g. psychoeducation, occupational therapy) (Cheng & Zhang, 2020). These previous studies are primarily focused on carers at later stages, and the existing interventions have demonstrated null or weak results for carer anxiety and worries (Cheng & Zhang, 2020). Moreover, the interventions that directly target feelings of guilt in family carers are scarce (Gallego-Alberto et al., 2021), which may be critical for family carers in the ES.

Our findings provided important clinical implications, highlighting the need for multicomponent interventions that are specifically designed for family carers in the ES. These interventions may include dyadic psychological intervention to support the acceptance of the diagnosis, carer intervention aimed at undermining feelings of guilt in seeking support and tailored practical advice provided by healthcare professionals and peers to improve anxiety and worries. The co-production and prototyping of such interventions with family carers and stakeholders are key stepping stones towards the successful delivery of support services for family carers in the ES.

This study also has some methodological limitations. Although the sample size was large enough to hold sufficient information power and it mirrored the carer demographic characteristics of previous studies, a larger sample would have allowed the identification of patterns in each group according to gender and the types of relationship with the care recipient. It is particularly important to recognise that information on the ethnicity of carers was not collected as part of the study. However, the participants were recruited from the East of England and Greater London areas, where most of the community is White British. It is recommended that future studies explore whether the experiences identified in this study are shared by other subgroups of carers, such as carers from ethnic minority groups.

Conclusion

This study showed that carers of people with AD experience several challenges in the ES, such as frequent and extensive worries, overwhelming feelings of the need to fulfil a family obligation and feelings of guilt in seeking help. These challenges acted as barriers to seeking support and, since the information and support received after the diagnosis was non-existent or not sufficient, carers ended up having several unmet needs, which may lead to more difficulties in later stages. The development of multicomponent interventions specifically designed for family carers in the ES is recommended. Dyadic psychological intervention to support the acceptance of the diagnosis, carer intervention aimed at undermining feelings of guilt in seeking support and tailored practical advice provided by healthcare professionals and peers to improve anxiety and worries may be critical components of such future interventions.

Chapter 7

General Discussion

Summary of key findings

This thesis aimed to identify modifiable factors that can predict QoL in family carers of people with dementia in order to understand their complex needs using a QoL measure suitable for this population (i.e. the ICECAP-O). Moreover, this thesis aimed to identify critical components that need to be considered in the development of future interventions aiming to improve carer QoL.

Chapter 2 quantitatively synthesised the existing evidence and demonstrated that carer depression and burden and people with dementia's neuropsychiatric symptoms were significantly associated with carer QoL when the outcome variable was measured by generic QoL instruments. This chapter also showed that the social and economic development status of the country where study participants resided did not moderate these correlations.

Chapter 3 showed that carer anxiety, a factor that is commonly neglected in the carer literature, was the only risk factor predicting carer QoL, as measured by the ICECAP-O. In chapter 4, different protective factors were explored and carer psychological flexibility was found to be the only factor significantly predicting carer QoL. Chapter 4 also demonstrated that psychological flexibility was still predicting carer QoL, despite the presence of factors affecting carers physical health, such as comorbidities and sleep difficulties. Chapter 4 and 5 emphasised that interventions aimed at improving psychological flexibility, such as ACT, could have a strong potential in improving QoL among dementia carers.

Finally, chapter 6 qualitatively explored the educational and support needs of carers in the early stages of Alzheimer's disease to supplement the findings from previous chapters, which employed quantitative methods. In this chapter, difficult feelings (e.g. guilt and worries) and the need for interpersonal support were identified to be relevant in the early stages of Alzheimer's disease.

Towards the development of interventions to improve the QoL of family carers.

Existing interventions targeting QoL

Several non-pharmacological interventions have been developed for dementia carers. According to the latest meta-analysis evaluating the effectiveness of carer interventions (Cheng et al., 2020), only 32 randomised control trials out of 131 measured their impact on carer QoL (i.e. less than one-quarter of the total number of interventions developed for this population). Most of the interventions targeting carer QoL were psychoeducational (i.e. 12 trials), which included programmes aiming at increasing carers' knowledge about dementia and educating dementia- and caregiving-related coping skills, such as symptoms management and stress control strategies. Some studies did not provide the underlying psychological theories or principles, which informed such psychological components of these interventions, while others clearly stated that proposed components were informed by psychotherapeutic perspectives such as cognitive-behavioural theories (Cheng et al., 2020).

In this meta-analysis, only five psychoeducational interventions were found to have improved QoL after completing the programme (Cheng et al., 2020). All the interventions involved individual sessions with dementia carers and two of them also included group sessions. Improvements in all components of QoL were found in two interventions (Heydari et al., 2017; Martín-Carrasco et al., 2009), while the remaining interventions only improved specific domains of QoL, such as the mental health component (Kurz et al., 2010; Livingston et al., 2013) and physical, social relations and environment domains (Foss et al., 2007).

There were several limitations to these studies, which demonstrated some preliminary effects of the interventions on QoL. Firstly, the studies used an HRQoL measure such as the SF-36 (Heydari et al., 2017; Kurz et al., 2010; Martín-Carrasco et al., 2009) and the Health status questionnaire (Livingston et al., 2013), or a generic measure of QoL, such as the WHOQOL-brief (Foss et al., 2007). The limitations of using these types of measures to assess carers' QoL have been previously discussed in this thesis and their ubiquitous use is consistent with the findings from the meta-analysis described in chapter 2. Furthermore, the effect of these improvements was small (Kurz et al., 2010); or carers' QoL in the experimental group did demonstrate pre-post improvements but such difference was not statistically significant when compared with the control group (Heydari et al., 2017), which hinders results interpretation.

Considering the limitations of the existing evidence and the lack of interventional studies that used appropriate measures to assess QoL in family carers of people with dementia, this thesis provides valuable insights for the development of future interventions, particularly multi-component programmes. Multicomponent interventions combine multiple approaches in the same programme without any component being more dominant. According to the findings reported in chapters 2-6, the following components are recommended for new interventions aiming to improve the QoL of dementia family carers.

Recommended key educational components for future interventions

The qualitative study conducted in chapter 6 highlighted that carers wanted to receive more information about dementia following the diagnosis, which was consistent with previous studies (Karnieli-Miller et al., 2012; Killen et al., 2016; Lee et al., 2019). Even though chapter 4 showed that knowledge about dementia was neither associated with nor predicting QoL, it is critical that carers' needs are met and, for this reason, it is recommended to include information about dementia as a key component.

Chapter 6 revealed that carers wanted to learn how to provide better care for the person with dementia (i.e. how to identify and meet the care recipient's needs). This component could include pieces of advice for improving the care recipient's lifestyle and QoL, such as diet, exercise and social activities. Furthermore, carers wanted to receive practical advice on financial (e.g. costs of private carers or benefits) and legal aspects (e.g. importance of putting a lasting power of attorney in place) and the use of assistive technology to facilitate the caregiving tasks and the care recipient's independence.

Carers also expressed the need to receive more information about the characteristics and the expected progressions of the diseases causing dementia and how to manage challenging symptoms. The care recipient's neuropsychiatric symptoms were found to have a significant role across chapters 2 and 3. The meta-analysis showed that the pooled correlations with QoL were significant for this variable and that this finding was robust in the context of publication bias. Moreover, although neuropsychiatric symptoms were not predicting carer QoL in the regression model proposed in chapter 3, there was still a significant correlation between both variables. For these reasons, providing information on expected symptoms at different stages and how to respond to different challenging situations and symptoms could potentially lead to improvements in carers' QoL, while also meeting their educational needs.

Recommended key psychotherapeutic components for future interventions

Chapter 6 also shed light on an important challenge that dementia carers experience in the early stages of dementia: the difficulty to see themselves as carers. In the qualitative study, this was identified as a critical barrier in recognising their own needs and seeking support in the early stages. Perceiving the caregiving tasks as a family obligation has been previously linked to the concept of familism, which is the strong identification and attachment of individuals with their families. Familism also involves strong feelings of loyalty, reciprocity and solidarity among members of the same family (Sabogal et al., 1987). While some positive effects have been associated with familism, previous studies also found that, for some carers, it may represent obligation more than positive feelings about family support (Kim et al., 2007). Familism has been explored in different cultural groups and it was significantly associated with carer depression in White British carers (Parveen et al., 2013). Therefore, providing support to carers so they can see themselves as carers and start identifying their own needs from the early stages may also be a critical component to consider in future interventions.

It is also well documented that family carers of people with dementia often experience feelings of guilt (Gallego-Alberto et al., 2020; Losada et al., 2018). The majority of previous studies are focused on carers looking after someone in the later stages of dementia, but the findings reported in chapter 6 suggested that these significant feelings of guilt are present from the early stages. Furthermore, these findings demonstrated that such feelings of guilt emerge from the complex interpersonal dynamics between carer and their care recipient. However, the impact of feelings of guilt on QoL was not assessed, which is a limitation of this thesis. Thus, it is not possible to asseverate that targeting guilt in future interventions would lead to improvements in carer QoL but there is the potential to explore this variable further.

Another important finding of this thesis was the significant role that carer anxiety played in reducing QoL. Chapter 2 showed that the association between anxiety and QoL was not sufficiently explored in the carer literature. This finding was consistent with a meta-analysis that found that, even though anxiety is as prevalent as depression among dementia carers, this variable is somewhat neglected in the existing studies (Kaddour & Kishita, 2019). Indeed, chapter 3 revealed that anxiety was the only predictor of QoL when compared to other well-established predictors such as carer depression, burden and the care recipient's neuropsychiatric symptoms. Moreover, chapter 6 showed that carers have frequent and extensive worries about the future, such as how quickly the disease would progress and how they would cope in the more severe stages. Hence, it is recommended that future interventions incorporate strategies that could help carers to deal with these worries more effectively in the ES so that the chances of developing symptoms of anxiety in later stages are reduced, which could also lead to improvements in their QoL.

Psychological flexibility was identified to have a key role in predicting improvements on QoL, even in the presence of sleep difficulties and comorbidities. Chapters 4 and 5 suggested that interventions aiming to improve carers psychological flexibility, such as ACT, may have a strong potential in improving QoL. ACT is a behavioural therapy that postulates that human existence contains inevitable challenges and suffering that cannot be eliminated (Hayes et al., 2012). For this reason, ACT does not aim to change uncomfortable feelings and thoughts but rather to reduce their impact and influence on individuals' lives by helping carers learn to step back from such internal struggles and embrace them as they are. Furthermore, ACT helps carers to clarify what is truly important and meaningful to them beyond caring (values) and to use that knowledge to enhance goal-directed behaviours (Harris, 2019; Hayes et al., 2012).

ACT is underpinned by a transdiagnostic model of treatment and thus addresses universal processes rather than a specific diagnosis. ACT has shown to be effective across a broad range of physical and mental health conditions, including depression and anxiety as well as across different groups (Gloster et al., 2020). In the dementia literature, a randomised controlled trial with family carers demonstrated that ACT was effective for improving symptoms of anxiety and depression (Losada et al., 2015; Márquez-González et al., 2020). These studies did not directly measure the effect of ACT on carer QoL, but they do suggest that future interventions aiming to target symptoms of anxiety can benefit from including ACT-based components.

As previously mentioned in chapter 5, a recent systematic review demonstrated that ACT also had a significant effect on primary and comorbid insomnia and sleep quality and that it was recommended as an appropriate treatment method to control and improve sleep difficulties in different populations (Salari et al., 2020). Moreover, recent studies on dementia carers' guilt also have recommended ACT as a potential intervention for dealing with these types of feelings (Gallego-Alberto et al., 2020; Gallego-Alberto et al., 2021). Learning acceptance skills could also be beneficial to help carers embrace upsetting thoughts and feelings related to the diagnosis and to better adapt to the inevitable changes (Márquez-González et al., 2010). The transdiagnostic nature of ACT may be well suited to this population, addressing multiple key factors identified in this thesis, and future studies should investigate the impact of ACT on these outcomes beyond anxiety and depression.

Peer support groups

The qualitative study conducted in chapter 6 revealed that carers in the early stages had a great desire for interpersonal support. Carers particularly wanted to talk to other peers going through similar difficulties and to learn from their experiences. A previous systematic review (Lauritzen et al., 2015) showed that peer support groups had emotional benefits, as the groups gave carers the possibility to express mutual understanding and to alleviate the feelings of stress and being alone in such a difficult situation. Another meta-analysis also found that peer support groups for dementia carers had a significant positive effect on carers' psychological well-being, depression and burden (Chien et al., 2011). Considering these findings, the needs identified in chapter 6 and that the interventions involving peer support groups improved general QoL (Wang & Chien, 2011; Wang et al., 2012), it is recommended that future interventions consider including peer support groups as one of the components.

Delivery of future interventions

The qualitative study conducted in chapter 6 also revealed that carers wanted to receive more formal interpersonal support from the healthcare system. There was a shared feeling that the whole diagnosis situation was solely focused on the care recipient and that carers and their needs were ignored. This lack of interaction between carers and healthcare professionals could potentially increase the worries that are frequently experienced by carers. The provision of comprehensive tailored interpersonal support may be challenging due to the resources available in the current healthcare system, but there are several recommendations on how future interventions, which incorporate factors identified in this thesis, could be delivered to overcome these challenges.

A way to reduce the costs of implementing future interventions could be to deliver them by using a group format combined with an internet-based self-help format. Group interventions are useful in simultaneously reaching a small group of carers in a more standardised way while utilising the group dynamic as another therapeutic element (Cheng et al., 2019). On the other hand, internet-based interventions facilitate access to family carers who are often unable to leave the care recipient unattended, as well as those limited by geographic and mobility constraints (Lappalainen et al., 2021). Although several advantages have been reported in the use of internet-based interventions (Lappalainen et al., 2021), it is recommended that this self-help approach is blended with some interactions with therapists to meet carers' individual needs. Both modes of delivery have greater cost-effectiveness than individual face-to-face interventions and are helpful when the availability of highly qualified professional therapists is limited. These modes of delivery are also supported by the findings reported in Chapter 6.

Another important aspect that will have to be considered in the delivery of future interventions is the impact of COVID-19 public health restrictions. Since the beginning of the COVID-19 pandemic, the stress of family carers who were isolated with a person with dementia has severely increased for several reasons. The loss of social services for people with dementia and their carers due to COVID-19 had a detrimental effect on carers' mental wellbeing (Giebel et al., 2021). A report prepared by Alzheimer's Society (2020) revealed that extra caring hours had negatively impacted physical or mental health in 95% of family carers responded, with 69% of over 1,000 people surveyed reported feeling constantly exhausted, 64% feeling anxious, 49% feeling depressed, and 50% developing problems sleeping during the pandemic. Considering the great impact that all these factors have had on carers' QoL, developing interventions targeting QoL acquired a new urgency in the context of the pandemic. The increased flexibility in how interventions are delivered (e.g. the use of internet and telephone) is particularly important in such a context.

Furthermore, chapter 6 also showed that dementia carers experience different challenges that may affect their QoL from the early stages of dementia. Unfortunately, the interventions for carers in this critical period are scarce. Dementia carers in the early stages are hard to identify as they do not see themselves as carers (Boots et al., 2015; Carduff et al., 2014) or they struggle to recognise their own needs due to difficulties in accepting the changed circumstances and the fear of stigma (Boots et al., 2015; Peterson et al., 2016). As a consequence, most of the existing controlled trials are conducted with carers of people in the moderate or severe stages of dementia. For this reason, developing early interventions for carers is necessary to support their transition into the carer role and to prevent future negative outcomes among dementia carers (Gaugler et al., 2003; Lee et al., 2019).

Developing and evaluating complex interventions

The Medical Research Council has formulated a guideline for developing and evaluating complex interventions. The key processes in the early stage of interventions development are: (i) identifying existing evidence by updating a systematic review; (ii) identifying or developing theory to understand the expected process of change; and (iii) modelling processes and outcomes (Craig et al., 2008).

The selection of the research methods used in this thesis followed these MRC recommendations. The first study detailed in chapter 2 was conducted to update and overcome the limitations of previous systematic reviews on factors associated with carer QoL, but also to quantitatively synthesise the existing evidence by conducting a meta-analysis for the first time. Following this, new theory was developed in chapters 3, 4 and 5 by employing quantitative methods to identify risk and protective factors predicting QoL, as measured by a more appropriate tool to use in this population (i.e. ICECAP-O). Finally, a qualitative study was conducted in chapter 6 to model the processes and outcomes by incorporating the experiences of stakeholders (i.e. family carers) and explore their views on future intervention design and implementation.

The use of mixed research methods to address the complex processes and factors affecting the QoL of dementia carers is a strength of this thesis. Using quantitative methods may allow the exploration of a larger number of topics simultaneously in a larger sample, while qualitative research can explore aspects of complex behaviours, attitudes, and in-depth specific needs and experiences from the standpoint of the participant (Braun & Clarke, 2013; Pope & Mays, 1995). However, both methods have their limitations and thus it is an advantage to combine the strengths of each method to answer the research questions, particularly when aiming to examine both outcomes as well as processes and experiences (Creswell et al., 2011; Plano Clark, 2010)

Recommendations for future research

This thesis contributes to improving the understanding of the different factors affecting the QoL of family carers of people with dementia and to identifying key components that should be considered in the development of future interventions for this population. However, the predictive effect of risk and protective factors on carers' QoL were explored using a cross-sectional design. Future studies should conduct longitudinal studies to draw a robust conclusion on the causal relationships between the variables involved.

It is also recommended that future studies explore the educational and support needs of carers of people with other types of dementia. Even though AD is the most common type of dementia, the symptoms of other types of dementia are different (Alzheimer's Society, 2013). Thus, carers of people with other types of dementia might experience additional challenges and needs that were not represented in the qualitative study conducted here.

An important limitation of this thesis was that the information on the ethnicity of carers was not collected as part of any of the studies conducted. Indeed, the participants were recruited from the East of England and Greater London areas, where most of the community is White British. Previous research has shown that most of the studies on dementia carers needs and their transition into the carer role have also been conducted in white populations (Lee et al., 2019; Novais et al., 2017). It has been proved that the understanding and perceptions of dementia may vary across different ethnic groups and that carers' race and ethnicity can have an impact on carer outcomes such as depression and burden (Connell & Gibson, 1997; Hossain et al., 2020; Janevic & Connell, 2001; Sun et al., 2012). For this reason, to fully understand the complex experience of carers, it is necessary to also explore the educational and support needs in carers of people with dementia from underrepresented racial and ethnic minority groups.

Although this thesis provided clear components that are important in the development of future interventions, there is still room for continuing to model the processes and outcomes. Particularly, researchers are encouraged to explore the views of healthcare professionals that would be likely to deliver these types of interventions. Finally, it is necessary that in the design of the next research phase, which involves the feasibility and piloting of the intervention (Craig et al., 2008), service users are consulted and actively involved. Patient and public involvement (PPI) is necessary because the people affected by a condition (i.e. dementia carers) have the right to have a say in decisions about research that may affect them. Besides, involving the service-users could benefit the research process by ensuring research is relevant, appropriately conducted, that it is participant friendly and that the results of the research are made accessible and provided with sensitivity to study participants and the wider public once the study is complete (Bagley et al., 2016).

Conclusion

Most of the interventions for dementia carers included in the existing reviews had a limited impact on family carer QoL. These interventions tended to focus on specific targets such as increasing knowledge or improving negative mood and, therefore, they demonstrated improvement only in domain-specific outcomes while many studies did not even include any QoL measures. Those studies that included QoL measures tended to use generic QoL or HRQoL instruments that are not sensitive enough to measure changes in carer QoL. Therefore, it was necessary to identify modifiable risk and protective factors that could predict QoL, as measured by an appropriate tool validated in this population.

This thesis found that people with dementia's neuropsychiatric symptoms and carers' depression and burden had a significant association with generic QoL. Furthermore, this thesis revealed that carers anxiety, psychological flexibility and sleep quality were significant predictors of QoL, as measured by the ICECAP-O. The qualitative study identified the challenges that carers experienced in the early stages of dementia, such as extensive worries, feelings of guilt and difficulty to see themselves as carers beyond the familial bond. This study also identified the educational and support needs of carers from the ES and their preferred sources and settings for learning and receiving support. The information obtained from this thesis contributes to the understanding of the complex needs of family carers and provides strong evidence of the components that should be included in the development of future interventions aiming to improve dementia carers QoL beyond domain-specific outcomes.

References

Al-Janabi, H., Coast, J., & Flynn, T. N. (2008). What do people value when they provide unpaid care for an older person? A meta-ethnography with interview follow-up. *Social Science & Medicine*, *67*(1), 111-121. https://doi.org/10.1016/j.socscimed.2008.03.032

Al-Janabi, H., Flynn, T. N., & Coast, J. (2011). Estimation of a preference-based carer experience scale. *Medical Decision Making*, *31*(3), 458-468. https://doi.org/10.1177/0272989x10381280

Alzheimer's Association. (2019). 2019 Alzheimer's disease facts and figures. *Alzheimer's & Dementia*, *15*(3), 321-387. https://doi.org/https://doi.org/10.1016/j.jalz.2019.01.010

Alzheimer's Society. (2013). *The dementia guide: living well after diagnosis*. Alzheimer’s Society. https://www.alzheimers.org.uk/sites/default/files/2018-07/AS_NEW_The%20dementia%20guide_update%203_WEB.pdf

Alzheimer's Society. (2017). *Turning Up the Volume: unheard voices of people with dementia*. Alzheimer's Society. https://www.alzheimers.org.uk/sites/default/files/migrate/downloads/turning_up_the_volume_unheard_voices_of_people_with_dementia.pdf

Alzheimer's Society. (2018). *Dementia-the true cost: Fixing the care crisis*. Alzheimer’s Society. https://www.alzheimers.org.uk/sites/default/files/2018-05/Dementia%20the%20true%20cost%20-%20Alzheimers%20Society%20report.pdf

Alzheimer's Society. (2020). *Worst hit: dementia during coronavirus*. Alzheimer's Society. https://www.alzheimers.org.uk/sites/default/files/2020-09/Worst-hit-Dementia-during-coronavirus-report.pdf

Amador-Marín, B., & Guerra-Martín, M. D. (2017). Effectiveness of non-pharmacological interventions in the quality of life of caregivers of Alzheimer. *Gaceta Sanitaria*, *31*(2), 154-160. https://doi.org/10.1016/j.gaceta.2016.09.006

Amorim, F. A. d., Giorgion, M. d. C. P., & Forlenza, O. V. (2017). Social skills and well-being among family caregivers to patients with Alzheimer s disease. *Archives of Clinical Psychiatry*, *44*, 159-161. https://doi.org/10.1590/0101-60830000000143

Andreakou, M. I., Papadopoulos, A. A., Panagiotakos, D. B., & Niakas, D. (2016). Assessment of health-related quality of life for caregivers of Alzheimer's disease patients [Article]. *International Journal of Alzheimer's Disease*, *2016*, Article 9213968. https://doi.org/10.1155/2016/9213968

Andrén, S., & Elmståhl, S. (2005). Family caregivers' subjective experiences of satisfaction in dementia care: aspects of burden, subjective health and sense of coherence. *Scandinavian Journal of Caring Sciences*, *19*(2), 157-168. https://doi.org/10.1111/j.1471-6712.2005.00328.x

Annear, M. J., Toye, C., Elliott, K.-E. J., McInerney, F., Eccleston, C., & Robinson, A. (2017). Dementia knowledge assessment scale (DKAS): confirmatory factor analysis and comparative subscale scores among an international cohort. *BMC Geriatrics*, *17*(1), 168. https://doi.org/10.1186/s12877-017-0552-y

Annear, M. J., Toye, C. M., Eccleston, C. E., McInerney, F. J., Elliott, K. E., Tranter, B. K., Hartley, T., & Robinson, A. L. (2015). Dementia Knowledge Assessment Scale: Development and Preliminary Psychometric Properties. *Journal of the American Geriatrics Society*, *63*(11), 2375-2381. https://doi.org/10.1111/jgs.13707

Bagley, H. J., Short, H., Harman, N. L., Hickey, H. R., Gamble, C. L., Woolfall, K., Young, B., & Williamson, P. R. (2016). A patient and public involvement (PPI) toolkit for meaningful and flexible involvement in clinical trials – a work in progress. *Research Involvement and Engagement*, *2*(1), 15. https://doi.org/10.1186/s40900-016-0029-8

Bamford, S., Holley-Moore, G., & Watson, J. (2014). *New perspectives and approaches to understanding dementia and stigma*. International Longevity Centre UK. https://ilcuk.org.uk/wp-content/uploads/2018/10/Compendium-Dementia.pdf

Banerjee, S., Murray, J., Foley, B., Atkins, L., Schneider, J., & Mann, A. (2003). Predictors of institutionalisation in people with dementia. *Journal of Neurology, Neurosurgery & Psychiatry*, *74*(9), 1315-1316. https://doi.org/10.1136/jnnp.74.9.1315

Baumgarten, M., Becker, R., & Gauthier, S. (1990). Validity and reliability of the dementia behavior disturbance scale. *Journal of the American Geriatrics Society*, *38*(3), 221-226. https://doi.org/10.1111/j.1532-5415.1990.tb03495.x

Beck, A. T., Steer, R. A., & Carbin, M. G. (1988). Psychometric properties of the Beck Depression Inventory: Twenty-five years of evaluation. *Clinical Psychology Review, 8*(1), 77-100. https://doi.org/10.1016/0272-7358(88)90050-5

Bond, F. W., Hayes, S. C., Baer, R. A., Carpenter, K. M., Guenole, N., Orcutt, H. K., Waltz, T., & Zettle, R. D. (2011). Preliminary Psychometric Properties of the Acceptance and Action Questionnaire–II: A Revised Measure of Psychological Inflexibility and Experiential Avoidance. *Behavior Therapy, 42*(4), 676-688. https://doi.org/10.1016/j.beth.2011.03.007

Bonevski, B., Randell, M., Paul, C., Chapman, K., Twyman, L., Bryant, J., Brozek, I., & Hughes, C. (2014). Reaching the hard-to-reach: a systematic review of strategies for improving health and medical research with socially disadvantaged groups. *BMC Medical Research Methodology, 14*(1), 42. https://doi.org/10.1186/1471-2288-14-42

Boots, L. M. M., Wolfs, C. A. G., Verhey, F. R. J., Kempen, G. I. J. M., & de Vugt, M. E. (2015). Qualitative study on needs and wishes of early-stage dementia caregivers: the paradox between needing and accepting help. *International Psychogeriatrics, 27*(6), 927-936. https://doi.org/10.1017/S1041610214002804

Borenstein, M., Hedges, L. V., Higgins, J. P. T., & Rothstein, H. R. (2005). *Comprehensive Meta-analysis* (Version 3) [Software]. Biostat.

Borenstein, M., Hedges, L. V., Higgins, J. P. T., & Rothstein, H. R. (2009). *Introduction to Meta-Analysis*. John Wiley & Sons, Ltd.

Borghi, A. C., Sassá, A. H., de Matos, P. C., Decesaro, M. N., & Marcon, S. S. (2011). Quality of life of elders with Alzheimer's disease and of their caregivers. *Revista gaúcha de enfermagem, 32*(4), 751-758. https://doi.org/10.1590/S1983-14472011000400016

Bowling, A., Rowe, G., Adams, S., Sands, P., Samsi, K., Crane, M., Joly, L., & Manthorpe, J. (2015). Quality of life in dementia: a systematically conducted narrative review of dementia-specific measurement scales. *Aging & Mental Health, 19*(1), 13-31. https://doi.org/10.1080/13607863.2014.915923

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

Braun, V., & Clarke, V. (2013). *Successful Qualitative Research: A Practical Guide for Beginners*. SAGE Publications.

Brodaty, H., & Donkin, M. (2009). Family caregivers of people with dementia. *Dialogues in Clinical Neuroscience, 11*(2), 217-228. https://doi.org/10.31887/DCNS.2009.11.2/hbrodaty

Brown, A., Page, T. E., Daley, S., Farina, N., Basset, T., Livingston, G., Budgett, J., Gallaher, L., Feeney, Y., Murray, J., Bowling, A., Knapp, M., & Banerjee, S. (2019). Measuring the quality of life of family carers of people with dementia: development and validation of C-DEMQOL. *Quality of Life Research, 28*(8), 2299-2310. https://doi.org/10.1007/s11136-019-02186-w

Bruvik, F. K., Ulstein, I. D., Ranhoff, A. H., & Engedal, K. (2012). The quality of life of people with dementia and their family carers. *Dementia and Geriatric Cognitive Disorders, 34*(1), 7-14. https://doi.org/10.1159/000341584

Buysse, D. J., Reynolds, C. F., Monk, T. H., Berman, S. R., & Kupfer, D. J. (1989). The Pittsburgh sleep quality index: A new instrument for psychiatric practice and research. *Psychiatry Research*, *28*(2), 193-213. https://doi.org/10.1016/0165-1781(89)90047-4

Carduff, E., Finucane, A., Kendall, M., Jarvis, A., Harrison, N., Greenacre, J., & Murray, S. A. (2014). Understanding the barriers to identifying carers of people with advanced illness in primary care: triangulating three data sources. *BMC Family Practice*, *15*(1), 48. https://doi.org/10.1186/1471-2296-15-48

Carpenter, B. D., Balsis, S., Otilingam, P. G., Hanson, P. K., & Gatz, M. (2009). The Alzheimer's Disease Knowledge Scale: development and psychometric properties. *The Gerontologist*, *49*(2), 236-247. https://doi.org/10.1093/geront/gnp023

Charlson, M., Szatrowski, T. P., Peterson, J., & Gold, J. (1994). Validation of a combined comorbidity index. *Journal of Clinical Epidemiology*, *47*(11), 1245-1251. https://doi.org/https://doi.org/10.1016/0895-4356(94)90129-5

Cheng, S.-T., Au, A., Losada, A., Thompson, L. W., & Gallagher-Thompson, D. (2019). Psychological Interventions for Dementia Caregivers: What We Have Achieved, What We Have Learned. *Current Psychiatry Reports*, *21*(7), 59. https://doi.org/10.1007/s11920-019-1045-9

Cheng, S.-T., & Zhang, F. (2020). A comprehensive meta-review of systematic reviews and meta-analyses on nonpharmacological interventions for informal dementia caregivers. *BMC Geriatrics, 20*(1), 137. https://doi.org/10.1186/s12877-020-01547-2

Cheng, S. T., Li, K. K., Losada, A., Zhang, F., Au, A., Thompson, L. W., & Gallagher-Thompson, D. (2020). The effectiveness of nonpharmacological interventions for informal dementia caregivers: An updated systematic review and meta-analysis. *Psychology and Aging, 35*(1), 55-77. https://doi.org/10.1037/pag0000401

Chiao, C. Y., Wu, H. S., & Hsiao, C. Y. (2015). Caregiver burden for informal caregivers of patients with dementia: A systematic review. *International Nursing Review, 62*(3), 340-350. https://doi.org/10.1111/inr.12194

Chien, L.-Y., Chu, H., Guo, J.-L., Liao, Y.-M., Chang, L.-I., Chen, C.-H., & Chou, K.-R. (2011). Caregiver support groups in patients with dementia: a meta-analysis. *International Journal of Geriatric Psychiatry, 26*(10), 1089-1098. https://doi.org/10.1002/gps.2660

Coast, J., Flynn, T. N., Natarajan, L., Sproston, K., Lewis, J., Louviere, J. J., & Peters, T. J. (2008). Valuing the ICECAP capability index for older people. *Social Science & Medicine, 67*(5), 874-882. https://doi.org/10.1016/j.socscimed.2008.05.015

Coen, R. F., O'Boyle, C. A., Swanwick, G. R. J., & Coakley, D. (1999). Measuring the impact on relatives of caring for people with Alzheimers disease: Quality of life, burden and well-being. *Psychology & Health, 14*(2), 253-261. https://doi.org/10.1080/08870449908407326

Cohen, J. (1960). A coefficient of agreement for nominal scales. *Educational and Psychological Measurement, 20*, 37-46. https://doi.org/10.1177/001316446002000104

Cohen, J. (1988). *Statistical Power Analysis for the Behavioral Sciences* (2nd ed.). Routledge. https://doi.org/10.4324/9780203771587

Collins, R. N., & Kishita, N. (2020). Prevalence of depression and burden among informal care-givers of people with dementia: a meta-analysis. *Ageing and Society, 40*(11), 2355-2392. https://doi.org/10.1017/S0144686X19000527

Conde-Sala, J. L., Garre-Olmo, J., Turró-Garriga, O., Vilalta-Franch, J., & López-Pousa, S. (2010). Quality of life of patients with Alzheimer's disease: Differential perceptions between spouse and adult child caregivers. *Dementia and Geriatric Cognitive Disorders, 29*(2), 97-108. https://doi.org/10.1159/000272423

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

Contreras, M., Mioshi, E., & Kishita, N. (2020a). Factors Related to the Quality of Life in Family Carers of People With Dementia: A Meta-Analysis. *Journal of Geriatric Psychiatry and Neurology*, 0891988720924713. https://doi.org/10.1177/0891988720924713

Contreras, M., Mioshi, E., & Kishita, N. (2020b). Risk and protective factors affecting the quality of life of family carers of people with dementia. *Alzheimer's & Dementia, 16*(S7), e040277. https://doi.org/10.1002/alz.040277

Craig, P., Dieppe, P., Macintyre, S., Michie, S., Nazareth, I., & Petticrew, M. (2008). Developing and evaluating complex interventions: the new Medical Research Council guidance. *BMJ*, *337*, a1655. https://doi.org/10.1136/bmj.a1655

Creese, J., Bédard, M., Brazil, K., & Chambers, L. (2008). Sleep disturbances in spousal caregivers of individuals with Alzheimer's disease. *International Psychogeriatrics, 20*(1), 149-161. https://doi.org/10.1017/S1041610207005339

Crellin, N. E. (2015). *The role of self-efficacy in the health-related quality of life of family carers of individuals with dementia* [Doctoral dissertation, University College London]. https://discovery.ucl.ac.uk/id/eprint/1469087/2/CRELLIN%2C%20N.%20E.%20THESIS%20FINAL%20VERSION%20Copyright%20material%20removed.pdf

Creswell, J. W., Klassen, A. C., Plano Clark, V. L., & Smith, K. C. (2011). *Best practices for mixed methods research in the health sciences.* Office of Behavioral and Social Sciences Research (OBSSR). https://obssr.od.nih.gov/wp-content/uploads/2016/02/Best_Practices_for_Mixed_Methods_Research.pdf

Cummings, J. L., Mega, M., Gray, K., Rosenberg-Thompson, S., Carusi, D. A., & Gornbein, J. (1994). The Neuropsychiatric Inventory: comprehensive assessment of psychopathology in dementia. *Neurology, 44*(12), 2308-2308. https://doi.org/10.1212/WNL.44.12.2308

Cupidi, C., Realmuto, S., Lo Coco, G., Cinturino, A., Talamanca, S., Arnao, V., Perini, V., D'Amelio, M., Savettieri, G., & Lo Coco, D. (2012). Sleep quality in caregivers of patients with Alzheimer's disease and Parkinson's disease and its relationship to quality of life. *International Psychogeriatrics, 24*(11), 1827-1835. https://doi.org/10.1017/S1041610212001032

de Oliveira, D. C., Vass, C., & Aubeeluck, A. (2015). Ageing and quality of life in family carers of people with dementia being cared for at home: a literature review. *Quality in Primary Care*, *23*(1), 13.

de Oliveira, D. C., Vass, C., & Aubeeluck, A. (2018). The development and validation of the Dementia Quality of Life Scale for Older Family Carers (DQoL-OC). *Aging & Mental Health, 22*(5), 709-716. https://doi.org/10.1080/13607863.2017.1293004

Densham, S., Williams, D., Johnson, A., & Turner-Cobb, J. M. (2016). Enhanced psychological flexibility and improved quality of life in chronic fatigue syndrome/myalgic encephalomyelitis. *Journal of Psychosomatic Research*, *88*, 42-47. https://doi.org/10.1016/j.jpsychores.2016.07.009

Department of Health & Social Care. (2018). *Carers Action Plan 2018-2020 - Supporting carers today*. Department of Health and Social Care, UK. https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/713781/carers-action-plan-2018-2020.pdf

Department of Health UK. (2016). *Prime Minister’s Challenge on Dementia 2020 Implementation Plan*. HM Government UK. https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/507981/PM_Dementia-main_acc.pdf

Dijkers, M. (1997). Quality of life after spinal cord injury: a meta analysis of the effects of disablement components. *Spinal Cord, 35*(12), 829-840. https://doi.org/10.1038/sj.sc.3100571

Dow, J., Robinson, J., Robalino, S., Finch, T., McColl, E., & Robinson, L. (2018). How best to assess quality of life in informal carers of people with dementia; A systematic review of existing outcome measures [Review]. *PLoS ONE, 13*(3), Article e0193398. https://doi.org/10.1371/journal.pone.0193398

Downes, M. J., Brennan, M. L., Williams, H. C., & Dean, R. S. (2016). Development of a critical appraisal tool to assess the quality of cross-sectional studies (AXIS). *BMJ Open, 6*(12), e011458. https://doi.org/10.1136/bmjopen-2016-011458

Duval, S., & Tweedie, R. (2000). Trim and fill: A simple funnel-plot-based method of testing and adjusting for publication bias in meta-analysis. *Biometrics, 56*(2), 455-463. https://doi.org/10.1111/j.0006-341X.2000.00455.x

Farina, N., Page, T. E., Daley, S., Brown, A., Bowling, A., Basset, T., Livingston, G., Knapp, M., Murray, J., & Banerjee, S. (2017). Factors associated with the quality of life of family carers of people with dementia: A systematic review. *Alzheimer's & Dementia, 13*(5), 572-581. https://doi.org/10.1016/j.jalz.2016.12.010

Farran, C. J., Loukissa, D., Perraud, S., & Paun, O. (2004). Alzheimer's disease caregiving information and skills. Part II: family caregiver issues and concerns. *Research in Nursing & Health, 27*(1), 40-51. https://doi.org/10.1002/nur.20006

Feast, A., Orrell, M., Russell, I., Charlesworth, G., & Moniz‐Cook, E. (2017). The contribution of caregiver psychosocial factors to distress associated with behavioural and psychological symptoms in dementia. *International Journal of Geriatric Psychiatry, 32*(1), 76-85. https://doi.org/10.1002/gps.4447

Ferrara, M., Langiano, E., Di Brango, T., De Vito, E., Di Cioccio, L., & Bauco, C. (2008). Prevalence of stress, anxiety and depression in with Alzheimer caregivers. *Health and Quality of Life Outcomes, 6*, Article 93. https://doi.org/10.1186/1477-7525-6-93

Fletcher, L., & Hayes, S. C. (2005). Relational frame theory, acceptance and commitment therapy, and a functional analytic definition of mindfulness. *Journal of Rational-Emotive & Cognitive-Behavior Therapy, 23*(4), 315-336. https://doi.org/10.1007/s10942-005-0017-7

Fonareva, I., & Oken, B. S. (2014). Physiological and functional consequences of caregiving for relatives with dementia. *International Psychogeriatrics, 26*(5), 725-747. https://doi.org/10.1017/s1041610214000039

Foss, M. P., Lange, C., Silva Filho, J. H., Brunini, F., & Carvalho do Vale, F. A. (2007). Support groups for caregivers of patients with Dementia: A comparative study.

Dementia & Neuropsychologia, 1(2), 196-202. https://doi.org/10.1590/s1980-57642008dn10200013

Gallego-Alberto, L., Losada, A., Cabrera, I., Romero-Moreno, R., Pérez-Miguel, A., Pedroso-Chaparro, M. D. S., & Márquez-González, M. (2020). "I Feel Guilty". Exploring Guilt-Related Dynamics in Family Caregivers of People with Dementia. *Clinical Gerontologist*, 1-10. https://doi.org/10.1080/07317115.2020.1769244

Gallego-Alberto, L., Márquez-González, M., Romero-Moreno, R., Cabrera, I., & Losada, A. (2021). Pilot study of a psychotherapeutic intervention for reducing guilt feelings in highly distressed dementia family caregivers (Innovative practice). *Dementia, 20*(2), 759-769. https://doi.org/10.1177/1471301219886761

Gao, C., Chapagain, N. Y., & Scullin, M. K. (2019). Sleep Duration and Sleep Quality in Caregivers of Patients With Dementia: A Systematic Review and Meta-analysis. *JAMA Network Open, 2*(8), e199891-e199891. https://doi.org/10.1001/jamanetworkopen.2019.9891

Gaugler, J. E., Wackerbarth, S. B., Mendiondo, M., Schmitt, F. A., & Smith, C. D. (2003). The characteristics of dementia caregiving onset. *American Journal of Alzheimer's Disease & Other Dementias, 18*(2), 97-104. https://doi.org/10.1177/153331750301800208

Giebel, C., Lord, K., Cooper, C., Shenton, J., Cannon, J., Pulford, D., Shaw, L., Gaughan, A., Tetlow, H., Butchard, S., Limbert, S., Callaghan, S., Whittington, R., Rogers, C., Komuravelli, A., Rajagopal, M., Eley, R., Watkins, C., Downs, M., Reilly, S., Ward, K., Corcoran, R., Bennett, K., & Gabbay, M. (2021). A UK survey of COVID-19 related social support closures and their effects on older people, people with dementia, and carers. *International Journal of Geriatric Psychiatry, 36*(3), 393-402. https://doi.org/10.1002/gps.5434

Gilleard, C., & Groom, F. (1994). A study of two dementia quizzes. *British Journal of Clinical Psychology, 33*(4), 529-534. https://doi.org/10.1111/j.2044-8260.1994.tb01149.x

Gitlin, L. N., Marx, K. A., Stanley, I. H., Hansen, B. R., & Van Haitsma, K. S. (2014). Assessing neuropsychiatric symptoms in people with dementia: a systematic review of measures. *International psychogeriatrics, 26*(11), 1805-1848. https://doi.org/10.1017/S1041610214001537

Glasby, J., & Thomas, S. (2019). *Understanding and Responding to the Needs of Carers of People with Dementia in the UK, US and Beyond*. University of Birmingham, School of Social Policy. https://lx.iriss.org.uk/sites/default/files/carers-of-people-with-dementia.pdf

Gloster, A. T., Walder, N., Levin, M. E., Twohig, M. P., & Karekla, M. (2020). The empirical status of acceptance and commitment therapy: A review of meta-analyses. *Journal of Contextual Behavioral Science, 18*, 181-192. https://doi.org/https://doi.org/10.1016/j.jcbs.2020.09.009

Graham, C., Ballard, C., & Sham, P. (1997). Carers' knowledge of dementia, their coping strategies and morbidity. *International Journal of Geriatric Psychiatry, 12*(9), 931-936. https://doi.org/10.1002/(SICI)1099-1166(199709)12:9%3C931::AID-GPS666%3E3.0.CO;2-8

Grewal, I., Lewis, J., Flynn, T., Brown, J., Bond, J., & Coast, J. (2006). Developing attributes for a generic quality of life measure for older people: Preferences or capabilities? *Social Science & Medicine, 62*(8), 1891-1901. https://doi.org/10.1016/j.socscimed.2005.08.023

Han, A., Yuen, H. K., Lee, H. Y., & Zhou, X. (2020). Effects of acceptance and commitment therapy on process measures of family caregivers: A systematic review and meta-analysis. *Journal of Contextual Behavioral Science, 18*, 201-213. https://doi.org/https://doi.org/10.1016/j.jcbs.2020.10.004

Harding, R., Gao, W., Jackson, D., Pearson, C., Murray, J., & Higginson, I. J. (2015). Comparative Analysis of Informal Caregiver Burden in Advanced Cancer, Dementia, and Acquired Brain Injury. *Journal of Pain and Symptom Management, 50*(4), 445-452. https://doi.org/10.1016/j.jpainsymman.2015.04.005

Harris, R. (2019). *ACT made simple: An easy-to-read primer on acceptance and commitment therapy*. New Harbinger Publications.

Häusler, A., Sánchez, A., Gellert, P., Deeken, F., Rapp, M. A., & Nordheim, J. (2016). Perceived stress and quality of life in dementia patients and their caregiving spouses:

Does dyadic coping matter? *International Psychogeriatrics, 28*(11), 1857-1866. https://doi.org/10.1017/S1041610216001046

Hayes, S. C. (2004). Acceptance and commitment therapy, relational frame theory, and the third wave of behavioral and cognitive therapies. *Behavior Therapy, 35*(4), 639-665. https://doi.org/10.1016/S0005-7894(04)80013-3

Hayes, S. C., Strosahl, K. D., & Wilson, K. G. (2012). *Acceptance and commitment therapy: The process and practice of mindful change,* (2nd ed). Guilford Press.

Helter, T. M., Coast, J., Łaszewska, A., Stamm, T., & Simon, J. (2020). Capability instruments in economic evaluations of health-related interventions: a comparative review of the literature. *Quality of Life Research, 29*(6), 1433-1464. https://doi.org/10.1007/s11136-019-02393-5

Heydari, M., Razban, F., Mirzaei, T., & Heidari, S. (2017). The Effect of Problem Oriented Coping Strategies Training on Quality of Life of Family Caregivers of Elderly with Alzheimer. *Asian Journal of Nursing Education and Research, 7*(2), 5. https://doi.org/10.5958/2349-2996.2017.00034.9

Hlabangana, V., & Hearn, J. H. (2020). Depression in partner caregivers of people with neurological conditions; associations with self-compassion and quality of life. *Journal of Mental Health*, *29*(2), 176-181. https://doi.org/10.1080/09638237.2019.1630724

HM Government UK. (2010). *Recognised, Valued and Supported: Next Steps for the Carers Strategy*. HM Government UK https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/213804/dh_122393.pdf

HM Government UK. (2014). *Carers Strategy: Second National Action Plan 2014 - 2016.* HM Government UK. https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/368478/Carers_Strategy_-_Second_National_Action_Plan_2014_-_2016.pdf

Horton, M. C., Oyebode, J., Clare, L., Megson, M., Shearsmith, L., Brayne, C., Kind, P., Hoare, Z., Al Janabi, H., Hewison, V., Tennant, A., & Wright, P. (2021). Measuring Quality of Life in Carers of People With Dementia: Development and Psychometric

Evaluation of Scales measuring the Impact of DEmentia on CARers (SIDECAR). *Gerontologist*, *61*(3), e1-e11. https://doi.org/10.1093/geront/gnz136

Hossain, M., Crossland, J., Stores, R., Dewey, A., & Hakak, Y. (2020). Awareness and understanding of dementia in South Asians: A synthesis of qualitative evidence. *Dementia*, *19*(5), 1441-1473. https://doi.org/10.1177/1471301218800641

Hounsome, N., Orrell, M., & Edwards, R. T. (2011). EQ-5D as a quality of life measure in people with dementia and their carers: Evidence and key issues. *Value in Health*, *14*(2), 390-399. https://doi.org/10.1016/j.jval.2010.08.002

Hubbard, R. (2016). The importance of replication research—significant sameness. In *Corrupt Research: The Case for Reconceptualizing Empirical Management and Social Science*. SAGE Publications, Inc. https://doi.org/10.4135/9781506305332

Huis In Het Veld, J. G., Verkaik, R., Mistiaen, P., Van Meijel, B., & Francke, A. L. (2015). The effectiveness of interventions in supporting self-management of informal caregivers of people with dementia; A systematic meta review Health services research. *BMC Geriatrics*, *15*(1), Article 147. https://doi.org/10.1186/s12877-015-0145-6

Ismail, Z., Agüera-Ortiz, L., Brodaty, H., Cieslak, A., Cummings, J., Fischer, C. E., Gauthier, S., Geda, Y. E., Herrmann, N., Kanji, J., Lanctôt, K. L., Miller, D. S., Mortby, M. E., Onyike, C. U., Rosenberg, P. B., Smith, E. E., Smith, G. S., Sultzer, D. L., Lyketsos, C., Research, N. P. S. P. I. A. o. t. I. S. o. t. A. A. s., & Treatment. (2017). The Mild Behavioral Impairment Checklist (MBI-C): A Rating Scale for Neuropsychiatric Symptoms in Pre-Dementia Populations. *Journal of Alzheimer's disease*, *56*(3), 929-938. https://doi.org/10.3233/JAD-160979

Jackson, D., Turner-Stokes, L., Murray, J., Leese, M., & McPherson, K. (2009). Acquired brain injury and dementia: A comparison of carer experiences. *Brain Injury*, *23*(5), 433-444. https://doi.org/10.1080/02699050902788451

Janevic, M. R., & Connell, C. M. (2001). Racial, ethnic, and cultural differences in the dementia caregiving experience: recent findings. *The Gerontologist*, *41*(3), 334-347. https://doi.org/10.1093/geront/41.3.334

Jenkins, C., & Feldman, G. (2018). Recognition of preclinical signs of dementia: A qualitative study exploring the experiences of family carers and professional care assistants. *Journal of Clinical Nursing, 27*(9-10), 1931-1940. https://doi.org/10.1111/jocn.14333

Jensen, M., Agbata, I. N., Canavan, M., & McCarthy, G. (2015). Effectiveness of educational interventions for informal caregivers of individuals with dementia residing in the community: Systematic review and meta‐analysis of randomised controlled trials. *International Journal of Geriatric Psychiatry, 30*(2), 130-143. https://doi.org/10.1002/gps.4208

Jones, C., Edwards, R. T., & Hounsome, B. (2011). A systematic review of the cost-effectiveness of interventions for supporting informal caregivers of people with dementia residing in the community. *International Psychogeriatrics, 24*(1), 6-18. https://doi.org/10.1017/S1041610211001207

Jones, C., Edwards, R. T., & Hounsome, B. (2012). Health economics research into supporting carers of people with dementia: A systematic review of outcome measures. *Health and Quality of Life Outcomes, 10*(1), 142. https://doi.org/10.1186/1477-7525-10-142

Jones, C., Edwards, R. T., & Hounsome, B. (2014). Qualitative exploration of the suitability of capability based instruments to measure quality of life in family carers of people with dementia. *International Scholarly Research Notices, 2014,* Article 919613. https://doi.org/10.1155/2014/919613

Kaddour, L., & Kishita, N. (2019). Anxiety in Informal Dementia Carers: A Meta-Analysis of Prevalence. *Journal of Geriatric Psychiatry and Neurology*, 891988719868313. https://doi.org/10.1177/0891988719868313

Karg, N., Graessel, E., Randzio, O., & Pendergrass, A. (2018). Dementia as a predictor of care-related quality of life in informal caregivers: a cross-sectional study to investigate differences in health-related outcomes between dementia and non-dementia caregivers. *BMC Geriatrics, 18*(1), 189. https://doi.org/10.1186/s12877-018-0885-1

Karnieli-Miller, O., Werner, P., Aharon-Peretz, J., Sinoff, G., & Eidelman, S. (2012). Expectations, experiences, and tensions in the memory clinic: the process of diagnosis disclosure of dementia within a triad. *International Psychogeriatrics, 24*(11), 1756-1770. https://doi.org/10.1017/s1041610212000841

Katz, S., Ford, A. B., Moskowitz, R. W., Jackson, B. A., & Jaffe, M. W. (1963). Studies of illness in the aged. The index of ADL: A standardized measure of biological and psychosocial function. *JAMA, 185*, 914-919. https://doi.org/10.1001/jama.1963.03060120024016

Kaufman, A. V., Kosberg, J. I., Leeper, J. D., & Tang, M. (2010). Social support, caregiver burden, and life satisfaction in a sample of rural African American and White caregivers of older persons with dementia. *Journal of Gerontological Social Work, 53*(3), 251-269. https://doi.org/10.1080/01634370903478989

Killen, A., Flynn, D., De Brún, A., O'Brien, N., O'Brien, J., Thomas, A. J., McKeith, I., & Taylor, J. P. (2016). Support and information needs following a diagnosis of dementia with Lewy bodies. *International Psychogeriatrics, 28*(3), 495-501. https://doi.org/10.1017/s1041610215001362

Kim, J. H., Knight, B. G., & Longmire, C. V. (2007). The role of familism in stress and coping processes among African American and White dementia caregivers: effects on mental and physical health. *Health Psychology, 26*(5), 564-576. https://doi.org/10.1037/0278-6133.26.5.564

Kim, S. K., Park, M., Lee, Y., Choi, S. H., Moon, S. Y., Seo, S. W., Park, K. W., Ku, B. D., Han, H. J., Park, K. H., Han, S.-H., Kim, E.-J., Lee, J.-H., Park, S. A., Shim, Y. S., Kim, J. H., Hong, C. H., Na, D. L., Ye, B. S., Kim, H. J., & Moon, Y. (2016). Influence of personality on depression, burden, and health-related quality of life in family caregivers of persons with dementia. *International Psychogeriatrics, 29*(2), 227-237. https://doi.org/10.1017/S1041610216001770

Kim, Y., & Schulz, R. (2008). Family caregivers' strains: comparative analysis of cancer caregiving with dementia, diabetes, and frail elderly caregiving. *Journal of Aging and Health, 20*(5), 483-503. https://doi.org/10.1177/0898264308317533

Kishita, N., Contreras, M., West, J., & Mioshi, E. (2020). Exploring the impact of carer stressors and psychological inflexibility on depression and anxiety in family carers of people with dementia. *Journal of Contextual Behavioral Science, 17*, 119-125. https://doi.org/10.1016/j.jcbs.2020.07.005

Kishita, N., Hammond, L., Dietrich, C. M., & Mioshi, E. (2018). Which interventions work for dementia family carers?: an updated systematic review of randomized controlled trials of carer interventions. *International Psychogeriatrics, 30*(11), 1679-1696. https://doi.org/10.1017/s1041610218000947

Kishita, N., & Laidlaw, K. (2017). Cognitive behaviour therapy for generalized anxiety disorder: Is CBT equally efficacious in adults of working age and older adults? *Clinical Psychology Review*, *52*, 124-136. https://doi.org/10.1016/j.cpr.2017.01.003

Knight, B. G., & Sayegh, P. (2010). Cultural values and caregiving: the updated sociocultural stress and coping model. *The Journals of Gerontology: Series B*, *65b*(1), 5-13. https://doi.org/10.1093/geronb/gbp096

Kramer, B. J. (1993). Marital history and the prior relationship as predictors of positive and negative outcomes among wife caregivers. *Family Relations: An Interdisciplinary Journal of Applied Family Studies, 42*(4), 367-375. https://doi.org/10.2307/585336

Kroenke, K., Spitzer, R. L., & Williams, J. B. (2001). The PHQ-9: validity of a brief depression severity measure. *Journal of general internal medicine*, *16*(9), 606-613. https://doi.org/10.1046/j.1525-1497.2001.016009606.x

Kryger, M. H., Roth, T., & Dement, W. C. (2010). *Principles and Practice of Sleep Medicine* Saunders.

Kuhn, D., King, S. P., & Fulton, B. R. (2005). Development of the knowledge about memory loss and care (KAML-C) test. *American Journal of Alzheimer's Disease and other Dementias*, *20*(1), 41-49. https://doi.org/10.1177/153331750502000108

Kurz, A., Wagenpfeil, S., Hallauer, J., Schneider-Schelte, H., & Jansen, S. (2010). Evaluation of a brief educational program for dementia carers: The AENEAS Study. *International Journal of Geriatric Psychiatry, 25*(8), 861-869. https://doi.org/10.1002/gps.2428

Langenhoff, B. S., Krabbe, P. F., Wobbes, T., & Ruers, T. J. (2001). Quality of life as an outcome measure in surgical oncology. *British Journal of Surgery*, *88*(5), 643-652. https://doi.org/10.1046/j.1365-2168.2001.01755.x

Lappalainen, P., Pakkala, I., Lappalainen, R., & Nikander, R. (2021). Supported Web-Based Acceptance and Commitment Therapy for Older Family Caregivers (CareACT) Compared to Usual Care. *Clinical Gerontologist,* 1-17. https://doi.org/10.1080/07317115.2021.1912239

Lauritzen, J., Pedersen, P. U., Sørensen, E. E., & Bjerrum, M. B. (2015). The meaningfulness of participating in support groups for informal caregivers of older adults with dementia: a systematic review. *JBI Evidence Synthesis, 13*(6). https://doi.org/10.11124/jbisrir-2015-2121

Lee, D. (2008). Health-related quality of life in dementia caregiving: relationships with sleep quality and daytime sleepiness. *Primary Care & Community Psychiatry, 13*(3), 119-125.

Lee, K., Puga, F., Pickering, C. E. Z., Masoud, S. S., & White, C. L. (2019). Transitioning into the caregiver role following a diagnosis of Alzheimer's disease or related dementia: A scoping review. *International Journal of Nursing Studies, 96*, 119-131. https://doi.org/10.1016/j.ijnurstu.2019.02.007

Lenze, E. J., Mulsant, B. H., Mohlman, J., Shear, M. K., Dew, M. A., Schulz, R., Miller, M. D., Tracey, B., & Reynolds, C. F. (2005). Generalized Anxiety Disorder in Late Life: Lifetime Course and Comorbidity With Major Depressive Disorder. *The American Journal of Geriatric Psychiatry, 13*(1), 77-80. https://doi.org/10.1097/00019442-200501000-00011

Lewis, F., Karlsberg Schaffer, S., Sussex, J., O'Neill, P., & Cockcroft, L. (2014). *Trajectory of Dementia in the UK – Making a Difference*. Alzheimer's Research UK & OHE Consulting. https://www.alzheimersresearchuk.org/wp-content/uploads/2015/01/OHE-report-Full.pdf

Li, R., Cooper, C., Bradley, J., Shulman, A., & Livingston, G. (2012). Coping strategies and psychological morbidity in family carers of people with dementia: a systematic review and meta-analysis. *Journal of Affective Disorders, 139*(1), 1-11. https://doi.org/10.1016/j.jad.2011.05.055

Lima-Silva, T. B., Bahia, V. S., Carvalho, V. A., Guimarães, H. C., Caramelli, P., Balthazar, M., Damasceno, B., Bottino, C. M. d. C., Brucki, S. M. D., Mioshi, E., Nitrini, R., & Yassuda, M. S. (2013). Translation, cross-cultural adaptation and applicability of the Brazilian version of the Frontotemporal Dementia Rating Scale (FTD-FRS). *Dementia & Neuropsychologia, 7*, 387-396. https://doi.org/10.1590/S1980-57642013DN74000006

Livingston, G., Barber, J., Rapaport, P., Knapp, M., Griffin, M., King, D., Livingston, D., Mummery, C., Walker, Z., Hoe, J., Sampson, E. L., & Cooper, C. (2013). Clinical effectiveness of a manual based coping strategy programme (START, STrAtegies for RelaTives) in promoting the mental health of carers of family members with dementia: pragmatic randomised controlled trial. *BMJ*, *347*, f6276. https://doi.org/10.1136/bmj.f6276

Lloyd, J., Muers, J., Patterson, T. G., & Marczak, M. (2019). Self-Compassion, Coping Strategies, and Caregiver Burden in Caregivers of People with Dementia. *Clinical Gerontologist*, *42*(1), 47-59. https://doi.org/10.1080/07317115.2018.1461162

Logsdon, R. G., Gibbons, L. E., McCurry, S. M., & Teri, L. (1999). Quality of life in Alzheimer's disease: Patient and caregiver reports. *Journal of Mental Health and Aging*, *5*(1), 21-32.

Losada, A., Márquez-González, M., Romero-Moreno, R., Mausbach, B. T., López, J., Fernández-Fernández, V., & Nogales-González, C. (2015). Cognitive–behavioral therapy (CBT) versus acceptance and commitment therapy (ACT) for dementia family caregivers with significant depressive symptoms: Results of a randomized clinical trial. *Journal of Consulting and Clinical Psychology*, *83*(4), 760-772. https://doi.org/10.1037/ccp0000028

Losada, A., Márquez-González, M., Vara-García, C., Gallego-Alberto, L., Romero-Moreno, R., & Pillemer, K. (2018). Ambivalence and guilt feelings: Two relevant variables for understanding caregivers' depressive symptomatology. *Clinical Psychology & Psychotherapy*, *25*(1), 59-64. https://doi.org/10.1002/cpp.2116

Losada, A., Montorio, I., Knight, B., Márquez, M., & Izal, M. (2006). Explanation of caregivers distress from the cognitive model: the role of dysfunctional thoughts. *Psicología Conductual*, *14*(1), 115-128.

Malterud, K., Siersma, V. D., & Guassora, A. D. (2016). Sample Size in Qualitative Interview Studies: Guided by Information Power. *Qualitative Health Research*, *26*(13), 1753-1760. https://doi.org/10.1177/1049732315617444

Manthorpe, J., & Bowling, A. (2016). Quality of life measures for carers for people with dementia: measurement issues, gaps in research and promising paths. *Research, Policy and Planning*, *31*(3), 15.

Markowitz, J. S., Gutterman, E. M., Sadik, K., & Papadopoulos, G. (2003). Health-related quality of life for caregivers of patients with Alzheimer disease. *Alzheimer Disease & Associated Disorders, 17*(4), 209-214. https://doi.org/10.1097/00002093-200310000-00003

Márquez-González, M., Romero-Moreno, R., Cabrera, I., Olmos, R., Pérez-Miguel, A., & Losada, A. (2020). Tailored versus manualized interventions for dementia caregivers: The functional analysis-guided modular intervention. *Psychology and Aging, 35*(1), 41-54. https://doi.org/10.1037/pag0000412

Márquez-González, M., Romero-Moreno, R., & Losada, A. (2010). Caregiving issues in a therapeutic context: New insights from the acceptance and commitment therapy approach. In N. Pachana, K. Laidlaw & R. Knight (Eds.), C*asebook of clinical geropsychology: International perspectives on practice* (pp. 33-53). Oxford University Press.

Marshall, E.-J., & Brockman, R. N. (2016). The Relationships Between Psychological Flexibility, Self-Compassion, and Emotional Well-Being. *Journal of Cognitive Psychotherapy* (1), 60-72. https://doi.org/10.1891/0889-8391.30.1.60

Martín-Carrasco, M., Martín, M. F., Valero, C. P., Millán, P. R., García, C. I., Montalbán, S. R., Vázquez, A. L. G., Piris, S. P., & Vilanova, M. B. (2009). Effectiveness of a psychoeducational intervention program in the reduction of caregiver burden in alzheimer's disease patients' caregivers. *International Journal of Geriatric Psychiatry, 24*(5), 489-499. https://doi.org/10.1002/gps.2142

McAteer, G., & Gillanders, D. (2019). Investigating the role of psychological flexibility, masculine self-esteem and stoicism as predictors of psychological distress and quality of life in men living with prostate cancer. *European Journal of Cancer Care, 28*(4), e13097. https://doi.org/10.1111/ecc.13097

McConaghy, R., & Caltabiano, M. L. (2005). Caring for a person with dementia: Exploring relationships between perceived burden, depression, coping and well-being. *Nursing & Health Sciences, 7*(2), 81-91. https://doi.org/10.1111/j.1442-2018.2005.00213.x

McCracken, L. M., & Velleman, S. C. (2010). Psychological flexibility in adults with chronic pain: A study of acceptance, mindfulness, and values-based action in primary care. *Pain, 148*(1), 141-147. https://doi.org/10.1016/j.pain.2009.10.034

McCurry, S. M., Logsdon, R. G., Teri, L., Gibbons, L. E., Kukull, W. A., Bowen, J. D., McCormick, W. C., & Larson, E. B. (1999). Characteristics of sleep disturbance in community-dwelling Alzheimer's disease patients. *Journal of Geriatric Psychiatry and Neurology, 12*(2), 53-59. https://doi.org/10.1177/089198879901200203

McCurry, S. M., & Teri, L. (1995). Sleep disturbance in elderly caregivers of dementia patients. *Clinical Gerontologist, 16*(2), 51-66. https://doi.org/10.1300/J018v16n02_05

McLean, C. L., Fiorillo, D., & Follette, V. M. (2018). Self-Compassion and Psychological Flexibility in a Treatment-Seeking Sample of Women Survivors of Interpersonal Violence. *Violence and Victims* (3), 472-485. https://doi.org/10.1891/0886-6708.v33.i3.472

McLennon, S. M., Habermann, B., & Rice, M. (2011). Finding meaning as a mediator of burden on the health of caregivers of spouses with dementia. *Aging & Mental Health, 15*(4), 522-530. https://doi.org/10.1080/13607863.2010.543656

McNaughton, M. E., Patterson, T. L., Smith, T. L., & Grant, I. (1995). The relationship among stress, depression, locus of control, irrational beliefs, social support, and health in Alzheimer's disease caregivers. *The Journal of Nervous and Mental Disease, 183*(2), 78-85. https://doi.org/10.1097/00005053-199502000-00003

Meyer, E. C., Frankfurt, S. B., Kimbrel, N. A., DeBeer, B. B., Gulliver, S. B., & Morrisette, S. B. (2018). The influence of mindfulness, self-compassion, psychological flexibility, and posttraumatic stress disorder on disability and quality of life over time in war veterans. *Journal of Clinical Psychology, 74*(7), 1272-1280. https://doi.org/10.1002/jclp.22596

Mioshi, E., Hsieh, S., Savage, S., Hornberger, M., & Hodges, J. R. (2010). Clinical staging and disease progression in frontotemporal dementia. *Neurology, 74*(20), 1591-1597. https://doi.org/10.1212/WNL.0b013e3181e04070

Mittelman, M. S., Epstein, C., & Pierzchala, A. (2014). *Counseling the Alzheimer's Caregiver: A Resource for Health Care Professionals*. American Medical Association Press.

Moher, D., Liberati, A., Tetzlaff, J., & Altman, D. G. (2009). Preferred reporting items for systematic reviews and meta-analyses: the PRISMA statement. *PLoS Med, 6*(7), e1000097. https://doi.org/10.1371/journal.pmed.1000097

Moreno, J. A., Nicholls, E., Ojeda, N., De los Reyes-Aragón, C. J., Rivera, D., & Arango-Lasprilla, J. C. (2015). Caregiving in dementia and its impact on psychological functioning and health-related quality of life: Findings from a Colombian sample. *Journal of Cross-Cultural Gerontology, 30*(4), 393-408. https://doi.org/10.1007/s10823-015-9270-0

Morgado, F. F. R., Meireles, J. F. F., Neves, C. M., Amaral, A. C. S., & Ferreira, M. E. C. (2017). Scale development: ten main limitations and recommendations to improve future research practices. *Psicologia: Reflexão e Crítica, 30*(1), 3. https://doi.org/10.1186/s41155-016-0057-1

Narayan, S., Lewis, M., Tornatore, J., Hepburn, K., & Corcoran-Perry, S. (2001). Subjective responses to caregiving for a spouse with dementia. *Journal of gerontological nursing, 27*(3), 19-28. https://doi.org/10.3928/0098-9134-20010301-05

National Alliance for Caregiving in partnership with the Alzheimer’s Association. (2017). *Dementia Caregiving in the U.S*. Alzheimer's Association. https://www.caregiving.org/wp-content/uploads/2020/05/Dementia-Caregiving-Report-2017_Research-Recommendations_FINAL.pdf

Neff, K. D. (2003). Self-Compassion: An Alternative Conceptualization of a Healthy Attitude Toward Oneself. *Self and Identity, 2*(2), 85-101. https://doi.org/10.1080/15298860309032

NHS Digital. (2017). Personal Social Services Survey of Adult Carers in England, 2016-17. *Adult Social Care Statistics Team*. https://files.digital.nhs.uk/publication/a/o/sace_report_2016-17.pdf

NICE. (2013). *Guide to the methods of technology appraisal*. National Institute for Health and Clinical Excellence. https://www.nice.org.uk/process/pmg9/resources/guide-to-the-methods-of-technology-appraisal-2013-pdf-2007975843781

NICE. (2018). *Dementia: assessment, management and support for people living with dementia and their carers* National Institute for Health and Clinical Excellence https://www.nice.org.uk/guidance/ng97/resources/dementia-assessment-management-and-support-for-people-living-with-dementia-and-their-carers-pdf-1837760199109

Nickel, F., Barth, J., & Kolominsky-Rabas, P. L. (2018). Health economic evaluations of non-pharmacological interventions for persons with dementia and their informal caregivers: a systematic review. *BMC Geriatrics, 18*(1), 69. https://doi.org/10.1186/s12877-018-0751-1

Nogueira, M. M. L., Neto, J. P. S., Sousa, M. F. B., Santos, R. L., Rosa, R. D. L., Belfort, T., Torres, B., & Dourado, M. C. N. (2015). Spouse-caregivers' quality of life in Alzheimer's disease. *International Psychogeriatrics, 27*(5), 837-845. https://doi.org/10.1017/S1041610214002646

Novais, T., Dauphinot, V., Krolak-Salmon, P., & Mouchoux, C. (2017). How to explore the needs of informal caregivers of individuals with cognitive impairment in Alzheimer's disease or related diseases? A systematic review of quantitative and qualitative studies. *BMC Geriatrics, 17*(1), 86. https://doi.org/10.1186/s12877-017-0481-9

Novelli, M. M. P. C., & Caramelli, P. (2010). The influence of neuropsychiatric and functional changes on quality of life in Alzheimer's disease. *Dementia e Neuropsychologia*, *4*(1), 47-53. https://doi.org/10.1590/S1980-57642010DN40100008

Page, T. E., Farina, N., Brown, A., Daley, S., Bowling, A., Basset, T., Livingston, G., Knapp, M., Murray, J., & Banerjee, S. (2017). Instruments measuring the disease-specific quality of life of family carers of people with neurodegenerative diseases: A systematic review. *BMJ Open*, *7*(3), Article 013611. https://doi.org/10.1136/bmjopen-2016-013611

Papastavrou, E., Andreou, P., Middleton, N., Papacostas, S., & Georgiou, I. K. (2014). Factors associated with quality of life among family members of patients with dementia in Cyprus. *International Psychogeriatrics, 26*(3), 443-452. https://doi.org/10.1017/s104161021300224x

Park, M., Sung, M., Kim, S. K., Kim, S., & Lee, D. Y. (2015). Multidimensional determinants of family caregiver burden in Alzheimer's disease. *International Psychogeriatrics, 27*(8), 1355-1364. https://doi.org/10.1017/S1041610215000460

Parveen, S., Morrison, V., & Robinson, C. A. (2013). Ethnicity, familism and willingness to care: Important influences on caregiver mood? *Aging & Mental Health, 17*(1), 115-124. https://doi.org/10.1080/13607863.2012.717251

Peng, H. L., & Chang, Y. P. (2013). Sleep disturbance in family caregivers of individuals with dementia: a review of the literature. *Perspectives in Psychiatric Care, 49*(2), 135-146. https://doi.org/10.1111/ppc.12005

Pereira, L. S. M., & Soares, S. M. (2015). Factors influencing the quality of life of family caregivers of the elderly with dementia. *Ciencia e Saude Coletiva, 20*(12), 3839-3851. https://doi.org/10.1590/1413-812320152012.15632014

Perkins, M., Howard, V. J., Wadley, V. G., Crowe, M., Safford, M. M., Haley, W. E., Howard, G., & Roth, D. L. (2013). Caregiving strain and all-cause mortality: evidence from the REGARDS study. *The Journals of Gerontology: Series B, 68*(4), 504-512. https://doi.org/10.1093/geronb/gbs084

Perrin, P. B., Morgan, M., Aretouli, E., Sutter, M., Snipes, D. J., Hoyos, G. R., Buraye, J. A., & Arango-Lasprilla, J. C. (2014). Connecting health-related quality of life and mental health in dementia caregivers from Colombia, South America. *Journal of Alzheimer's Disease, 39*(3), 499-509. https://doi.org/10.3233/jad-130764

Perry-Duxbury, M., van Exel, J., Brouwer, W., Sköldunger, A., Gonçalves-Pereira, M., Irving, K., Meyer, G., Selbæk, G., Woods, B., Zanetti, O., Verhey, F., Wimo, A., Handels, R. L. H., & The Actifcare, C. (2020). A validation study of the ICECAP-O in informal carers of people with dementia from eight European Countries. *Quality of Life Research, 29*(1), 237-251. https://doi.org/10.1007/s11136-019-02317-3

Peterson, K., Hahn, H., Lee, A. J., Madison, C. A., & Atri, A. (2016). In the Information Age, do dementia caregivers get the information they need? Semi-structured interviews to determine informal caregivers' education needs, barriers, and preferences. *BMC Geriatrics, 16*(1), 164. https://doi.org/10.1186/s12877-016-0338-7

Pierre Moïse, Michael Schwarzinger, & Um, M.-Y. (2004). Dementia Care in 9 OECD Countries: A Comparative Analysis. *OECD Health Working Papers*, Article 13. https://doi.org/10.1787/18152015

Pinquart, M., & Sörensen, S. (2003). Differences between caregivers and noncaregivers in psychological health and physical health: A meta-analysis. *Psychology and Aging, 18*(2), 250-267. https://doi.org/10.1037/0882-7974.18.2.250

Pinquart, M., & Sörensen, S. (2007). Correlates of Physical Health of Informal Caregivers: A Meta-Analysis. *The Journals of Gerontology: Series B, 62*(2), P126-P137. https://doi.org/10.1093/geronb/62.2.P126

Plano Clark, V. L. (2010). The adoption and practice of mixed methods: US trends in federally funded health-related research. *Qualitative Inquiry, 16*(6), 428-440. https://doi.org/10.1177/1077800410364609

Pope, C., & Mays, N. (1995). Qualitative Research: Reaching the parts other methods cannot reach: an introduction to qualitative methods in health and health services research. *BMJ, 311*(6996), 42-45. https://doi.org/10.1136/bmj.311.6996.42

Post, M. W. (2014). Definitions of quality of life: what has happened and how to move on. *Topics in Spinal Cord Injury Rehabilitation, 20*(3), 167-180. https://doi.org/10.1310/sci2003-167

Pot, A. M., Gallagher-Thompson, D., Xiao, L. D., Willemse, B. M., Rosier, I., Mehta, K. M., Zandi, D., Dua, T., & team, i. d. (2019). iSupport: a WHO global online intervention for informal caregivers of people with dementia. *World Psychiatry, 18*(3), 365-366. https://doi.org/10.1002/wps.20684

Prina, A. M., Mayston, R., Wu, Y.-T., & Prince, M. (2019). A review of the 10/66 dementia research group. *Social psychiatry and psychiatric epidemiology, 54*(1), 1-10. https://doi.org/10.1007/s00127-018-1626-7

Prince, M., Graham, N., Brodaty, H., Rimmer, E., Varghese, M., Chiu, H., Acosta, D., & Scazufca, M. (2004). Alzheimer Disease International's 10/66 Dementia Research Group - one model for action research in developing countries. *International Journal of Geriatric Psychiatry, 19*(2), 178-181. https://doi.org/10.1002/gps.1059

Prince, M., Knapp, M., Guerchet, M., McCrone, P., Prina, M., Comas-Herrera, M., Wittenberg, A., Adelaja, R., Hu, B., King, B., Rehill, D., & Salimkumar, D. (2014). *Dementia UK: Update*. Alzheimer's Society. https://www.alzheimers.org.uk/sites/default/files/migrate/downloads/dementia_uk_update.pdf

Prince, M., Wimo, A. G. M., Ali, G. C., Wu, Y. T., & Prina, M. (2015). *World Alzheimer Report 2015: the global impact of dementia: an analysis of prevalence, incidence, cost and trends*. Alzheimer's Disease International. https://www.alzint.org/u/WorldAlzheimerReport2015.pdf

Proctor, R., Martin, C., & Hewison, J. (2002). When a little knowledge is a dangerous thing…: a study of carers' knowledge about dementia, preferred coping style and psychological distress. *International Journal of Geriatric Psychiatry, 17*(12), 1133-1139. https://doi.org/10.1002/gps.762

Proud, L., McLoughlin, C., & Kinghorn, P. (2019). ICECAP-O, the current state of play: a systematic review of studies reporting the psychometric properties and use of the instrument over the decade since its publication. *Quality of Life Research, 28*(6), 1429-1439. https://doi.org/10.1007/s11136-019-02114-y

Pyszkowska, A. (2020). Personality predictors of self-compassion, ego-resiliency and psychological flexibility in the context of quality of life. *Personality and Individual Differences, 161*, 109932. https://doi.org/https://doi.org/10.1016/j.paid.2020.109932

Quirk, A., Smith, S., Hamilton, S., Lamping, D., Lelliott, P., Stahl, D., Pinfold, V., & Andiappan, M. (2012). Development of the carer well‐being and support (CWS) questionnaire. *Mental Health Review Journal, 17*(3), 128-138. https://doi.org/10.1108/13619321211287184

Raes, F., Pommier, E., Neff, K. D., & Van Gucht, D. (2011). Construction and factorial validation of a short form of the Self-Compassion Scale. *Clinical Psychology & Psychotherapy, 18*(3), 250-255. https://doi.org/10.1002/cpp.702

Rahman, A., Anjum, R., & Sahakian, Y. (2019). Impact of Caregiving for Dementia Patients on Healthcare Utilization of Caregivers. *Pharmacy (Basel), 7*(4). https://doi.org/10.3390/pharmacy7040138

Rapp, S. R., Shumaker, S., Schmidt, S., Naughton, M., & Anderson, R. (1998). Social resourcefulness: Its relationship to social support and wellbeing among caregivers of dementia victims. *Aging & Mental Health, 2*(1), 40-48. https://doi.org/10.1080/13607869856920

Reed, C., Barrett, A., Lebrec, J., Dodel, R., Jones, R. W., Vellas, B., Wimo, A., Argimon, J. M., Bruno, G., & Haro, J. M. (2017). How useful is the EQ-5D in assessing the impact of caring for people with Alzheimer’s disease? *Health and Quality of Life Outcomes, 15*. https://doi.org/10.1186/s12955-017-0591-2

Richardson, T. J., Lee, S. J., Berg-Weger, M., & Grossberg, G. T. (2013). Caregiver health: Health of caregivers of Alzheimer's and other dementia patients topical collection on geriatric disorders. *Current Psychiatry Reports*, *15*(7), Article 367. https://doi.org/10.1007/s11920-013-0367-2

Romero-Moreno, R., Losada, A., Márquez-González, M., & Mausbach, B. T. (2016). Stressors and anxiety in dementia caregiving: multiple mediation analysis of rumination, experiential avoidance, and leisure. *International Psychogeriatrics, 28*(11), 1835-1844. https://doi.org/10.1017/S1041610216001009

Rosenthal, R. (1979). The file drawer problem and tolerance for null results. *Psychological Bulletin, 86*(3), 638-641. https://doi.org/10.1037/0033-2909.86.3.638

Sabogal, F., Marín, G., Otero-Sabogal, R., Marín, B. V., & Perez-Stable, E. J. (1987). Hispanic Familism and Acculturation: What Changes and What Doesn't? *Hispanic Journal of Behavioral Sciences*, *9*(4), 397-412. https://doi.org/10.1177/07399863870094003

Salari, N., Khazaie, H., Hosseinian-Far, A., Khaledi-Paveh, B., Ghasemi, H., Mohammadi, M., & Shohaimi, S. (2020). The effect of acceptance and commitment therapy on insomnia and sleep quality: A systematic review. *BMC Neurology*, *20*(1), 300. https://doi.org/10.1186/s12883-020-01883-1

Santos, R. L., de Sousa, M. F. B., Simões-Neto, J. P., Nogueira, M. L., Belfort, T. T., Torres, B., da Rosa, R. D. L., Laks, J., & Dourado, M. C. N. (2014). Caregivers’ quality of life in mild and moderate dementia. *Arquivos de Neuro-Psiquiatria*, *72*(12), 931-937. https://doi.org/10.1590/0004-282X20140155

Santos, R. L., Sousa, M. F. B. d., Ganem, A. C., Silva, T. V., & Dourado, M. C. N. (2013). Cultural aspects in dementia: differences in the awareness of Brazilian caregivers. *Trends in Psychiatry and Psychotherapy*, *35*, 191-197. https://doi.org/10.1590/S2237-60892013000300006

Schiffczyk, C., Romero, B., Jonas, C., Lahmeyer, C., Müller, F., & Riepe, M. W. (2013). Appraising the need for care in Alzheimer's disease. *BMC Psychiatry, 13*. https://doi.org/10.1186/1471-244X-13-73

Scholzel-Dorenbos, C. J., Draskovic, I., Vernooij-Dassen, M. J., & Olde Rikkert, M. G. (2009). Quality of life and burden of spouses of Alzheimer disease patients. *Alzheimer Disease & Associated Disorders*, *23*(2), 171-177. https://doi.org/10.1097/wad.0b013e318190a260

Shanley, C., Russell, C., Middleton, H., & Simpson-Young, V. (2011). Living through end-stage dementia: The experiences and expressed needs of family carers. *Dementia, 10*(3), 325-340. https://doi.org/10.1177/1471301211407794

Shin, I. S., Carter, M., Masterman, D., Fairbanks, L., & Cummings, J. L. (2005). Neuropsychiatric symptoms and quality of life in Alzheimer disease. *The American Journal of Geriatric Psychiatry, 13*(6), 469-474. https://doi.org/10.1176/appi.ajgp.13.6.469

Spira, A. P., Beaudreau, S. A., Jimenez, D., Kierod, K., Cusing, M. M., Gray, H. L., & Gallagher-Thompson, D. (2007). Experiential avoidance, acceptance, and depression in dementia family caregivers. *Clinical Gerontologist*, *30*(4), 55-64. https://doi.org/10.1300/J018v30n04_04

Spitzer, R. L., Kroenke, K., Williams, J. B., & Löwe, B. (2006). A brief measure for assessing generalized anxiety disorder: the GAD-7. *Archives of Internal Medicine, 166*(10), 1092-1097. https://doi.org/10.1001/archinte.166.10.1092

Sun, F., Ong, R., & Burnette, D. (2012). The influence of ethnicity and culture on dementia caregiving: a review of empirical studies on Chinese Americans. *American Journal of Alzheimer's Disease and other Dementias*, *27*(1), 13-22. https://doi.org/10.1177/1533317512438224

Takahashi, M., Tanaka, K., & Miyaoka, H. (2005). Depression and associated factors of informal caregivers versus professional caregivers of demented patients. *Psychiatry and Clinical Neurosciences, 59*(4), 473-480. https://doi.org/10.1111/j.1440-1819.2005.01401.x

Takai, M., Takahashi, M., Iwamitsu, Y., Oishi, S., & Miyaoka, H. (2011). Subjective experiences of family caregivers of patients with dementia as predictive factors of quality of life. *Psychogeriatrics, 11*(2), 98-104. https://doi.org/10.1111/j.1479-8301.2011.00354.x

Tay, L., Chua, K. C., Chan, M., Lim, W. S., Ang, Y. Y., Koh, E., & Chong, M. S. (2014). Differential perceptions of quality of life (QoL) in community-dwelling persons with mild-to-moderate dementia. *International Psychogeriatrics, 26*(8), 1273-1282. https://doi.org/10.1017/S1041610214000660

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

The EuroQol Group. (1990). EuroQol--a new facility for the measurement of health-related quality of life. *Health Policy, 16*(3), 199-208. https://doi.org/10.1016/0168-8510(90)90421-9

The World Bank. (2020). *World Bank Country and Lending Groups*. The World Bank Group. https://datahelpdesk.worldbank.org/knowledgebase/articles/906519-world-bank-country-and-lending-groups

Thompson, R. L., Lewis, S. L., Murphy, M. R., Hale, J. M., Blackwell, P. H., Acton, G. J., Clough, D. H., Patrick, G. J., & Bonner, P. N. (2004). Are there sex differences in emotional and biological responses in spousal caregivers of patients with Alzheimer's disease? *Biological research for nursing, 5*(4), 319-330. https://doi.org/10.1177/1099800404263288

Toye, C., Lester, L., Popescu, A., McInerney, F., Andrews, S., & Robinson, A. L. (2013). Dementia Knowledge Assessment Tool Version Two: Development of a tool to inform preparation for care planning and delivery in families and care staff. *Dementia, 13*(2), 248-256. https://doi.org/10.1177/1471301212471960

Turró-Garriga, O., Hermoso Contreras, C., Olives Cladera, J., Mioshi, E., Pelegrín Valero, C., Olivera Pueyo, J., Garre-Olmo, J., & Sánchez-Valle, R. (2017). Adaptation and validation of a Spanish-language version of the Frontotemporal Dementia Rating Scale (FTD-FRS). *Neurología, 32*(5), 290-299. https://doi.org/10.1016/j.nrleng.2015.12.002

UNDP. (2018). *Human Development Indices and Indicators 2018 Statistical Update*. United Nations Development Programme.

http://hdr.undp.org/sites/default/files/2018_human_development_statistical_update.pdf

Valentine, J. C., Pigott, T. D., & Rothstein, H. R. (2010). How Many Studies Do You Need?: A Primer on Statistical Power for Meta-Analysis. *Journal of Educational and Behavioral Statistics, 35*(2), 215-247. https://doi.org/10.3102/1076998609346961

Välimäki, T. H., Vehviläinen-Julkunen, K. M., Pietilä, A.-M. K., & Pirttilä, T. A. (2009). Caregiver depression is associated with a low sense of coherence and health-related quality of life. *Aging & Mental Health, 13*(6), 799-807. https://doi.org/10.1080/13607860903046487

Vara-García, C., Romero-Moreno, R., Márquez-González, M., Mausbach, B. T., von Känel, R., Gallego-Alberto, L., Olmos, R., & Losada, A. (2019). Stress and Blood Pressure in Dementia Caregivers: The Moderator Role of Mindfulness. *Clinical Gerontologist, 42*(5), 512-520. https://doi.org/10.1080/07317115.2018.1554611

Vargas Escobar, L. M., & Afanador, N. P. (2010). Calidad de vida del cuidador familiar y dependencia del paciente con Alzheimer. *Avances en Enfermería, 28*(1), 116-128.

Vitaliano, P. P., Zhang, J., & Scanlan, J. M. (2003). Is Caregiving Hazardous to One's Physical Health? A Meta-Analysis. *Psychological Bulletin, 129*(6), 946-972. https://doi.org/10.1037/0033-2909.129.6.946

Vowles, K. E., & McCracken, L. M. (2010). Comparing the role of psychological flexibility and traditional pain management coping strategies in chronic pain treatment outcomes. *Behaviour Research and Therapy, 48*(2), 141-146. https://doi.org/10.1016/j.brat.2009.09.011

Wang, J., Xiao, L. D., He, G.-P., & De Bellis, A. (2014). Family caregiver challenges in dementia care in a country with undeveloped dementia services. *Journal of Advanced Nursing, 70*(6), 1369-1380. https://doi.org/10.1111/jan.12299

Wang, L.-Q., & Chien, W.-T. (2011). Randomised controlled trial of a family-led mutual support programme for people with dementia. *Journal of Clinical Nursing, 20*(15‐16), 2362-2366. https://doi.org/10.1111/j.1365-2702.2011.03746.x

Wang, L.-Q., Chien, W.-T., & Lee, I. Y. M. (2012). An experimental study on the effectiveness of a mutual support group for family caregivers of a relative with dementia in mainland China. *Contemporary Nurse, 40*(2), 210-224. https://doi.org/10.5172/conu.2012.40.2.210

Wang, X. R., Robinson, K. M., & Carter-Harris, L. (2014). Prevalence of chronic illnesses and characteristics of chronically ill informal caregivers of persons with dementia. *Age and Ageing, 43*(1), 137-141. https://doi.org/10.1093/ageing/aft142

Ware, J. E., Jr., & Sherbourne, C. D. (1992). The MOS 36-item short-form health survey (SF-36). I. Conceptual framework and item selection. *Medical Care, 30*(6), 473-483.

Weisman de Mamani, A., Weintraub, M. J., Maura, J., Martinez de Andino, A., & Brown, C. A. (2017). Stigma, expressed emotion, and quality of life in caregivers of individuals with dementia. *Family Process*. https://doi.org/10.1111/famp.12325

WHO. (1995). The World Health Organization quality of life assessment (WHOQOL): Position paper from the World Health Organization. *Social Science & Medicine, 41*(10), 1403-1409. https://doi.org/10.1016/0277-9536(95)00112-K

WHO. (2017). *Global action plan on the public health response to dementia*. World Health Organization https://apps.who.int/iris/bitstream/handle/10665/259615/9789241513487-eng.pdf;jsessionid=45D5FB9484FBFBEED5F84C11E8BC7C0A?sequence=1

Wimo, A., Gauthier, S., & Prince, M. (2018). *Global estimates of informal care*. Alzheimer's Disease International. https://www.alz.co.uk/adi/pdf/global-estimates-of-informal-care.pdf

Wittenberg, R., Hu, B., Barraza-Araiza, L., & Rehill, A. (2019). *Projections of older people with dementia and costs of dementia care in the United Kingdom, 2019–2040*. Care Policy and Evaluation Centre, London School of Economics and Political Science. https://www.alzheimers.org.uk/sites/default/files/2019-11/cpec_report_november_2019.pdf

Wong, J. N., McAuley, E., & Trinh, L. (2018). Physical activity programming and counseling preferences among cancer survivors: a systematic review. *International Journal of Behavioral Nutrition and Physical Activity, 15*(1), 48. https://doi.org/10.1186/s12966-018-0680-6

Woodruff, S. C., Glass, C. R., Arnkoff, D. B., Crowley, K. J., Hindman, R. K., & Hirschhorn, E. W. (2014). Comparing Self-Compassion, Mindfulness, and Psychological Inflexibility as Predictors of Psychological Health. *Mindfulness, 5*(4), 410-421. https://doi.org/10.1007/s12671-013-0195-9

Wortmann, M. (2012). Dementia: a global health priority - highlights from an ADI and World Health Organization report. *Alzheimer's Research & Therapy, 4*(5), 40. https://doi.org/10.1186/alzrt143

Yu, D. S. F., Cheng, S.-T., & Wang, J. (2018). Unravelling positive aspects of caregiving in dementia: An integrative review of research literature. *International Journal of Nursing Studies, 79*, 1-26. https://doi.org/10.1016/j.ijnurstu.2017.10.008

Zarit, S., Orr, N. K., & Zarit, J. M. (1985). *The Hidden Victims of Alzheimer's Disease: Families Under Stress*. NYU Press.

Zawadzki, L., Mondon, K., Peru, N., Hommet, C., Constans, T., Caillard, P., & Camus, V. (2011). Attitudes towards Alzheimer's disease as a risk factor for caregiver burden. *International Psychogeriatrics, 23*(9), 1451-1461. https://doi.org/10.1017/S1041610211000640

Appendices

Supplementary table 2.1 PRISMA checklist.

	#	Checklist item	Reported on page #
TITLE			
Title	1	Identify the report as a systematic review, meta-analysis, or both.	24
ABSTRACT			
Structured summary	2	Provide a structured summary including, as applicable: background; objectives; data sources; study eligibility criteria, participants, and interventions; study appraisal and synthesis methods; results; limitations; conclusions and implications of key findings; systematic review registration number.	n/a within thesis chapter
INTRODUCTION			
Rationale	3	Describe the rationale for the review in the context of what is already known.	24-27
Objectives	4	Provide an explicit statement of questions being addressed with reference to participants, interventions, comparisons, outcomes, and study design (PICOS).	27
METHODS			
Protocol and registration	5	Indicate if a review protocol exists, if and where it can be accessed (e.g., Web address), and, if available, provide registration information including registration number.	27
Eligibility criteria	6	Specify study characteristics (e.g., PICOS, length of follow-up) and report characteristics (e.g., years considered, language, publication status) used as criteria for eligibility, giving rationale.	27
Information sources	7	Describe all information sources (e.g., databases with dates of coverage, contact with study authors to identify additional studies) in the search and date last searched.	27
Search	8	Present full electronic search strategy for at least one database, including any limits used, such that it could be repeated.	28
Study selection	9	State the process for selecting studies (i.e., screening, eligibility, included in systematic review, and, if applicable, included in the meta-analysis).	28
Data collection process	10	Describe method of data extraction from reports (e.g., piloted forms, independently, in duplicate) and any processes for obtaining and confirming data from investigators.	28
Data items	11	List and define all variables for which data were sought (e.g., PICOS, funding sources) and any assumptions and simplifications made.	28
Risk of bias in individual studies	12	Describe methods used for assessing risk of bias of individual studies (including specification of whether this was done at the study or outcome level), and how this information is to be used in any data synthesis.	29
Summary measures	13	State the principal summary measures (e.g., risk ratio, difference in means).	29-30
Synthesis of results	14	Describe the methods of handling data and combining results of studies, if done, including measures of consistency (e.g., I^2) for each meta-analysis.	29-30

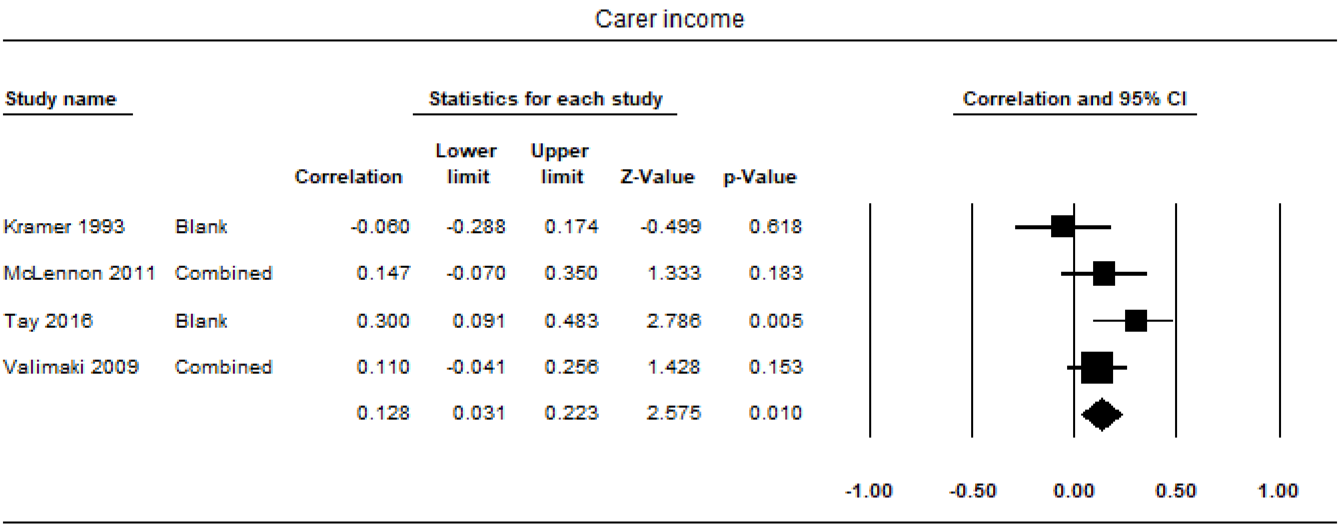
Section/topic	#	Checklist item	Reported on page #
Risk of bias across studies	15	Specify any assessment of risk of bias that may affect the cumulative evidence (e.g., publication bias, selective reporting within studies).	30
Additional analyses	16	Describe methods of additional analyses (e.g., sensitivity or subgroup analyses, meta-regression), if done, indicating which were pre-specified.	30
RESULTS			
Study selection	17	Give numbers of studies screened, assessed for eligibility, and included in the review, with reasons for exclusions at each stage, ideally with a flow diagram.	31
Study characteristics	18	For each study, present characteristics for which data were extracted (e.g., study size, PICOS, follow-up period) and provide the citations.	32
Risk of bias within studies	19	Present data on risk of bias of each study and, if available, any outcome level assessment (see item 12).	33
Results of individual studies	20	For all outcomes considered (benefits or harms), present, for each study: (a) simple summary data for each intervention group (b) effect estimates and confidence intervals, ideally with a forest plot.	41-43
Synthesis of results	21	Present results of each meta-analysis done, including confidence intervals and measures of consistency.	33-44
Risk of bias across studies	22	Present results of any assessment of risk of bias across studies (see Item 15).	44
Additional analysis	23	Give results of additional analyses, if done (e.g., sensitivity or subgroup analyses, meta-regression [see Item 16]).	44-45
DISCUSSION			
Summary of evidence	24	Summarize the main findings including the strength of evidence for each main outcome; consider their relevance to key groups (e.g., healthcare providers, users, and policy makers).	45-48
Limitations	25	Discuss limitations at study and outcome level (e.g., risk of bias), and at review-level (e.g., incomplete retrieval of identified research, reporting bias).	48-49
Conclusions	26	Provide a general interpretation of the results in the context of other evidence, and implications for future research.	49-50
FUNDING			
Funding	27	Describe sources of funding for the systematic review and other support (e.g., supply of data); role of funders for the systematic review.	n/a

From: Moher D, Liberati A, Tetzlaff J, Altman DG, The PRISMA Group (2009). Preferred Reporting Items for Systematic Reviews and Meta-Analyses: The PRISMA Statement. *PLoS Med 6*(7): e1000097. https://doi.org/10.1371/journal.pmed.1000097

Supplementary table 2.2 Search strategy.

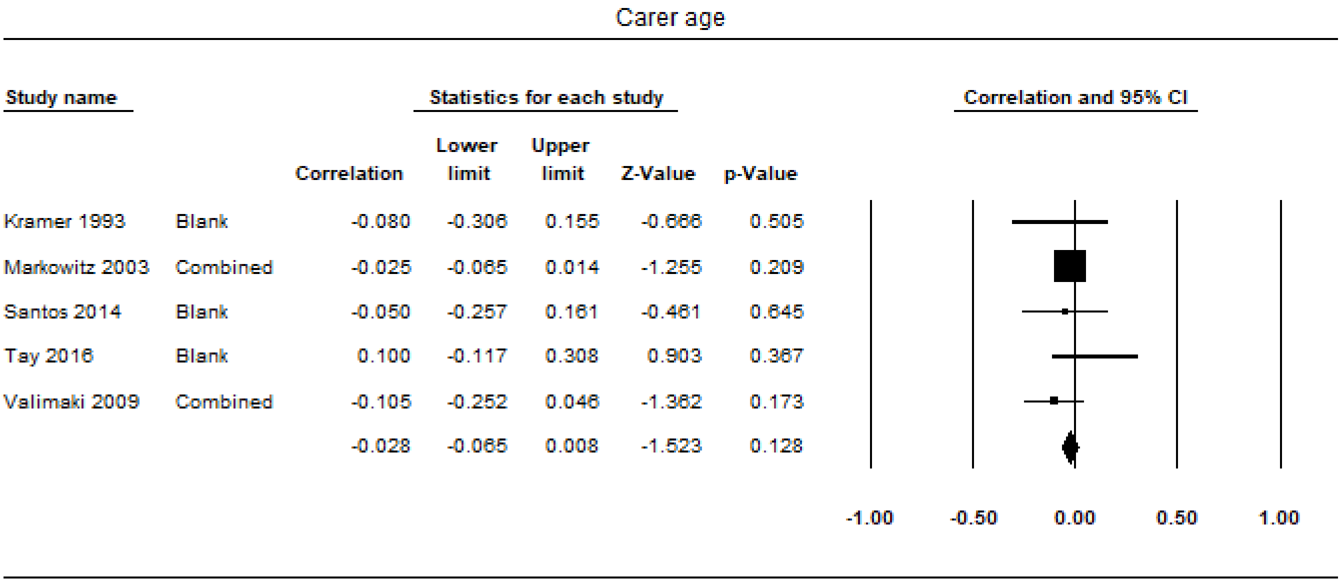
Search terms		
#1 demen*	#8 "quality of life"	#19 informal*
#2 alzheimer*	#9 QOL	#20 unpaid
#3 (#1 OR #2)	#10 QL	#21 spous*
#4 carer*	#11 HRQOL	#22 espos*
#5 caregiver*	#12 HRQL	#23 famil*
#6 cuidador*	#13 "calidad de vida"	#24 (#19 OR #20 OR #21 OR #22 OR #23)
#7 (#4 OR #5 OR #6)	#14 "qualidade de vida"	#25 (#3 AND #7 AND #18 AND #24)
	#15 wellbeing	
	#16 bienestar	
	#17 "bem-estar"	
	#18 (#8 OR #9 OR #10 OR #11 OR #12 OR #13 OR #14 OR #15 OR #16 OR #17)	

Supplementary Figure 2.1 Forest plot for independent variables with non-significant effect.



Carer income

Study name		Correlation	Lower limit	Upper limit	Z-Value	p-Value
Kramer 1993	Blank	-0.060	-0.288	0.174	-0.499	0.618
McLennon 2011	Combined	0.147	-0.070	0.350	1.333	0.183
Tay 2016	Blank	0.300	0.091	0.483	2.786	0.005
Valimaki 2009	Combined	0.110	-0.041	0.256	1.428	0.153
		0.128	0.031	0.223	2.575	0.010



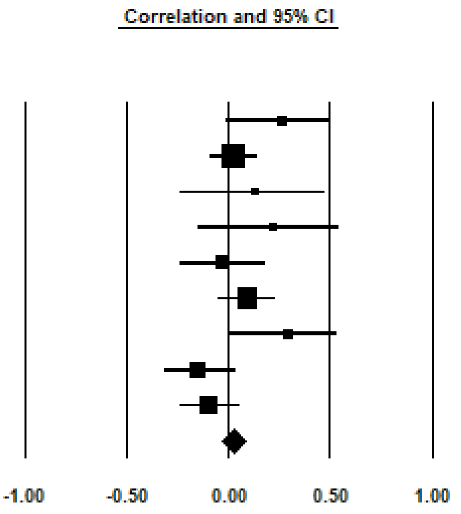
Carer age

Study name		Correlation	Lower limit	Upper limit	Z-Value	p-Value
Kramer 1993	Blank	-0.080	-0.306	0.155	-0.666	0.505
Markowitz 2003	Combined	-0.025	-0.065	0.014	-1.255	0.209
Santos 2014	Blank	-0.050	-0.257	0.161	-0.461	0.645
Tay 2016	Blank	0.100	-0.117	0.308	0.903	0.367
Valimaki 2009	Combined	-0.105	-0.252	0.046	-1.362	0.173
		-0.028	-0.065	0.008	-1.523	0.128

Supplementary Figure 2.1 (continued)

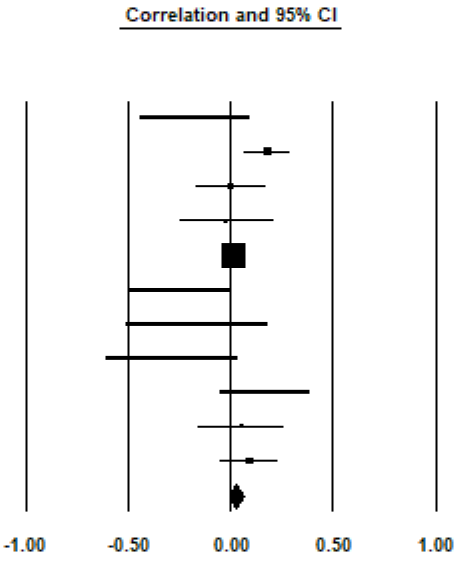
PwD cognitive functioning

Study name		Statistics for each study				
		Correlation	Lower limit	Upper limit	Z-Value	p-Value
Coen 1999	Blank	0.260	-0.020	0.502	1.824	0.068
Crellin 2015	Combined	0.025	-0.091	0.140	0.423	0.672
Novelli 2010 mild	Blank	0.130	-0.242	0.468	0.679	0.497
Novelli 2010 moderate	Blank	0.220	-0.152	0.538	1.162	0.245
Santos 2014	Blank	-0.030	-0.238	0.181	-0.277	0.782
Schiffczyk 2013	Blank	0.090	-0.052	0.228	1.247	0.212
Scholzel-Dorenbos 2009	Blank	0.290	-0.000	0.535	1.958	0.050
Takai 2011	Blank	-0.150	-0.322	0.032	-1.621	0.105
Valimaki 2009	Combined	-0.098	-0.245	0.053	-1.273	0.203
		0.023	-0.039	0.085	0.729	0.466



PwD functionality (ADL)

Study name		Statistics for each study				
		Correlation	Lower limit	Upper limit	Z-Value	p-Value
Coen 1999	Blank	-0.190	-0.445	0.093	-1.319	0.187
Crellin 2015	Combined	0.175	0.061	0.285	2.992	0.003
Jackson 2009	Combined	-0.000	-0.171	0.171	-0.000	1.000
Kramer 1993	Combined	-0.025	-0.255	0.208	-0.210	0.834
Markowirtz 2003	Combined	0.015	-0.024	0.054	0.747	0.455
Nogueira 2015	Blank	-0.270	-0.502	-0.002	-1.977	0.048
Novelli 2010 mild	Combined	-0.190	-0.515	0.182	-1.001	0.317
Novelli 2010 moderate	Combined	-0.331	-0.618	0.033	-1.787	0.074
Papastavrou 2014	Blank	0.170	-0.056	0.380	1.477	0.140
Santos 2014	Blank	0.050	-0.161	0.257	0.461	0.645
Vargas Escobar 2010	Blank	0.090	-0.052	0.229	1.241	0.215
		0.024	-0.010	0.057	1.401	0.161



Supplementary material 6.1 Participant interview guide

Participant Interview Guide

I would like you to try to remember some of the experiences you had during the early stages of dementia of your loved one, when you received the diagnosis and the following months after that. And before I ask you any questions that might get you thinking about specific things, what was the most challenging thing during that time?

- Did you receive any information about the disease that might have helped you to care for the person with AD more effectively at that moment? [Explore: medical treatment options and/or about the tasks involved in helping take care of someone with Alzheimer's disease]

- If so, from what sources? [Explore: Doctor, other medical provider, print materials from the doctor's office, family, friends, other people taking care of someone with the same condition, library, other print materials, internet (what sites), support groups, classes].

- If so, what sources of information did you find to be most helpful at that time? Why?

- Did you receive any support for yourself or any information about how to look after your own physical and mental health or how to enhance your quality of life at that moment?

- If so, from what sources? If so, what sources of information did you found to be most helpful? Why?

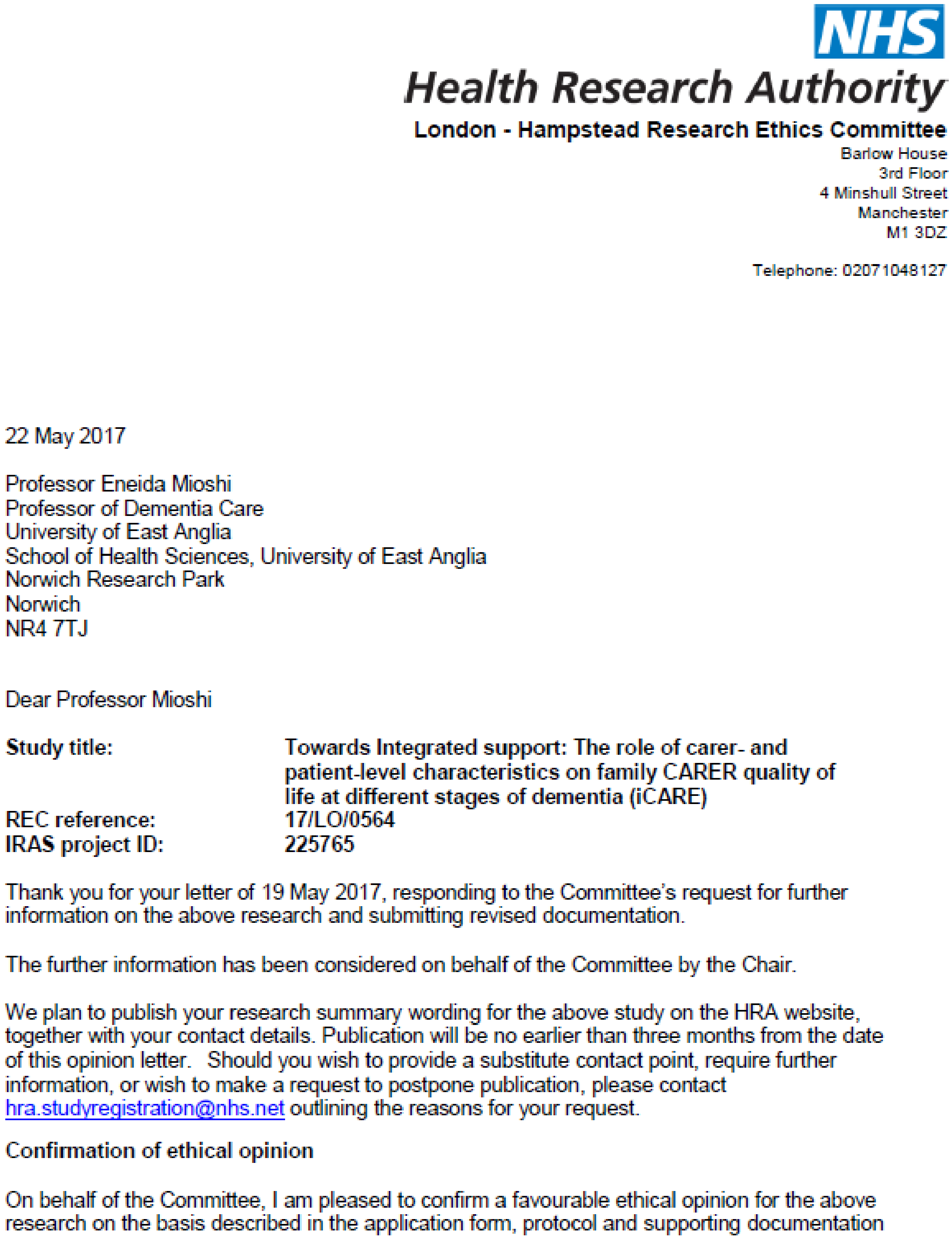
- Is there anything you wish you would have learned at that time or is there any kind of support that might have helped you enhance your caring experience and your quality of life at that moment?

- From which organisations or people would you have expected or preferred to receive this information from at that time?

- Which methods would you have preferred to learn from? [Explore: Directly from another person, one on one; with a teacher in a class; from a support group of others facing the same issues; written materials; Internet or other digital sources; slide show; audio program; video.]

- In what settings do you think you would have preferred to learn this kind of information? [Explore: at home; in a classroom or other group setting; in a public or health library; in a doctor's clinical exam room; in a doctor's waiting room.]

Letter of ethical approval for the studies conducted in chapters 3-5



NHS
Health Research Authority
London - Hampstead Research Ethics Committee
Barlow House
3rd Floor
4 Minshull Street
Manchester
M1 3DZ

Telephone: 02071048127

22 May 2017

Professor Eneida Mioshi
Professor of Dementia Care
University of East Anglia
School of Health Sciences, University of East Anglia
Norwich Research Park
Norwich
NR4 7TJ

Dear Professor Mioshi

Study title:	**Towards Integrated support: The role of carer- and patient-level characteristics on family CARER quality of life at different stages of dementia (iCARE)**
REC reference:	**17/LO/0564**
IRAS project ID:	**225765**

Thank you for your letter of 19 May 2017, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chair.

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

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

Conditions of the favourable opinion

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

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

Management permission should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements. Each NHS organisation must confirm through the signing of agreements and/or other documents that it has given permission for the research to proceed (except where explicitly specified otherwise).

Guidance on applying for NHS permission for research is available in the Integrated Research Application System, www.hra.nhs.uk or at http://www.rdforum.nhs.uk.

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

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

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

Registration of Clinical Trials

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

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

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

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

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

Ethical review of research sites

NHS sites

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

Approved documents

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

Document	*Version*	*Date*
Copies of advertisement materials for research participants		23 February 2017
Covering letter on headed paper	v1.0	10 March 2017
Covering letter on headed paper		17 May 2017
GP/consultant information sheets or letters	v1.1	28 April 2017
IRAS Application Form [IRAS_Form_15032017]		15 March 2017
IRAS Application Form XML file [IRAS_Form_15032017]		15 March 2017
IRAS Checklist XML [Checklist_15032017]		15 March 2017
IRAS Checklist XML [Checklist_19052017]		19 May 2017
Other [REC17LO0015 Unfavourable opinion]		24 January 2017
Participant consent form	v1.1	17 May 2017
Participant information sheet (PIS) [v1.1]	v1.1	28 April 2017
Referee's report or other scientific critique report [Letter from an independent external reviewer]		03 May 2017
Referee's report or other scientific critique report [Letter from a statistician re the statistical review]		10 May 2017
Referee's report or other scientific critique report [The result of PPI exercises]		
Research protocol or project proposal	v1.1	09 May 2017
Summary CV for Chief Investigator (CI)		10 March 2017
Validated questionnaire [MCA assessment sheet]		
Validated questionnaire [Carer interview questionnaires]		
Validated questionnaire [Carer self-report questionnaires]		

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Reporting requirements

The attached document *"After ethical review – guidance for researchers"* gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

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

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

User Feedback

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website:
http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance/

HRA Training

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

17/LO/0564	**Please quote this number on all correspondence**

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

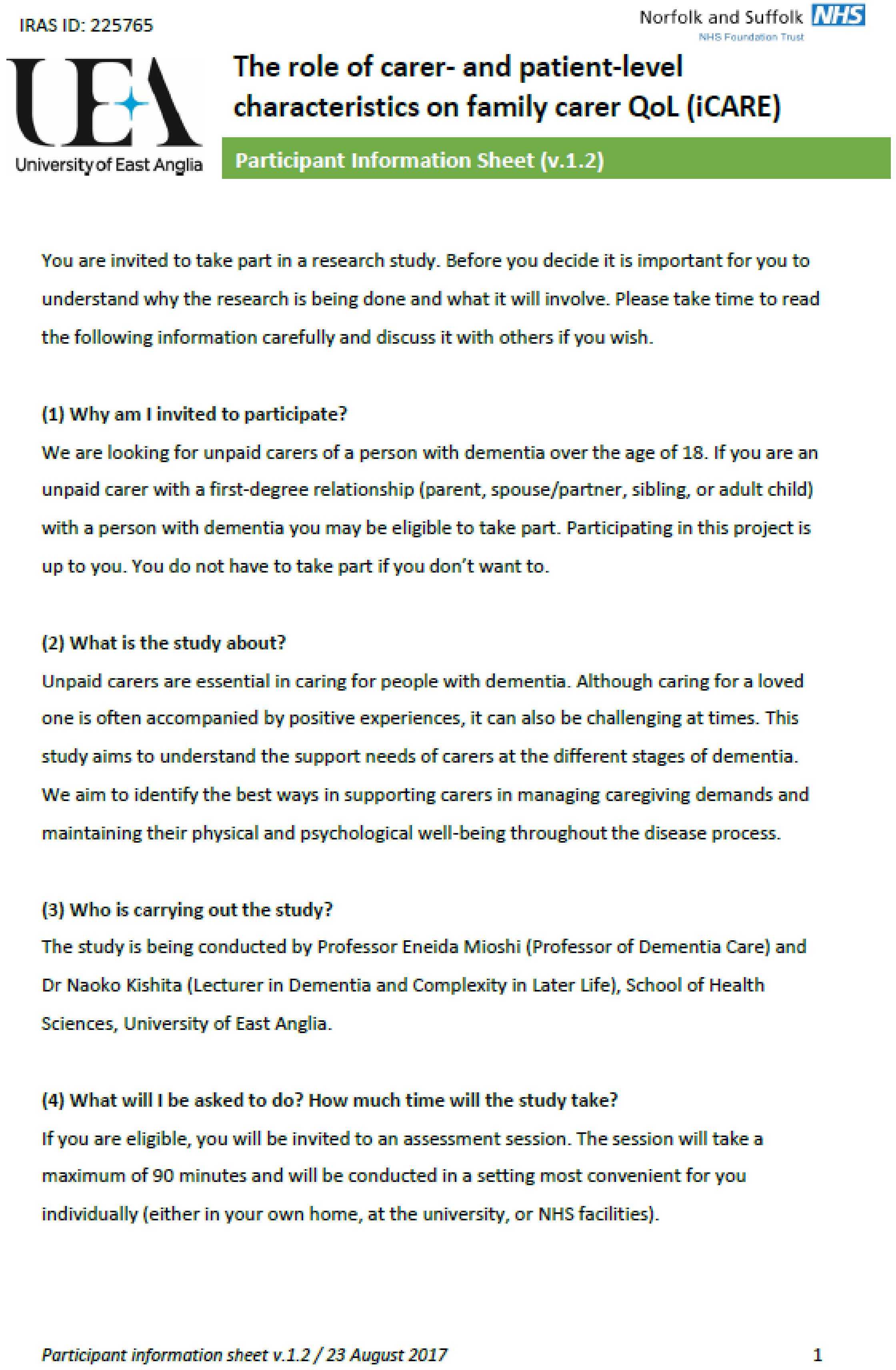
Yours sincerely

Signed on behalf of
Miss Stephanie Ellis BEM
Chair

Email:nrescommittee.london-hampstead@nhs.net

Enclosures:	"After ethical review – guidance for researchers" *SL-AR2*
Copy to:	*Dr Bonnie Teague, Norfolk and Suffolk NHS Foundation Trust Research and Development*

Participant information sheet used for the studies conducted in chapters 3-5



IRAS ID: 225765

Norfolk and Suffolk NHS
NHS Foundation Trust

University of East Anglia

The role of carer- and patient-level characteristics on family carer QoL (iCARE)

Participant Information Sheet (v.1.2)

You are invited to take part in a research study. Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish.

(1) Why am I invited to participate?

We are looking for unpaid carers of a person with dementia over the age of 18. If you are an unpaid carer with a first-degree relationship (parent, spouse/partner, sibling, or adult child) with a person with dementia you may be eligible to take part. Participating in this project is up to you. You do not have to take part if you don't want to.

(2) What is the study about?

Unpaid carers are essential in caring for people with dementia. Although caring for a loved one is often accompanied by positive experiences, it can also be challenging at times. This study aims to understand the support needs of carers at the different stages of dementia. We aim to identify the best ways in supporting carers in managing caregiving demands and maintaining their physical and psychological well-being throughout the disease process.

(3) Who is carrying out the study?

The study is being conducted by Professor Eneida Mioshi (Professor of Dementia Care) and Dr Naoko Kishita (Lecturer in Dementia and Complexity in Later Life), School of Health Sciences, University of East Anglia.

(4) What will I be asked to do? How much time will the study take?

If you are eligible, you will be invited to an assessment session. The session will take a maximum of 90 minutes and will be conducted in a setting most convenient for you individually (either in your own home, at the university, or NHS facilities).

We will conduct an interview and ask you questions about the level of disability of the person you are caring for, the services you are currently using, and your own health. You will also be asked to self-complete questionnaires regarding your thoughts and feelings about your role as a carer and your own health. We may access your medical records by contacting your GP if further information is needed regarding your health conditions.

(5) Should I discuss the study with the person I care for?

Yes, please discuss the study with the person you care for. Although the most of the questionnaires include questions about yourself, there are also some questionnaires that ask about the person you care for (e.g., type of dementia, education history, marital status, the level of disability). Please discuss your participation with the person you care for before you decide to take part.

If the person whom you care for is not able to communicate to inform you a decision due to impairment, please discuss with someone who knows the person well and/or is involved in their care for their advice to inform a decision.

If there are any questions you do not wish to answer for yourself or the person you care for, you can opt not to answer those questions during the assessment session.

(6) Can I withdraw from the study?

Being in this study is completely voluntary - you are not under any obligation to consent. If you do consent, but change your mind at a later stage, you can withdraw at any time without affecting the quality of healthcare received by you or the person you care for.

(7) Will anyone else see my data?

All information associated with this research is confidential and stored securely in compliance with the Data Protection Act (1998). Your identifiable data (i.e., name and contact details) will be stored under secure conditions within the School of Health Sciences at the University of East Anglia in a separate location to the questionnaire data to ensure anonymity. The individual results will remain anonymous, as participants' names will be replaced with a numerical code.

Hard copy data will be stored under secure conditions within the School of Health Science at the University of East Anglia; electronic data will be stored on secure servers and managed using databases encrypted with industry standard methods and protected by passwords. Data will be stored for a minimum of 10 years and destroyed thereafter.

Only the research team will have access to the data. Only you, the research team, and your GP will know that you are participating in the study. Should concerns arise about safeguarding issues, either with regard to yourself or the person you care for, it may in these circumstances be necessary to breach confidentiality.

We will also ask your permission to use your questionnaire data for other ethically approved studies being conducted by this study team, and for which you have consented to participate in, to avoid duplication of measures between studies.

In addition, sometimes anonymised information may be used by other researchers in the University of East Anglia (School of Medicine and Health Sciences) or our international research collaborators. All such studies will have full ethical approval and the information will be anonymised prior to sharing.

If you are interested to be informed about research opportunities, which might arise in the future, please initial the appropriate box on the consent form (this is optional). If any opportunities arise in the future, we will contact you first in case of changes to your circumstances before sending any study information.

(8) Will the study benefit me?

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 dementia, which may improve the wellbeing of others, now or in the future.

You will not receive any payment for taking part in the study, but any travel costs incurred will be reimbursed.

(9) What are the risks of taking part?

There are no known risks from taking part in this study. However, some people may find it upsetting to talk about their thoughts and feelings in relation to their caregiving experiences; the research team is experienced in supporting people during conversations like this and will do everything possible to make you feel more comfortable.

(10) What happens at the end of the study?

A report of the results from the study will be submitted for publication (individual participants will not be identifiable). The outcomes will be shared with Older People's Services and dementia teams across the Trust. We will also send you a summary of the findings at the end of the study if you wish.

(11) Can I tell other people about the study?

Yes, you can tell your family and friends about the study.

(12) What if I require further information about the study or my involvement in it?

When you have read this information, a member of the study team will discuss it with you further and answer any questions you may have. If you would like to know more at any stage, contact details for the study team are provided at the end of this information sheet.

(13) What if I have a complaint or any concerns?

In the unlikely event of anything untoward happening, you may complain either directly to the Chief Investigator (Professor Eneida Mioshi), or the Head of the School of Health Sciences at the University of East Anglia (Professor Rosalynd Jowett). Alternatively you may wish to contact the Patient Liaison and Advisory Service (PALS) at Norfolk and Suffolk NHS Foundation Trust. PALS provides service users, their carers and families with help, information and support to resolve concerns quickly and efficiently. Compensation arrangements for negligent harm are covered by the normal NHS indemnity.

For more information about the study, contact the study team:

Dr Naoko Kishita
UEA Co-Lead Investigator
Phone: 01603 593599
Email: N.Kishita@uea.ac.uk

Juniper West
NSFT Principle Investigator
Phone: 01603 421850
Email: juni.west@nsft.nhs.uk

or the Norfolk and Suffolk NHS Foundation Trust Research & Development office:

Phone: 01603 421255
Email: RDofficemailbox@nsft.nhs.uk

To make a complaint, contact:

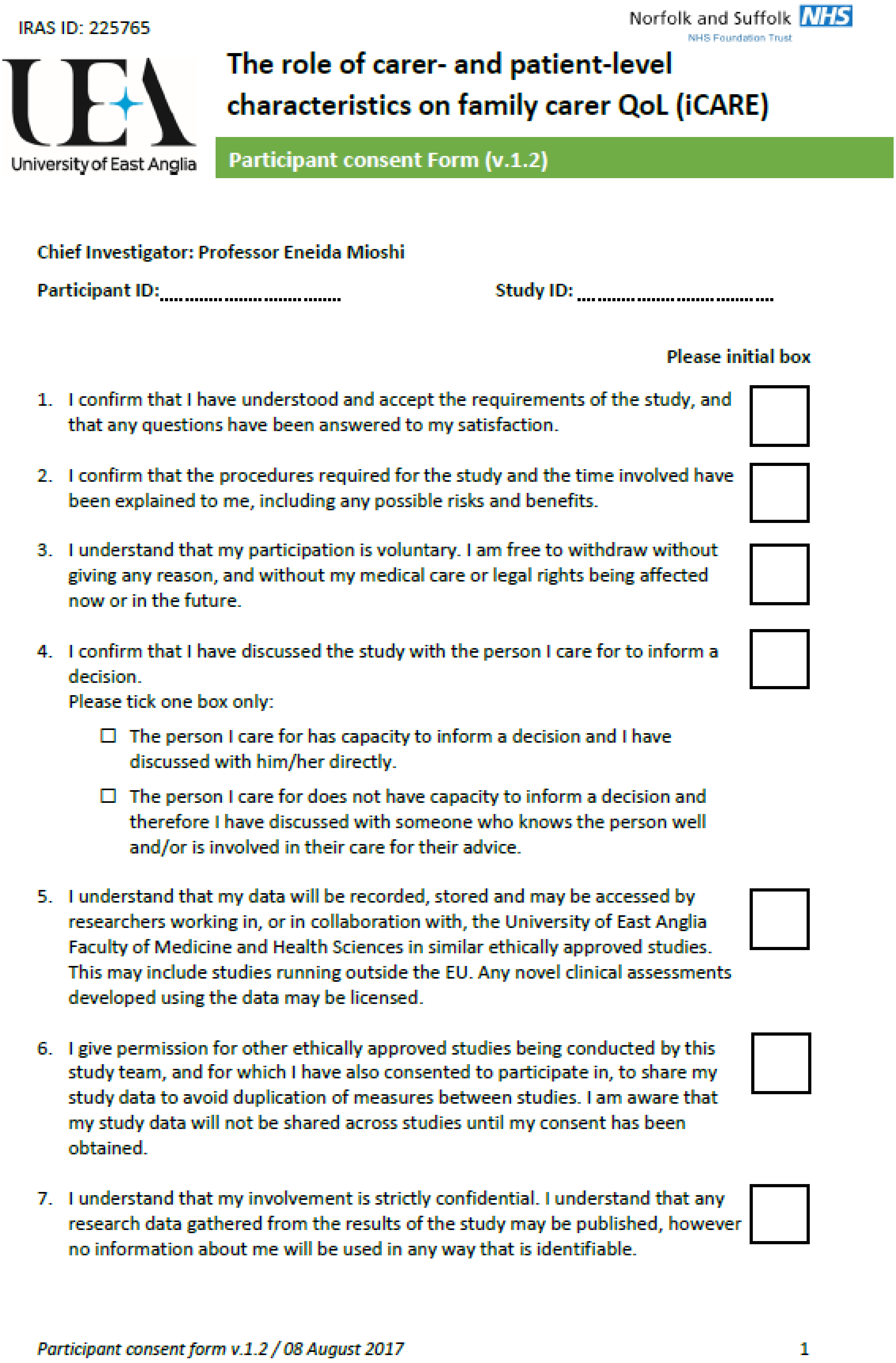
Professor Eneida Mioshi
Chief Investigator
Phone: 01603 593300
Email: e.mioshi@uea.ac.uk

Professor Rosalynd Jowett
Head of School of Health Sciences
Phone: 01603 593940
Email: r.jowett@uea.ac.uk

To contact PALS:

Email: pals@nsft.nhs.uk Phone: 01603 421191 or BT Freephone: 0800 279 7257 (calls from mobiles may be charged). Office open 9am to 5pm Monday to Friday. Outside these hours, please leave an answerphone message.

Consent form used for the studies conducted in chapters 3-5



IRAS ID: 225765

Norfolk and Suffolk NHS
NHS Foundation Trust

University of East Anglia

The role of carer- and patient-level characteristics on family carer QoL (iCARE)

Participant consent Form (v.1.2)

Chief Investigator: Professor Eneida Mioshi

Participant ID:................................ **Study ID:** ....

Please initial box

1. I confirm that I have understood and accept the requirements of the study, and that any questions have been answered to my satisfaction. ☐
2. I confirm that the procedures required for the study and the time involved have been explained to me, including any possible risks and benefits. ☐
3. I understand that my participation is voluntary. I am free to withdraw without giving any reason, and without my medical care or legal rights being affected now or in the future. ☐
4. I confirm that I have discussed the study with the person I care for to inform a decision. ☐
   Please tick one box only:
   - ☐ The person I care for has capacity to inform a decision and I have discussed with him/her directly.
   - ☐ The person I care for does not have capacity to inform a decision and therefore I have discussed with someone who knows the person well and/or is involved in their care for their advice.
5. I understand that my data will be recorded, stored and may be accessed by researchers working in, or in collaboration with, the University of East Anglia Faculty of Medicine and Health Sciences in similar ethically approved studies. This may include studies running outside the EU. Any novel clinical assessments developed using the data may be licensed. ☐
6. I give permission for other ethically approved studies being conducted by this study team, and for which I have also consented to participate in, to share my study data to avoid duplication of measures between studies. I am aware that my study data will not be shared across studies until my consent has been obtained. ☐
7. I understand that my involvement is strictly confidential. I understand that any research data gathered from the results of the study may be published, however no information about me will be used in any way that is identifiable. ☐

Participant consent form v.1.2 / 08 August 2017 1

8. I agree to my GP being informed of my participation in the study. I also agree that the research team may access my medical records for the purposes of this research project. ☐

9. I agree to take part in the study. ☐

10. I agree to be contacted by the study team about research opportunities, which might arise in the future. This is optional and please initial the box if you wish to be informed about future studies. ☐

....	....	....
Name of Participant *(Please print)*	Date	Signature
....	....	....
Name of Research Team Member *(Please print)*	Date	Signature

When completed, original to be kept in care record, 1 copy for participant and 1 copy for research file

For more information about the study, contact the study team:

Name: Juni West	Dr Naoko Kishita
Phone: 01603 978409	Phone: 01603 593599
Email: juni.west@nsft.nhs.uk	Email: N.Kishita@uea.ac.uk

or the Norfolk and Suffolk NHS Foundation Trust Research & Development office:

Phone: 01603 421255	Email: RDofficemailbox@nsft.nhs.uk

To make a complaint, contact:

Professor Eneida Mioshi	Professor Rosalynd Jowett
Chief Investigator	Head of School of Health Sciences
Phone: 01603 593300	Phone: 01603 593940
Email: e.mioshi@uea.ac.uk	Email: r.jowett@uea.ac.uk

To contact PALS:

Email: pals@nsft.nhs.uk Phone: 01603 421191 or BT Freephone: 0800 279 7257 (calls from mobiles may be charged). Office open 9am to 5pm Monday to Friday. Outside these hours, please leave an answerphone message.

Letter of ethical approval for the study conducted in chapter 6

Faculty of Medicine and Health Sciences Research Ethics Committee

University of East Anglia

NORWICH MEDICAL SCHOOL
Bob Champion Research & Educational Building
Rosalind Franklin Road
University of East Anglia
Norwich Research Park
Norwich NR4 7UQ

Email: fmh.ethics@uea.ac.uk
www.med.uea.ac.uk

Milena Contreras
School of Health Sciences
University of East Anglia
Norwich Research Park
Norwich
NR4

Date:

Dear Milena

Title: What are the educational and support needs of families looking after someone in the early stages of Alzheimer's disease? A qualitative retrospective approach

Reference: 2019/20-150

Thank you for your email of 10th August 2020 notifying us of the amendments you would like to make to your above proposal. These have been considered and I can confirm that your amendments have been approved.

Please can you ensure that any further amendments to either the protocol or documents submitted are notified to us in advance, and that any adverse events which occur during your project are reported to the Committee.

Approval by the FMH Research Ethics Committee should not be taken as evidence that your study is compliant with GDPR and the Data Protection Act 2018. If you need guidance on how to make your study GDPR compliant, please contact your institution's Data Protection Officer.

Please can you arrange to send us a report once your project is completed.

Yours sincerely

Dr Jackie Buck
Chair
FMH Research Ethics Committee

COVID-19: *The FMH Research Ethics Committee procedures remain as normal. Please note that our decisions as to the ethics of your application take no account of Government measures and UEA guidelines relating to the coronavirus pandemic and all approvals granted are, of course, subject to these. If your research is COVID-19 related it will naturally be expedited. If the current situation means that you will have to alter your study, please submit an application for an amendment in the usual way.*

Participant information sheet used for the study conducted in chapter 6

University of East Anglia

Educational and support needs of families looking after someone in the early stages of Alzheimer's disease

Participant Information Sheet V1 / 06 August 2020

My name is Milena Contreras and I am a doctoral student at the University of East Anglia. I would like to invite you to participate in this research project. Before deciding whether to take part, please take your time to read the following information carefully and discuss it with your partner, relatives or friends if you wish. Please feel free to ask me if there is anything that is not clear or if you would like more information (contact details below).

(1) Why am I invited?

I am looking for unpaid carers of a person with dementia. If you are over the age of 18 and an unpaid carer with a first-degree relationship (spouse/partner or adult child) with a person with moderate to very severe Alzheimer's disease you may be eligible to take part.

(2) What is the study about?

Unpaid family carers are essential in caring for people with dementia and thus exploring their specific needs is important. Previous research suggests that the information on needs of family carers of people with early-stage dementia (early-stage carers) is still scarce. This is because many early-stage carers struggle to recognise their own needs and accept or seek help due to difficulties in understanding and accepting the changes. This project aims to understand the educational and support needs of carers of people with early stages of Alzheimer's disease. The project aims to do this by exploring the retrospective views and recommendations of more experienced carers.

(3) What will I be asked to do? How much time will the study take?

If you decide to take part in the study, I will ask you to return the signed consent form via post or email. I will contact you via telephone and provide further instruction on how you can complete this step. Following this, I will ask you to participate in an initial screening session. If you are eligible, you will be then invited to take part in the interview session.

Initial screening session

This session will take a maximum of 30 minutes and will be conducted via telephone. During the initial screening session, you will be asked to answer some questions about you and about the person you are caring for. I need to use this information to see whether you meet the study criteria. If you do not meet the criteria, unfortunately, I will not be able to include you in the study. If this happens, I will explain this to you and make sure that you have the opportunity to ask questions. If you are eligible, I will invite you to the interview session, which will be conducted on a different day.

Interview session

This session will last a maximum of 60 minutes and will be conducted via telephone or video chat, depending on your preference. During the interview session, you will be asked to answer some demographics questions about you and the person you care for. After that, I will conduct an interview where you will be asked to recall some of the experiences you had during the early stages of your relative's dementia, the challenges you had and the information and support you wished you had at that time.

(4) Can I withdraw from the study?

Being in this study is completely voluntary - you are not under any obligation to consent. If you do consent, but change your mind at a later stage, you can withdraw without an explanation any time up until the completion of the interview. If you withdraw from the study all your information will be destroyed. Once the data collected from the interview is transcribed and anonymised, it will no longer be possible to withdraw your participation as I will not be able to extract your anonymised data.

(5) Will data be kept confidential?

All information associated with this research is confidential and stored securely in compliance with the UK Data Protection Act (2018) and the EU General Data Protection Regulation (GDPR). The individual results will remain anonymous, as participants' names will be replaced with a numerical code.

Hard copy data will be stored under secure conditions within the School of Health Science at the University of East Anglia; electronic data will be stored on secure servers and managed using databases encrypted with industry-standard methods and protected by passwords. Data will be stored for a minimum of 10 years and destroyed thereafter.

Digital audio data recorded on the voice recorder will be transferred and stored on the University East Anglia's password-protected secure electronic network. All data will be deleted from the voice recorder after the data has been transferred. Following the interview session, a transcription of your interview will be completed and anonymised. The recorded interviews will be completely deleted from the secure electronic network as soon as the accuracy of anonymised transcripts has been checked. The anonymised transcripts will be stored for a minimum of 10 years and destroyed thereafter.

Only you, my academic supervisors and I will know that you are participating in the study. I may need to break confidentiality if you tell me anything which may put yourself, the person you care for or others at risk of harm. If this happens, I will explain why I will need to break confidentiality and I will notify your GP so that you can receive further support.

(6) Will the study benefit me?

The study may not be of direct benefit to you, but your participation is likely to help us find out more about the experiences of carers. The information gathered may help improve the wellbeing of future carers. You will not receive any payment for taking part in the study.

(7) What are the risks of taking part?

There are no known risks from taking part in this study. However, some people may find it upsetting to talk about their thoughts and feelings in relation to their caregiving experiences. If this happens, I will do everything possible to make you feel more comfortable. Please also note that you can stop and withdraw from the study any time during the interview.

(8) What happens at the end of the study?

At the end of the study, I will analyse all of your anonymised information with other participants' anonymised information. The results of this study will contribute to my PhD thesis. I will also publish the findings in an academic journal and will disseminate them at relevant conferences under the supervision of my academic supervisors. I will send you a summary of the research findings at the end of the study if you request this. Your information will not be identified in any publication arising from this study.

(9) Who is organising and funding the research?

I have organised this study under the supervision of my academic supervisors, Dr Naoko Kishita (Associate Professor in Dementia and Complexity in Later Life) and Professor Eneida Mioshi (Professor of Dementia Care). My PhD is funded by the National Institute for Health Research, the Norfolk and Suffolk Primary and Community Care Research Office, and the Faculty of Medicine and Health Sciences.

(10) What if I have a complaint or any concerns?

In the unlikely event of anything untoward happening, you may complain directly to my Primary Supervisor. If you wish to make a complaint to someone independent from the study, please contact the Dean of the School of Health Sciences at the University of East Anglia.

For more information about the study, I can be contacted via the following:

Milena Contreras
Principal Investigator (Postgraduate researcher)
School of Health Sciences (Queens Building 1.23)
Faculty of Medicine and Health Sciences
University of East Anglia
Norwich Research Park
Norwich, NR4 7TJ

Phone: 07557157058 (Work mobile available from 10am to 5pm Monday to Friday)

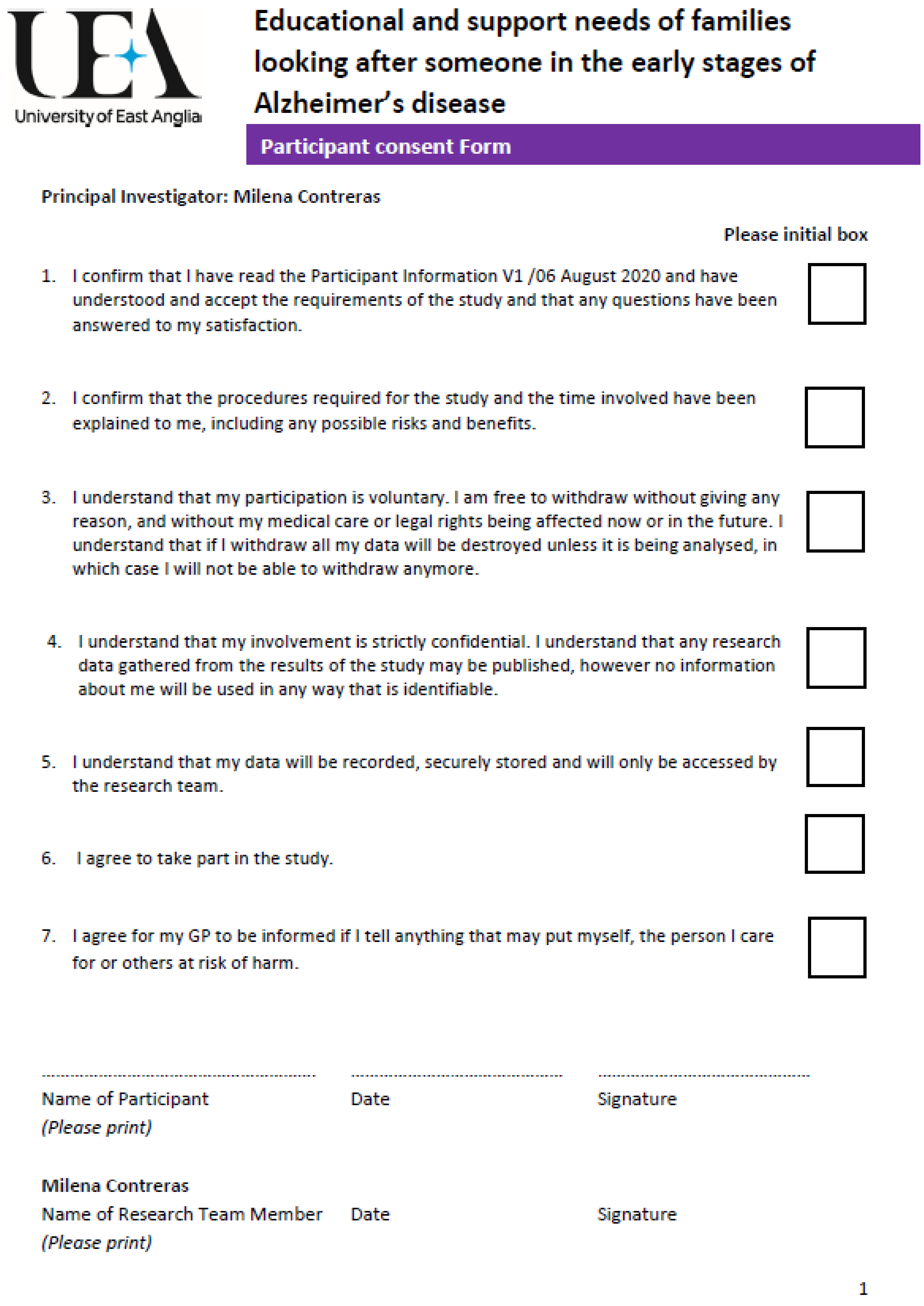
Email: M.Contreras@uea.ac.uk

To make a complaint, contact:

Dr Naoko Kishita	Professor Sally Hardy
Primary Supervisor	Dean of School of Health Sciences
Phone: 01603 593599	Phone: 01603 593940
Email: N.Kishita@uea.ac.uk	Email: S.Hardy@uea.ac.uk

Thank you for taking the time to read this information sheet.

Consent form used for the study conducted in chapter 6



University of East Anglia

Educational and support needs of families looking after someone in the early stages of Alzheimer's disease

Participant consent Form

Principal Investigator: Milena Contreras

Please initial box

1. I confirm that I have read the Participant Information V1 /06 August 2020 and have understood and accept the requirements of the study and that any questions have been answered to my satisfaction. ☐
2. I confirm that the procedures required for the study and the time involved have been explained to me, including any possible risks and benefits. ☐
3. I understand that my participation is voluntary. I am free to withdraw without giving any reason, and without my medical care or legal rights being affected now or in the future. I understand that if I withdraw all my data will be destroyed unless it is being analysed, in which case I will not be able to withdraw anymore. ☐
4. I understand that my involvement is strictly confidential. I understand that any research data gathered from the results of the study may be published, however no information about me will be used in any way that is identifiable. ☐
5. I understand that my data will be recorded, securely stored and will only be accessed by the research team. ☐
6. I agree to take part in the study. ☐
7. I agree for my GP to be informed if I tell anything that may put myself, the person I care for or others at risk of harm. ☐

....	....	....
Name of Participant *(Please print)*	Date	Signature
Milena Contreras Name of Research Team Member *(Please print)*	Date	Signature

When completed, original to be kept in care record, 1 copy for participant and 1 copy for research file

For more information about the study, contact the Principal Investigator:

Ms Milena Contreras

Principal Investigator

Phone: 07716470722

Email: M.Contreras@uea.ac.uk

To make a complaint, contact:

Dr Naoko Kishita	Professor Sally Hardy
Primary Supervisor	Dean of School of Health Sciences
Phone: 01603 593599	Phone: 01603 593940
Email: N.Kishita@uea.ac.uk	Email: S.Hardy@uea.ac.uk